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LIMITATIONS ON THE PRECEDENT AUTONOMY OF ALZHEIMER'S PATIENTS AS TO NUTRITION, HYDRATION, AND PALLIATIVE SEDATION

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LIMITATIONS ON THE PRECEDENT AUTONOMY OF ALZHEIMER'S PATIENTS AS TO NUTRTION, HYDRATION, AND PALLIATIVE SEDATION

by

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Dedication

For my mother, Maureen Elizabeth Schwertdfeger Gaido,
and my wife, Mary Kay Gallagher Gaido

Preface

As overall life expectancies continue to lengthen, it is not far fetched in the least to envision a virtual epidemic of dementia as we reach the mid point of this new century. 70 million American Baby Boomers began to turn sixty- five on May 11, 2011, and it is clear that millions of these will ultimately suffer from some form of dementia. The functional impairment and loss caused by Alzheimer's disease has a particular route of progression and thus generally predictable trajectory. Equally foreseeable are the medical treatment and care issues that will likely arise as a consequence of that trajectory, as are the treatment and care option for addressing those issues. Given sufficient relevant as well as accurate information and guidance, an individual diagnosed with Alzheimer's disease and his/her family can develop a reasonably accurate set of expectations, and can prepare accordingly to make informed choices re: medical treatment.

The legal right to accept or reject even life-sustaining medical treatment is well established. Prior to the loss of decisional capacity an individual diagnosed with Alzheimer's disease possesses the legal authority to reject life-sustaining medical treatment, including, but not limited to, artificial nutrition and hydration, subject only to constitutionally valid limitations on that authority imposed by state legislation, currently in force only in a handful of states. Subject to certain constitutionally valid limitations and/or evidentiary standards re: the determination of his/her previously expressed or implied intention, an individual diagnosed with Alzheimer's disease, in anticipation of the possible loss of decisional capacity, possesses the legal authority to refuse, in advance, life-sustaining medical treatment, including artificial nutrition and hydration. Given sufficient relevant as well as accurate information and guidance, an individual diagnosed

with Alzheimer's disease and his/her family can effectively plan how his/her legal authority to accept or reject medical treatment should be exercised in order to be maximized.

Many, although certainly not all, individuals need some form of reassurance that in making significant decisions, especially those decisions involving life and death, that they are doing the "right thing." Awareness that one has the requisite legal authority to accept or reject life-sustaining medical treatment may not in and of itself provide that reassurance. Accordingly, many individuals contemplating whether they would, under certain circumstances, reject a means of sustaining their own lives, including but not limited to artificial nutrition and hydration, want to know whether they possess the requisite moral authority to do so. Given sufficient relevant as well as accurate information and guidance, an individual diagnosed with Alzheimer's disease and his/her family not only should be able to determine to their satisfaction whether he/she possesses the requisite moral authority to reject life-sustaining medical treatment, including but not limited to artificial nutrition and hydration, in the circumstances specific to his/her injury/illness/disease and available overall resources, but to effectively plan how that moral authority should be exercised in order to be maximized.

For many Americans, exclusively secular moral authority and legal authority to reject a means of sustaining their own lives provides insufficient license to make such a choice. These individuals require some form of religious approbation. Depending on his/her/their religious preference, an individual diagnosed with Alzheimer's disease and/or his/her family, given sufficient relevant as well as accurate information and guidance, should be able to determine to their satisfaction whether there is religious approbation for his/her rejection of life-sustaining medical treatment, including but not limited to artificial nutrition and hydration, in the circumstances specific to his/her injury/illness/disease and available overall resources.

The purpose of this inquiry is to provide sufficient relevant as well as accurate information and guidance re: legal authority, moral authority, and religious approbation that an individual diagnosed with Alzheimer's disease and/or his/her family can make informed choices regarding both present and future medical treatment. The intent is not to provide answers to every question that might conceivably be posed by an individual diagnosed with Alzheimer's disease and/or his/her family, but instead to assist those most impacted by an Alzheimer's diagnosis in becoming conversant enough with the issues that usually arise with that diagnosis that meaningful questions can be formed and appropriately directed to those professional and non-professional sources of information and guidance available and willing to share knowledge, insights, and perhaps even wisdom, and thus provide assistance. A compelling argument can be made that the authenticity, legitimacy and authority of a decision to accept or reject medical treatment, especially life-sustaining medical treatment, is directly proportional to the relevance and accuracy of the information and guidance, especially professional guidance, upon which that decision is, at least presumably, based. Accordingly, the intent of this inquiry, regardless of whether an individual diagnosed with Alzheimer's disease and/or his/her family ultimately decide to accept or reject life-sustaining medical treatment, is to maximize the authenticity, legitimacy, and authority of that decision.

Acknowledgements

This all began as an effort to be a better Sunday school teacher that slowly evolved into an interest in Roman Catholic moral theology and finally morphed into a desire to apply principles of moral theology to modern medicine. Heartfelt thanks to the Institute for the Medical Humanities for not only accepting a student closing in on the end of his sixth decade but permitting me, from my very first class, to actively pursue my preoccupation, some might say obsession, with the moral issues that arise with the rejection of artificial nutrition and hydration. I am no stranger to higher education. The quality of the instruction I received at UTMB was nothing short of superb. Special thanks is due Dr. Bill Winslade for his patience and guidance and the members of my dissertation committee, who without complaint, suffered through a final draft full of one sentences paragraphs that approached 800 pages.

A simple, “Thank you,” seems inadequate to express my gratitude to Donna Vickers. She is, as every IMH student knows too well, the guardian angel that mops brows, holds hands, and solves every conceivable problem. It is hard to imagine how anyone could be so dedicated to their job. I cannot remember sending an e-mail to Miss Donna that, regardless of day or night, wasn’t answered within a matter of minutes. Thank you for seeing me through.

I am a product of the instruction given me by the Galveston Catholic Schools, the Galveston Independent School District, the University of Texas at Austin College of Education, the University of Texas School of Law, the St. Thomas University Graduate School of Theology at Saint Mary’s Seminary, and of course, the Institute for the Medical Humanities. I have been blessed with many pedagogical sources of affirmation and inspiration, but it is clear to me that

somewhere along the way their love of learning became my love of learning, and for that most of all, I am deeply, deeply grateful.

Finally, I give thanks to the two women in my life who are most responsible for who I am and whatever success, however modest, I have enjoyed. Though we are separated by death, at least for the time being, Kewpie Gaido's words still echo in my ears: "Life is what you make it, and what you make it is up to you. This isn't a dress rehearsal! Get out there and get going." Thanks, Momma, for your unceasing encouragement and genetically speaking, for the "motor" that always seems to start and has never, not yet anyway, run short of fuel. For all the nights, too many nights, that after dinner I marched upstairs to read and study, all the weekends that we planned around my assignments, all the moments that I seemed lost in thought, I thank you, Mackey Gaido. There are few, if any wives, who could have endured what you endured in order for me to pursue my dream. Thanks, too, for being genuinely interested in what I was learning and permitting me to "bounce" concepts and insights off of you *ad naseum*. You were twice "widowed" by me. Once for a quarter century as you spent countless nights and weekends with our three children as I sold fish for a living, once again for more than a decade, as I pursued an education in moral theology and finally, bioethics. All you had to say was, "I've had enough. You never did. Thank you, Baby, for the incredible gift of your love.

Limitations on the Precedent Autonomy of Alzheimer's Patients as to Nutrition, Hydration, and Palliative Sedation

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Abstract: Over the course of the next two decades an unprecedented number of Americans will be diagnosed with Alzheimer's disease. In order that their consent to or rejection of medical treatment is truly informed, they need accurate and relevant information, including, but not limited to, the following: The functional impairment and loss caused by Alzheimer's disease has a particular route of progression and thus generally predictable trajectory. Equally foreseeable are the medical treatment and care issues that will likely arise as a consequence of that trajectory, as are the treatment and care option for addressing those issues. Accordingly, individuals diagnosed with Alzheimer's disease and their families can develop a reasonably accurate set of expectations, and can prepare accordingly. Prior to the loss of decisional capacity individuals diagnosed with Alzheimer's disease possess the legal authority to reject life-sustaining medical treatment, including, but not limited to, artificial nutrition and hydration, subject only to constitutionally valid limitations on that authority imposed by state legislation,

currently in force only in a handful of states. Subject to certain constitutionally valid limitations and/or evidentiary standards re: the determination of their previously expressed or implied intention, individuals diagnosed with Alzheimer's disease, in anticipation of the possible loss of decisional capacity, have the legal authority to refuse, in advance, life-sustaining medical treatment, including artificial nutrition and hydration. Individuals diagnosed with Alzheimer's disease also possess the moral authority to make such a rejection, when in their assessment; the life-sustaining medical treatment in question imposes a foreseeable harm(s) and/or continuing burden(s) that is, on balance, disproportionate to its foreseeable benefit, if any.

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Introduction

Americans are living longer, and absent a breakthrough of the magnitude of Salk's vaccine for polio, dementia, most visibly manifested in Alzheimer's disease, may well become the scourge of the 21st century. Anne Monias and Diane Meier report that the "[p]revalence of dementia increases with each decade of life over age 65: "Nineteen percent of the population [will suffer] from dementia by age 80, 49% by age 90, and 60% among centenarians." [1] As overall life expectancies continue to lengthen, it is not far fetched in the least to envision a virtual epidemic of sufferers as we reach the mid point of this new century. [2] 70 million American Baby Boomers began to turn sixty- five on May 11, 2011, and it is clear that many millions of these will ultimately suffer from some form of dementia.

Fear of the consequences of Alzheimer's disease is hardly irrational, and in Stephen Post's view, it is clear why many Americans fear dementia as much or even more than cancer: "[W]ith cancer self-identity is not usually at stake and physical pain can in most instances be controlled without compromising mental lucidity. The person with cancer will retain his or her autobiography, or life story, and the sense of temporal continuity between the past, present, and the future, but the person with AD will eventually outlive most of his or her brain." [3] For Post, "[s]eldom does the human experience require more courage than in living with the diagnosis of

[1] Anne Monias and Diane Meier. "Palliative Care in Early, Moderate, and Advanced Dementia." In *Geriatric Medicine: An Evidence Based Approach*, edited by Christine Cassel, 343-50. (New York, NY: Springer, 2003), 345.

[2] Leonard F. M. Scinto and Kirk R. Daffner. *Early Diagnosis of Alzheimer's Disease. (*Totowa, NJ: Humana Press, 2000), 1. Scinto and Daffner claim that"[b]ased on the current rates, and in the absence of effective prevention, it is estimated that in fifty years, there will be as many as 14 million cases of clinically diagnosed Alzheimer's disease in the United States alone."

[3] Stephen Post, *The Moral Challenge of Alzheimer's Disease*. (Baltimore, MD: John Hopkins University Press, 2000), 1.

irreversible progressive dementia," [4] and it is easy to see why: "While the body of a person with dementia often will remain strong for a number of years, mental capacities as well as the accumulated competencies and memories of a lifetime painfully slip away. This slippage is less emotionally traumatic for affected individuals only when they begin to forget that they forgot." [5] Unfortunately, Alzheimer's disease requires courage from more than just the AD patient. Let there be no illusions, AD is especially tough on caregivers, subjecting them not only to potential financial ruin, [6],[7],[8] but a 24/7 ordeal often characterized by overwhelming feelings of isolation and despair. At present there is no proven means of prevention and no cure for Alzheimer's disease, only methods of mitigating symptoms and temporarily slowing the otherwise inexorable progress of the disease.

The journey from the initial diagnosis of Alzheimer's disease to ultimate death, either from complications of the disease or another pathology such as cancer or heart disease, is almost

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[4] *Ibid.*

[5] *Ibid*.

[6] Abhilash Desai and George T. Grossberg. "Diagnosis and Treatment of Alzheimer's Disease." *Neurology* 64, no. 12 (Supp. 3 (June 28, 2005): S36. Desia and Grossberg report that"[t]he annual cost of AD in the United States is approximately 100 billion: approximately 18,408/pateint per year for mild AD, 36,132/patient per year for severe AD."

[7] Post, Stephen, "The Moral Challenge," 26. According to Post, the cost of care for Alzheimer's patients is potentially ruinous, especially because of the inability of many patients to qualify for state and/or federal assistance in providing long-term care: "Neither Medicare nor most private health insurance covers the long-term care most patients require. Almost 75% of the home care for patients is provided by family and friends. Half of all nursing home patients suffer from AD or a related disorder. The average cost for nursing home care amounts to $42,000 per year, but can exceed $70,000 in some areas of the country. The average lifetime cost per patient exceeds 174, 000."

[8] John L. Shuster. "Palliative Care for Advanced Dementia." *Clinics in Geriatric Medicine* 16, no. 2 (May 2000): 381. John Shuster concludes that the crux of the problem is that Medicare was not designed to finance the kind of long term care needed by those suffering with dementia, and Medicare is available only to those who have exhausted their financial assets: "Because Medicare is not designed to function as a primary reimbursement system for long-term care, only care for the complications of dementia (or collateral illnesses) is relatively well reimbursed. The care of such complications is shifted toward general medical facilities and away from care settings often more suitable for patients with advanced dementia. The public 'safety net' reimbursement system, Medicaid, is available only to persons who become thoroughly impoverished. Once a patient qualifies for Medicaid, care reimbursement under the system is often so limited as to present its own barrier to appropriate care. These reimbursement systems, if applied to the patient with advance dementia, encourage fragmentation of care, limited availability of appropriate care, and extreme rationing of patient and family financial assets."

always a difficult road to travel for the patient, and all others concerned, and requires numerous, and in many instances agonizingly difficult, decisions to be made regarding medical treatment and care, either by the patient or by someone else on the patient's behalf. Prior to an assessment that he/she is no longer medically or legally capable of making these decisions, an individual diagnosed with Alzheimer's disease may, if he/she is willing to do so, make his/her own decisions re: medical treatment and care, including decisions made in anticipation of the loss of decisional capacity, regarding *future* medical treatment and care. Regardless of who it is that ultimately makes these decisions, it is critically important that he/she be fully informed, well in advance, of both the probable and possible decisions that will ultimately be necessary, with as much information as practical as to the foreseeable consequences of each decision, in order to knowledgably make the best possible medical treatment and care choices. In general, this inquiry seeks to provide to the lay person that information, with as much detail as is readily comprehensible, and in so doing provide clarity, insight, and hopefully some measure of guidance for those diagnosed with Alzheimer's disease, and their families. Particular emphasis is placed on preparing the individual diagnosed with Alzheimer's to make his/her own decisions re: medical treatment and care, while he/she still possesses the decisional capacity to do so.

There is at least some measure of uncertainty as to whether an Alzheimer patient with decisional capacity possesses the legal authority, moral authority, and religious approbation to reject in advance, through the use of an advance directive(s), [9] artificial nutrition and hydration (ANH) when and if he/she is no longer willing or able, even with assistance, to eat and drink sufficiently to sustain his/her life and to insist on preemptive palliative sedation (PPS) to

[9] Advance directive is a general term employed to describe those legal documents that permit individuals to provide written instructions re: their future medical treatment preferences (living will), and /or to appoint some other person to make medical treatment decisions on their behalf ("durable power of attorney for health care"), should illness or injury render them unable to do so through loss of consciousness or decisional capacity. Both forms of directives are discussed in detail in Chapter 12.

eliminate the possibility of any form of suffering once terminal dehydration has begun. There is in addition, further uncertainty as to whether a rejection of ANH and request for PPS, made in this manner and under these circumstances, will be honored by this patient's legally designated surrogates and the medical professional(s) entrusted with his/her medical treatment. Specifically, this inquiry seeks to address these uncertainties.

The first chapter provides a brief history of Alzheimer's disease and examines the physiology of Alzheimer's and the other forms of dementia. Particular emphasis is placed on risk factors, prevention, screening, and diagnosis. The second chapter examines the usual trajectory of Alzheimer's disease, including loss of functional and especially decisional capacity, medical treatment issues that are likely to arise, probable life expectancy, and likely cause of death. Particular emphasis is placed on current protocols of treatment, especially the mitigation of symptoms and methods of slowing the overall progress of the disease, as well as suggested methods of providing ethical and compassionate care. Emphasis is also placed on how Alzheimer's disease is experienced by an Alzheimer patient's family/caregivers as well as speculation as to how the disease is experienced by the patient himself/herself, so that the quality of life of both the Alzheimer's patient and his/her family/caregivers can be maximized. Absent some intervening fatal injury or pathology, an individual diagnosed with Alzheimer's disease will ultimately be unwilling or unable, even with assistance, to eat and drink sufficiently to sustain his/her own life. Alzheimer's disease may destroy his/her ability to swallow without life-threatening aspiration of food and fluids into the lungs, or in the alternative, he/she may progressively lose most if not all of his/her desire to eat and drink either because of the progression of the disease or simply as a result of the consequences of the natural shut down of

bodily processes at the end of life. The third chapter examines the physiology of artificial nutrition and hydration (ANH), terminal dehydration, and preemptive palliative sedation

The fourth chapter asks, under what circumstances, if any, an individual possesses the requisite legal authority to *reject* a means of sustaining his/her life, including, but not limited to artificial nutrition and hydration (ANH), and can make that rejection in advance, through the use of an advance directive(s), in anticipation of the loss of the requisite decisional capacity. That an individual possesses the legal authority to reject a means of sustaining his/her life does not, however, necessarily mean that he/she also possesses the moral authority to do so. Although it can be asked, with at least some justification, why moral authority is of any consequence whatsoever, so long as legal authority exists, the assessment that one possesses moral authority for a particular action or course of conduct can nevertheless be of great significance.

Many, although certainly not all, individuals need some form of reassurance that in making significant decisions, especially those decisions involving life and death, that they are doing the "right thing." Awareness that one has the requisite legal authority may not in and of itself provide that reassurance. In addition, legal authority alone, without corresponding moral authority, may not be sufficient to insure that an individual's decision to reject a means of sustaining his/her life will be honored, especially if he/she subsequently loses consciousness or decisional capacity, or otherwise provides those who oppose such a decision an opportunity to ignore or overturn it. As long as an individual's consciousness and decisional capacity both remain unimpaired, there is a much greater probability that his/her rejection of artificial nutrition and hydration will be honored. If, on the other hand, either decisional capacity or consciousness is lost, even temporarily, an individual determined to reject artificial nutrition and hydration requires, at minimum, the acquiescence of others. Those whose acquiescence is needed, whether

legally designated surrogate decision makers, care givers, attending medical personnel or even family members, are much more likely to acquiesce to the decision to reject ANH if they are persuaded that the decision-maker possessed both the legal *and* moral authority to do so at the time the decision was made, *especially* when they *disagree* with that decision. Accordingly, the fifth chapter examines whether an individual has the *moral* authority, from an exclusively secular perspective, to reject a means of sustaining his/her life, including, but not limited to, artificial nutrition and hydration, especially when he/she is unwilling or unable, even with assistance, to eat and drink sufficiently to sustain his/her own life.

That an advance directive(s) has legal authority does not mean that it also has moral authority and the assessment that an advance directive has moral authority, especially in a circumstance where decisional capacity but not consciousness is lost, can also be of considerable significance. Legal authority alone, without corresponding moral authority, may not be sufficient to insure that preferences regarding medical treatment expressed in an advance directive(s) are honored as written. Those asked to assist in carrying out another's preferences regarding medical treatment expressed in an advance directive, whether they be legally designated surrogate decision makers, care givers, attending medical personnel or even family members, are much more likely to do so faithfully when persuaded that an advance directive has both legal *and* moral authority, *especially* when they *disagree* with the medical preferences expressed therein. The extent to which an advance directive has legitimate moral authority is accordingly the focus of chapter six.

For many Americans, exclusively secular moral authority and legal authority to reject a means of sustaining their own lives provides insufficient license to make such a choice. These individuals require some form of religious approbation. Chapters seven through ten focus on the

teachings of Islam, Judaism, Roman Catholicism, and the official positions of the Episcopal, Presbyterian, Lutheran, Methodist, and Baptist churches, as representative of mainstream American Protestant Christianity, regarding an individual's rejection of life-sustaining medical treatment, especially the rejection by an Alzheimer's patient, through the use of a previously executed advance medical directive(s), of artificial nutrition and hydration (ANH) when he/she is no longer willing or able, even with assistance, to eat and drink sufficiently to sustain his/her life and the concomitant request for preemptive palliative sedation (PPS) once terminal dehydration has begun.

Chapter eleven explores the perspective of professional medicine re: ANH and PPS as revealed in the official statements of medical associations and in the published opinions of individual physicians, and inquires as to whether, despite professional medicine's protocol for palliative sedation, an individual who has rejected ANH has the moral authority to insist on PPS once terminal dehydration has begun. Although there is certainly more than one way to thoughtfully and prudently respond to a diagnosis of Alzheimer's disease, the final chapter is offered as a step-by-step guide to maximizing the legal and moral authority of one's Alzheimer's specific advance directive(s).

Chapter One: History, Physiology, Risk, Prevention, Screening, and Diagnosis

This chapter provides a brief history of Alzheimer's disease and examines the physiology of Alzheimer's and the other forms of dementia. Particular emphasis is placed on risk factors, prevention, screening, and diagnosis. The overall focus of this initial chapter is to provide as much information as possible to an individual diagnosed with Alzheimer's disease, as well as his/her family, so that along with information contained in the remaining chapters, important choices, especially decisions regarding medical treatment and care, can be made knowledgeably, especially while the Alzheimer's patient still has the opportunity to make those choices on his/her own behalf.

History

It is apparent that various forms of dementia, including Alzheimer's disease, have afflicted mankind throughout the millennia. Zaven Khachaturian and Teresa Radebaugh not only report that there is "no evidence to indicate that the incidence of the disease—that it is the rate of occurrence of new cases—has increased over the years," [10] . . . "ancient Greek and Roman writers, as well as Elizabethan chroniclers accurately described the symptoms of AD, thus suggesting that it or very similar dementing disorders have long been part of the human condition." [11] Richard Torack observes that "Hippocrates did not include it among his mental disorders, which probably means that senile dementia was considered a routine part of the aging

[10] Zaven S Khachaturian and Teresa S. Radebaugh, eds. *Alzheimer's Disease: Cause(s), Diagnosis, Treatment, and Care.* (Boca Raton, FL: CRC Press, 1996), 4.

[11] *Ibid*

process." [12] Torack further notes that "[b]y [the early eighteenth century], autopsies were being performed for the first time since the 4th century B.C.," [13] and there is evidence that from post-mortem examination of brain tissue, researchers had begun to conclude that the human brain undergoes physical change as it ages. [14] There was not, however, as yet any apparent recognition of a linkage between anatomical changes in the brain and acute mental impairment. According to Torack, it was "Esquirol working with Pinel who [in 1838] really defined senile dementia: "Senile dementia is established slowly. It commences with enfeeblement of memory, particularly the memory of recent impressions." [15],[16] It was probably inevitable that with enough post-mortem examinations of the brains of individuals with acute mental impairment a link between that impairment and visual changes in the brain would be established, and Torack informs that "[t]he first definitive description of [brain] atrophy [as a result of senile dementia] appears to be that of Wilks in 1864," [17] after which "atrophy becomes a constant feature in the pathology of dementia." [18]

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[12] Richard M. Torack. "The Early History of Senile Dementia." In *Alzheimer's Disease*, edited by Barry Reisberg, 23-8. (New York, NY: Free Press, 1983), 23.

[13] *Ibid*, 25.

[14] *Ibid*. Torack claims that ""Haller (1708-77) wrote, "in madness the brain is dry, hard, and friable."

[15] *Ibid*, 26

[16] Peter J. Whitehouse, Konrad Maurer, and Jesse F. Ballenger, eds. *Concepts of Alzheimer's Disease, Biological, Clinical, and Cultural Perspectives.* (Baltimore, MD: John Hopkins University Press, 2000), 47. Peter Whitehouse suggests that in roughly this same time period other researchers had begun to distinguish dementia from other forms of mental impairment: "[*D*]*ementia*, implying loss of mentation. . .was differentiated from *amentia* or mental retardation; that is, dementia requires normal intelligence and a deterioration to an impaired level of thinking ability. . Dementia was also distinguished from delirium, which was defined as changes in cognition occurring often in response to medical illness. Thus, the initial characterization of neuropsychiatric diseases depended on the skills of the clinicians (or others) to observe individuals and to cluster their symptoms into certain categories."

[17] Torack, "The Early History," 26.

[18] *Ibid*, 27

2007 was the 100th anniversary of the German Alois Alzheimer's history-making publication, "A Characteristic Disease of the Cerebral Cortex." In it, Alzheimer not only described the symptoms of severe mental impairment,[19] experienced by Augusta D., a fifty-one year old woman from Frankfurt, but provided the results of both a visual and microscopic analysis [20] of brain tissue obtained from an autopsy of her brain. According to Peter Rabins, Alzheimer reported that "her brain showed loss of nerve cells [neurons] and two specific pathological abnormalities: *neuritic* plaques, now known to be comprised of degenerated nerve cells that are deposited in the supporting brain tissue, i. e. *outside* neurons; and *neurofibrillary tangles*, twisted fibrils that are located *within* brain neurons." [21] This two page article, and the subsequent publications by Bonfiglio (1908), Perusini (1909), and again Alzheimer in 1911, led to the eponym Alzheimer's disease first used by Emil Kraepelin in his 1910 textbook of psychiatry [*Psychiatrie*]. [22],[23] Henk ten Have and Ruth Portillo report that is was not until the

[19] Whitehouse, Maurer, and Ballenger, "Concepts of Alzheimer's Disease," 5. According to Peter Whitehouse, Alzheimer described this severe mental impairment as including "hallucination, delusions, and psychosocial incompetence."

[20] Henk A. M. J. ten Have and Ruth B. Purtilo. "Historical Overview of a Current Global Challenge." in Purtilo, Ruth B. and Henk A.M.J. ten Have, editors. In *Ethical Foundations of Palliative Care for Alzheimer's Disease*, edited by Ruth B. Purtilo and Henk A.M.J. ten Have. (Baltimore, MD: Johns Hopkins University Press, 2004), 2. Clearly, the research breakthrough achieved by Alzheimer and colleagues was unprecedented, and Ten Have and Purtilo explain what made it possible: "These typical clinical and anatomical observations were possible because of the particular conditions in which Alzheimer worked. He was director of the research laboratories of the newly built psychiatric clinic in Munich. . .established. . .and headed by Emil Kraepelin. . . Alzheimer, after working with Kraepelin in Heidelburg, in 1902 moved with his teacher to Munich. . . A school of psychiatric researchers was trained there, with Fritz Lewy, Alfons Jakob, and Hans Creutzfeld as disciples of Alzheimer. The focus of the laboratories was on neuropathology, using innovative techniques and instruments such as chemical staining and powerful microscopes to investigate the brains of deceased patients."

[21] Peter V. Rabins. "Dementia and Alzheimer's Disease: An Overview." *Georgia Law Review* 35 No. 1 (Winter 2001): 453.

[22] Whitehouse, Maurer, and Ballenger, "Concepts of Alzheimer's Disease," 5

[23] ten Have and Purtilo, "Historical Overview," 2. Ten Have and Purtilo are inclined to assign much of the credit for the discovery of Alzheime's disease to Perusini and Kraepelin, although it was named for Alzheimer: "In 1907, Alzheimer published his case of the unusual brain disease. Three years later, G. Perusini, an assistant to Alzheimer, published a more extensive report, with four cases (including Alzheimer's earlier one). Perusini did extensive pathological investigations of the brain. He concluded that the findings indicated a disease picture of a characteristic type: the clinical symptoms as well as the neuropathology were

eighth edition of his textbook that "Kraepelin introduced the concept of 'Alzheimer disease,' based on. . four published cases,. . .assum[ing] a parallel manifestation of clinical symptoms and brain pathology. . .[and] conclud[ing]that this disease was different from 'senile dementia." [24] Surprisingly, ten Have and Purtilo also claim that it although [Kraepelin] gave priority to the peculiar symptoms and the course of the disease. . .[in essence claiming that it began] at a 'presenile' age). . .Alzheimer himself,. . .since the neuropathological changes could not always be demonstrated. . .dismissed the idea that there was a separate disease." [25]

Despite the significance of the scientific breakthrough achieved by Kraepelin and colleagues in Munich, and continuing research into the pathological basis of dementia, carried out over the course of the next fifty years, [26] there was apparently continuing uncertainty re: dementia within both medical research circles and the clinical practice of medicine. German research had established a correlation between severe mental impairment and neuritic plaques and neurofibrillary tangles in the brain that was not limited to individuals historically considered old enough for senile dementia, but a causal relationship had yet to be proven. The clinical diagnosis of senile dementia continued to be made, but because of the likely paucity of postmortem analysis of brain tissue, it was impossible to know the strength or nature of the association between that diagnosis and neuritic plaques/neurofibrillary tangles. With so much

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similar to the changes in senile dementia, but progressed further and at an earlier stage, which he termed 'the presenile age period,' Both publications motivated Kraepelin to proclaim the existence of a new disease named after Alzheimer."

[24] *Ibid*, 3

[25] *Ibid*

[26] Robert D Terry, "History of the Morphology of Alzheimer's Disease," 31. According to Terry, "[i]n 1927, the Belgian Divry recognized that the more or less amorphous material in the core of the [neuritic] plague[s] is amyloid.. . .Scholtz recognized amyloid in the cortical and meningeal blood vessels in 1938 and it was the latter location that gave Glenner the opportunity to isolate and sequence the amyloid peptide some 45 years later."

death from infection and transmittable disease, even in developed countries, an average life span that made dementia a relatively infrequent fatal pathology, and the no doubt widespread assumption that dementia was a natural consequence of aging, further research into dementia could not have been viewed as much of a priority.

Not surprisingly, physicians apparently continued to have a difficult time differentiating between normal age-related cognitive deficiencies and brain pathology. As a result, according to Ralph Richter, "[f]or a number of years, Alzheimer's disease (AD) was artificially divided into two entities: presenile dementia in individuals under 65 years of age and senile dementia of the Alzheimer's type for those over 65 years of age." [27] So difficult, in Peter Whitehouse, Konrad Maurer, and Jesse Ballenger's view, was the establishment of a firm basis in brain pathology for the clinical expression of dementia, that when American psychiatrist David Rothschild observed that some individuals who had plaques and tangles did not develop dementia, American psychiatrists began to emphasize the role of psychosocial factors in the disease, [28] and this "psychodynamic theory of senile dementia was, in fact, dominant in American literature [in the 1940's and 1950's]." [29]

In stark contrast to the first fifty years of the twentieth century, the last fifty years were especially productive for research into dementia and Alzheimer's disease. Although they did not occur sequentially, five developments were of particular significance. First, biopsies of *living* tissue obtained from the brains of patients with advanced dementia and examined with the new

[27] Ralph W. Richter. "Medical Diagnosis and Workup of Alzheimer's Disease." In *Alzheimer's Disease: A Physician's Guide to Practical Management*, edited by Ralph W. and Brigitte Zoeller Richter, 75-87. (Totowa, NJ: Humana Press, 2004), 75.

[28] Whitehouse, Maurer, and Ballenger, "Concepts of Alzheimer's Disease," 49.

[29] *Ibid.*

electron microscope confirmed the existence of abnormal twisted fibers in their brains. [30] Second, a greater understanding of brain biochemistry, based in part on the recognition that scopolamine, an amnesia inducing drug used by anesthesiologists, prevented the creation/retention of short term memory by blocking the production of the enzyme, choline acetyltransferase, necessary for the synthesis of the neurotransmitter, acetylcholine, prompted speculation among researchers that memory loss in Alzheimer's disease was, at least in part, a result of the absence of acetylcholine, and that a method of assisting the brain in creating/transferring this memory critical neurotransmitter could reduce memory loss. [31]

Third, results of the study of the age of dementia sufferers led to a clearer distinction between early-onset and late-onset variations of the disease, much more extensive autopsies of the brains of individuals who had been diagnosed with dementia demonstrated that Alzheimer's disease was far and away the leading cause of dementia, and thanks to ever increasing life expectancies had become at last a serious threat to public health, deserving much greater public attention. [32]

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[30] Robert D. Terry, "History of the Morphology," 9. Terry provides a first hand description of the process of obtaining these brain biopsies: "In 1959 Saul Korey, who was chief of Neurology and a well-trained neurochemist at the Einstein College of Medicine, and [I] decided to study the disease utilizing brain biopsy tissue. . .[T]he changes [in the brain] were diffuse so that the neurosurgeon could remove a small portion (less than one gram) from any 'silent' region of the neocortex and could expect it to contain lesions. . . [A] half dozen of these biopsies [were performed] at Einstein within the first few years, and none of these patients had any post-operative difficulties. The tangles were easily found with the electron microscope and were revealed to be made up of curious, twisted fibers which Kidd, working simultaneously at Maida Vale Hospital with McMenemy in London, reported correctly as paired helical filaments (PHF) (8) but what we in New York thought were twisted tubules."

[31] Khachaturian and Radebaugh, *Alzheimer's Disease*, 20. Khachaturian and Radebaugh describe the breakthrough in brain biochemistry: "[R]eports of the selective vulnerability of cholinergic neurons [to a deficiency in acetylcholine production] in the brains of Alzheimer's patients independently emanate[ed] from three different laboratories in Great Britain. A putative role of acetylcholine in memory was provided by the knowledge that a cholinergic antagonist, scopolamine, had been used for decades as an amnesic drug by anesthesiologists, particularly in producing 'twilight sleep' during childbirth so that the pain of childbirth would be forgotten. . . Drachman and Leavitt had shown that scopolamine produced memory deficits in young volunteers not dissimilar to that observed in Alzheimer's disease."

[32] Robert Katzman. "Current Research on Alzheimer's Disease in a Historical Perspective." In *Alzheimer's Disease:Cause(s), Diagnosis, Treatment, and Care.* edited by Zaven S Khachaturian and Teresa S. Radebaugh, 15-

Fourth, it had apparently long been suspected that at least some forms of Alzheimer's disease had a strong familial component, but according to Whitehouse, Maurer, and Ballenger, it was not until it was observed that "plaques and tangles occurred in the brains of individuals suffering from Down's syndrome, if they lived beyond the age of 40 or so," [33] that attention began to be focused on a genetic predisposition for Alzheimer's. In their view, "[t]he fact that [it was finally discovered that] Down's syndrome was caused by an extra copy of the 21st chromosome led to the search for clues to the genetic basis of [at least some forms [34] of Alzheimer's disease]." [35] As they quite correctly observe, Alzheimer's disease, initially described "at an anatomic/pathologic level, followed by [a] neurochemical/neurotransmitter level of description, [was] now. . .[described] at the molecular/genetic level." [36] Finally, as pointed out by John C. Morris, "uniform clinical diagnostic criteria [for Alzheimer's disease and other forms of dementia] were introduced by the Work Group convened by the National Institute on Neurological and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association [37] and provided a basis for the accurate recognition of the disorder." [38]

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30. (Boca Raton, Fl: CRC Press, 1996), 20. Katzman describes what prompted these conclusions: "Early epidemiological studies such as that by Gruenberg indicated that senile dementia increased exponentially with age, afflicting perhaps 4 to 5% of those over the age of 65, if one defined dementia in terms of impairment so severe that the individual can no longer live independently, and perhaps another 5 to 10% with very mild impairment. Once the identity of the senile and presenile forms of Alzheimer's disease were recognized, and autopsy showed that at least the majority of cases of dementia were due to Alzheimer's disease—even in the series of over 1000 autopsies reported by Jellinger in 1976—it became evident that Alzheimer's disease was a major public health problem. I had the opportunity of arguing for the importance of the prevalence and malignancy of Alzheimer's disease in a 1976 editorial in the *Archives of Neurology*. This editorial struck an immediate response and widespread interest began to develop in the disorder."

[33] Whitehouse, Maurer, and Ballenger, "Concepts of Alzheimer's Disease," 50.

[34] autonsomonal dominant Alzheimer's disease on the 21st chromosome.

[35] Whitehouse, Maurer, and Ballenger, "Concepts of Alzheimer's Disease," 50.

[36] *Ibid*, 51

[37] John C. Morris. Foreword to *Early Diagnosis of Alzheimer's Disease*, by Leonard F. M.Scinto, and Kirk R. Daffner. (Totowa, NJ: Humana Press) vii. John Morris suggests that another milestone in the understanding of

Before examining the physiology on a cellular level of the human brain and the pathology of Alzheimer's disease and other forms of dementia, it is useful to define what is meant by the terms, dementia, and Alzheimer's disease, respectively, briefly discuss, in general terms, their causes, and distinguish dementia from the far more benign memory loss associated with normal aging.

Definition

David Knopman, Bradley Boeva, and Ronald Petersen suggest that the belief that significant cognitive impairment is a natural and inevitable consequence of aging is a myth that must be put to rest if dementia is going to be fully understood:

> The myth that forgetfulness is an inevitable consequence of aging exerts a powerful influence on the view of lay people and physicians alike. Memory function as measured by delayed recall of newly learned material is notsubstantially decreased for most older people. Studies have shown that when individuals destined to develop dementia in a few years are excluded from the group called 'normal elderly,' there are few decrements with age in functions such as delayed recall. [39]

They claim that "elderly persons experience a type of memory loss manifested by digit span testing—their rote memory declines [but] in terms of information that they are allowed time to acquire, they experience no more memory loss over time of newly acquired material than do

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Alzheimer's was "Glenner and Wong['s] isolate[ion] [of] the beta amyloid peptide from the meningeal vessels in Alzheimer's disease brains."

[38] *Ibid*.

[39] David S Knopman, Bradley F. Boeva, and Ronald C. Petersen. "Essentials of the Proper Diagnoses of Mild Cognitive Impairment, Dementia, and Major Subtypes of Dementia." *Mayo Clinic Proceedings* 78, no. 10 (October 2003): 1291.

young people." [40] In their view, examination of the available science from neuropsychology and experimental psychology yields only one reasonable conclusion: "Typical aging per se does not degrade memory, disease does." [41]

The problem, according to John C. Morris, is the risk that very early symptoms of Alzheimer's disease may be interpreted as the effects of normal aging, as "underscored," in his view, "by the plethora of terms that have been introduced to characterize borderline states in which the individual is neither clearly normal nor clearly demented: 'benign senescent forgetfulness,' 'age-associated memory impairment,' 'pathological aging,' 'cognitive impairment, no dementia,' and 'mild cognitive impairment." [42] Pointing to what he describes as "accumulating evidence to suggest that truly healthy brain aging can occur into the ninth and tenth decade of life and may be associated with less cognitive decline and neuropathological changes than usually are assumed," [43] he suggests that "more than minimal cognitive decline may not be 'normal' for age and that much (perhaps most) of what presently is described as mild cognitive impairment and similar states may represent incipient or very mild Alzheimer's disease." [44]

Knopman, Boeva, and Petersen claim that two principles define dementia. First, "(1) the affected person has experienced a decline from some previously higher level of functioning and (2) the dementia 'significantly interferes with work or usual social activities." [45] Second,

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[40] Knopman, Boeva, and Petersen, "Essentials," 1291.

[41] *Ibid.*

[42] *Ibid.*

[43] *Ibid.*

[44] *Ibid.*

[45] Knopman, Boeva, and Petersen, "Essentials," 1292-3.

resulting "[c]ognitive dysfunction [must be] demonstrable on [a] mental status examination or neuropsychological assessment, [and] [d]eficits should be apparent in more than one cognitive domain." [46], [47] David Drachman, Robert Friedland, Eric Larson, and Mark Williams add that the "impairment in the patient's cognitive function [must be] below the level you might expect for his age and background," [48] along with what they describe as an important but sometimes overlooked corollary: "these changes must occur when the patient's level of consciousness is unaffected and the sensorium [49] is unclouded." [50]

Ladislav Volicer describes dementia as "the most common neurological disease in the elderly. . .[with an]incidence that increases from 4.3 cases per/1000 persons/year among 65-69 year olds to 85.6 cases/1000 persons/year among individuals 90 years and older." [51] He identifies at least eleven causes of what he terms potentially reversible dementias, [52] noting that

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[46] *Ibid*, 1293.

[47] *Ibid*, 1293.Knopman, Boeva, and Petersen identify four core cognitive domains: (1) the ability to learn, retain, and retrieve newly acquired information (recent memory); (2) the ability to comprehend and express verbal information (language); (3) the ability to manipulate and synthesize nonverbal, geographic, or graphic information (visuospatial function); and (4) the ability to perform abstract reasoning, solve problems, plan for future events, mentally manipulate more than one idea at a time, maintain mental focus in the face of distraction, or shift mental effort easily."

[48] David Drachman, Robert P. Friedland, Eric P. Larson, and Mark E. Williams. "Making Sure It's Really Alzheimer's." *Patient Care* 25, no. 18 (November 15, 1991): 13.

[49] The parts of the brain concerned with the reception and transportation of sensory stimuli.

[50] Drachman, Friedland, Larson, and Williams, "Making Sure," 3.

[51] Ladislav Volicer. "Palliative Medicine in Dementia." In *Oxford Textbook of Palliative Medicine,* edited by Geoffrey Hanks, Nathan I. Cherney, Nicholas A. Christakis, and Marie Falton, et. al, 1375- 85. (Oxford, UK: Oxford University Press, 2010), 1375.

[52] Ladislav Volicer, "Palliative Medicine in Dementia," 1375.

Potentially reversible dementias:
Tumors both in brain and peripheral tissues
Metabolic disorders: thyroid disease, electrolyte imbalance, renal or hepatic failure
Head trauma
Poisoning: heavy metals, alcoholism, solvents, and insecticides
Brain infections
Autoimmune disorders: brain vasculitis, lupus erythematosus, multiple sclerosis

"[a]lthough some disorders are reversible through medical or surgical treatment, the number of patients with remedial dementias is rather small," [53] and that "[m]ost dementing conditions considered potentially reversible produce structural changes to the brain that do not respond to treatment." [54] Unfortunately, he reports that the "[t]he vast majority of dementias, especially in older individuals, [are] caused by degenerative changes in the brain that progress over time," [55] and "include dementias caused by neurodegenerative disease, vascular insufficiencies, and infections." [56],[57] Finally, Volicer notes that of the "four main types of progressive dementias:

Drug adverse effects
Nutritional disorders: deficiency of vitamins B12, B6, B1, and folate
Psychiatric disorders
Normal pressure hydrocephalus
AIDS encephalopathy

[53] *Ibid*.

[54] *Ibid*.

[55] *Ibid.*

[56] *Ibid*.

[57] *Ibid*.

Irreversible Dementias:
Neurogenerative diseases:
Alzheimer's disease
Dementia with Lewy bodies
Fronto-temporal dementia
Pick's Disease
Huntington's disease
Parkinson's disease
Progressive supra nuclear palsy
Vascular dementias:
Multi-infarct dementia
Binswanger's disease
Occlusive cerebrovascular disease
Cerebral embolism
Anoxia secondary to cardiac arrest or carbon monoxide poisioning
Infections:
Creutzfeldt-Jakob disease
Postencephalitic dementia

Alzheimer's disease (AD), vascular dementia, [58] dementia with Lewy bodies, [59] and fronto-temporal dementia,"[60] Alzheimer's disease is by far "the most common. . .[with][a]utopsy studies [revealing] that approximately 60 per cent of demented patients have pure AD and another 15 per cent have AD combined with other disorders." [61] Paul Dash and Nicole Villermarette-Pittman add that "[a]pproximately 15 percent [of dementia is] due solely to stroke. . .10 percent attributed to a combination of AD and stroke. . . 10 percent are caused by Lewy body disease, and 5 percent are attributed to reversible causes." [62]

According to Rabins, "Alzheimer's disease is defined by the presence of impaired *cognitive* capacities (an inclusion criterion) and an absence of other diseases that may cause the symptoms (an exclusion criterion)." [63] "Pure" Alzheimer's disease, which as noted above, account for sixty per cent of all forms of dementia, must, therefore, be distinguished from other causes that account for the other forty per cent of the disease. It is important to note that

[58] *Ibid*, 1376. Volicer provides a brief description of vascular dementia: "Vascular dementia refers to impaired cognitive function caused by cerebral injury that is related to different forms of cerebral vascular disease. . . The incidence and prevalence of vascular dementia vary widely. It is the leading cause of dementia in the elderly in Japan, Russia, and China. . . [T]here is a significant overlap between symptoms of Alzheimer's disease and vascular dementia. The diagnosis is also problematic because of the frequent combination of Alzheimer and vascular changes found during autopsy."

[59] *Ibid*. Volicer also provides a brief description of dementia with Lewy bodies: "Dementia with Lewy bodies (also sometimes called Lewy body disease) is characterized by a fluctuating course of cognitive impairment that includes episodic confusion and lucid intervals similar to delirium . . . . The clinical features of dementia with Lewy bodies persists over a long period of time, in contrast to the shorter time course of delirium, and dementia with Lewy bodies progresses to severe dementia."

[60] *Ibid*. Finally. Volicer gives a brief description of frontotemproal demenatia: "There is no uniform terminology for frontotemporal dementia, which accounts for up to ten per cent of cases with progressive degenerative dementia. . . The personality changes in frontotemporal dementia are similar to changes induced by damage of frontal lobes by other causes (injury, stroke) and include behavioral disinhibition, loss of social or personal awareness, or disengagement with apathy. Patients with frontotemporal dementia differ from Alzheimer's patients because they maintain some abilities (elementary drawing and calculations) into the later stages of dementia."

[61] *Ibid*, 1375.

[62] Paul Dash and Nicole Villermarette-Pittman, *Alzheimer's Disease*. (New York, NY: Demos Medical Publishing, 2005), 58.

[63] Peter V. Rabins, "Dementia and Alzheimer's Disease," 456.

professional medicine draws a distinction between a relatively rare form of Alzheimer's caused by specific genetic abnormalities found in certain families, that generally shows its effects earlier, and a much more common form of Alzheimer' s whose symptoms generally manifest only with age. Maire E. Percy claims that "[a]bout 90% of cases of Alzheimer's disease in the general population manifest after the age of 65 years [and] is called *late-onset Alzheimer's disease*. . . [while] [t]he other 10% of cases manifest before 65 and are called *early-onset Alzheimer's disease*." [64]

Physiology

Although virtually any layman can correctly surmise that the cognitive impairment seen in dementia is a result of some sort of malfunction within the brain, understanding how and why the brain is malfunctioning requires at least a minimal understanding of brain cell anatomy and function. Neuron is the scientific term for nerve cells, including those nerve cells present in the brain. *Neurons* are designed for a life time of service, but can under certain circumstances, malfunction and/or die. Brain function, especially in ordering complex body functions such as memory, speech, swallowing, and walking requires sophisticated communication and coordination between neurons. Communication between neurons takes place across a *synapse*, a very small space between the cells across which impulses are sent through the action of a *neurotransmitter*, a chemical substance created and released by a neuron, such as acetylcholine, dopamine, norepinephrine, and serotonin.

[64] Maire E. Percy. "Risk Factors and Biological Consequences." In *Dementia, Aging, and Intellectual Disabilities: A Handbook*, edited by Matthew P. Janicki and Arthur J. Dalton 55-83. (Philadelphia, PA: Brunner/Mazel, 1998), 60.

Dementia disrupts communication between neurons, by impairing the function of synapses, blocking the production or reception/absorption of a neurotransmitter(s), or directly/indirectly damaging or destroying neurons themselves. According to Abhilash Desia and George Grossberg, "[s]ynaptic loss is the best pathologic correlate of cognitive decline, and synaptic dysfunction is evident long before synapses and neurons are lost." [65] As a consequence, in their view, "[o]nce synaptic function fails, even in the setting of surviving neurons, there may be little chance of effectively interfering with the disease process." [66] Khachaturian and Radebaugh report that"[i]n the case of specific behaviors seen in AD patients—namely cognitive impairment and performance decline—the most immediate precipitating event in the brain are alterations in the chemical communication pathways within and among neurons." [67] As noted above, researchers discovered that the neurotransmitter, acetylcholine, critical for the creation and retention of short term memory was abnormally low in the brains of AD patients. [68] Subsequent to that discovery, according to Khachaturian and Radebaugh, "it has been shown that

[65] Abhilash Desia and George Grossberg. "Diagnosis and Treatment of Alzheimer's Disease." *Neurology* 64, no. 12 (Supp. 3 (June 28, 2005): S3

[66] *Ibid.*

[67] Khachaturian and Radebaugh, *Alzheimer's Disease*, 6.

[68] Joan K. Glickstein, *Therapeutic Interventions in Alzheimer's Disease*. (Gaithersburg, MD: Aspen Publishers, 1997), 13. Glickstein claims that this discovery was the "first clear biochemical abnormality associated with Alzheimer's disease. . . and represented a major advance in our understanding of the disease." As also noted above, Glickstein reports that "[w]hile studying the hippocampus and cerebral cortex of Alzheimer's patients, investigators have consistently found the activity of the enzyme choline acetyltransferase (CAT) to be severely reduced. . . reflect[ing] the loss of cholinergic, or acetylcholine-releasing, nerve terminals in these two regions of the brain." According to Glickstein, "[d]ecreases in acetylcholine metabolism have been shown to correlate with both neuropathological and cognitive changes in Alzheimer's disease." Of significance for evaluating the overall significance of neurotransmitter loss, Glickstein notes that '[a]lthough nerve cells that make acetylcholine seem to be the earliest and most severely affected cells, many other types of nerve cells also deteriorate,. . . include[ing] normadrenaline, serotonin, somatostatin, corticotrophin releasing factor, and others."

the disease also involves abnormalities in other neurotransmitters as well as in other chemical signals that modulate neuronal activity." [69]

Neurons are not without their own significant vulnerability to damage and death. [70] Khachaturian and Radebaugh claim that "survival of nerve cells in the brain depends on the proper functioning of many interrelated systems. . . [that] modulate [a nerve cell's] *communication, metabolism, and repair*." [71] In their view, "disruption of the function of these systems can occur as a result of internal (endogenous) factors, such as changes in an individual's nutritional, immune, or neuroendocrine status," or from "external (exogenous) factors such as toxins, trauma, or infectious agents." [72]

All the cells in the body need adequate blood flow, transporting sufficient oxygen and a source of energy to the cell and carrying away carbon dioxide and waste products. Neurons are no exception, but may exhibit a greater sensitivity and thus vulnerability than most other cells. Any form of sustained compromise in the blood flow to a cell can inflict permanent damage, and it is well known that neurons in the brain are especially vulnerable to an acute loss of oxygen occurring as a result of a blood clot that blocks the flow of blood (stroke), or a significant reduction or elimination of oxygen in the blood due to inhalation of water (drowning) or other short term calamity temporarily interrupting the lung's' capacity to exchange carbon dioxide for oxygen. What is less well known is that neurons can also be damaged by a chronic reduction in

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[69] Khachaturian and Radebaugh, *Alzheimer's Disease,* 6.

[70] Teresa Gomez-Isla and Tara Spies, et. al. Gomez-Isla, Teresa, Tara Spies, Alix De Calignon and Bradley T. Hyman. "Neuropathology of Alzheimer's Disease." In *Handbook of Clinical Neurology*, edited by Michael J. Aminoff, Francois Boller, and Dick F. Swaab, 233-43. (Edinburgh, Scotland: Elsevier, 2008), 236.Gomez-Isla and Spies claim that research findings suggest that "cortical neurons, primarily responsible for cortico-cortical projections, are specifically and selectively vulnerable in Alzheimer's disease."

[71] Khachaturian and Radebaugh, *Alzheimer's Disease,* 6.

[72] *Ibid*.

blood flow occurring over a much longer period of time that slowly but inexorably impairs their functional capacity. Dementia can thus result from either an acute episode of oxygen deprivation to certain neurons in the brain or a chronic reduction in blood flow to those neurons over time. Neurons also need a constant supply of energy to function properly, and are, according to Khachaturian and Radebaugh, "extremely demanding and fussy about the metabolic fuel they consume; they need an abundant supply of pure glucose." [73] Khachaturian and Radebaugh report that "positive emission tomography (PET), has shown that in AD patients certain parts of the brain involved in cognitive functioning are unable to utilize glucose properly," and that not only is the '[t]he synthesis of acetylcholine, the key neurotransmitter for memory,. . highly dependent on glucose metabolism in the brain," [74] but that "[a]nother consequence of chronic glucose insufficiency in the brain is the conversion of a harmless and essential neurotransmitter, glutamate, into a potential killer of neurons." [75],[76]

Khachaturian and Radebaugh further inform that yet another "essential system for maintaining the health of a neuron is its ability to control and balance opposing biochemical events, one involving the mechanisms of protein and membrane synthesis, the other involving the processes that degrade or digest proteins." [77],[78] In their view, a "mistake in the synthesis of

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[73] Khachaturian and Radebaugh, *Alzheimer's Disease*, 8.

[74] *Ibid*.

[75] *Ibid*.

[76] *Ibid*. Khachaturian and Radebaugh explain how glutamate kills neurons: "Glutamate is an excitatory amino acid; in appropriate amounts it is essential for development and normal functioning of neurons, but, as with other excitatory amino acids, in excessive amounts it can become toxic to the very neurons it normally stimulates. Glutamate becomes neurotoxic when too much of it is present at a synapse or when, in normal amounts, it stimulates a glucose-deprived neuron. Glutamate toxicity is mediated by the influx of calcium into the cell, and it is the excessive internal concentration of calcium that eventually kills the cell."

[77] *Ibid*, 9.

any one of these proteins could interfere with essential cellular function and lead to a failure in a neuron's ability to communicate vital information." [79] As noted above, compromise of the body's immune system, and/or malfunction of its neuroendocrine system can also precipitate dementia. Finally, Domenico Pratico implies that excessive oxidation might also damage neurons. He claims that "AD brains exhibit evidence of. . . oxidative stress," [80] "report[ing] that "[t]he evidence accumulated so far clearly indicates that oxidative stress is an early and specific aspect of AD but not other forms of dementia." [81]

Sources of injury internal to the body are not the only threat to neurons; they can also be damaged or destroyed from external sources such as trauma, infections, or toxins. That serious head injury can cause significant brain damage is well known. Various infectious agents can also damage and destroy neurons, especially in individuals with a compromised immune system. Khachaturian and Radebaugh suggest that damage to brain cells from exposure to toxic compounds can result, at least in part, from Alzheimer's disease induced failure of the blood-brain barrier in the brain:

> Pathological changes in the capillaries of the brain imply that the function of the blood-brain barrier (BBB) is altered in AD," which is of no little significance since "[t]he BBB allows oxygen, glucose, and other essential nutrients and chemicals to pass from the capillary circulation into brain tissue while at the same time preventing the passage of undesirable compounds such

[78] *Ibid.* Khachaturian and Radebaugh claim that "[a] neuron, to function properly, must renew between 50,000 and 100,000 different types of protein."

[79] *Ibid*, 9

[80] Domenico Pratico. "Oxidative Stress in the Development of Alzheimer's Disease and other Dementias." In *Alzheimer's Disease: A Physician's Guide to Practical Management*, edited by Ralph W. and Brigitte Zoeller Richter, 33-38. (Totowa, NJ: Humana Press, 2004), 33.

[81] *Ibid*, 37.

as environmental toxins [such as aluminum] [82], pathogens, and drugs. [83]

Teresa Gomez-Isla and Tara Spies, et. al report that Alzheimer's disease is characterized by the presence of lesions in the brain: "The intraneuronal neurofibrillary tangles and extracellular deposits of amyloid called [neuritic] senile plaques [are the positive lesions], . . . the negative lesions are "massive neuronal loss, especially in limbic and association cortices, leading to gross atrophy of the brain [decreasing brain weight by as much as a third]" [84] [85] and, in their view, "a substantial loss of presynaptic markers such as synaptophysin, suggestive of an impairment of function of neural systems." [86] They further inform that" functional studies from PET techniques to functional MRI confirm marked alterations in neural metabolism in the advanced Alzheimer brain," [87] suggesting that a "third type of lesion occur[s] in denedrites and axons that. . .reflect changes in morphology, trajectories, and post-synaptic structures that may also contribute to the breakdown of neural system function." [88],[89]

[82] Khachaturian and Radebaugh, *Alzheimer's Disease,* 9. Khachaturian and Radebaugh report that autopsy results appear to implicate aluminum in Alzheimer's disease: "Among the many potentially neurotoxic compounds in the environment, aluminum has captured the most attention. . . While autopsy analyses of the brains of AD patients have produced conflicting results depending on methods used, there appears to be a modest accumulation of aluminum in the brain lesions."

[83] *Ibid*, 8.

[84] Gomez-Isla, Spies, deCalignon, and Hyman, "Neuropathology of Alzheimer's," 233.

[85] National Hospice and Palliative Care Organization. "Caring for Persons with Alzheimer's and Other Dementias." 16. http:www.nhpco.org/files/public/Dementia-Caring Guide-Final.pdf. The NHPCO claims that brain shrinkage is not just due to neuron loss but from the accumulated debris from dead neurons: "Studies have shown that a brain with advanced Alzheimer's disease has undergone severe shrinkage due to cell loss and widespread debris from dead and dying neurons."

[86] Gomez-Isla, Spies, deCalignon, and Hyman, "Neuropathology of Alzheimer's," 233.

[87] *Ibid*.

[88] *Ibid*.

[89] *Ibid*.

The neurofibrillary tangles are composed of a protein, tau, which occurs naturally in neurons, and as pointed out above, are composed of a paired helical filament that appears to resemble a tangle. Joan Glickstein claims that although these tangles can be "found in the brains of persons who have never developed Alzheimer's disease, they are not normally present in large quantities in the human brain, regardless of age," [90] but "ha[ve] been identified in the brains of boxers who have suffered a condition known as 'dementia pugilistica' or punch-drunk syndrome,' leading some scientists to conjecture a relationship between head trauma and the onset of Alzheimer's." [91] According to Glickstein, tangles can be "found in the neuritis, the long extensions of neurons through which impulses are transmitted to synapses; the hippocampus; and the cerebral cortex, . .[and in brainstem neurons that release neurotransmitters." [92] Given the possible distribution of tangles in the brain, they appear to be ample opportunities for them to disrupt the function of neurons and synapses, and retard the production/reception/absorption of neurotransmitters.

As noted, the plaques are primarily composed of amyloid, specifically, as reported by Gomez-Isla and Spies, an "amyloid beta peptide, Alpha Beta 40 and Alpha Beta 42, derived from the amyloid precursor protein [APP]." [93] Glickstein informs that "[a]myloid is a minor byproduct of APP metabolism that accumulates slowly with age, [94] [but that]. . .[i]n the AD brain the amyloid byproduct of APP appears to collect more rapidly and is concentrated at first in the

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[90] Joan Glickstein, *Therapeutic Interventions*, 11.

[91] *Ibid*.

[92] *Ibid*.

[93] Gomez-Isla, Spies, deCalignon, and Hyman, "Neuropathology of Alzheimer's," 233.

[94] Dennis J. Selkoe. "Biochemistry and Molecular Biology of Amyloid Beta-protein and the Mechanism of Alzheimer's Disease." In *Handbook of Clinical Neurology*, edited by Michael J. Aminoff, Francois Boller, and Dick F. Swaab, 245-60. (Edinburgh, Scotland: Elsevier, 2008), 249. According to Selkoe, "Alpha-Beta is actually secreted by healthy cells through out life and occurs in the cerebrospinal fluid (CSF) and plasma of normal humans."

muscular middle layer of a brain blood vessel and advances outward." [95],[96] It must be noted, that similar to the presence of tangles in the brains of individuals with no apparent clinical symptoms of dementia, the presence of plaques may not necessarily impact neuronal function sufficiently to produce clinical symptoms. "Diffuse" plaques, according to Gomez-Isla and Spies, "do not appear to have a substantial effect on the landscape of neurons . . . [yet] 'neuritic' plaques. . .are surrounded by disruption in the neuropil, local glial activation, and often dystrophic axons and dendrites." [97] Glickstein points to research by Glenner, who "examined a series of 350 brains of patients diagnosed with having Alzheimer's disease premorbidity and found deposits of amyloid plaques in 92% of the brains studied, . . usually located in the cerebral cortex, the hippocampus, and the amygdale. . . and tend[ing] to correlate closely with the extent of dementia." [98] (11). Once again, and as was noted above re: tangles, given the possible distribution of neuritic plagues in the brain, there are apparently ample opportunities for them to disrupt the function of neurons and synapses, and retard the production/reception/absorption of neurotransmitters.

Khachaturian and Radebaugh report that neuritic plaques and neurofibrillary tangles "which are found in the brains of AD patients at autopsy. . .are both consequences of abnormalities in the processing of different types of proteins." [99],[100] In their assessment, the neurofibrillary tangles form as a result of "abnormal phosporylation" of tau, a process that

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[95] Joan Glickstein, *Therapeutic Interventions,* 11.

[96] Khachaturian and Radebaugh, *Alzheimer's Disease*, 9. According to Khachaturian and Radebaugh, "[a]myloid protein has the unusual characteristics of being highly insoluble and resistant to degradation, thus readily accumulating within the nervous system"

[97] Gomez-Isla, Spies, deCalignon, and Hyman, "Neuropathology of Alzheimer's," 233.

[98] *Ibid*.

[99] Khachaturian and Radebaugh, *Alzheimer's Disease*, 9.

[100] Joan Glickstein, *Therapeutic Interventions,* 11. Glickstein reports that "it is hypothesized that the brains of Alzheimer's patients synthesize below-normal quantities of proteins in general [and]. . . [o]ne explanation may be deficiency of RNA, the nucleic acid that mediates the translation of DNA to manufacture protein."

interferes with the protein's role in the construction of vital intercellular transport structures known as microtubules." [101] They concede that how the neuritic plaques "interfere with cell function is not totally clear, but there are some suggestions that the aggregations of [Alpha]-[B]eta-amyloid become highly toxic to neurons in a way similar to glutamate." [102],[103]
As to a comparative assessment of the respective damage done by tangles, plaques, and what they described above as massive neuronal loss, Gomez-Isla and Spies claim that although "[n]euronal loss is striking, [it is] to a great extent circumscribed to the specific areas of the neocortex, limbic systems, and subcortical ascending projection systems." [104] On the other hand, they note that "[e]ven in areas that develop tangles, neuronal loss far exceeds the number of tangles that are formed." In comparing the probable damage from tangles relative to the probable damage from plaques, in their view, "numerous clinical pathological correlation studies suggest that tangles are more closely related to clinical symptoms than plaques. . .[and that] [t]angle distribution matches dementia better than plaques in a cohort of Alzheimer's patients." [105]

There is no doubt that the presence of both plaques and tangles in the brains of individuals without apparent symptoms of dementia seems to challenge any theory that plaques and tangles

[101] Khachaturian and Radebaugh, *Alzheimer's Disease*, 9.

[102] *Ibid*.

[103] John P. Blass "Metabolism and Alzheimer's Disease." In *Alzheimer's Disease: A Physician's Guide to Practical Management*, edited by Ralph W. and Brigitte Zoeller Richter, 39-47. (Totowa, NJ: Humana Press, 2004), 39. Blass suggests that the abnormal production of amyloid also impacts the function of synapses: "The dominant although still controversial opinion . . .is that the most important seminal alteration of AD is abnormal metabolism of amyloid,. . . the amyloid cascade hypothesis. In its most recent form this hypothesis states that soluble fragments of amyloid precursor protein. . . interfere directly with synaptic function and thereby interfere with information processing by the AD brain."

[104] Gomez-Isla, Spies, deCalignon, and Hyman, "Neuropathology of Alzheimer's," 233.

[105] *Ibid*, 236.

are the primary mechanism of neuronal damage and death. Ladislav Volicer discusses the possible implications:

> Neuritic plaques and neurofibrillary tangles are present in small quantities even in the brains of elderly individuals who were not demented before they died. This finding indicates that formation of plaques and tangles may be a part of the normal aging process but that does not mean that everybody who develops plaques and tangles has to develop dementia. Only about one-half of individuals who on autopsy had enough plaques and tangles to be diagnosed as having AD but did not have any cerebrovascular changes were clinically demented before death. [106]

One possible explanation, as noted, is the nature of the plaques as well as the location of the tangles. As pointed out by Dennis Selkoe, "the brains of aged, cognitively intact humans often contain Alpha-Beta [amyloid] deposits, but these are overwhelmingly of the diffuse type, with relatively few neuritic plaques and neurofibrillary tangles found in the cerebral cortex." [107]

Another explanation is that the tangles and plaques are precursors of eventual neuronal dysfunction and loss that has not as yet manifested itself sufficiently to create clinical symptoms. Selkoe suggests that"[i]n this context, it is not unreasonable to draw a rough analogy between the diffuse Alpha-Beta [amyloid] deposits and the fatty streaks observed in the arteries of humans who have not yet experienced any clinically noticeable cardiovascular or cerebrovascular events." [108] A third explanation is that the plaques and tangles are not the primary mechanism that causes neuronal dysfunction and death, but simply coincidental with another cause, and can

[106] Ladislav Volicer, "Palliative Medicine in Dementia," 1376.

[107] Dennis Selkoe, "Biochemistry and Molecular Biology," 247.

[108] *Ibid*, 246.

therefore, be present in the brain without neuronal impairment significant enough to produce clinical symptoms of dementia. [109]

Even if it there is at least general agreement that tangles are, at least potentially, more injurious to neurons in the brain than plaques, there remains some apparent uncertainty as to the relationship between tangles and plaques. The prevailing theory is that plaques precede tangles. According to Christian Schultz, Kelly Del Tredici, and Heiko Braak "[i]t has been postulated [though apparently not demonstrated to everyone's satisfaction] that neurofibrillary changes are a secondary phenomenon induced by the toxic influence of extra cellular Alpha-Beta-amyloid deposits known as 'plagues." [110] Richard Caselli, Thomas Beach, Roy Yaari, and Eric Reiman describe what has been termed the amyloid cascade hypothesis:

> The accumulated evidence suggests that plaques occur prior to tangles in neocortical regions and that the latter are formed mainly as a neuronal reaction to plaques (although the earliest neurofibrillary changes in transentorhinal and entorhinal cortex may precede other neuropathology) . . .The 'amyloid hypothesis' posits that Alpha-Beta aggregation is the primary event leading to AD that secondarily causes all other relevant pathologic changes in the disease, including neurofibrillary tangle formation, loss of synapses, neuronal death, and dementia.[111], [112], [113]

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[109] Marie E. Percy, "Risk Factors and Biological Consequences," 66-7. This is similar to a possible explanation posited by Marie Percy: "It is speculated that a fundamental problem in Alzheimer's disease may be an impaired ability of neurons and other cells to protect themselves against normal wear and tear. Perhaps [tangles] and [plaques] develop as a response to injury of neurons and blood vessels and the deposition of amyloid beta protein is involved in this process. Markers on damaged neurons or blood vessels (or that are released by them) might muster the microglia and astrocytes into action to inactivate, engulf and/or 'wall off' the injured cells."

[110] Christian Schultz, Kelly Del Tredici, and Heiko Braak. "Neuropathology of Alzheimer's Disease." In *Alzheimer's Disease: A Physician's Guide to Practical Management,* edited by Ralph W. and Brigitte Zoeller Richter, 21-32. (Totowa, NJ: Humana Press, 2004), 27.

[111] Richard Caselli, Thomas G. Beach, Roy Yaari, and Eric M. Reiman. "Alzheimer's Disease a Century Later." *Journal of Clinical Psychiatry* 67, no. 11 (November 2006):1789-90.

[112] Caselli, Beach, Yaari, and Reiman. "Alzheimer's Disease A Century Later," 1790. Caselli, Beach, Yaari, and Reiman also claim that "[i]ncreasing evidence suggests that soluble Alpha-Beta oligomers may be more damaging to neurons than the nonsoluble plaques, themselves."

Nevertheless, for Teresa Gomez-Isla and Tara Spies, et. al., the need to know with certainty the relationship between tangles and plaques may be an academic distinction. In their view, both tangles and plaques create neuronal dysfunction and death:

> It now seems clear that both types of lesion dramatically target connections between specific neuroanatomical units" (238). Synapses are lost, dendrites are misshapen, dendritic spines disappear, axons become dysmorphic and adopt bizarre trajectories, and white matter lesions are readily evident even at the level of MRI scans. Taken together, it appears as if tangles and plaques both target and disrupt the fundamental units of neuronal function: the dendritic-axonal networks whose normal function is critically dependent on the timing of volleys of afferent information among neural units.[114], [115]

Given the foregoing discussion of the possible mechanisms by which dementia, especially Alzheimer's disease, disrupts and ultimately destroy the ability of neurons to communicate, it becomes clear why dementia is most often experienced by individuals sixty-five years old and older. The explanation, provided by Paul Dash and Nicole Villermarette-Pittman, is that the neurons in older brains already suffer from minimal conductivity:

> The changes undergone by the brain in the process of normal aging explain, at least in major part, the differences between early-onset AD and the late-onset form. The older brain has lost synapses and has shrunken or lost pyramidal neurons. This still normal older brain is, therefore, closer to a threshold of minimal connectivity where signs of dementia would appear with only relatively

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[113] There remains at least some measure of uncertainty as to the relationship between tangles and plaques and their individual role in brain pathology. Further discussion of these issues is provided in the Appendix, number 1.

[114] Gomez-Isla, Spies, deCalignon, and Hyman, "Neuropathology of Alzheimer's," 238.

[115] Volicer Ladislav, "Palliative Medicine in Dementia,"1376. Volicer describes the anatomical pathology in the brain in Dementia with Lewy Bodies and Frontotemporal Dementia that distinguish these forms of dementia from Alzheimer's: "Dementia with Lewy bodies is characterized during autopsy by the presence of round structures called Lewy bodies. These structures are found inside the nerve cells in the brain cortex. Lewy bodies are also present in Parkinson's disease, but in Parkinson's disease, they are limited to subcortical areas of the brain" "Atrophy of the frontal and temporal lobes of the brain and proliferation of non-neuronal glial cells in these areas characterize pathological findings in frontotemporal dementia."

little further loss due to disease.[116]

It also seems apparent that the neurons in certain areas of the brain are more vulnerable to mechanisms that cause dysfunction and death than those neurons located in other regions of the brain, and this may help explain why Alzheimer related impairments ordinarily have a particular sequence and the disease a generally predictable trajectory. According to Schultz, Del Tredici, and Braak, "[t]he destructive process that underlies the neurofibrillary pathology in AD commences in a few susceptible types of nerve cells in predisposed cortical induction sites and subsequently invades other portions of the cerebral cortex and specific sets of subcortical nuclei. . . but. . . targets only a few of the many types of nerve cells in the human brain." [117] They note that "[t]he pathological changes evolve according to a predictable topographic sequence with little variation among individuals," and concede that" it is still unknown why some kinds of neurons tend to develop [neurofibrillary tangles and/or neuritic plaques whereas others do not do so until the last stages of the disease." [118]

Agnieszka Jaworska claims that "[i]n the early stages of Alzheimer's the neuronal damage affects primarily the hippocampus. . .[and even as the damage spreads elsewhere, it] continues to be affected much more severely than the other regions of the brain." [119] Dash and Villermarette-Pittman maintain that "Alzheimer's disease pathology begins in the hippocampus [as well as the] *entorhinal cortex,* [and] because short-term memory requires these brain areas, problems with it

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[116] Dash and Villermarette-Pittman, *Alzheimer's Disease,* 34.

[117]Schultz, Del Tredici, and Braak, "Neuropathology of Alzheimer's Disease," 21.

[118] *Ibid*, 12.

[119] Agnieszka Jaworska,. "Respecting the Margins of Agency: Alzheimer's Patients and the Capacity to Value." *Philosophy and Public Affairs*. 28, no. 2 (Spring 1999):109.

are usually among the first and most prominent of AD symptoms." [120] Jaworska further claims that although "[t]he hippocampus is of crucial importance in acquisition and processing of long-term explicit memory for facts and events. . . [it] is [actually] [n]ot involved in short-term memory or in the eventual storage of long-term memories. . . [but essential] nonetheless. . .in transforming a fresh short-term memory into a lasting long-term memory." [121] Typically, in her view, "[d]amage to the hippocampus affects neither a person's processing of her immediate experience nor her memories of events that occurred long before the damage, [but does] cause her to lose track of ongoing events soon after they happen so that she typically has no recollection of the previous day." [122]

Eventually, according to Dash and Villermarette-Pittman , when parts of the cerebral cortex are damaged. . . old memories may be lost." [123] Gomez-Isla and Spies, et. al. observe:

> Neuronal loss [in Alzheimer's disease] is striking, yet to a great extent circumscribed to the specific areas of the neocortex, limbic systems, and subcortical ascending projection systems. . . [often leaving] [p]rimary motor and sensory cortices. . .preserved even in advanced AD. . . [and]stand[ing] out as appearing almost normal in contrast to severe atrophy of frontal, parietal, and temporal association cortex. [124]

The foregoing discussion of the physiology of dementia is obviously focused on scientific research findings re: pathological processes in the brain on the *cellular* level. Scientific understanding of pathological processes in the brain on a molecular level though by no means as

[120] Dash and Villermarette-Pittman, *Alzheimer's Disease*, 34

[121] A. Jaworska, "Respecting the Margins of Agency," 121.

[122] *Ibid*

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[123] Dash and Villermarette-Pittman, *Alzheimer's Disease*, 31

[124] Gomez-Isla, Spies, deCalignon, and Hyman, "Neuropathology of Alzheimer's," 233

advanced as the cellular level, is also critical to the understanding of the physiology of dementia and specifically Alzheimer's disease and is examined as part of the following examination of the risk factors for dementia.

Risk Factors

Risk factors for dementia can be divided, for purposes of examination, into two categories: risks that can, at least theoretically, be reduced if not completely avoided, and risks that are apparently totally unavoidable. Unavoidable risks can be further divided into risks that have a proven genetic linkage and risks either presumed to have no genetic linkage or with a genetic linkage that is, at the time this inquiry is conducted, unproven.

Not surprisingly, a considerable amount of scientific research has been directed at identifying suspected risks of dementia that can, at least theoretically, be reduced if not completely avoided. These include cardiovascular disease, cerebrovascular disease, hypothyroidism, [125] depression, [126],[127] infections, herpes simplex type 1 virus. [128] chronic inflammation, [129] oxidative stress, [130] smoking, alcohol consumption, lack of higher education, a stressful life, [131] exposure to electromagnetic radiation, [132] and adult exposure to

[125] Marie E. Percy, "Risk Factors and Biological Consequences," 66.

[126] Richard. Mayeux. "Alzheimer's Disease Epidemiology." In *Handbook of Clinical Neurology*, edited by Michael J. Aminoff, Francois Boller, and Dick F. Swaab, 195-202. (Edinburgh, Scotland: Elsevier, 2008), 198. Mayeux notes that a history of depression may be associated with Alzheimer's disease."

[127] Marie E. Percy,"Risk Factors and Biological Consequences," 62. Percy also references a link between depression and dementia.

[128] *Ibid.* 63. Percy also reports a link between dementia and a combination of an "[AP0E-e4] genotype and expression of herpes simplex type 1 virus (HSVI)."

[129] Richard Mayeux, "Alzheimer's Disease Epidemiology" 199. Mayeux observes that "[c]hronic low grade inflammation has been associated with amyloid deposition, which it turn activates the complement cascade."

tuberculosis. [133] Obviously, a claim can be advanced that all of these, save exposure to electromagnetic radiation, may involve some level of inherited predisposition, but there nevertheless seems little doubt that reduction or elimination of these risks cannot be totally excluded.

Richard Mayeux has written a superb article on the epidemiology of Alzheimer's disease based on reported scientific research. In it he observes that a "history of heart disease, hypetension, hyperlipidemia, homocysteinemia, diabetes, obesity and the metabolic syndrome have all been implicated." [134] in Alzheimer's disease and that a "history of diabetes and hyperinsulinemia doubles the risk of Alzheimer's disease overall." [135] Anne Harding adds that in a 2011 study conducted in Japan, "researchers found that people with diabetes were twice as likely as the other study participants to develop Alzheimer's disease within 15 years. They were also 1.75 times more likely to develop dementia of any kind." [136]

Mayeux claims that "[p]ropsective studies have shown that smokers have a 2-4-fold increase in the risk of Alzheimer's disease, particularly those individuals without an APOE-e4 allele," [137] and that "[e]xcessive alcohol use has been shown as a possible cause of dementia,

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[130] *Ibid*. Mayeux reports that "[o]xidative stress may contribute to the aging process and the pathological changes associated with Alzheimer's disease."

[131] Ladislav Volicer, "Palliative Medicine in Dementia," 1376.

[132] Marie E. Percy, "Risk Factors and Biological Consequences," 62.

[133] *Ibid*.

[134] Richard Mayeux, "Alzheimer's Disease Epidemiology" 199.

[135] *Ibid*.

[136] Anne Harding, "Diabetes Doubles Alzheimer's Risk." 1. http://health.yahoo.net/articles/alzheimers/diabetes-doubles-alzheimers (accessed on October, 30, 2011).

[137] Richard Mayeux, "Alzheimer's Disease Epidemiology" 199.

mainly through associated nutritional deficiencies and through acute toxic toxicity." [138] Khachaturian and Radebaugh report that "[p]eople who achieve only a low level of education double the risk of developing AD compared to those who have had 6 to 8 more years of schooling," [139] commenting that "[e]ducation presumably increases the brain's reserve capacity such that the clinical manifestations of AD are delayed or become more difficult to detect." [140] Mayeux, on the other hand, observes that although "[f]ailure to attain higher education has been associated with an increased risk for Alzheimer's disease . . . despite the robust inverse association between educational achievement and Alzheimer's disease, quantitative post mortem studies do not provide confirmation" [141],[142],[143]

Scientific research has also identified totally unavoidable risk factors for dementia. These include, age, female gender, and traumatic head injury. That age is a critical risk factor for dementia seems unchallenged. In fact, the American Association for Geriatric Psychiatry, the Alzheimer's Association, and the American Geriatrics Society's joint statement (hereafter referred to as Consensus Statement) indicates that the "primary risk factors for AD are age and family history." [144] Khachaturian and Radebaugh inform that "[t]he percentage of the population affected doubles for every decade people live beyond the age of 65." [145] Accordingly, in their

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[138] *Ibid*.

[139] Khachaturian and Radebaugh, *Alzheimer's Disease*, 5.

[140] *Ibid*.

[141] Richard Mayeux, "Alzheimer's Disease Epidemiology," 199.

(a) [142] American Association for Geriatric Psychiatry, et. al., "Consensus Statement," 5. The Consensus Statement also points to a link between lower educational level and Alzheimer's disease.

[143] Ladislav Volcier,"Palliative Medicine in Dementia," 1376.

[144] American Association for Geriatric Psychiatry, et. al.,"Consensus Statement," 4.

[145] Khachaturian and Radebaugh, *Alzheimer's Disease*, 5.

estimation, “10% of all people 65 and older have AD, 20% of the over 75 population will be affected, and 40% over age 85.” [146] Khachaturian and Radebaugh also claim that [a] “ history of severe head injury that leads to brief loss of consciousness doubles the risk of developing AD,” [147] but Mayeux counters that “[t]he relationship between traumatic head injury and Alzheimer’s disease remains inconsistent.” [148],[149],[150] Finally, the Consensus Statement claims that females have a greater risk of dementia [151] than males, although it is not clear how much of this risk is attributable to their greater longevity.

Other unavoidable risk factors for dementia exist. These risks come about as result of either a well-established link to an inherited genetic abnormality, or a link to genetic abnormality that is, at the time this inquiry is conducted, suspected but unproven. There is little doubt of the existence of some sort of genetic predisposition to dementia. According to Selkoe, “[i]t has long been recognized that AD can occur in an inherited form that transmits an autosomal [transmitted to both sexes] dominant trait.” [152] He claims that “[e]stimates of the portion of AD cases that are genetically based have varied widely from as low as 10% to as high as 40% or more, and [that]

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[146] *Ibid*.

[147] *Ibid*, 4.

[148] Richard Mayeux, “Alzheimer’s Disease Epidemiology,” 199.

[149] Ladislav Volicer, “Palliative Medicine in Dementia,” 1376.

[150] American Association for Geriatric Psychiatry, et. al., “Consensus Statement,” 4. The Consensus Statement also points to a link between previous head injury and Alzheimer’s disease.

[151] *Ibid*, 4.

[152] Dennis Selkoe,“Biochemistry and Molecular Biology,” 249.

some investigators believe that, in the fullness of time, virtually all cases will be shown to have some polymorphic genetic risk factors." [153] Glickstein reports:

> In a series of studies conducted on families from Minnesota, Heston demonstrated an increased risk for secondary cases of Alzheimer's disease in first degree relatives; [specifically that]. . .close relatives of a person with Alzheimer's disease (parents and siblings) are about twice as likely to develop the disease as more distant relatives, but not necessarily twice as likely as the public at large. [154]

There is clearly some uncertainty as to the significance of this risk. Stephen Post apparently claims that the risk doubles: "Informal estimates are that, at current life expectancies, the risk of eventual AD is about one in five in a random sampling of people, [but] may rise to about two in five in a sample of people with an AD-affected first-degree relative." [155] Khachaturian and Radebaugh, on the other hand, seem to suggest that the risk is even higher: "[A] history of AD in a first degree relative (parent or sibling) increases the odds of developing AD three-to fourfold." [156] Some of the uncertainty may result from a failure to separate the inherited genetic risk of early-onset Alzheimer's disease from the risk of late-onset Alzheimer's disease. It is an important distinction.

Mayeux identifies three inherited genetic abnormalities that dramatically increase the risk of early-onset (usually occurring before the age of 65) Alzheimer's disease: "Mutations in the amyloid precursor protein (APP) gene on chromosome 21, the presenilin 1 (PSEN1) on chromosome 14 and the presenilin 2 (PSEN2) on chromosome 1 result in an autosomal dominant

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[153] *Ibid*.

[154] Joan Glickstein, *Therapeutic Interventions*, 10.

[155] Stephen Post, "The Moral Challenge," 66.

[156] Khachaturian and Radebaugh, *Alzheimer's Disease*, 4.

form of the disease beginning as early as the third decade of life." [157] According to Gomez-Isla and Spies, et. al. "[t]he presenelin 1, presenelin 2, and amyloid precursor protein genes each contain mutations that lead to increased production of amyloid-Beta protein, increased production of the longer form of Alpha-Beta (Alpha-Beta 42), or an increased propensity of Alpha-Beta to form fibrils." [158] Percy informs that "[presenelin 1 mutations] account for about 50% of early onset familial [159] Alzheimer's disease. . .[while] cases of Alzheimer's disease associated with mutations in the presenilin 2. . .occur rarely. . .are not always expressed. . . are highly variable and are expressed over a wide age range from 45 to 88 years." [160] Glickstein claims that "[r]esearchers know now that people with particular abnormalities in the sequence of their amyloid precursor protein (APP) gene on chromosome 21 are almost certain to develop Alzheimer's disease by the age of 60. . . [but there is] no evidence that these chromosomes are associated with cases that occur after age 65." [161] Individuals with Down's syndrome have three copies of chromosome 21 instead of the normal two. Mayeux reports that "[t]he risk of Alzheimer's disease associated with a family history of Down's syndrome is increased 2-3-fold." [162] As significant as the risk of early-onset may be to certain families, it is important to note, as pointed out by Stephen Post, that "only an estimated 2 to 3 per cent of AD is early on-set familial." [163],[164]

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[157] Khachaturian and Radebaugh, *Alzheimer's Disease*, 196.

[158] Gomez-Isla, Spies, deCalignon, and Hyman, "Neuropathology of Alzheimer's," 235.

[159] Marie E. Percy, "Risk Factors and Biological Consequences," 60. Percy notes that "17 apparently pathogenic mutations resulting in familial Alzheimer's disease have been described in [presenilin 1]."

[160] *Ibid*.

[161] Joan Glickstein, *Therapeutic Interventions*, 10.

[162] Richard Mayeux, "Alzheimer's Disease Epidemiology," 198.

[163] Stephen Post, "The Moral Challenge," 66.

Mayeux reports that the "[t]he epsilon 4 (e4) variant of the apoliporpotein-E (APOE) [on Chromosome 19] has been associated with both sporadic and familial disease with onset usually after 65." [165],[166],[167] There are three different alleles of this gene, APOE-e2, APOE-e3, and APOE-e4, respectively. Because an individual inherits an APOE gene from his/her mother and one from his father, he/she can have six different combinations of APOE alleles. [168] As pointed out by Glickstein, much depends on which combination of alleles are inherited:

> The e4 version (APOE-e4), normally present in about 14% of the population, is much more common in people with late-onset Alzheimer's disease (40-50%) than it is in people without the disease. This is true for people with or without a history of Alzheimer's disease. However, there are many Alzheimer's patients who do not have this gene. [169] Because this gene has also been identified in people over the age of 80 who do not have Alzheimer's disease, APOE-e4 has been called a susceptibility gene. [170],[171],[172]

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[164] Marie E. Percy,"Risk Factors and Biological Consequences," 61. Percy reports the discoveries of an association between early-onset Alzheimer's disease and two additional genetic abnormalities: "[A] lowered age at onset of early-onset was found to be associated with the HLA-2A locus in the major histocompatability complex on chromosome 6."

[165] Richard Mayeux, "Alzheimer's Disease Epidemiology," 198.

[166] Joan Glickstein, *Therapeutic Interventions*," 10. Glickstein informs that "[a]s the name implies, [apolipoprotein-E] is part lipid and part protein. . . [and] [i]ts known function is to help guide cholesterol around the body and into cells."

[167] Khachaturian and Radebaugh, *Alzheimer's Disease*, 10. Khachaturian and Radebaugh provide a more detailed description of brain pathology for individuals that possess a APOE-e4 gene(s): "Among Alzheimer's patients, those who have the gene for [AP0E-e4] have larger plaques than those who lack the gene. It appears that [AP0E-e4] acts as a chaperone to APP and, in some unknown way, promotes the formation of neuritic plaques. It has also been postulated that it plays an important role in the formation of neurofibrillary tangles. In the brain ApoE proteins are taken up by the neurons in large quantities after neuronal injury and appear to play an important role in various recuperative processes and in neuronal plasticity."

[168] 2:2. 2:3, 2:4, 3:3, 3:4, and 4:4

[169] Marie E. Percy, "Risk Factors and Biological Consequences," 61. Maire. E. Percy reports that "more than 90% of people with [an e-4 allele] do not have Alzheimer 's disease."

[170] Joan Glickstein, *Therapeutic Interventions*, 10-11.

[171] *Ibid*. Glickstein claims that "[s]usceptibility genes differ from disease genes in their expression. . . [for] [u]nlike the 'disease' gene that dictates certainty in the development of the disease, a susceptibility gene increases the risk but often requires other factors to trigger its action."

The Mayo Clinic claims that although having at least one e4 gene increases an individual's risk of developing Alzheimer's disease, two e4 genes creates an even higher risk. [173] According to Glickstein, "[a]bout 2 to 3% of the US population carry two e-4 genes and develop Alzheimer's disease at age 70." [174] Khachaturian and Radebaugh add that these individuals "have a 5:1 odds of developing AD, compared with 15:1 odds in individuals who have a single ApoE4 gene,. . .[and make up] between 25 and 40 % of AD cases. . . including 90%. . .of the late-onset sporadic cases of AD before age 85." [175]

Glickstein reports that individuals with two e3 genes "develop Alzheimer's disease 15 years later, on average, than people with two e-4s. . . [and][with] a combination of one e-3 and one e-2, the typical onset is later still." [176],[177] e-2 genes are not only the least common, Glickstein calls it "relatively rare," [178] the presence of two -e2 genes, according to Glickstein, "suggests that persons with this [allele combination] may have a reduced risk of the disease." [179] Mayeux cautions that although "[t]he association between the APOE-e4 allele and Alzheimer's disease

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[172] Mayo Clinic Staff. "Alzheimer's Disease." MayoClinic,com http:www.mayoclinic.com/health/alzheimers-genes/AZ00047 (accessed on October, 30, 2011).The Mayo Clinic staff claims that the e-4 is "not a causative gene, which means that "other genetic and environmental factors are likely involved in the development of Alzheimer's."

[173] *Ibid*.

[174] Joan Glickstein, *Therapeutic Interventions*, 11.

[175] Khachaturian and Radebaugh, *Alzheimer's Disease*, 10.

[176] Joan Glickstein, *Therapeutic Interventions*,11.

[177] Mayo Clinic Staff. "Alzheimer's Disease." The Mayo Clinic informs that individuals with two e-3 genes, the most popular of the APOE alleles, don't appear to have their risk of developing Alzheimer's affected one way or the other."

[178] Joan Glickstein, *Therapeutic Interventions*, 11.

[179] *Ibid*.

has been established world-wide [it] is less robust among ethnic groups." [180] Genetic abnormality may also play a role in the development of Dementia with Lewy bodies. [181]

Percy reasons that if "mutations in the APP, PS-1 and PS-2 genes, and the [APOE-e4] allele. . .account for only about 50% of Alzheimer's disease cases. . .there must be other yet unidentified Alzheimer's disease susceptibility genes. . environmental risk factors. . .[or] [m]utations in mitochondrial DNA." [182] Not surprisingly, much scientific research has been directed at identifying additional genetic abnormalities that increase the risk for developing both early and late onset dementia. In 2007, researchers identified abnormalities in a gene identified as SORL-1 that increased the risk for late-onset Alzheimer's. [183],[184] Dr. Peter St. George-Hyslop, one of the key researchers, said it is premature to say what percentage of late-onset Alzheimer's disease can be attributed to SORL-1, but Richard Mayeux was much more enthusiastic, commenting that "[t]his appears to be the fifth Alzheimer's gene, and there are likely to be other important genetic variants that need to be identified before the entire picture is complete." [185] In 2011 Charlene Laino reported, at the annual meeting of the American Academy of Neurology, that researchers had announced the discovery of a gene identified at MTHFD1L that apparently

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[180] Richard Mayeux, "Alzheimer's Disease Epidemiology,"197.

[181] Ladislav Volicer, "Palliative Medicine in Dementia,"1376. Volicer reports that dementia with Lewy bodies may also result from a genetic abnormality: "Lewy bodies contain an alpha –synuclein protein, a substance that plays a role in apoptosis. Mutation of the alpha-synuclein gene, which is present on chromosome 2, leads to development of severe dementia with Lewy bodies."

[182] Marie E. Percy, "Risk Factors and Biological Consequences," 81.

[183] Yahoo News, "New Alzheimer's Gene." http://news.yahoo.com/s/nm/20070114/hl_nm/alzheimers_gene_dc (accessed on January 14, 2007).

[184] *Ibid*. According to the unidentified author of this article, "The researchers looked at DNA samples from 6,000 people from four ethnic groups: Caribbean-Hispanics, North Europeans, black Americans and Israeli-Arabs, and found certain variations of SORL1 more often in people with late-onset Alzheimer's disease than in healthy people."

[185] *Ibid*.

doubles the risk of late-onset Alzheimer's disease but only accounts for 5 % of inherited cases of the disease. [186] Margaret Pericak-Vance, director of the University of Miami's Mille School of Medicine's John P. Hussman Institute for Human Genomics commented that "MTHFD1L may help to explain another 5% of inherited cases of the disease,. . .[and] what makes the discovery so exciting is that the gene is known to be involved with the metabolism of foliate, which in turn influences the body's level of homocysteine which has been shown to be a risk factor for Alzheimer's." [187] "A lot of time," in her view, "we find a gene and have to figure out how it ties in to the disease, . . . [but]This finding melds the genetics to the biology." [188]

It seems almost inevitable that additional genetic abnormalities will eventually be found that are associated with the development of dementia. Pericak-Vance seems quite correct in implying that an important part of the value of the identification of an association between a genetic mutation and the development of some variation of the disease is the knowledge it provides as to how the abnormality influences a particular dementia pathology. Until science is capable of preventing genetic abnormalities or their expression, knowledge of a mutation can only serve as a potential biomarker of the disease unless scientists can use the knowledge of the genetic linkage to better understand the pathways by which pathological processes are initiated and advanced and from that understanding improve treatment methods and perhaps eventually develop a cure.

[186] Charlene Laino."New Alzheimer's Gene Found." http:www.webmd.com/alzheimers/news/20100414/bew-alzheimes. (accessed on October 30, 2011).

[187] *Ibid.*

[188] *Ibid.*

Prevention

Absent the ability to prevent genetic abnormalities or their expression, efforts at preventing dementia must, of necessity, focus on risks for developing one of the various forms of the disease that are, at least theoretically, preventable. Obviously excluded are those risks that arise from age, gender, and serious head injury, with focus placed instead on those risks identified above, as possibly preventable, including cardiovascular disease, cerebrovascular disease, hypothyroidism, depression, infections, the herpes simplex type 1 virus, chronic inflammation, oxidative stress, smoking, alcohol consumption, lack of higher education, a stressful life, exposure to electromagnetic radiation, and adult exposure to tuberculosis. In a 2006 article in the *Journal of Clinical Psychiatry* Caselli, Beach, Yaari, and Reiman reported on the result of a comprehensive survey of published research into the efficacy of various dementia prevention strategies:

> Some but not all experimental or observational studies suggest several primary prevention therapies worthy of further investigation, including but not limited to aerobic exercise, [189] mental exercise, [190] food or dietary supplements containing vitamin A, vitamin C, vitamin E, [191] flavonoids, omega-3 fatty acids, vitamin B-12, vitamin B-complex supplements, foliate or curcumin; caloric intake, the Mediterranean diet, [192],[193] moderate amounts of ethanol or red wine,

[189] Sieguer, Erica. "Alzheimer's Disease: Research Advances and Medical Reality." *The Commonwealth Fund* (July 2005): 3 www.cmfw.org. Erica Sieguer claims that "[t]wo recent studies have found a reduced risk of dementia and improved cognitive function in individuals who lead active lifestyles."

[190] Richard Mayeux, "Alzheimer's Disease Epidemiology," 199. Mayeux reports that "[t]ime spent engaged in physical and mental activities during later life has been associated with a lower risk of Alzheimer's disease."

[191] *Ibid*

[192] Defined as intake of vegetables, legumes, fruits, cereals, unsaturated fatty acids primarily from olive oil, moderately high intake of fish, regular but moderate intake of ethanol primarily from wine and low intake of meat, poultry and dairy products.

[193] Richard Mayeux, "Alzheimer's Disease Epidemiology," 199. According to Mayeux, "[w]hile the general conclusion is that diets rich in antioxidants, such as the Mediterranean diet, are beneficial [193] there have been no randomized trials as yet to support any special dietary intervention."

[194],[195] cholesterol-lowering agents, antihypertensives, insulin-sensitizing agents, and anti-inflammatory agents, [196] hormonal therapies, [197] and those putative AD-slowing treatments that prove to be safe and well tolerated in patients. [198]

To this extensive list Percy adds anti-oxidants, and the removal of toxic metals from the body, including "administration of desferrioxamine" and "chelation therapy." [199] Douglas Galasko reports research involving immunization, [200] lithium, [201] and the "inhibit[tion] of some of the key enzymes and activators of cell death [that]. . .confer neuroprotection in cell or animal models of neuron loss." [202]

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[194] Which according to the authors have led some to investigate the amyloid-modifying effects of resveratrol in grapes.

[195] Richard Mayeux, "Alzheimer's Disease Epidemiology," 199. Mayeux claims that "[s]everal studies have shown that moderate daily consumption of wine is accompanied by a lower risk of Alzheimer's disease."

[196] *Ibid*, 199. According to Mayeux, the "[u]se of anti-inflammatory agents was found to be less frequent among patients with Alzheimer's disease than among controls."

[197] Caselli, Beach, Yaari, and Reiman. "Alzheimer's Disease A Century Later," 1796; Douglas Galasko. "New Approaches to Diagnose and Treat Alzheimer's Disease: A Glimpse of the Future." *Clinics in Geriatric Medicine* 17, no. 2 (May 2001): 398; Richard Mayeux, "Alzheimer's Disease Epidemiology," 199; and Marie E. Percy, "Risk Factors and Biological Consequences," 63. Galasko, Mayeux, and Percy all also claim that estrogen reduces the risk of developing Alzheimer's disease. Caselli, Beach, Yaari, and Reiman note, however, that that "hormonal therapies might be perhaps be introduced sooner after menopause than in the Women's Healthy Initiative Memory Study which, in contrast to several earlier observational studies, found that estrogen and progesterone administration led to an increased risk of dementia in women who were at least 65 years of age."

[198] Caselli, Beach, Yaari, and Reiman. "Alzheimer's Disease A Century Later," 1796.

[199] Marie E. Percy, "Risk Factors and Biological Consequences," 64.

[200] Douglas Galasko, "New Approaches," 4. Galasko claims that "[a]nother approach to lowering levels of [Alpha-Beta amyloid] in the brain is to enhance its removal or clearance. . . [and informs that] [t]here are several enzymes within and outside cells that are capable of breaking down [Alpha-Beta amyloid]. . . He reports that "[w]hen immunization with [Alpha-Beta amyloid] was started in young mice and continued on a regular basis, there was a dramatic decrease in [Alpha-Beta amyloid] levels in the brain and in the formation of amyloid plaques." He concedes that "[i]t is not clear whether a strategy of active or passive immunization with Abeta will be successful in humans with AD."

[201] *Ibid, 6.* Galasko also claims that "[l]ithium, used in the treatment of bipolar depression, activates signaling pathways that lead to a net removal of phosphate from tau and can protect cultured neurons from toxicity caused by [Alpha-Beta amyloid]."

[202] *Ibid*.

As to the efficacy of any or all of these prevention strategies, Laino reported encouraging news from findings presented at the at the Alzheimer's Association International Conference in July of 2011. Epidemiological data regarding Alzheimer's made public at the conference provided a statistical analysis of what risk factors researchers believe have an influence on the development of the disease:

> Worldwide, low education—specifically, not finishing secondary school—had the biggest impact on Alzheimer's cases, accounting for 19% of cases. . . Another 14% of cases worldwide were attributed to smoking, 13% to physical inactivity, 10% to depression, 5% to midlife hypertension, 2% to diabetes, and 2% to obesity. In the US however, lack of exercise was the No. 1 problem, contributing 21% of preventable cases of Alzheimer's disease. . .Depression had the second largest impact on Alzheimer's cases in the US, accounting for 15% of cases, followed by smoking at 11%. 8% of cases were attributable to midlife hypertension, 7% to midlife obesity, 7% to low education, and 3% to diabetes. [203]

According to Deborah Barnes, PhD, associate professor of psychiatry at the University of California, San Francisco, researchers reported that "[u]p to half of Alzheimer's cases worldwide could be prevented through lifestyle changes and treatment of chronic medical conditions such as diabetes. . . [and] [a] modest reduction in seven modifiable risk factors for dementia, including smoking, obesity, sedentary lifestyles, and midlife high blood pressure, could have a huge impact." [204]

[203] Laino, Charlene "Lifestyle Changes May Prevent Alzheimer's Disease." http:www.webmd.com/alzheimers/news/20110719/lifestyle-change… (accessed on October 30, 2011).

[204] *Ibid*.

Screening

One distinction that can be drawn between screening for a particular disease and diagnosing that disease is that screening is, at least presumably, done proactively, before the appearance of any clinical symptoms. Since Alzheimer's disease pathology precedes the clinical manifestations of the disease, it is possible to detect the disease before clinical symptoms appear. The technical ability to accurately screen for Alzheimer's disease is critically important, even though, as noted, there is not as yet a cure, for two reasons. First, once clinical symptoms become apparent, brain pathology may have been underway for decades, [205] and the damage already inflicted may well be irreparable. Second, if detected early enough, the progress of the disease may, nevertheless, be at least slowed if not completely stopped. Especially important, however, in the assessment of the results of any method of screening for Alzheimer's disease is a clear understanding of the nature of the information being provided. As pointed out by Scinto and Daffner, "it is important to distinguish assays that mark the presence of a specific pathological process from tests that only assess the risks for the disease." [206] Just as important, is the recognition that there is a wide spectrum of risk, ranging all the way from the inconsequential to virtual certainty, and even the certainty that a pathological process is underway does not in and of itself, insure if or when clinical symptoms will appear.

Given as discussed above, the significant link between genetic abnormalities and the development of Alzheimer's disease, screening for genetic abnormalities would appear to have a high priority. Unfortunately, this approach raises a number of concerns. First, scientific

[205] Schultz, Del Tredici, and Braak, "Neuropathology of Alzheimer's Disease, 28. Schultz, Del Tredici, and Braak et. al. report that "[t]hrough postmortem examination, six stages in the evolution of neurofibrillary changes can be differentiated. . . [and] [s]everal decades elapse between the onset of histologically verifiable lesions and those stages of illness in which the damage is extensive enough for clinical symptoms to become apparent."

[206] Scinto and Daffner, "Early Diagnosis of Alzheimer's Disease," 11.

understanding of the genetic link to Alzheimer's disease is as yet incomplete and, it can be argued, is subject to at least minor revision almost yearly. Second, as discussed in some detail above, certain genetic abnormalities indicate an extremely high risk that Alzheimer's disease will eventually develop but provide only an educated guess and a time range as to when clinical symptoms will appear. Other genetic abnormalities only indicate an increased risk which may or may not result in the development of the disease. It must again be emphasized, that not everyone with genetic abnormalities ultimately develops Alzheimer's disease.

Third, it is important that anyone contemplating genetic testing for Alzheimer's disease make a reasonable assessment of the pros and cons of conducting the test(s), for there is definitely the possibility of disappointment, and perhaps even regret. Most members of families having an increased risk for early-onset Alzheimer's disease are probably well aware of their risk. For everyone else considering genetic testing, it is important to pause and gather as much information as is practical before reaching a final decision. Two sources of information about genetic testing, provided by not-for-profit United States government agencies, and readily available on the Internet, are particularly informative and reliable: the Human Genome Project Information, and Gene Tests.

There is no doubt that legitimate concerns have been raised about random genetic testing in general and genetic testing for Alzheimer's disease, in particular. The Human Genome Project Information, although acknowledging the value of genetic testing in certain instances, nevertheless advises that "[m]any in the medical establishment feel that uncertainties surrounding test interpretation, the current lack of medical options for these diseases, the tests' potential for provoking anxiety, and the risks for discrimination and social stigmatization could

outweigh the benefits of testing." [207] Speaking to genetic testing specifically for Alzheimer's disease, and acknowledging that"[i]f additional susceptibility genes are found, [the] prevailing view [could] change," [208] Stephen Post, writing in 2000, claimed that "[a]ll the major interest groups have recommended against susceptibility testing in asymptomatic individuals because the data are not very useful, even if they hold some statistical significance. [209] According to Post, "Robert N. Butler, editor of *Geriatrics*, urged clinicians to be cautious about requests for susceptibility testing . . . emphasiz[ing] that APOE testing was not yet established as a diagnostic or predictive marker, that people should avoid the emotional toll of thinking that the APOE genotype means they are doomed after forgetting the care keys, and that discrimination in employment and insurance was likely." [210]

Identification of genetic abnormalities is not the only method of screening for Alzheimer's disease. A significant amount of scientific interest and research has been directed at the identification of additional biomarkers of the disease. Scinto and Daffner suggest that non-genetic biomarkers can be used with two different strategies: "One strategy takes advantage of the characteristic anatomic distribution of the neuropathological changes of AD. . . [while [t]he other strategy measures presumed byproducts of the underlying pathological processes in, for example, cerebrospinal fluid (CSF), serum, urine, or skin." [211]

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[207] Oak Ridge National Laboratory. "Human Genome Project Information." 2 http://www.ornl.gov/sci/techresources/Human_Genome/medicine /gen....(accessed on December 1, 2011).

[208] Stephen Post."Key Issues in the Ethics of Dementia Care." *Neurologic Clinics*. 18, no. 4 (November 2000):1022.

[209] *Ibid*.

[210] *Ibid*.

[211] Scinto and Daffner, "Early Diagnosis of Alzheimer's Disease," 8.

Observing and measuring neuropathological changes in the brain are, of course, only possible because of the continual advances made in the technology of neuroimaging, especially over the course of the last thirty years. According to David Galasko:

> Neuroimaging provides many ways to map the structure or function of the brain, and recent advances have improved the precision of the measur[ement of] changes. . . [including the use of an MRI] to compute the volume of the brain or substructures, such as the hippocampus, [so that atrophy can be quantified]. . [and] the rate of progressive decline of total brain or hippocampal volume. . . measured. [212]

SPECT (single photon emission computerized tomography and PET (positive emission tomography) scans can provide even more sophisticated images of neuropathological changes. Even with the most sophisticated methods of examining brain anatomy, however, there is the problem of distinguishing observed abnormalities, such as atrophy, from the effects of normal aging, and establishing a linkage with both known and suspected Alzheimer's and other dementia pathologies. Scinto and Daffner explain how a characteristic pattern of progression of Alzheimer's disease pathology in the brain makes such linkage possible:

> Like any degenerative illness, AD does not afflict all neuroanatomical locations with equal severity. . .[T]here is a characteristic pattern of progression in the cortex that initially emphasizes limbic and posterior association regions and tends to spare primary sensormotor areas. This distribution differs substantially from other degenerative processes such as frontotemporal dementia , which has a predilection for frontal and anterior temporal lobes. [213]

[212] Douglas Galasko, "New Approaches," 7-8.

[213] Scinto and Daffner, "Early Diagnosis of Alzheimer's Disease," 8.

Not surprisingly, as they point out, "[m]any of the proposed diagnostic strategies take advantage of the relative anatomical selectivity of AD pathology, especially early in the course of the illness." [214],[215]

There is little doubt that neuroimaging will continue to become more and more sophisticated, as demonstrated by two recent developments. In January of 2011, Gina Kolata reported that it was likely that a new method of utilizing a PET scan would be approved by the FDA:

> [A]n advisory committee of the Food and Drug Administration recommended . . .that the agency approve the first test—a brain scan—that can show the characteristics of Alzheimer's disease in the brain of a living person. The approval was contingent on radiologists agreeing on what the scans say and doctors being trained in how to read the scans. . .The approval would be for a dye that hones in on plaque in the brain, making it visible on PET scans. [216]

In July of that same year, Marilyn Marchione reported that at an Alzheimer's Association International Conference in France, Australian researchers announced the development of a new eye test for detecting Alzheimer's disease: "Brain scans can find evidence of Alzheimer's a decade or more before it causes memory and thinking problems, but they're too expensive and too impractical for routine use. A simple eye test and warning signs like falls could be a big help. The eye study involved photographing blood vessels in the retina, the nerve layer lining the back

[214] *Ibid.*

[215] *Ibid*. Scinto and Daffner explain that the "[t]he early involvement of the limbic regions such as the entorhinal cortex and hippocampus is the basis for using morphometric MRI analysis of mesial temporal structures to distinguish patients with AD from normal controls. . . [and that] "[t]he early destruction of these regions is essential to neuropsychological functions such as memory provides the anatomical basis for the pattern of neuropsychological deficits that mark the preclinical and early stages of the illness."

[216] Gina Kolata. "Alzheimer's Test Gains Approval of Expert Panel," *Houston Chronicle*, January 21, 2011.

of the eyes." [217] Marchione quoted the study's leader, Shaun Frost of Australia's National Science Agency, CSIRO, as explaining that "[m]ost eye doctors have the cameras used for this, but it takes a special computer program to measure blood vessels for the experimental test doctors are using in the Alzheimer's research." [218] She also quoted Susan Stark of Washington University in Saint Louis, who led the first study tying falls to a risk of developing Alzheimer's disease before mental changes show up, that"[t]he risk of falling was nearly three times greater for each unit of increase in the sticky plaque that scans revealed in their brains." [219],[220] It is apparently well known in scientific circles that tell-tale signs, that pathological processes of Alzheimer's and other forms of dementia are underway and ongoing in the brain, sooner or later show up in samples of cerebrospinal fluid (CSF), serum, urine, or skin, and that these, and other byproducts of underlying pathological changes have enormous potential as screening strategies for early detection of these diseases.

Percy informs that "[b]ecause brain tissue is bathed by CSF, there are changes in the composition of the CSF that reflect reactive and degenerative processes that are taking place in the brain." [221] At least potentially, these include increased levels of neuron thread protein, [222] the

[217] Marchione, Marilyn."Falls, Eye Tests May Give Clues to Alzheimer's" *YAHOO News* http://news.yahoo.com/falls-eye-test-may-clues-alzheimers-0739042 (accessed on October, 10, 2011).

[218] *Ibid*.

[219] *Ibid*.

[220] Marie E. Percy, "Risk Factors and Biological Consequences," 74. This is apparently a different eye test than that described by Percy in 1998: "Scinto et.al. 1994 have described a potential noninvasive eye test for Alzheimer's disease. Marked hypersensitivity of the response of the pupil to the cholinergic antagonist drug called tropicamide was observed in a much higher percentage of persons with clinically diagnosed probable or suspected Alzheimer's disease compared with a series of elderly 'control' individuals. Although some groups have confirmed this finding, other have not been able to. Like some CSF and blood tests, this eye pupil test may not be specific for Alzheimer's disease."

[221] *Ibid*, 68.

protein tau, [223] various amlyoid proteins, [224] and isoprostanes. [225] Mayeux claims that "[b]iomarkers in [the] serum and plasma [of blood] such as homocysteine, folate, amyloid Beta, cytokines, inflammatory proteins and antioxidants [226],[227] are of increasing interest yet have not been found to be consistent predictors." [228] To these Percy adds serum p97, [229] mitochondrial mutations, [230] and greater compression in the external membrane of blood platelets. [231],[232]

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[222] *Ibid*. Percy reports that "levels of neuron thread protein (which is increased in the Alzheimer's disease brain probably in response to cellular damage) are up to 10 times higher in Alzheimer's disease CSF compared with normal controls."

[223] Marie E. Percy, "Risk Factors and Biological Consequences," 71; Douglas Galasko, "New Approaches," 12. Percy also reports on elevated levels of tau: "The presence of elevated levels of tau (or phosphorylated tau) in CSF of Alzheimer's disease patients has been confirmed in quite a number of studies. . . If a group of well-defined healthy normals is used as a comparative control, the specificity of detecting probable Alzheimer's disease is high (75% to 90%). However, the utility of the ability of this test to discriminate Alzheimer's disease from other types of dementia (e. g. vascular dementia, frontal lobe dementia, or Parkinson's disease is more limited." Galasko adds that "CSF phospho-tau levels seem to have greater disease specificity than total tau."

[224] Marie E. Percy, "Risk Factors and Biological Consequences," 71-72; Douglas Galasko, "New Approaches," 12. Percy finds that the presence of various forms of amyloid proteins in CSF is of more uncertain determinative significance: "A considerable number of studies suggest that the CSF measures of A beta protein 1-40 on their own are not likely to be useful as a a diagnostic aid for Alzheimer's disease. However, one type of A beta protein I-42 (43) shows an overall decrease in the CSF of persons with Alzheimer's disease, although it is elevated in very early stages of Alzheimer's disease." Galasko adds that "longer forms of A beta ending at Amino acid 42 are implicated in AD. . . [and] levels of A beta 42 in CSF are significantly decreased in patients with AD relative to controls."

[225] Douglas Galasko, "New Approaches," 8.Galasko reports that "isoprostanes are stable prostaglandin metabolites that reflect oxidative processes. . . [and] [t]heir levels are increased in plasma, urine, and CSF of AD patients relative to controls."

[226] Marie E. Percy, "Risk Factors and Biological Consequences," 74-75. Percy describes the potential of testing for an enzyme known to increase when cells undergo rapid oxidation theorized to occur in the pathological processes of Alzheimer's disease: "Increased production of free radicals resulting from altered oxygen metabolism has been postulated to cause damage to brain cells in Alzheimer's disease. In support of this finding is the observation that the activity of an enzyme called copper, zinc superoxide dismutase (SOD-1. which is known to increase in cells that are exposed to oxidizing agents) is increased in red cells of persons with Alzheimer's disease."

[227] Douglas Galasko, "New Approaches," 8. As noted above, Galasko reports also reports that "isoprostanes. . reflect oxidative processes. . . [and] [t]heir levels are increased, [not only in CSF but] in plasma [and] urine. . .of AD patients relative to controls."

[228] Richard Mayeux, "Alzheimer's Disease Epidemiology," 200.

[229] Marie E. Percy, "Risk Factors and Biological Consequences," 72. Percy is enthusiastic about the potential of testing for serum p97 levels: "One blood test that appears very promising involves measuring levels of the iron-binding protein p97 in serum. Serum levels of p97. . .were reported to be greatly elevated in persons with Alzheimer's disease in comparison with gender and age-matched healthy normal individuals, and to increase with

Not only does it appear that a greater understanding of Alzheimer's disease pathology will have to occur before biomarkers present in CSF and blood can reach their full potential, Scinto and Daffner caution that biomarkers, by their very nature, have inherent limitations:

> All strategies that take advantage of the distributional and predilection of AD pathological processes suffer from the same potential limitations. . . Other diseases that may affect similar areas of the brain could generate similar patterns and thus 'false positives' results. Moreover, atypical cases of AD, with an unusual distribution of pathology, would likely yield false negative results. [233]

In their estimation, "[i]t seems unlikely that any single marker will predict the development of clinical symptoms with 100% certainty," [234] and due apparently in significant part to the present limitations of both genetic testing, neuroimaging, and biomarkers, they concede that "short of brain biopsy, which is rarely done, there is currently no 'gold standard' marker for AD." [235] Nevertheless, Percy recommends an alternate strategy that seems to make sense:

> It is not likely that one peripheral biological marker will be found that identifies Alzheimer's disease with high sensitivity and specificity at a very early age. Rather, a more practical approach might involve combining the results of genetic tests, neuropsychological tests, neurobehavioral tests, and measures of certain

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increasing duration of Alzheimer's disease, implying that p97 might be an early biological marker for Alzheimer's disease."

[230] *Ibid*, 73. According to Percy, "[p]ersons with Alzheimer's disease have been found to have a higher percentage of mitochondria in their blood with specific types of mutations than healthy normal individuals."

[231] *Ibid*, 75. According to Percy, "[t]he external membrane of blood platelets has been found to be more compressible (i. e. more fluid) in persons with Alzheimer's disease than in healthy normal individuals."

[232] *Ibid*. Percy also notes that "[s]ome cells with an extra chromosome 21 have been detected in cultured lymphocytes or fibroblasts of persons with Alzheimer's disease."

[233] Scinto and Daffner, "Early Diagnosis of Alzheimer's Disease," 9.

[234] *Ibid*, 10

[235] *Ibid*, 14

> biological markers to yield a probability that a person will develop (or be affected by) Alzheimer's disease. [236]

Writing in 2008, Selkoe expressed optimism that "[b]ased on] the current rate of progress in the laboratory and in the clinic. . .some level of practical success [in detecting Alzheimer's disease] may come sooner that one expects." [237] His enthusiasm apparently stemmed from his expectation of the use of an Alzheimer's disease specific risk assessment profile for individuals 50 years of age and older "modeled on that now widely used to judge the risk of atherosclerotic disease." [238] In his opinion, an Alzheimer's disease specific risk assessment profile could include:

> [I]nquiry about a positive family history of AD, identification of specific predisposing genetic factors, structural and functional brain imaging to detect evidence of presymptomatic lesions—including the exciting prospect of imaging the amyloid deposits non-invasively and measurement of Alpha-beta 42, tau and other markers of the neuropathology of CSF and perhaps (in the case of Alpha-Beta) in blood. [239] [240]

Diagnosis

Section 1.01 Not only is there no single method of screening, short of a biopsy of brain tissue, that will, with 100% accuracy, detect Alzheimer's disease before clinical symptoms are apparent, there is apparently no absolutely inerrant method, short of biopsy or autopsy, of

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[236] Marie E. Percy, "Risk Factors and Biological Consequences," 76.

[237] Dennis Selkoe, "Biochemistry and Molecular Biology,"257.

[238] *Ibid*.

[239] Selkoe, 257.

[240] *Ibid*. According to Selkoe, "[b]ased on further epidemiologic experience with such assessment measures in large populations of healthy elderly, mild cognitive impairment and AD subjects, it should be possible to estimate—first crudely and later more accurately—the likelihood that an individual will develop AD."

diagnosing Alzheimer's disease. According to Ralph and Brigitte Richter, "[a]lthough diagnostic criteria have been established, "[a] definitive diagnosis of AD based on clinical observation [alone] is impossible and requires confirmation [of the presence of neuritic plaques and neurofibrillary tangles in the brain." [241],[242] Eventually neuroimaging techniques may be capable of unequivocally confirming the presence of tangles and plaques in the brain, but until a nonivasive technique is acknowledged to have that capability, an unqualified diagnosis of Alzheimer's disease requires a biopsy or autopsy. Claire Murphy informs that "since [absent a biopsy] the diagnosis of AD cannot be made until death, the diagnosis of "probable AD" is given in the living patient." [243]

As noted above, a diagnosis of probable Alzheimer's disease is simultaneously inclusionary and exclusionary. Inclusionary in that certain defining characteristics of Alzheimer's disease must be shown to be present in the individual being evaluated. Exclusionary in that other possible causes for these defining characteristics must be shown to be inapplicable in the case at hand. [244] With a diagnosis of probable Alzheimer's being, of necessity, both inclusionary and exclusionary, it is probably not much of a surprise that Alzheimer's disease is

[241] Ralph W. Richter and Brigitte Zoeller Richter, eds. *Alzheimer's Disease: A Physician's Guide to Practical Management.* (Totowa, NJ: Humana Press, 2004), 21.

[242] Caselli, Beach, Yaari, and Reiman. "Alzheimer's Disease A Century Later," 1789. Caselli, Beach, Yaari, and Reiman suggest that the insistence on plaques and tangles may result in the extent of the disease being underestimated: "An unresolved issue with all diagnostic criteria for AD is the significance of plaques and tangles in nondemented elderly persons. Current practice restricts the diagnosis of AD to those diagnosed with dementia during life, but clearly this may result in underestimating the number of elderly with the disease who die during a preclinical stage."

[243] Claire Murphy. "Loss of Olfactory Function in Patients with Alzheimer's Disease." In *Alzheimer's Disease: A Physician's Guide to Practical Management,*. edited by Ralph W. and Brigitte Zoeller Richter, 165-73. (Totowa, NJ: Humana Press, 2004), 165.

[244] Dash and Villermarette-Pittman, *Alzheimer's Disease*, 58. According to Dash and Villermarette-Pittman, "[w]hen investigating potential causes, the reversible dementias are considered first, even though they are responsible for only a small proportion of dementia cases,. . . [and]. . .are fairly easy to rule out because they are identifiable through laboratory tests."

likely to be under diagnosed. Drachman, et. al. comment that "[d]espite the amount of publicity AD has garnered, it is probably under diagnosed and detection is typically delayed." [245] One possible cause, as pointed out in the Consensus Statement, is that "many patients do not seek evaluation." [246] On the other hand, Dash and Villermarette-Pittman claim that "[m]any studies have shown that primary care doctors routinely miss the diagnosis of mild AD." [247]

In the defense of primary care physicians, there is widespread acknowledgment of the difficulty in making an accurate diagnosis of Alzheimer's disease, and it is not difficult to see why. First, according to Drachman et. al., "[d]ementia is. . .a clinical diagnosis with a large subjective component." [248] With subjective assessment an important part of diagnosis, at least some degree of honest error in perception seems almost inevitable. Also contributing to the difficulty in diagnosis, however, is the possibility that certain clinical symptoms suspected of being caused by Alzheimer's disease may actually have another etiology. Drachman, et. al. claim that"[b]ecause the geriatric population as a whole has substantial illness and is the most heavily medicated segment of society, most cases of suspected AD are not conducive to a cut-and-dried diagnosis. . . [but] must usually be confirmed in the context of coexisting medical conditions and treatments." [249] The Consensus Statement states that "[t]he presence of either delirium or depression may confound dementia recognition. . . [and their] differentiation presents a diagnostic challenge." [250] Drachman, et. al. also report that dementia can "coexist with either or

[245] Drachman, Friedland, Larson, and Willaims, "Making Sure its Really Alzheimer's," 3.

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[246] American Association for Geriatric Psychiatry, et. al. ,"Consensus Statement,"14.

[247] Dash and Villermarette-Pittman, *Alzheimer's Disease*, 17.

[248] Drachman, Friedland, Larson, and Williams, "Making Sure its Really Alzheimer's," 3.

[249] *Ibid*, 8.

[250] American Association for Geriatric Psychiatry, et. al., "Consensus Statement," 5.

both." [251] It must also be acknowledged that it is not at all unusual that an individual suspected of having Alzheimer's disease also suffers from depression. Anne Monias and Diane Meier report that "[p]atients with AD are often diagnosed with depression as much as two years before the diagnosis of AD is made." [252]

Yet another diagnostic dilemma in the diagnosis of probable Alzheimer's disease is the presence of other forms of dementia that have similar symptoms. Knopman et. al. actually suggest that "[m]ore than one underlying pathology should be expected." [253] In their view, "overlap is common among AD, dementia with cerebrovascular disease (DCVD), and [dementia with Lewy bodies] DLB. . . [and as a result a] diagnosis of dementia starts with the intention of identifying a single syndrome but often concludes with the realization that elements of more than 1 syndrome are present." [254] Volicer adds that "it is not uncommon that an autopsy examination finds evidence for more than one kind of dementia and the relative contribution of these causes to the clinical syndrome is unclear." [255] Adding further to the confusion, Scinto and Daffner claim that a "small portion of demented individuals with underlying AD pathology will manifest clinical patterns that are atypical for dementia of the Alzheimer's type.,. . .[and] [r]ather than exhibiting salient memory problems, these patients may present with relatively isolated disruption of language, visuospatial functions, or excessive cognitive functions." [256]

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[251] Drachman, Friedland, Larson, and Williams, "Making Sure its Really Alzheimer's," 3.

[252] Monias and Meier, "Palliative Care," 3.

[253] Knopman, Boeva, and Petersen, "Essentials of the Proper Diagnosis," 1293.

[254] *Ibid*, 1293.

[255] Ladislav Volicer, "Palliative Medicine in Dementia,"1375.

[256] Scinto and Daffner, "Early Diagnosis of Alzheimer's Disease," 309.

Finally, diagnosis is heavily dependent on a personal interview of not only the individual suspected of having Alzheimer's disease but perhaps one or more family members, usually a spouse. Because a physician must rely on someone else to provide critical information regarding such issues as impairment of short-term memory, behavioral changes, personality changes, such as frequent irritability and suspiciousness, and insomnia, especially day/night inversion disturbances, there is ample opportunity for not only intentional and unintentional misrepresentation, but even the possibility of contradictory testimony. The Consensus Statement notes that "family members tend to compensate for deficits." [257]

Despite the apparent difficulty, the Consensus Statement states that"[in] approximately 90% of cases, the diagnosis [of Alzheimer's disease] can be made on the basis of a general medical and psychological evaluation." [258] Knopman et. al. suggest that the "a physician must obtain a thorough patient history and assess function, administer and interpret mental status examinations, and perform a neurologic examination." [259] Drachman, et. al. claim that the "personal interview (with some form of mental status testing) is the most powerful diagnostic tool." [260]

Knopman, et. al. have identified diagnostic criteria for a general diagnosis of probable dementia, and a specific diagnosis of probable Alzheimer's disease. Both are worth examining in detail:

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[257] American Association for Geriatric Psychiatry, et. al., "Consensus Statement," 14.

[258] *Ibid*, 5.

[259] Knopman, Boeva, and Petersen, "Essentials of the Proper Diagnosis," 1300.

[260] Drachman, Friedland, Larson, and Williams, "Making Sure its Really Alzheimer's," 3.

Diagnostic Criteria for Dementia

A. On the basis of evidence from a patient's history and mental status examination, dementia is characterized by the presence of at least two of the following impairments.
   1. Impaired learning and impaired retention of new or recently acquired information (impaired short-term memory.
   2. Impaired handling of complex tasks.
   3. Impaired reasoning ability (impaired abstract thinking).
   4. Impaired spatial ability and orientation (constructional difficulty and agnosia).
   5. Impaired language.

B. The cognitive impairments in A notably interfere with work or usual social activities or relationships with others.

C. The cognitive impairments in A represent a notable decline from a previous level of functioning.

D. The impairments in A do not occur exclusively during the course of delirium.

E T.he impairments in A are not better explained by a major psychiatric diagnosis.

Diagnostic Criteria for the Anterograde Amnesic Syndrome of Alzheimer Disease [261]

A. On the basis of evidence from a patient's history and mental status examination, Alzheimer's disease is characterized by the presence of major impairments in learning and in retaining new information and at least one of the following impairments.
   1. Impaired handling of complex tasks.
   2. Impaired reasoning ability.
   3. Impaired spatial ability and orientation.
   4. Impaired language..

B. The impairments in A notably interfere with work or usual social activities or relationships with others.

C. The impairments in A represent a notable decline from a previous level of functioning.

D. The impairments in A are insidious at onset and progressive.

E. The impairments in A do not occur exclusively during the course of delirium

F. The impairments in A are not better explained by a major psychiatric diagnosis

G. The impairments in A are not better explained by a systemic disease or another brain disease [262]

[261] The authors note that two criteria from the National Institute of Neurological and Communicative Disorders and Stroke—Alzheimer's Disease and Related Disorders Association have been dropped: the age limitation and the requirement for psychometric test confirmation.

It seems highly probable that despite the specificity of the foregoing diagnostic criteria, physicians accustomed to diagnosing Alzheimer's disease develop their own litmus tests for the disease. Drachman, et. al. share one such rule-of-thumb "If he has trouble remembering which floor of a garage he parked on, there is little cause for concern, but if he forgets that he drove to your office and takes public transportation home, leaving his car in your garage, his cognition may be declining." [263]

It must also be acknowledged that there is a diagnosis of impaired cognitive capacity that falls short of a diagnosis of probable Alzheimer's disease, sometimes called MCI (mild cognitive impairment). As discussed above, MCI is a somewhat controversial diagnosis. According to Dash and Villermarette-Pittman, although "[a]t a given point in time, the distinction between healthy and normal aging may be relatively straightforward. . . [d]istinguishing normal from pathologic can be difficult. . .especially when the person experiences only mild symptoms as a result of an early stage of the disease." [264] A diagnosis of MCI probably comes about as a result of an unwillingness to inaccurately diagnose probable Alzheimer's in the absence of all of the necessary characteristics of the disease, yet concern over the inability to indicate a level of cognitive impairment that was clearly abnormal, although short of that necessary for a diagnosis of probable Alzheimer's disease, but with strong potential to develop in time to the full blown disease. Knopman, et. al. claim:

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[262] Knopman, Boeva, and Petersen, "Essentials of the Proper Diagnosis." Knopman, et. al. have also identified diagnostic criteria for specific diagnosises for Dementia with Cerebrovascular Disease (1295), Dementia with Lewy Bodies (1297), Frontotemporal Dementia (1298), Primary Progressive Aphasia (1299), and CJD (Creutzfeldt-Jakob Disease) (1299).

[263] Drachman, Friedland, Larson, and Williams, "Making Sure its Really Alzheimer's," 3.

[264] Dash and Villermarette-Pittman, *Alzheimer's Disease*, 15.

> Clinicians have shown that they readily recognize a large intermediate zone between a cognitively normal elderly person and one with clear dementia . . . usually. . .referred to as mild cognitive impairment . . . [that includes] individuals who are not normal because of deficits in at least 1 cognitive domain (usually recent memory) but who appear to function independently in daily affairs. [265]

The obvious dilemma for the clinician is having recognized that the individual being evaluated has a cognitive deficit(s), making the completely subjective determination of whether his/her level of independent function justifies a diagnosis of MCI rather than probable Alzheimer's disease.

It would seem that a diagnosis of MCI might be somewhat less problematic for a clinician if there was absolute assurance that MCI always progressed to full blown Alzheimer's disease. A diagnosis of MCI could, therefore, function as an early warning of certain Alzheimer's disease. Despite, however, Knopman, et. al.'s report that"[t]he likelihood of individuals with MCI developing dementia is 5 to 10 times that of cognitively healthy individuals," [266],[267] Dash and Villermarette-Pittman also report that "[a]s many as half of all MCI patients will not progress to AD, and some (up to one-fourth) will actually show improvement." [268],[269] Knopman, et. al. have also identified diagnostic criteria for MCI, and they deserve attention:

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[265] Knopman, Boeva, and Petersen, "Essentials of the Proper Diagnosis," 1292.

[266] *Ibid*, 1293.

[267] Scinto and Daffner, "Early Diagnosis of Alzheimer's Disease," 6. Scinto and Daffner also report that "s]everal research groups have demonstrated that elders who exhibit this kind of mild impairment in memory and daily functioning go on to develop a full-blown syndrome of dementia at a rate of 10% to 15% per year, which is approximately 5 to 7 times higher than for age-matched individuals who do not exhibit such impairment."

[268] Dash and Villermarette-Pittman, *Alzheimer's Disease*, 16.

Diagnostic Criteria for Amnesic Mild Cognitive Impairment

A. The presence of a new memory complaint, preferably corroborated by an informant.
B. Objective evidence of impairment of short-term memory (for age)
C. Normal general cognitive functions
D. No substantive interference with work, usual social activities, or other activities of daily living
E. No dementia, according to criteria in [Diagnostic Criteria for Dementia].

It cannot escape the careful reader's attention that a diagnosis of probable Alzheimer's disease may be of only limited value. As noted above, and as affirmed by Scinto and Daffner. "[a] large body of evidence now points to the fact that the pathology of AD may represent an insidious process developing over as many as 15 to 20 years before there are any clinical manifestations." [270] The obvious consequence, in their view, is that"[b]y the time a patient is recognized as clinically demented, considerable irreversible brain damage has already taken place." [271] Expressing the nature of the damage more dramatically, they observe that "in patients who have just begun to show the earliest clinical symptoms of dementia (i.e. with Clinical Dementia Rating (CDR) score of 0.5. . ., 50% of the neurons in entorhimal cortex, a crucial anatomic component of memory processing, have already been lost." [272]

Given this reality, an ethical issue, at least arguably, arises re: disclosure, especially in the minds of those who pine for the paternalism of professional medicine last seen in this country in

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[269] *Ibid*, 17. Neverthless, Dash and Villermarette-Pittman claim that screening for Mild Cognitive Impairment (MCI) is worth considering: "Screening for MCI would seem to make perfect sense. It is prevalent in the population; not obvious to sufferers, their families, or even physicians; screening tools are inexpensive, safe, and easy to use; and most importantly, early detection can lead to early treatment that although presently cannot prevent MCI from progressing to Alzheimer's, can slow the rate of progression and mitigate its symptoms."

[270] Scinto and Daffner, "Early Diagnosis of Alzheimer's Disease," 3.

[271] *Ibid*, 3-4.

[272] *Ibid.*

the first half of the last century. Stephen Post, for one, is not in the least concerned, correctly it would seem, that there should be any legitimate misgivings about disclosing a diagnosis of probable Alzheimer's disease. After first quoting Joseph M. Foley, who stated: "All experienced health care professionals have gone through the situation of a family agonizing about whether to tell the patient about AD, only to have the patient say, "That's what I have thought all along," Post identifies what he sees as justification of full disclosure to *all* concerned of a diagnosis of probable Alzheimer's disease:

> By informing the person of the AD diagnosis, we enable him or her to (1) plan for optimal life experiences in remaining years of intact capabilities; (2) prepare a durable power of attorney for health care decisions-some may prepare a living will also, to be implemented upon eventual incompetence; (3) consider possible enrollment in AD research programs based on comprehended choice; (4) participate actively in Alzheimer support groups; and make the highly personal decision about taking antidementia compounds. [273]

[273] Stephen Post, "Key Issues," 3.

Chapter Two: Disease Trajectory, Issues and Options for Medical Treatment and Care

Because certain regions of the brain are more vulnerable than others to damage from the pathological processes associated with Alzheimer's disease, the more vulnerable regions are almost always going to be first affected by these processes and first to fail. As a consequence, the functional impairment and loss caused by Alzheimer's disease (AD) has a particular route of progression and thus generally predictable trajectory. Although there will certainly be individual differences in the way in which Alzheimer's patients' bodies, especially their brains, respond to AD, as a practical matter, an individual diagnosed with Alzheimer's disease and his/her family can develop a reasonably accurate set of expectations for how the disease will progress, subject, of course, to revision as the disease unfolds and its impact is felt, observed, and measured. Apprised of the likely trajectory of the disease, it is possible to make informed preparation not only for what is anticipated, but also for necessary adjustments should the possible, though improbable, ultimately occur. Among the conceivable aspects of preparation, perhaps none is of greater importance than developing a plan for maximizing the quality of life of the Alzheimer's patient as well as his/her family/caregivers by making decisions for both future medical treatment and future care. Just as the trajectory of AD is generally predictable, equally foreseeable are the medical treatment and care issues that will likely arise as a consequence of that trajectory. Information as to disease trajectory, resultant medical treatment/care issues, and available medical treatment/care options, are obviously of critical importance to an individual

diagnosed with Alzheimer's disease who wishes to make medical treatment and care decisions on his/her own behalf while he/she still possesses the medical and legal decisional capacity to do so, especially decisions re: future medical treatment and care *after* his/her decisional capacity is lost.

This information is also of critical importance, however, in those instances where an individual diagnosed with Alzheimer's disease is unable or unwilling to make medical treatment and care decisions on his/her own behalf, and these decisions must be made by someone else to whom authority to do so has been assigned. It seems almost undeniable that prior awareness of decisions that will, in all likelihood, have to be made, coupled with a further awareness of possible options, their consequences and justification, can significantly contribute to the quality of decision making. It is of course conceivable that the ultimate decision maker may be completely uncomfortable preparing for, much less making, any decision in advance, opting instead to make choices only as they arise and are otherwise unavoidable. Nevertheless, even if this is the strategy one chooses to employ, the venerable adage, 'forewarned is forearmed,' applies here, if for no other reason than to reduce or eliminate the shock of having to make without warning an agonizingly difficult decision.

This chapter is directed at providing as much information as is practical re: the probable as well as the possible trajectory of Alzheimer's disease, the equally predictable medical treatment and care issues that will likely arise a consequence of that trajectory, and finally the available options for medical treatment and care, their respective foreseeable consequences, and possible justification.. The overall focus of this second chapter is to provide as much information as practical to an individual diagnosed with Alzheimer's disease, as well as his/her family, so that

the quality of life of both the Alzheimer's patient and his/her family/caregivers can be maximized.

Trajectory

"As with any illness," according to Rabins, "Alzheimer's disease can vary widely in its course and rate of progression." [274] The Consensus Statement describes the progression of AD as gradual, continuous, yet variable, [275] with Khachaturian and Radebaugh reporting that "[t]he rate of cognitive impairment. . .differs markedly among individuals." [276] Volicer opines that the "[t]he progressive course of cognitive decline has been compared to reverse child development, with the most complex functions lost first. . . [but]there is no exact relationship, and variation is great." [277] "For instance," as he reports, "some patients with severe dementia are still able to read and some individuals may be completely mute but still able to drive." [278] There is, however, at least some general measure of consistency in the progression. Dash and Villermarette-Pittman claim that "two-thirds of mild AD patients will reach the severe stage within five years." [279]

Some of the variability in the rate of decline is apparently due to age and the influence of the onset of both related and unrelated disease processes. Surprisingly, Dash and Villermarette-Pittman claim that "[p]atients who are younger at the age of diagnosis tend to decline faster than

[274] Peter V. Rabins, "Dementia and Alzheimer's Disease," 454.

[275] American Association for Geriatric Psychiatry, et. al.,"Consensus Statement," 4.

[276] Khachaturian and Radebaugh, *Alzheimer's Disease*, 5.

[277] Ladislav Volicer, "Palliative Medicine in Dementia," 1377.

[278] *Ibid*, 1376-7.

[279] Dash and Villermarette-Pittman, *Alzheimer's Disease*, 52.

those who are older at onset. . . reflect[ing] [it is thought] a more virulent disease process." [280] They also report that "[p]atients suffering prominent behavioral disturbances, such as hallucinations. . .have a faster rate of decline.. . . [and that] the presence of Parkinsonian-like symptoms, such as motor slowness and stiffness, can [also] signal an accelerated rate of decline." [281] Dash and Villermarette-Pittman further inform that "episodes of significant medical illness are often associated with relatively sudden declines in Alzheimer's patients." [282] Greg Sachs, Joseph Shega and Dean Cox-Hayley add that these "acute illnesses. . .are [often] accompanied by delirium and decrements in mental and functional status, [and]. . ."[u]nlike the patient with CHF [congestive heart failure] who recovers from an acute illness near the prior baseline, the patient with dementia more commonly establish[es] a new, lower-level of cognitive and physical functioning." [283] Dash and Villermarette-Pittman report that "[t]he exact reasons for this are not clear, but a plausible explanation is that some of the relatively fragile connections between the neurons in their brains are disrupted by the co-occurring illness,. . . [and] [o]nce neural communication is interrupted, pathways may be difficult to reestablish." [284]

Scinto and Daffner suggest that "the 'journey' between normal brain function and clinical dementia can be divided into different stages:" [285] presymptomatic, preclinical, very early 'questionable' dementia, moderate dementia and severe dementia. [286] Volicer adds a final stage,

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[280] *Ibid.*

[281] *Ibid*, 52.

[282] *Ibid*.

[283] Greg A. Sachs, Joseph W. Shega, and Deon Cox-Hayley. "Barriers to Excellent End-of-life Care for Patients with Dementia." *Journal of General Internal Medicine* 19, no. 10 (October 2004):1058.

[284] Dash and Villermarette-Pittman, *Alzheimer's Disease*, 52.

[285] Scinto and Daffner, "Early Diagnosis of Alzheimer's Disease," 5.

[286] *Ibid*, 5-8.

he calls the terminal stage. [287] According to Scinto and Daffner, in the *presymptomatic* stage there is "no mental or behavioral symptoms, no impairment of everyday functioning, and no abnormalities on neurpsychological testing, even using tests sensitive to subtle increments in performance." [288] "The existence of such a stage," in their view, "is supported by a pathology series showing characteristic AD lesions in the absence of any observable or measurable clinical deficits on an *ante mortem* evaluation." [289]

Scinto and Daffner describe the *preclinical* stage as characterized as by the appearance of "[s]ubtle deficits, especially in memory, [that] are detectable by formal testing of cognitive performance." [290] Of most significance, and as they point out, "these deficits are not associated with any impairments of daily living. . . [and[[s]uch individuals would still rate a 0 classification on the CDR [Clinical Dementia Rating] scale." [291],[292] Scinto and Daffner's next stage, what they term "[v]ery early 'questionable dementia," [293] appears to be comparable to what Volicer calls the mild stage of dementia. [294] Scinto and Daffner report that it is in this stage that there are "subtle signs of functional and cognitive deterioration . . . and. . .individuals exhibit mild forgetfulness, along with subtle impairment of judgment, home and community activities,

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[287] LadislavVolicer, "Palliative Medicine," 1377.

[288] Scinto and Daffner, "Early Diagnosis of Alzheimer's Disease," 5.

[289] *Ibid*.

[290] *Ibid.*

[291] *Ibid.*

[292] *Ibid.* Scinto and Daffner claim that "[d]eficits in this stage can be detected by employing a comprehensive and sensitive battery of neuropsychological tests."

[293] *Ibid*, 6.

[294] Ladislav Volicer, "Palliative Medicne," 1376.

or occupational functioning." [295],[296] Volicer adds that in addition to memory problems and spatial disorientation, [individuals at this stage] may have some personality changes." [297] "By the time individuals reach a CDR stage of 1.0," there is, according to Scinto and Daffner, "no doubt that they have dementia," [298] and they describe a wide range of disruption in functional capacity for what they call moderate dementia:

> Memory impairment interferes with everyday activities. There are growing difficulties handling complex problems and managing independence in household responsibilities and daily activities such as maintaining one's residence, handling finances, or reliably taking medication for concomitant medical illnesses. Patients with dementia of moderate severity (CDR stage 2), exhibit significant memory loss, frequent disorientation, impairment of social judgment, and an increasing need for supervision in their daily activities, including maintenance of personal hygiene and the cleanliness and safety of their residence. [299]

Volicer claims that in this stage individuals "start having language difficulties, become unable to use tools and utensils, and become confused." [300] He suggests that "[c]onfusion may lead to agitation and there also may be sleep disturbances." [301] He concedes that an individual at this stage "may [still] be able to feed themselves if a finger food is provided." [302]

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[295] Scinto and Daffner, "Early Diagnosis of Alzheimer's Disease," 6.

[296] *Ibid*. Scinto and Daffner report that "[t]he Clinical Dementia Rating scale has designated this period with a score of 0.5."

[297] Ladislav Volicer, "Palliative Medicne," 1377.

[298] Scinto and Daffner, "Early Diagnosis of Alzheimer's Disease," 5.

[299] *Ibid*, 6.

[300] Ladislav Volicer, "Palliative Medicne," 1377.

[301] *Ibid*, 1376.

[302] *Ibid*, 1377.

Some time between the onset of this moderate stage and severe dementia, much more significant impairment of functional capacity probably begins to be experienced by the AD patient and observed by his/her family, including what Rabins identifies as "impairments in language (called aphasia), in performing everyday learned activities (called apraxia), in recognizing the familiar and perceiving the world as it is (agnosia), and in executive function (the abilities to initiate, sustain, and stop activities, to be flexible and to abstract)." [303] It is possible that the ability to recall more distant memories begins to be lost, [304] and a general disorientation and anxiety coupled with increased irritability and lack of meaningful rest because of various sleep disorders; begin to bring about personality changes, perhaps including agitation and various forms of aggressive behavior. Rabins claims that "many patients with Alzheimer's disease suffer from symptoms that are conceptualized as behavioral, psychiatric, or psychological . . . and their appearance even at this moderate stage of the disease cannot be automatically excluded." [305],[306] A reduction in appetite perhaps due in part to impairment in the sense of smell, [307] coupled with difficulty chewing and swallowing may begin to reduce food and drink intake. Impairment of the swallowing reflex may also result in the aspiration of food into the lungs. Control of bladder [308]

[303] Peter V. Rabins, "Dementia and Alzheimer's Disease," 454.

[304] American Association for Geriatric Psychiatry, et. al.,"Consensus Statement," 5

[305] Peter V. Rabins, "Dementia and Alzheimer's Disease," 457.

[306] *Ibid*, 456. Rabins claims that a "study showed that sixty-seven per cent of persons with Alzheimer's disease developed a 'psychotic' symptom (an hallucination or delirium) during the course of Alzheimer's disease again emphasizing the fact that these symptoms are common manifestations of the illness."

[307] See Claire Murphy, "Loss of Olfactory," 165.

[308] Caselli, Beach, Yaari, and Reiman. "Alzheimer's Disease a Century Later," 1793. According to Caselli, et. al., [t]wo of the most common causes of urinary frequency and incontinence in patients with dementia are flaccid distended bladders that cause overflow incontinence and spastic bladders."

and bowel may begin to be lost, and impairment in gross motor skills may make walking without some form of assistance more and more difficult.

Volicer claims that"[t]he severe stage is characterized by further progression of cognitive deficits with impaired comprehension." [309] . . . [and] individuals often [not only] do not recognize the need for basic activities of daily living. . .[but]. . .resist when caregivers attempt to provide care." [310] According to Scinto and Daffner, once this "stage of the illness (CDR stage of 3 and beyond) [is reached] patients are totally dependent on others for personal care and everyday problem solving." [311] Stephen Post insists that the "[i]nability to swallow is one clear marker of AD's severe stage," [312] and it is a potentially critical loss from the standpoint of life-threatening medical complications.

Christian Shultz, Kelly Del Tredici, and Heiko Braak inform that "in the disease's final stages, dysfunction of the motor system [occurs] in the form of a hypokinetic-hypertonic syndrome." [313] Volicer explains that because of motor difficulties. . . [i]ndividuals may not be able to feed themselves at all and start having difficulty walking. . . [and] either develop an unsteady or narrow based gait (scissoring)." [314],[315] Although dementia patients are, in his view,

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[309] Ladislav Volicer, "Palliative Medicine," 1377.

[310] *Ibid*, 1377.

[311] Scinto and Daffner, "Early Diagnosis of Alzheimer's Disease," 6.

[312] Stephen Post, "The Fear of Forgetfulness: A Grassroots Approach to the Ethics of Alzheimer's Disease." *Journal of Clinical Ethics* 9, no. 1 (Spring 1998): 75

[313] Schultz, Del Tredici, and Braak, "Neuropathology of Alzheimer's Disease," 21

[314] Ladislav Volicer, "Palliative Medicine," 1377.

[315] Ladislav Volicer. "Alzheimer's Disease and Dementia: Management of Severe Alzheimer's Disease and End-Of-Life Issues." *Clinics in Geriatric Medicine* 17, no. 2 (May 2001):1.Volicer reports that "50% of demented individuals [are] unable to ambulate independently 7.8 years after the onset of dementia . . . [and their] [ina]bility to ambulate is not only important to facilitate meaningful activities but also to prevent medical complications."

"at a high risk for falls. . .[he concedes that] they still may be able to walk with assistance." [316] [317] Volicer reports that by this stage "[m]ost individuals also develop incontinence." [318] It is with severe dementia that care giving may be the most difficult, where problems due to disorientation, confusion, agitation and inability to sleep manifested in wandering and perhaps even physical aggression, probably reach their high-water mark.

Volicer claims that"[o]nce individuals are unable to walk, even with assistance, they progress into the terminal phase of dementia." [319] This is also a critical loss from the standpoint of life-threatening medical complications, because short of a concerted effort by caregivers to get the AD patient up and out of bed and into a wheelchair, inability to walk, even with assistance, may mean that the patient is effectively bedridden. [320],[321] At this stage, AD patients may be unwilling or unable, even with assistance to eat and drink sufficiently to sustain their lives. As will also be discussed in greater detail, there are a number of reasons why late stage AD patients may be unwilling to eat and drink sufficiently to sustain their lives, including loss of appetite as well as loss of the recognition that food and water are critical to sustaining life. The inability to eat and drink, even with assistance, is likely a result of impairment in the swallowing mechanism, and if that mechanism has not already failed, it often finally fails at this stage, as

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[316] Ladislav Volicer, "Palliative Medicine," 1377.

[317] See Sophie Pautex, Dina Zekry, Gilbert Zulian, Gabriel Gold, and Jean-Pierre Michel. "Pain and Palliative Care in Late Stage Dementia Patients." In *Alzheimer's Disease: A Physician's Guide to Practical Management*, edited by Ralph W. and Brigitte Zoeller Richter, 217-223. (Totowa, NJ: Humana Press, 2004), 214

[318] Ladislav Volicer. "Alzheimer's Disease and Dementia," 1.

[319] *Ibid*, 1377.

[320] See Peter V. Rabins, "Dementia and Alzheimer's Disease," 456

[321] Dash and Villermarette-Pittman, *Alzheimer's Disease*, 21. Dash and Vilermarette claim that AD patients "die because in the late stages they are almost certainly bedridden."

pointed out by Volicer, "caus[ing] choking on food and liquids. . .[that] may lead to aspiration of nasopharyngeal secretions." [322] Aspiration of nasopharyngeal secretions into the lungs creates a significant threat of aspiration pneumonia. Volicer also claims that "[i]n the terminal stage, individuals become either mute or unable to have meaningful verbal communication, and may not be able to maintain eye contact." [323] Absent the ability to communicate, exercise of whatever, if any, decisional capacity that has not already been lost is obviously out of the question. Scinto and Daffner report that AD patients may be unable to recognize caregivers, [324] and although this loss does not have significance re: medical complications, it can clearly be very difficult for caregivers. It is in this final stage that delirium and hallucinations are probably most likely.

Although the overall trajectory of AD is generally predictable in that phases of decline and functional impairment/loss are more or less sequential, it is difficult, apparently for even the most experienced clinicians, to predict with much accuracy the rate of progression of a particular individual's disease. There are simply too many individual differences in the way that bodies respond to the underlying pathologies. It is equally difficult to know with certainty what an AD patient thinks and feels as the disease progresses, although books, such as *My Journey into Alzheimer's Disease* have attempted to describe the experience. Most of the insight into how Alzheimer's disease is experienced is drawn from conversations with AD patients and/or inferentially from their observed behavior. There is some level of confidence that Alzheimer's

[322] Ladislav Volicer, "Palliative Medicine," 1377.

[323] *Ibid*, 1377.

[324] Scinto and Daffner, "Early Diagnosis of Alzheimer's Disease," 6.

disease is generally not physically painful. [325],[326] Not surprisingly, Joseph Foley reports significant differences in how Alzheimer's disease patients apparently respond to AD: "At least some patients are aware that they are in intellectual decline, that they have a disease that is progressive, that their behavior is abnormal, and that other people are being affected by their condition. Such relatively full awareness, although demonstratable more easily in the early or middle stages, can persist into the later or more severe stages." [327] Other patients, in his view, "are aware only part of the time. . . [while still others]. . .are aware that all is not right, but cannot comprehend the nature of the problem or its significance for themselves or others." [328] He reports that at least "[s]ome patients, aware that something is wrong, actively deny it and set up schemes of rather transparent concealment, convincing themselves that they are successful." [329],[330] Foley concedes that there is wide range of visceral reaction from AD patients:

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[325] Muriel R. Gillick. "Artificial Nutrition and Hydration in the Patient with Advanced Dementia: Is Withholding Treatment Compatible with Traditional Judaism." *Journal of Medical Ethics* 27, no. 1 (February 2001): 14. Gillick acknowledges that "[d]ementia is not inherently a *physically* painful condition," although she also notes that "it is often associated with painful problems" (14). She provides at least two examples: "The immobility of the person with advanced dementia, for example, may lead to the development of a pressure ulcer, a painful skin condition,. . . [and] [i]n addition, patients with advanced dementia develop contractures (the inability to straighten their limbs)."

[326] Sachs, Shega, and Deon Cox-Hayley. "Barriers to Excellent," 1059. Sachs, Shega, and Deon Cox-Hayley. although also noting that dementia does not usually involve physical pain, remind that dementia patients are likely to suffer from age related ailments: "While dementia does not cause physical pain per se, patients with dementia are likely to be suffering from arthritis, osteoporosis, peripheral neuropathy, and many other pain-causing comorbid conditions that increase in prevalence with advanced age."

[327] Joseph Foley. "The Experience of Being Demented." In *Dementia and Aging: Ethics, Values, and Policy Choices,* edited by Robert H. Binstock, Stephen G. Post, and Peter J. Whitehouse, 30-43. (Baltimore, MD: John Hopkins Press, 1992), 30.

[328] *Ibid,* 31.

[329] *Ibid,* 41.

[330] Muriel R. Gillick, "Artificial Nutrition," 14. Muriel Gillick claims that "[p]atients with advanced dementia so not have the cognitive capacity to experience *existential suffering*—they are unaware of their condition, they do not know or understand that they were once able to think and to reason, and therefore they cannot be distressed by their loss." This claim seems to be somewhat overstated, at least with regard to the earlier stages of dementia, especially in view of Foley's observations.

> There is a full spectrum of emotional responses. Some are placid and seemingly resigned; others are agitated and angry. Here, also, there are variations in content and intensity at different times. Placidity may prevail for hours or days or even weeks, to be succeeded again by agitation. Some patients, seemingly completely uncommunicative and badly demented, may open windows of clarity for minutes or hours. [331]

Insightfully, Foley argues that there are limits to inference. "We too often assume that the absence of emotional display means that no emotion is being experienced. . . [and] that because communication is absent, internal mental process has stopped." [332] Regardless, however, of varying levels of AD patients' insight into their diagnosis, prognosis, and overall level of awareness, not only among patients, but between different stages of disease progression, it is reasonable to conclude that many AD patients will likely experience significant levels of psychological stress, if only for a brief period, until such time, as Stephen Post comments, "they begin to forget that they forget." [333]

Loss of Decisional Capacity

One question certain to be on the minds of many individuals diagnosed with Alzheimer's disease, especially those who intend to make medical treatment and care decisions on their own behalf is, once diagnosed, how much longer they will possess the medical and legal capacity to make their own decisions. In answering this question, it must first be noted, as will be discussed in chapter 4, that decisional capacity is task specific and that although the decisional capacity to make a complex decision may, at some point in the progression of the disease, be irretrievably

[331] Joseph Foley, "The Experience of Being Demented," 31.

[332] *Ibid*, 37.

[333] Stephen Post, "The Moral Challenge," 1.

lost, the capacity to make a much simpler decision may be retained for some time. Second, it must also be noted that at least some individuals, believed to have permanently lost all decisional capacity, can have moments of remarkable clarity seemingly 'out-of-the blue' and thus regain, if only for a brief period, decisional capacity for at least some decisions.

For most individuals, however, decisional capacity is going to be impaired, if not lost, sometime during the moderate stage of the disease. Rabins claims that "symptoms [of aphasia, apraxia, and agnosia] can interfere with a person's ability to comprehend options, to remember facts, to make judgments and to communicate choices. . . [and] [a]s a result. . .can impair the ability to choose and make decisions, necessary elements of decisional capacity." [334] Regardless of whether decisional capacity is lost with moderate dementia, Rabins reports that during what he describes as the "last three-year period of Alzheimer's. . . many individuals lack the capacity to make or express preferences for [even] minor decisions." [335] Given, as noted above, that decisional capacity is task specific, it seems very likely that decisional capacity for major decisions re: care and medical treatment will be lost completely when dementia is assessed as severe.

Survival

Another question certain to be on the minds of virtually all individuals diagnosed with Alzheimer's disease is, once diagnosed, how long they can expect to live. Given the forgoing discussion describing the inability to accurately predict the rate of progression of the disease; it should come as no surprise that estimating survival, with any degree of precision, is exceedingly

[334] Peter V. Rabins, "Dementia and Alzheimer's Disease," 455.

[335] Peter V. Rabins, "Dementia and Alzheimer's Disease," 454.

difficult. Factor in the possibility that an individual diagnosed with Alzheimer's disease may die from a pathology unrelated to dementia,, such as heart disease or cancer, [336] as well as the obvious difference in survival time calculated from a relatively early diagnosis compared to a relatively late diagnosis, it becomes quite clear that an accurate diagnosis can only be made after the disease has progressed at least to the moderate stage and must even then be probably expressed in 6 month intervals. As will be discussed, one of the reasons that Alzheimer's patients have historically been denied access to hospice care is the inability of a doctor to affirm that a particular AD patient has six months or less to live.

Despite the difficulty of estimating survival with any significant degree of accuracy, it is nevertheless possible to provide those diagnosed with Alzheimer's disease with both a survival range and a probable cause of death, that can be provided at diagnosis and, absent a mostly unexpected and calamitous event such as cardiac arrest, can be adjusted as the disease progresses and the patient's prognosis changes. The estimated range of survival, in years, of individuals diagnosed with Alzheimer's disease, calculated from the time of the onset of clinical symptoms, is best shown comparatively:

Table 1. Comparative Estimates of Survival (in years) After a Diagnosis of Alzheimer's Disease

Source	**Possible**	**Earliest Probable**	**Average**	**Latest Probable**	**Rarely**
Mitchell [337]		3		6	
Sachs, et. al. [338]		4		9	

[336] Ladislav Volicer, "Palliative Medicine in Dementia," 1378. Volicer comments that "[i]t remains very difficult to estimate prognosis in an individual with advanced dementia because of the unpredictability of intercurrent diseases that are the most common cause of death."

[337] Susan L. Mitchell. "A 93-Year-Old Man With Advanced Dementia and Eating Problems." JAMA 298, no. 21. (Dec. 5, 2007): 2528. Mitchell reports that "[t]he best current estimates indicate that median survival after the onset of symptoms of dementia ranges from 3 to 6 years, shorter than previously estimated."

Consensus [339]		3	10		20
Rabins [340]		3	9-10		22
Dash, et. al. [341]	2	5		10	20
Ill. Alzh. Ass. [342]	3		5		20
Khachaturian [343]	2				20
Knopman [344]			6		
Mayeux [345]	2		3-4		20
Post [346]			7-8		20

Source: Created from the above referenced Journal articles.

[338] Sachs, Shega, and Deon Cox-Hayley. "Barriers to Excellent," 1057. Sachs, et. al. report that"[w]hile a recent study suggests that median survival may be as short as 4 years most other studies report a median survival of around nine years."

[339] American Association for Geriatric Psychiatry, et. al.,"Consensus Statement," 4. According to the Consensus Statement, the "[t]he average course of AD is approximately a decade, with a range of 3 to 20 year's duration from diagnosis to death."

[340] Peter V. Rabins, "Dementia and Alzheimer's Disease," 454. Rabins claims that "some patients with Alzheimer's disease progress from first symptom to death in three years, while others live more than twenty-two years . . . [noting] [h]owever, on average patients live nine to ten years with the disease."

[341] Dash and Villermarette-Pittman, *Alzheimer's Disease*, 52. According to Dash and Villermarette-Pittman, "[i]n general, the estimated time from the appearance of the first symptoms of AD to the time of death is approximately 5 to 10 years, although the range can be from anywhere from 2 to 20 years."

[342] Alzheimer's Association of Greater Illinois. "Encouraging Comfort Care: A Guide for Families of People with Dementia Living in Care Facilities." (2010), 3.The Alzheimer's Association Greater Illinois Chapter claims that "[t]his chronic illness can last anywhere from three to twenty years with an average of about five years from the start of symptoms to death."

[343] Khachaturian and Radebaugh, *Alzheimer's Disease*, 4. Khachaturian and Radebaugh report that "[t]he time from the onset of symptoms to the end of life can vary from 2 to 20 years."

[344] Knopman, Boeva, and Petersen, "Essentials of the Proper Diagnosis." 1290. Knopman, et. al. report that "from the onset of symptoms to death, median survival is about six years."

[345] Richard Mayeux, "Alzheimer's Disease Epidemiology," 195. Mayeux claims that"[s]urvival with Alzheimer's disease varies from 2 to 20 years, but a more realistic estimate of survival is 3-4 years."

[346] Stephen Post, "The Moral Challenge," 1. According to Post, "[s]ome people with Alzheimer's disease. . .live for two decades after clinical symptoms appear, although most live on for no more than seven or eight years."

Despite the above demonstrated variance in the estimated range of survival of individuals diagnosed with Alzheimer's disease, some of which can probably be attributable to analysis of statistical data in some instances and educated guesses in others, there is no question that Alzheimer's disease shortens lives. Mayeux claims that "Alzheimer's disease increases mortality by approximately 40% in both men and women," [347] while Dash and Villermarette-Pittman report that "[w]omen live approximately one and one-half years longer [than men]. . . [and] [o]verall, it is estimated that AD shortens life expectancy by five years." [348],[349],[350] Despite these two different assessments of the relationship between gender and mortality, there is general disagreement as to the factors that reduce survival among AD patients.

Joyce Simard and Ladislav Volicer report that "[s]everal factors that affect the long–term survival of dementia patients have been identified,. . . include[ing] age, gender, duration of illness, rate of dementia progression, degree of cognitive and functional impairment, behavioral problems, presence of hypertension, other physical illness, depression, [351] cachexia, and wandering and falling." [352] Not surprisingly, the quality of care also has an impact on survival.

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[347] Richard Mayeux, "Alzheimer's Disease Epidemiology," 195.

[348] Dash and Villermarette-Pittman, *Alzheimer's Disease*, 53.

[349] Ladislav Volicer" Palliative Medicine," 1378. Volicer also claims that[d]ementia significantly decreases life expectancy," pointing to the results of population surveys: "A population survey in Shanghai, China that investigated predictors of mortality found that the mortality risk ratio was 5.4 for AD and 7.2 for vascular dementia in patients aged 65-74 years. The risk ratio for AD was similar to the mortality risk ratio for cancer. Among patients aged 75 years and older, the mortality risk factors were 2.8 for AD, 3.5 for vascular dementia, and 3.6 for other dementias. Because dementing disorders were common in subjects aged 75 years and older, 23.7 per cent of the risk of death could be attributed to these disorders. Similar results have been obtained in Swedish, Italian, and French studies."

[350] *Ibid*. Volicer apparently agrees with Dash and Villermarette-Pittman that women live longer, but also points to low education, as reducing survival.

[351] *Ibid.*

[352] Dash and Villermarette-Pittman, *Alzheimer's Disease*, 233.

Volicer claims that survival in traditional long-term care facilities averages about 6 years, but that survival in a long-term care facility specializing in dementia care averages about eight years. [353]

Cause of Death

It probably comes as something of a surprise to the average layperson that individuals afflicted with Alzheimer's disease don't die from dementia, at least directly. According to Brigette and Ralph Richter, "the most frequent immediate cause of death in patients with AD is a life-threatening infection, such as pneumonia, usually related to aspiration, malnutrition, immobility, and incontinence-consequences of the progressive functional impairment." [354] Providing further confirmation of the significance of pneumonia, Susan Mitchell, Joan Teno, Dan Kiely, Michelle Shaffer, and Richard Jones, et. al. followed 323 nursing home residents with advanced dementia for 18 months in 22 nursing homes, and reported their findings: "Over a period of 18 months, 54.8% of the residents died. . .the probability of pneumonia was 41.1 %. . . [and] after adjustment for age, sex, and disease duration, the 6-month mortality rate for residents who had pneumonia was 46.7%." [355] Nevertheless, Jean Chouinard's report of the reported cause of death among 291 patients with a primary diagnosis of dementia, is instructive, because it shows that nearly half of patients with dementia die from causes other than pneumonia:

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[353] Volicer, Ladislav. "Impact of Special Care Unit for Patients with Advanced Alzheimer's Disease on Patient's Discomfort and Costs." *American Geriatric Society* 2 (1994): 598.

[354] Ralph W. Richter and Brigitte Zoeller Richter, eds. *Alzheimer's Disease: A Physicia*"Alzheimer Disease: Epidemiological and Statistical Data." In *Alzheimer's Disease: A Physician's Guide to Practical Management*, edited by Ralph W. and Brigitte Zoeller Richter, 51-56. (Totowa, NJ: Humana Press, 2004), 53.

[355] Susan L Mitchell, Joan M. Teno, Dan K. Kiely, Michelle L. Shaffer, and Richard N. Jones, et. al. "The Clinical Course of Advanced Dementia." *New England Journal of Medicine* 361, no. 16 (Oct. 15, 2009): 1529.

"Pneumonia 53.3%, Ischemic Heart Disease 17.2%, Stroke (all types) 8.2%, Cancer 4.8%, Gangrene 3.8%. and other unidentified causes, 12.7%." [356]

Medical Issues

A number of medical issues arise with the typical Alzheimer's disease patient, including those issues that are directly related to the progression of the neurological pathologies associated with the disease, and those that arise and/or worsen in large part because of advancing age and the onset and/or progression of pathologies without a specific link to dementia, [357] but that are nevertheless especially prevalent in [358] or aggravated by dementia. These issues include, but are not limited to, general neurological conditions; neurological conditions that affect mood and behavior, malnutrition/dehydration, pressure sores, bone fractures, infection, heart failure, pain, and hospitalization. Before examination of these issues, it should be noted that their identification, and/or confirmation in a particular AD patient may be significantly hampered by cognitive impairment and loss of cognitive function. At some stage in the progression of the disease, Alzheimer's patients may present doctors with the same sort of challenges faced by veterinarians. They can't tell the doctor what is broken, what is breaking down, whether they are in pain, or if they are in pain where it hurts. In addition, as reported by Muriel Gillick,

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[356] Jean Chouinard. "Dysphasia in Alzheimer's Disease." *Journal of Nutrition, Health, and Aging.* 4, no. 4 (2000): 215..

[357] Ladislav Volicer, " Palliative Medicine," 1377. Although Volicer claims that "[t]here is no known biological association between either AD or frontotemporal dementia and other physical illnesses," he also notes that "[i]ndividuals with dementia may develop the whole spectrum of diseases that accompany normal aging."

[358] *Ibid*, 1377." Volicer also notes that "some diseases are more common in individuals with AD, especially in the late stages." He cites a "case control study using 7195 death certificates [which] found that patients who died with AD had a higher incidence of Parkinson's disease, epilepsy, sensory impairments, infections, malnutrition, hip fractures and other injuries, and pressures sores than did the control subjects."

"discomforts such as having [their] blood drawn, or other tests performed, discomforts that may be well-tolerated by a cognitively intact person who understands their justification, are often frightening to someone who cannot comprehend what is being done." [359]

According to Volicer, "[n]eurological complications include parkinsonism, stroke, myclonus, [360] and seizures." [361] "Development of extrapyramidal [362] symptoms in particular," in his view, "closely parallels psychotic symptoms and is associated with increased rate of progression of cognitive impairments, functional impairments, nursing home entry, or death." [363] Significantly, he also notes that '[e]xtrapyramidal symptoms may occur in isolated AD and presumably would develop in all patients with the disorder if they survived long enough." [364] Although these neurological complications are serious and even life-threatening, the neurological complications that are at least potentially most burdensome for caregivers and thus probably receive more attention re: possible treatment strategies, are those neurological complications that affect mood and behavior.

Volicer claims that "[d]epression is the most common mood disorder in demented individuals, . . is closely related to both behavioral symptoms of dementia and meaningful activities. . . [and] was reported to be present in 15 to 57% of patients suffering from Alzheimer's disease." [365] He further notes that the "prevalence [of depression] does not change

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[359] Muriel Gillick, "Artificial Nutrition," 14.

[360] involuntary twitching of muscle

[361] Ladislav Volicer, "Palliative Medicine,"1378.

[362] the neural network responsible for carrying nerve impulses that cause involuntary reflex action such as, but not limited to, involuntary twitching of muscle.

[363] Ladislav Volicer, "Palliative Medicine,"1378.

[364] *Ibid*, 1378.

[365] Ladislav Volicer, "Alzheimer's Disease and Dementia," 6.

with the progression of the disease,. . .[and][t]he wide range of reported frequency of depression is caused by difficulty diagnosing depression in this patient population. . . [because] speech impairment renders severely demented patients unable to describe their symptoms." [366],[367]

The Alzheimer's Association reports the irritability, anxiety, and depression sometimes observed in the early stages of the disease, may eventually be accompanied by anger, agitation, aggression, general emotional distress, physical or verbal outbursts, restlessness, hallucinations, and delusions in the later stages. [368] The Consensus Statement reports that "[a]gitation is a general term that that refers to a range of behavioral disturbances, including aggression, combativeness, shouting, hyperactivity, and disinhibition. . . [and that] [a]s many as 50% of all dementia patients exhibit agitation, particularly in middle and late stages of the disease." [369] "Psychosis (paranoia, delusions, and hallucinations)," it is further claimed, "is far less frequent but can cause distress to patients and lead to violence. . . [and] [t]hese symptoms can overlap, be difficult to distinguish, and are among the most common causes of institutionalization or specialist referral." [370] Anne Monias and Diane Meier report that "nearly 20% [of patients with Alzheimer's] physically assault their caregivers," [371] and Rabins claims that one "study showed

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[366] *Ibid*.

[367] *Ibid*. According to Volicer, "[t]he diagnosis of depression has to be based on nonverbal communication and vegetative symptoms."

[368] Alzheimer's Association. "Treatments for Behavior." 1. http://www.alz.org/alzheimers_disease_treatments_for_behavior.asp (accessed on December 8, 2011).

[369] American Association for Geriatric Psychiatry, et. al.,"Consensus Statement," 9.

[370] *Ibid.*

[371] Monias and Meier, "Palliative Care," 344.

that sixty-seven per cent of persons with Alzheimer's disease developed a 'psychotic' symptom (an hallucination or delirium) during the course of Alzheimer's disease." [372]

Volicer reports that "[b]ehavioral symptoms originate from three main consequences of dementia: (1) functional impairment, (2) mood disorders, and (3) delusions and hallucinations," [373] ,. . . [and] "[a]lthough most. . .occur in the moderate stage of the disease, many patients continue to have challenging behaviors in the severe and even terminal stages of dementia." [374] He maintains that "[f]unctional impairment results in dependence in activities of daily living and an inability to initiate meaningful activities. . . [which not only] increase the potential for restiveness during care caused by lack of understanding that such care is necessary. . . [but] could lead to agitation, apathy, [and] repetitive vocalization." [375] "Depression," in his opinion, "may decrease the ability to engage in meaningful activities; increase dependence in activities of daily living; and lead into several peripheral symptoms, such as agitation, repetitive vocalization, apathy, insomnia, food refusal, and also restiveness of care because depressed individuals are angry and irritable." [376] Delusions and hallucinations can obviously have an enormous impact on a patient's behavior.

Malnutrition from nutritional insufficiency and dehydration from inadequate intake of fluids are not only frequent concerns, especially in the later stages of dementia, but have serious, even life-threatening, consequences. In the above referenced study by Susan Mitchell and colleagues, "[t]he probability of. . .an eating problem [was] 85.8%.,. . . [and] [a]fter adjustment

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[372] Peter V. Rabins, "Dementia and Alzheimer's Disease,"

[373] Ladislav Volicer, "Alzheimer's Disease and Dementia," 5.

[374] *Ibid.*

[375] I*bid.*

[376] *Ibid.*

for age, sex, and disease duration, the 6-month mortality rate for residents who had. . .an eating problem [was] 38.6%." [377] Malnutrition obviously weakens a likely already weakened body, and impairs not only the body's ability to repair itself, but to protect itself from pressure sores, [378] bone fractures, bacterial and viral infections. An even more immediate threat to life is presented when an AD patient is unwilling or unable, even with assistance, to eat, and especially drink, sufficiently to sustain his/her life. In the total absence of any significant fluid intake, death from terminal dehydration can take place in less than two weeks.

Pressure sores, sometimes called bed sores, and bone fractures are not uncommon in the later stages of dementia and can not only be a source of considerable, though possibly unreported pain for the AD patient, but also can cause and/or exacerbate other more serious problems. Bone fractures obviously decrease patient mobility and immobility not only makes incontinence more likely, but makes lung infection much more difficult to overcome. [379] Immobility contributes to the development of pressure sores [380] and together with incontinence [381] make pressure sores more difficult to control and significantly raises the risk of sore infection.

Along with eating difficulties, Volicer claims that intercurrent [382] infections are "[t]he most important medical conditions in an individual with severe and terminal dementia." [383] In

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[377] Mitchell, Teno, Kiely, Shaffer, and Jones, "The Clinical Course," 1529.

[378] Ladislav Volcier" Palliative Medicine," 1377.Volicer claims that pressure sores are [also] related to both motor impairment and malnutrition."

[379] *Ibid.* Volicer reports that"[h]ip fractures and other injuries are related to motor impairment that is a risk factor for development of infections."

[380] Ladislav Volicer, "Alzheimer's Disease and Dementia," 3. Volicer reports that "[a]mbulation. . .decreases the risk for development of pressure ulcers."

[381] Ladislav Volicer," Palliative Medicine," 1378. Volicer claims that "[i]ncontinence also leads to impairment of skin integrity and development of pressure sores."

[382] Occurring at the same time and altering the course of another unrelated medical condtion or disease.

his view, "[a]n intercurrent infection is not just a complication of severe and terminal dementia. . . [but] an inevitable consequence. . . [because] [i]ndividuals with advanced dementia are predisposed to development of infections [due to] impairment of immunological function, [384] incontinence, [385] inability to ambulate, [386] and the development of aspiration." [387] He reports that "[t]he most common infections in individuals with dementia affect the urinary tract, upper and lower respiratory tracts, skin and subcutaneous tissues, gastrointestinal tract, and eyes,. . . and that generalized infections are the most common cause of death." [388] In the above referenced study by Susan Mitchell and colleagues "[t]he probability of pneumonia was 41.1 %. . .[and] [a]fter adjustment for age, sex, and disease duration, the 6-month mortality rate for residents who had pneumonia was 46.7%." [389] Volicer claims that bronchopneumonia caus[es] death in about 60 per cent of patients with AD." [390]

As noted above, progression of the pathological processes associated with Alzheimer's disease do not directly cause the AD patient physical pain. Nevertheless, AD patients, especially

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[383] Ladislav Volicer, "Alzheimer's Disease and Dementia," 3.

[384] Ladislav Volicer," Palliative Medicine," 1378. Volicer reports that "[p]atients with AD have impairment of cell-mediated immunity and changes in cytokine secretion and acute-phase proteins,. . .[and that] [t]hese changes may decrease immunological defenses."

[385] *Ibid*. Volicer reports that '[i]ncontinence is unavoidable once patients become unable to communicate and sit on a toilet, and the incidence of urinary tract infections is increased by the use of urinary catheters and by bowel incontinence."

[386] *Ibid*. Volicer describes how dementia impacts mobility and immobility contributes to infection: "Decreased mobility is a consequence of both gait problems and perceptual impairments. An unsteady gait and gait abnormality (narrow based gate) are secondary to increased muscle tone and rigidity. Patients also lose the ability to recognize obstacles in their path and may not be able to sit down safely in a chair. Inability to walk increases the risk for development of urinary tract infection by 3.4 times and risk of pneumonia by 6.6 times. Decreased mobility also is a risk factor for incidence of pressure sores, which may result in sepsis."

[387] Ladislav Volicer, "Alzheimer's Disease and Dementia," 4.

[388] Ladislav Volicer," Palliative Medicine," 1378.

[389] Mitchell, Teno, Kiely, Shaffer, and Jones, "The Clinical Course," 1529.

[390] Ladislav Volicer," Palliative Medicine," 1378.

in the late stages of the disease, almost certainly experience some form of physical pain. The above referenced study by Susan Mitchell et. al. reported that among nursing home residents with advance dementia,"[d]istressing symptoms, including dyspnea [391] (46.0%) and pain (39.1%) were common." [392] Likely causes of physical pain in AD patients, according to Volicer, include "pain. . result[ing] [from] an acute condition (fecal impaction, urinary retention, unrecognized fracture). . .[but more common[ly] [from]chronic conditions, such as arthritis, old fractures, neuropathy, and malignancy." [393] He adds that "[m]any aggressive medical interventions [also] produce discomfort, which may be compounded because patients often do not understand the need for a specific procedure." [394] Because many AD patients may sooner or later be unable to report physical pain, there is a great risk not only of under treatment, but perhaps not treatment at all.

Richter and Richter report that a "very common cause of death [in Alzheimer's disease] is. . .cardiovascular disease," [395] which could be significantly aggravated by an Alzheimer's patient's nutritional deficiencies. A resultant medical issue is whether to attempt resuscitation if and when an AD patient's heart stops. Hospitalization of an AD patient for acute care, which is by no means uncommon, also raises issues. According, once again, to the above referenced study by Mitchell, et. al., "[i]n the last three months of life, 40.7% of [nursing home] residents

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[391] shortness of breath

[392] Mitchell, Teno, Kiely, Shaffer, and Jones, "The Clinical Course," 1529.

[393] Ladislav Volicer," Palliative Medicine," 1381

[394] Ladislav Volicer, "Alzheimer's Disease and Dementia," 4.

[395] Richter and Richter, "Alzheimer Disease: Epidemiological," 53.

underwent at least one burdensome intervention. . . [including] hospitalization. . .[and/or an]emergency room visit." [396]

Medical Treatment

Although there is a wide range of available medical treatment for addressing an Alzheimer's patient's cognitive and functional impairment, as well as mood and behavior disorders, it must be understood that there is no currently available medical treatment that can reverse the damage already suffered by the Alzheimer brain or predictably slow the further progression of the disease. With this unfortunate reality firmly in mind, it is critically important to establish, from the very beginning, the overall goals of treatment. The American Association for Geriatric Psychiatry, American Alzheimer's Association and the American Geriatrics Society's Consensus Statement suggests:

> The primary goals of treatment of patients with AD [should be] to improve quality of life and maximize functional performance by enhancing cognition, mood, and behavior. . . [further suggesting that] [p]harmacologic treatment should be introduced only if nonpharmnacologic interventions prove ineffective, there is a significant risk of danger, or the patient is very distressed. [397]

Justification is offered for the recommendation: "First, the elderly have decreased renal clearance and slowed hepatic metabolism." [398] This means that drugs will likely remain in their systems longer. "Second, elderly patients often take multiple medications, so the clinician must

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[396] Mitchell, Teno, Kiely, Shaffer, and Jones, "The Clinical Course," 1529.

[397] American Association for Geriatric Psychiatry, et. al.,"Consensus Statement," 7.

[398] *Ibid.*

be aware of potential drug interactions and adverse effects. Third, elderly patients have decreased vascular tone and are subject to orthostasis,[399] leading to falls." [400] "Thus," according to the Consensus Statement, "low starting doses and small increases should be used,. . .the periods between drug changes should be extended. . . [and] [n]onessential polypharmacy should be avoided." [401]

As noted above, symptoms of cognitive impairment in AD include memory loss, confusion, disorientation, and impairment of both problem solving and communication skills. Also noted were disorders of mood and behavior. Understanding the cause(s) of cognitive impairment and mood and behavior disorders is obviously critical to identifying and applying the appropriate medical treatment. As described in the previous chapter, Alzheimer's patients suffer from cognitive impairment because the disease disrupts communication between neurons, by impairing the function of synapses, blocking the production or reception/absorption of a neurotransmitter(s), or directly/indirectly damaging or destroying neurons themselves. Any effort directed at improving cognitive function must slow, halt, or reverse these pathologies. Causes of mood and behavior disorders are somewhat more speculative. Volicer seems to suggest that an overall lack of stimulus may significantly affect an AD patient's mood and behavior:

> Patients are no longer able to engage in their hobbies and lose the comprehension of what they read or even what they watch on television.. Because of their speech impairment, patients have limited ability to engage in social interactions with other patients or staff. Unless the patients have opportunities to participate in specially designed programs, they may become isolated, apathetic, or wander aimlessly. [402]

[399] capacity of achieving and maintaining an upright standing position.

[400] American Association for Geriatric Psychiatry, et. al.,"Consensus Statement," 7.

[401] *Ibid*.

[402] Ladislav Volicer, "Alzheimer's Disease and Dementia," 2.

Volicer also insists that "[i]t is important to first eliminate the possibility that behaviors are due to environmental and physical causes, e. g. cold or hot temperature,, noise, and hunger or thirst. . . [and that] [t]he most common physical symptom that causes discomfort is unrecognized or undertreated pain." [403]

The Alzheimer's Association notes that "events or changes in a person's surroundings often play a role in triggering behavioral symptoms[404]. . . [and] everyone who develops behavior changes should receive a thorough medical evaluation, especially if symptoms appear suddenly." [405] According to the Association, the medical evaluation can reveal contributing conditions, including "drug side effects, [406] discomfort from infections and other conditions, [407] and uncorrected problems with hearing or vision." [408] Rabins reports that "[e]ven 'minor' medical procedures such as a urinary tract or upper respiratory tract infection can lead to significant deterioration of cognition, and behavior in a person with Alzheimer's disease." [409] The Consensus Statement adds that "pain, depression, loss of sleep, or delirium. . .[can, in particular]

[403] Ladislav Volicer," Palliative Medicine," 1378.

[404] Alzheimer's Association, "Treatments," 2. The Alzheimer's Association reports that situations affecting behavior may include: "Moving to a new residence or nursing home, Changes in a familiar environment or caregiver arrangements, Misperceived threats, Admission to a hospital, and Being asked to bathe or change clothes."

[405] *Ibid*, 1.

[406] American Association for Geriatric Psychiatry, et. al.,"Consensus Statement," 7. The Consensus Statement claims that "[a]nticholinergic adverse effects pose a particular problem in persons with AD, as they can worsen cognitive impairment and may even cause delirium. . . [and that] [d]rugs causing central nervous system sedation may also worsen cognition."

[407] Alzheimer's Association, "Treatments," 2-3. The Alzheimer's Association claims that the AD patient's inability to communicate makes unreported symptoms a potentially significant problem: "Pain from infections of the urinary tract, ear or sinuses may lead to restlessness or agitation. Discomfort from a full bladder, constipation, or feeling too hot or too cold also may be expressed through behavior."

[408] *Ibid*, 1-2.

[409] Peter V. Rabins, "Dementia and Alzheimer's Disease," 462.

cause agitation," [410] as can"'[u]naddressed interpersonal or emotional issues, such as fear of abandonment." [411]

Available medical treatment for the consequences of neurological damage can be divided into Drug Therapy for Cognitive and Functional Impairment, Drug Therapy for Mood and Behavior Disorders, and Nonpharmacological Strategies directed at both cognitive and functional impairment and mood and behavior disorders. Based on the recommendation of the Consensus Statement, nonpharmacological strategies will be examined first.

Nonpharmacological Strategies

It is important to remember that although nonpharmacological strategies are often primarily directed at both cognitive and functional impairment and mood and behavior disorders, the overall goal should probably be maximizing the overall quality of life of the AD patient and his/her caregivers. Rabins claims that [f]or cognitive symptoms, most clinicians believe that an environment which minimizes stress and the patient's need to use impaired capacities while maximizing the patient's remaining capacities allows all individuals to perform at their maximal level."[412] Unfortunately, the Consensus Statement reports that "[p]sychotherapeutic techniques proposed to restore cognitive [function] includ[ing] reality orientation and memory retraining. . . may yield some transient benefit but also provide frustration and depression in patients and caregivers." [413] The Consensus Statement further cautions that because "the cognitive benefits associated with reality orientation and memory retraining are weak, many specialists believe the

[410] American Association for Geriatric Psychiatry, et. al.,"Consensus Statement," 9.

[411] *Ibid*, 9.

[412] Peter V. Rabins, "Dementia and Alzheimer's Disease," 462.

[413]American Association for Geriatric Psychiatry, et. al.,"Consensus Statement," 8.

potential risks outweigh the benefits." [414] It must be noted, however, that an apparent distinction is drawn between techniques designed to restore cognitive function and techniques designed to reduce or eliminate mood and behavior disorders.

Volicer opines that the "[t]wo most common and most important behavioral symptoms are resistiveness to care and agitation/apathy. . . [and that] [i]t is important to prevent escalation of resistiveness to care into combative behavior that may result in injury to the caregiver or patient." [415] In his view, "[t]he appropriate non-pharmacological intervention for such a behavior is improvement in communication, delaying the care giving activity, or modifying care giving strategy." [416] One way of modifying care giving strategy is to emphasize what Volicer calls meaningful activities, which he identifies as "meaningful activities of daily living, physical activities, cognitive activities, and creative activities." [417] According to Volicer, AD patients "best respond to one-on-one contacts and interactions that take into account their stage of cognitive and functional impairment." [418] He is aware, however, that "[s]uch an interaction cannot be provided continually either in a home setting where a family caregiver is already stressed with other care responsibilities or in an institutional setting with limited staffing." [419] Nevertheless, he identifies a number of meaningful activities, including group activities, evoking of pleasant memories, art, music, pet and touch therapies, observing moving images, and

[414] *Ibid*, 8.

[415] Ladislav Volicer," Palliative Medicine," 1381.

[416] *Ibid*.

[417] *Ibid*, 1382.

[418] Ladislav Volicer, "Alzheimer's Disease and Dementia," 2.

[419] *Ibid*, 2.

activities that help the patient to maintain the ability to ambulate. [420] These activities may not only positively impact cognitive function but decrease behavioral problems and improve the mood of the patient his/her family/caregivers, and contribute to a safer and more peaceful overall environment.

Volicer notes that, unlike group activities "organized in nursing homes and assisted living settings. . .[which] are geared toward cognitively intact residents or residents with mild to moderate dementia,. . . r]esidents with severe dementia need specifically designed programs that are failure proof, do not require intact speech, and can accommodate different levels of involvement." [421] One "example of such an activity is 'Bright Eyes.'. . . [which] organizes an activity around a theme (e. g. baseball) and stimulates all senses in a group setting (smell by freshly cut grass, touch by a baseball hat, kinesthetic sense by tossing a baseball around, sight by a picture of a local baseball park, hearing by singing 'Tak[e] me out to the ballgame,' and taste by serving nonalcoholic beer." [422]

According to Volicer, "[r]ecalling pleasant memories is very often the main activity when family members visit their loved one in an institution. . .[and] [s]imilar experiences may be provided by an audiotape [or videotape] made by a family member or a staff member [using] simulated presence therapy." [423],[424] In his experience, even "[i]ndividuals in the terminal stage

[420] *Ibid*, 2-4.

[421] *Ibid*, 2

[422] *Ibid*, 4.

[423] *Ibid*, 3.

[424] Ladislav Volicer, "Alzheimer's Disease and Dementia," 2. Volicer describes how the tape functions: "This tape is similar to a one-sided telephone conversation and provides spaces for resident's responses. The tape can be played using a portable tape player and light-weight headphones allowing the resident to move around. Because of the severe impairment of short term memory, the tape can be played repeatedly in an auto-reverse tape layer and provides a new experience every time."

[of dementia can] still respond to touch, music and often also pet therapy." [425] The Consensus Statement affirms the value of "art and other expressive. . .therapies, [including] exercise, and dance. [426] Volicer also suggests that AD patients "may also enjoy observing simple moving images provided by Snoezelen. . . a multisensory stimulation environment originally developed for children with developmental deficits." [427],[428] As noted above, many individuals with Alzheimer's disease sooner or later lose their ability to walk without falling, and any activity that promotes the retention of that ability is worthwhile. According to Volicer, "[i]ndividuals who can ambulate can join more activities, including trips outside the home or institution. . . [and] ambulation itself may be a meaningful activity and important outlet for physical energy that may otherwise precipitate problem behaviors." [429] Maintenance of independent ambulation can be promoted," in his view, "by avoidance of restraints and by frequent ambulation either independently or with staff assistance," [430] especially with the use of specially designed walkers.

Finally, it is important to note that, despite the above described activities, activity level and the overall physical environment must be adapted to suit the needs of the individual patient. The Consensus Statement has an observation and recommendation:

> Dementia patients are sensitive to their environment and often do best with

[425] *Ibid*, 4.

[426] *Ibid*, 9.

[427] *Ibid*, 3.

[428] *Ibid*, 3. Volicer describes the Snoezelen sytem: "Two components of this system, which can easily be transported and used in group settings or in individual patients' rooms, include a projector and a music player. The projector is equipped with a rotating wheel containing colored oils and projects moving images on a screen, wall, or ceiling. Combinations of these images provides both stimulation and a soothing atmosphere for individuals with severe and terminal dementia."

[429] *Ibid.*

[430] *Ibid*.

> moderate stimulation. Too much stimulation may worsen confusion or cause agitation; too little may lead to withdrawal. [F]amilies [should be encouraged] to employ familiar surroundings to enhance mood and maximize existing cognitive functions; to promote a sense of safety and predictability through daily routines; and to stimulate memory and orientation through conspicuous displays of clocks, calendars, and to-do lists. Many patients benefit from links to the outside world through newspapers, radios, and televisions. [431]

Volicer is convinced that "meaningful activity may alleviate the symptoms of depression and sometimes eliminates the need for pharmacologic treatment." [432] The Consensus Statement supports his assessment, noting that "[d]espite a paucity of well-controlled data, preliminary studies and clinical practice suggest that these interventions may decrease behavioral problems and improve mood in patients and family alike." [433] Somewhat surprisingly, Volicer maintains that "[m]eaningful activities should be provided even in the terminal stage of dementia. . . [for] [a]lthough some individuals become completely mute and interact very little with their environment, they may never reach a persistent vegetative state where they are completely unable to respond to stimulation." [434]

A particularly primitive, and at least arguably, egregious method of controlling AD patients has, at least historically, been the use of physical constraints. Patients are literally strapped down to prevent them from dislodging an IV, feeding tube or other method of providing medical treatment or to prevent their wandering around unsupervised. Hopefully, this method will continue to be restricted to instances where its use is absolutely unavoidable rather than

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[431] *Ibid*, 11.

[432] *Ibid*, 6.

[433] American Association for Geriatric Psychiatry, et. al.,"Consensus Statement," 9.

[434] Ladislav Volicer, "Alzheimer's Disease and Dementia," 3.

merely for the convenience of the caregiver[s]. Needless to say, if all nonpharmacological strategies prove ineffective, drug therapies directed at both cognitive and functional impairment and mood and behavior disorders may be appropriate.

Drug Therapy for Cognitive and Functional Impairment

Caselli, et. al. report that "[t]wo classes of drugs have been approved for use to enhance memory and related intellectual skills in patients with AD: the cholinesterase inhibitors and the N-methyl-p-aspartate (NMDA) receptor antagonist memantine." [435],[436] According to the Alzheimer's Association, the current (2011) FDA approved cholinesterase inhibitors are Aricept (Donepezil) [437], Rivastigimine (Exelon), Galantamine (Razadyne), and (Cognex). [438],[439] The Association also notes that although not approved by the FDA "some doctors also prescribe high doses of vitamin E for [treating the] cognitive changes of Alzheimer's disease." [440]

It is important to understand what these drugs can, and perhaps more importantly, cannot do, as well as their possible side effects. According to the Alzheimer's Association, the cholinesterase inhibitors "delay worsening of symptoms for 6 to 12 months, for about half of the

[435] Caselli, Beach, Yaari, and Reiman. "Alzheimer's Disease A Century Later," 1792.

[436] Davis, John B., C. Bountra and J. Richardson. "Perspectives of Alzheimer's Disease Treatments." In *Handbook of Clinical Neurology*, edited by Michael J. Aminoff, Francois Boller, and Dick F. Swaab, 273-290. Edinburgh, Scotland: Elsevier, 2008. Davis, et. al.'s explanation of how memantine functions is instructive, and is provided in the Chapter Appendix (Number 1).

[437] American Association for Geriatric Psychiatry, et. al.,"Consensus Statement," 9. The Consensus Statement's analysis of Tacrine and Donepezil is instructive and is provided in the Appendix (Number 2).

[438] Alzheimer's Association, "Latest," 1.

[439] Davis, Bountra, and Richardson., "Perspectives of Alzheimer's," Another conceivable therapy that has attracted attention is intravenous nicotine. Davis, et. al.'s description of this therapy is provided in the Appendix (Number 3).

[440] Alzheimer's Association, "Latest," 10.

people who take them. . . [and although they] are generally well tolerated. . .[can cause] nausea, vomiting, loss of appetite and increased frequency of bowel movements." [441] The Association also reports that memantine "delays worsening of symptoms for some people [at least] temporarily. . . [but can also] cause side effects, including headache, constipation, confusion and dizziness." [442] Stephen Post cautions that "[p]atients and their families should know that the current drug treatments do not [slow the] development of symptoms in any long term fashion." [443] "After a period of time," he claims, "all patients will have declined to their former state and will then follow the typical downward course." [444]

Post further suggests that the brief mitigation by available drug therapies of some of the symptoms of cognitive impairment may create some unexpected difficulties for both patient and caregiver(s): "[E]ven if some symptoms are briefly mitigated,. . .patients and caregivers who have already navigated certain crises of cognitive decline may have to repeat this process. The individual who has lost insight into his or her losses may regain insight, along with renewed anxiety. For AD patients who have already adjusted to decline, the intrusion of a temporary enhancement may not necessarily enhance quality of life; for caregivers, some of the most taxing phases of care may need to be repeated, resulting in renewed stress." [445]

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[441] *Ibid*, 2.

[442] *Ibid*, 2.

[443] Stephen Post, "Key Issues," 5.

[444] The apparent failure to slow the progression of the pathologies associated with Alzheimer's has apparently been a disappoint to many. Speculation on the reason for the failure and how that assessment might guide future efforts is provided in the Appendix (Number 4).

[445] Davis, Bountra, and Richardson., "Perspectives of Alzheimer's, 275-276; American Association for Geriatric Psychiatry, et. al.,"Consensus Statement," 8. According to Davis, et. al. "[t]here is substantial physiological and behavioral evidence supporting the role of serotonin in the modulation of learning and memory." Other promising therapies for treating cognitive and functional impairment, in their view, include the "modulation of histamine levels, modulation off noradrenergicsystems, [and] [a]myloid lowering approaches, including NSAIDS and Cholesterol lowering drugs." The Consensus Statement

Drug Therapy for Mood and Behavior Disorders

The Alzheimer's Association recommends that "if non-drug approaches fail after being applied consistently, introducing medications may be appropriate for individuals with severe symptoms or who have the potential to harm themselves or others. . . [and that] while prescription medications can be effective in some situations, they must be used carefully and most effective when combined with non-drug approaches." [446] Just as importantly, the Association notes that as of 2011, "no drugs are specifically approved by the FDA to treat behavioral and psychiatric dementia symptoms." [447] In general, antidepressants are prescribed for low mood and irritability; anxiolytics for anxiety, restlessness, verbally disruptive behavior and resistance; and antipsychotics for hallucinations, delusions, aggression, agitation, hostility, and uncooperativeness. [448],[449]

Rabins claims that "[a] number of studies have demonstrated modest benefits for the pharmacological treatment of psychosis, agitation/aggression and depression." [450] "These medications," in his view, "have significant side effects, but attempts to decrease the use of antipsychotic drugs in nursing homes by requiring careful documentation have been only

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identifies "estrogen, nonsteroidal anti-inflammatory agents, and botanical agents such as ginkgo biloba. . . [but notes that] evidence of clinical benefit for any of these agents is inconclusive at this time."

[446] Alzheimer's Association, "Treatments," 3.

[447] *Ibid*.

[448] *Ibid*.

[449] *Ibid*. The Alzheimer's Association provides a list of the medications commonly used for treating behavioral and psychiatric symptoms of AD and it is provided in the Appendix (Number 5).

[450] Peter V. Rabins, "Dementia and Alzheimer's Disease," 462.

modestly successful." [451] The side effects of the antipsychotic drugs are the chief area of concern, and the Alzheimer's Association admonishes that should be used with extreme caution. [452] The Association reports that "[r]esearch has shown that these drugs are associated with an increased risk of stroke and death in older adults with dementia. . . [and] that the FDA has ordered manufacturers to label such drugs with a 'black box' warning about their risks and a reminder that they are not approved to treat dementia symptoms." [453],[454],[455] Unfortunately, Sophie Pautex and colleagues claim that while pain medication is under prescribed for dementia patients, antipsychotics are overprescribed. [456],[457]

Malnutrition/Dehydration

Easily the most controversial form of medical treatment provided to or withheld/withdrawn from Alzheimer's patients is the various forms of artificial nutrition and hydration (ANH) used to prevent malnutrition and/or dehydration, especially when withdrawn or

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[451] *Ibid*.

[452] Alzheimer's Association, "Treatments," 4.

[453] *Ibid.*

[454] *Ibid*, 5. The Alzheimer's Association suggests that antipsychotics should be used in one of the following conditions: 1.Behavioral symptoms are due to mania or psychosis, 2. The symptoms present a danger to the person or others, and 3. The person is experiencing inconsolable or persistent distress, a significant decline in function, or substantial difficulty receiving needed care."

[455] Stephen G. Post"Alzheimer's Disease: Ethics and the Progression of Dementia." *Clinics in Geriatric Medicine* 10. no. 2 (May 1994): 391. Post claims that "[a]ntipsychotic agents can cause dry mouth and lethargy, whereas long-term use can lead to tardive dyskinesia."

[456] Pautex, Zekry, Zulian, Gold, and Michel, "Pain and Palliative Care," 219.

[457] Additional information can be obtained from:
Food and Drug Administration www.ida.gov
MedlinePlus www.medlineplus.gov
Mayo Clinic www.mayoclinic.com
Cleveland Clinic www.clevelandclinic.org

withheld from a late-stage AD patient who is unwilling or unable, even with assistance, to eat and drink sufficiently to sustain his/her life. Alzheimer's disease may have destroyed his/her ability to swallow without life-threatening aspiration of food and fluids into the lungs, or in the alternative, he/she may have progressively lost most if not all of his/her desire to eat and drink either because of the progression of the disease or simply as a result of the consequences of the natural shut down of bodily processes at the end of life. Whether ANH must be utilized or can be withheld or withdrawn is not only controversial, but is a particular focus of this inquiry. Accordingly, the physiology of malnutrition and especially dehydration, the pathological processes that destroy an AD patient's desire for and/or ability to orally ingest food and water, as well as the mechanics of ANH, are discussed, in significant detail, in the following chapter.

Infection

Alzheimer's patients are prone to serious and even life-threatening infection. One such infection is of the urinary tract, and is aggravated by incontinence, immobility, and a weakened immune system. Far more potentially serious is aspiration pneumonia. Although there are a number of possible etiologies, among AD patients, aspiration pneumonia is primarily caused by malfunction of the swallowing mechanism and resultant aspiration of nasopharyengeal secretions into the lungs. An in depth examination of both the physiology of the swallowing mechanism and aspiration pneumonia is provided in the following chapter.

Medical treatment of aspiration pneumonia is especially difficult in all geriatric patients. According to Michael Feinberg, Janice Knebl, and Joann Tully, "[r]ecognition is often delayed because signs and symptoms can be subtle and differ from those seen in younger patients . . . [and] [t]reatment with antibiotics can be difficult in this population because of an inability to

identify the pathogen, altered drug metabolism, and associated medication side effects." [458] Nevertheless, according to Sachs, Shega and Cox-Hayley, dementia "[p]atients who [are] not end-stage did live considerably longer if they received antibiotics." [459] In their view, "[i]n a person with dementia, the therapies for a typical downturn caused by an infection—intravenous antibiotics, fluids, and adjustment of electrolytes—are fairly routine, not burdensome, relatively inexpensive, and usually effective." [460] Unfortunately, diagnosis and treatment apparently become more difficult and prognosis more problematic as dementia deepens.

Monias and Meier report that "infection in advance dementia patients may be detected later than in cognitively intact patients, secondary to atypical presentation and inability of the patient to express themselves." [461] Volicer claims that "[i]t is preferable to limit the use of intravenous therapy [such as might be used to introduce antibiotics into the body] to individuals with severe dementia, who do not understand the need for intravenous catheters, try to remove them, and may be restrained or given psychotropic drugs to allow the treatment to continue." [462] "Antibiotic [use]," in the advance stages of dementia is, in his view, "not without adverse effects," [463] and he justifies his assessment: "Patients may develop gastrointestinal upset, diarrhea, allergic reactions, hyperkalaemia, agranulocytosis, and *Clostridium difficile* infection. Diagnostic procedures, such as blood drawing and sputum suctioning, which are necessary for rational use of antibiotics, cause discomfort and confusion in demented individuals, who do not

[458] Michael J. Feinberg, Janice Knebl, and Joann Tully. "Prandial Aspiration and Pneumonia in an Elderly Population Followed Over 3 Years." *Dysphagia* 11, no. 2 (March 1996): 106.

[459] Sachs, Shega, and Deon Cox-Hayley. "Barriers to Excellent," 1059.

[460] *Ibid*.

[461] Monias and Meier, 7.

[462] Ladislav Volicer," Palliative Medicine," 1381.

[463] *Ibid.*

understand the need for them." [464] More importantly, antibiotics apparently lose effectiveness in patients in the advance stages of dementia, and Volicer explains why:

> A key reason for this lack of antibiotic effectiveness is the recurrent nature of infections in individuals with severe and terminal dementia. Because of the persistence of factors predisposing to the development of infections [such as persistent swallowing difficulties with aspiration], infection often recurs as soon as an antibiotic treatment is terminated. Repeated courses of antibiotic treatment lead to development of resistant strains of bacteria that eventually result in death from an infection or side effects of antibiotic treatments. [465]

Volicer reports, as noted above, that "[p]neumonia is the most common cause of death in demented individuals, reflecting the limited effectiveness of antibiotic therapy for infections in this patient population. [466] Jen-Hau Chen, Jennifer Lamberg, and Yen-Ching Chen, et. al. claim that "[a]ntibiotic therapy and hospitalization have not consistently been shown to improve the survival or reduce the discomfort of severely demented persons with pneumonia," [467] while Sean Morrison and Albert Siu inform that "[s]ix month mortality for patients with end-stage dementia and pneumonia was 53% compared to 13% for cognitively intact individuals." [468] Finally, Ann Hurley and Ladislav Volicer report that "[a]ntibiotic treatment did not extend survival in

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[464] *Ibid*.

[465] Ladislav Volicer, "Alzheimer's Disease and Dementia," 3-4.

[466] *Ibid*, 3.

[467] Jen-Hau Chen, Jennifer L. Lamberg, Yen-Ching Chen, Dan K. Kiely, and John K. Paige, et. al. "Occurrence and Treatment of Suspected Pneumonia in Long-Term Care Residents Dying With Advanced Dementia." *Journal of the American Geriatrics Society* 54, no. 2 (February 2006): 294.

[468] Sean Morrison and Albert L. Siu. "Survival in End-Stage Dementia Following Acute Illness." *JAMA* 284, no. 1 (July 5, 2000): 49.

cognitively impaired patients who were unable to ambulate [even with assistance] and were mute. . . . [and that] Luchins et. al. found no significant difference in survival rates between patients with advanced dementia who were treated with antibiotics and those who were not." [469]

Cardiopulmonary Resuscitation

Also controversial is the use, as well as the refusal, of cardiopulmonary resuscitation (CPR) if and when a AD patient's heart stops. Volicer claims that "[t]he immediate survival of resuscitated nursing home residents is 18.5 per cent; only 3.4 per cent are discharged from the hospital alive . . . . [and] [b]ecause the presence of dementia decreases the probability of successful CPR by three times, only 1 per cent of demented residents suffering cardiac arrest can be expected to be discharged alive from the hospital." [470] The Alzheimer's Association of Greater Illinois Chapter reports that Alzheimer's patients "who initially survive CPR are [usually] taken to an intensive care unit of a hospital where most die within 24 hours." [471] Volicer maintains that even if successful, "CPR is a stressful experience for those who survive," [472] and provides support for that assessment:

> They may experience CPR related injuries such as broken ribs, and often have to be on a respirator. The intensive care unit environment is not conducive to appropriate care for demented individuals, who may experience worsening confusion and often develop delirium. In addition, patients who are discharged alive from the hospital after CPR are much more impaired than they were before

[469] Ann Hurley and Ladislav Volicer. "Alzheimer's Disease: It's Okay, Mama, If You Want to Go, It's Okay." *JAMA* 288, no. 18 (November 2002): 2324.

[470] Ladislav Volicer," Palliative Medicine," 1380.

[471] Alzheimer's Association of Greater Illinois Chapter, "Encouraging Comfort Care," 13.

[472] Ladislav Volicer," Palliative Medicine," 1380.

the arrest.[473]

Physical Pain and Mental Suffering

According to Volicer,"[e]valuation of discomfort in a patient suffering from severe or terminal dementia is difficult because the patient is unable to verbalize feelings. It is possible, however," in his opinion, "to use a scale to evaluate discomfort by observing the patient and rating nonverbal cues, such as vocalization, facial expression, and body posture." [474] He maintains that "[p]ain should be treated aggressively, with an opioid if necessary." [475] It may be even more difficult to determine how much, if any, an Alzheimer's patient, especially in the later stages of the disease, is suffering, emotionally, psychologically, or spiritually. One issue is whether an AD patient possesses sufficient self-awareness to be aware of his/her condition and prognosis, and suffer as a result. As noted above, levels of awareness can vary greatly among AD patients, and even an individual patient can experience interludes of greater awareness. Pautex and colleagues report that "[s]ometimes [a] patient is confused and unaware of his or her condition; at other times [a] patient knows that she or he is dying and attempts to communicate those fears." [476] "Unfortunately," in their view, "instead of providing pain control and spiritual support during the dying process, there is a tendency of the medical system to concentrate on life-prolonging interventions. . .including cardiopulmonary resuscitation, renal dialysis, tube feeding, and antibiotic administration." [477] One possibility for treating various forms of mental

[473] *Ibid*.

[474]Ladislav Volicer, "Alzheimer's Disease and Dementia," 5.

[475] Ladislav Volicer, "Palliative Medicine,"1381.

[476] Pautex, Zekry, Zulian, Gold, and Michel, "Pain and Palliative Care," 219.

[477] *Ibid*, 221.

suffering, especially short term, is palliative sedation, which reduces a patient's level of consciousness. Palliative sedation, in particular preemptive palliative sedation, is examined in some detail in the next chapter.

Hospitalization/Acute Care

Volicer claims that the "available data indicate that transfer to an emergency room or hospital has significant degree of risks and relatively few benefits for individuals with severe dementia." [478] The presumed benefit, life extension, may be illusory, especially with regard to pneumonia. Volicer further claims that "[h]ospitalization for pneumonia does not seem to improve outcome in nursing home patients, and death and functional deterioration have been reported to be more frequent in hospitalized patients than in patients treated in the nursing home." [479] According to Volicer, hospitalization and acute care impose serious risks on AD patients:

> Even cognitively intact hospitalized elderly individuals develop depressed psycho-physiological functioning that includes confusion, falling, not eating, [480] and incontinence. These symptoms are often managed by medical interventions, such as psychotropic medications, restraints, [481] nasogsatric tubes, and urinary catheters, which expose the patient to possible complications, including thrombophlebitis, pulmonary embolus, aspiration pneumonia, urinary tract infection, and septic shock. [482]

[478] Ladislav Volicer," Palliative Medicine," 1380.

[479] Ladislav Volicer, "Alzheimer's Disease and Dementia," 4.

[480] *Ibid*. Volicer also notes that "hospitalization can result in a compromised nutritional state because acute care staff may be unfamiliar with the needs of demented individuals."

[481] *Ibid.* Volicer cautions that "the use of physical or chemical restraints. . [could] result in the development of contractures and pressure ulcers."

[482] Ladislav Volicer," Palliative Medicine," 1380.

The Alzheimer's Association Greater Illinois Chapter adds that "[a] new environment and routine, unfamiliar faces, combined with painful needle sticks, invasive testing, forced bed rest, and new medications may escalate fear and anxiety." [483] The ethical dilemma, in Volicer's view, "involves imposition of a significant burden on the patient because of aggressive medical interventions and hospital transfer that may not be balanced by significant benefits." [484] Once again, as recommended in the Consensus Statement, much depends on the overall goals of care for a particular patient. Volicer advises that hospitalization and acute care "should be used only when it is consistent with overall goals of care, and not as a default option." [485]

Overall goals of care can, and do, change, from preservation and extension of life, regardless of how intrusive, distressing, and debilitating transfer to an acute care facility and/or certain medical treatments might be, to an exclusive focus on comfort and quality of life, including pain reduction/elimination and spiritual support. If so, admission to hospice, where comfort not cure is the clear focus, has, at least historically, been difficult, chiefly because of a doctor's inability to definitively declare that an AD patient was terminally ill, and thus eligible for hospice, as defined by having less than six months to live. [486] Susan Mitchell reports that "Sachs et. al. estimated that [only] 1 in every 10 persons dying with dementia receives hospice care,. . . [and in] 2005, only 10% of all hospice enrollees nationwide had a primary diagnosis of

[483] The Alzheimer's Association Greater Illinois Chapter, "Encouraging Comfort Care," 10.

[484] Ladislav Volicer, "Alzheimer's Disease and Dementia," 4.

[485] Ladislav Volicer," Palliative Medicine," 1380.

[486] Susan L. Mitchell, "A 93-Year-Old," 2529. Mitchell reports that "[b]arriers to hospice enrollment include accurate prognostication and lack of recognition of dementia as a terminal condition and accessibility of hospice services in nursing homes. She also notes, however, that "[h]ospice providers cite prognostication as the most difficult of these challenges."

dementia compared with 46% with cancer." [487] Dan Kiely Jane Givens, and Michele Shaffer et. al. report that at least some change is apparent: "[R]ecent trends suggest that hospice referrals are gradually increasing," and that [t]he National Hospice and Palliative Care Organization reported that 11% of hospice patients had a primary diagnosis of dementia in 2008 (vs. 38% with cancer), an increase from 10% [from] the prior year." [488]

Providing Ethical and Compassionate Care

Regardless of how aggressively are addressed the medical issues that arise as Alzheimer's disease continues its relentless progression, the overall goal of care, as distinct from medical treatment, is to maximize the AD patient's quality of life. According to Peter Whitehouse, "tests by Brod, Logsdon, and Selai have demonstrated that mildly affected patients can reliably participate in discussions concerning their own quality of life." [489] At some juncture in the progression of the disease, however, caregivers are, of necessity, going to have to rely on non-verbal forms of communication and observational skills. Volicer opines that objectively speaking, "3 factors determine quality of life: management of physical symptoms, psychiatric symptoms, [and] providing meaningful activities." [490]

A number of authorities have created guidelines for the care of patients with dementia and they provide a helpful frame of reference for ethical and compassionate care. According to Peter

[487] *Ibid*, 2529.

[488] Dan Kiely, Jane L. Givens, Michelle L. Shaffer, Joan M. Teno, and Susan L. Mitchell. "Hospice Use and Outcomes in Nursing Home Residents with Advanced Dementia." *Journal of the American Geriatrics Society* 58, no. 10 (December 2010): 2284.

[489] Peter Whitehouse. "Conclusion Quality of Life: Future Directions." In *Assessing Quality of Life in Alzheimer's Disease,* edited by Steven M. Albert and Rebecca G. Logsdon, 179-183. (New York, NY: Springer Publishing, 2000), 180.

[490] Ladislav Volicer,"Palliative Medicine," 1381.

Whitehouse, "[b]etween October 1993 and June 1994, the Center for Biomedical Ethics of the School Of Medicine and the University Alzheimer Center of Case Western Reserve University, together with the Cleveland Chapter of the Alzheimer's Association, sponsored a community dialogue on ethical issues in dementia care." [491] The result of the dialogue was published as the Fairfield Guidelines, and is summarized in the Appendix (Number 6). The Alzheimer's Association has also published a set of guidelines, and these are provided in the Appendix (Number 7). Also worthy of examination are the guidelines published in 2008 by the California Workshop and the Ripich and Wykle seven step program for enhancing communication between nurses and AD patient using the acronym FOCUSED.

One especially encouraging breakthrough in the methodology of providing long term care of dementia patients, as reported by the Alzheimer's Association of Greater Illinois, is the creation of specialized care units: "A growing number of residential care facilities are moving away from [a] traditional approach to a new approach that puts the individual's needs before the needs of staff. Institutions are being turned into homes in which medical needs are on par with the emotional, social, and spiritual needs of residents." [492] Perhaps most astonishing is the new found flexibility, for according to the Association, "[i]nstead of everyone eating meals at the same time every day, residents are free to eat when they prefer, and have snacks available at all times." [493] Some families who have experienced the traditional nursing home regimen may find this new approach almost too good to be true. It is obvious that the Alzheimer's Association is suitably impressed: "In this nurturing environment, staff members engage residents in

[491] Peter Whitehouse. "Fairhill Guidelines on Ethics and the Care of People with Alzheimer's Disease." *The Moral Challenge of Alzheimer's Disease*, edited by Stephen G. Post, 44-65. (Baltimore, MD: John Hopkins University Press, 2000), 44-65.

[492] Alzheimer's Association of Greater Illinois, "Encouraging Comfort Care," 7.

[493] *Ibid*, 7.

meaningful activities and leisure opportunities. Families are treated like true partners in care and have a strong voice in decisions affecting their loved ones. Aggressive care is replaced with a comfort care approach to medical problems in order to enhance each person's quality of life." [494] The Association lists six principles of care that it claims "represent goals that better facilities take seriously and put into practice," and these are provided in the Appendix (Number 8).

At least two other positive by-products of specialized care units are worth noting. First, as pointed put by Volicer, because behavioral symptoms [of AD patients] are poorly tolerated if demented individuals are in the same space as cognitively intact residents,. . .[a] homogeneous patient population, possible on a Special Care Dementia Unit, eliminates these problems, because all residents are demented." [495] Second, Stephen Post claims that "[s]tate health care regulations that fine nursing homes if patients experience significant weight loss are misguided and prevent patients from legally and morally refusing nutrition and hydration." [496] Presumably, special care units will be much more sensitive to this issue and hopefully, with state acquiescence, respond appropriately.

Obviously, specialized care units provide marvelously innovative and resourceful care, but the perplexing issue is whether the average American family of an AD patient can afford it, except, perhaps, in the terminal phase of the disease. Truth be told, an obvious barrier to quality long term care is the expense. Long-term care for the elderly, even if provided by family members, is not without expense. Care giving by professionals is very expensive, and is generally not underwritten by government. "Medicare," according to its regulations, generally doesn't pay for long term care,. . . pay[ing] for skilled nursing care or home health care [only] if.

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[494] *Ibid*.

[495] Ladislav Volicer, "Alzheimer's Disease and Dementia," 6.

[496] Stephen Post, "The Moral Challenge," 63.

. .certain conditions [are met]." [497] According to John Shuster, Medicare was not created with long-term care, and especially not long-term care of dementia patients, in mind: "Because Medicare is not designed to function as a primary reimbursement system for long-term care, only care for the complications of dementia (or collateral illnesses) is relatively well reimbursed. The care of such complications is shifted toward general medical facilities and away from care settings often more suitable for patients with advanced dementia." [498] Medicaid, in his view, provides even less assistance:

> The public 'safety net' reimbursement system, Medicaid, is available only to persons who become thoroughly impoverished. Once a patient qualifies for Medicaid, care reimbursement under the system is often so limited as to present its own barrier to appropriate care. [499] These reimbursement systems, if applied to the patient with advance dementia, encourage fragmentation of care, limited availability of appropriate care, and extreme rationing of patient and family financial assets. [500]

Medicare does provide hospice care benefits, but as noted above, patients with dementia, even later stage dementia, often cannot qualify for these benefits because, according to Medicare regulations, a "patient's doctor and hospice medical director [must] certify that [the patient is] terminally ill and ha[s] 6 months or less to live if [the] illness runs its normal course." [501],[502]

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[497] Medicare, "Paying for Long Term Care." http://www.medicare.gov/LongTermCare/Static/Medicare.asp?dest... (accessed on December 11, 2011).

[498] John L. Shuster, "Palliative Care," 8.

[499] Jerald Winakur. "What Are We Going to Do With Dad." *Health Affairs* 24 no. 4 (July/August 2005): 1067. Winakur informs that Medicaid assistance is state sponsored, and can "often [be] problematic; depending on the level at which [a particular] state reimburses its long term care facilities."

[500] John L. Shuster, "Palliative Care," 8.

[501] Medicare. "Medicare Hospice Benefits." http://www.medicare.gov/Publications/Pubs/pdf/02154.pdf (accessed on December 11, 2011).

Caring for the Family Caregiver

According to Abhilash Desia and George Grossberg, "[t]he overwhelming majority of patients with AD live at home and are cared for by family and friends,. . . [and][m]ost caregivers are women (spouses or daughters over 50 years of age). . . [who] spend from 40 to 100 hours per week with the person with AD." [503] Volicer points out that "[s]ince Alzheimer's disease and other progressive dementias last on the average 8 years, caregivers often have to cope with functional impairment and behavioral symptoms for many years." [504] There is little doubt that when family members are the sole care givers for AD patients the care giver burden often greatly exceeds that imposed when the patient, although physically impaired and seriously ill, retains most of his/her cognitive capacity, and it is easy to see why.

As noted above, behavioral, psychiatric, or psychological problems are common in dementia and are a significant source of distress to family care providers with whom approximately two-thirds of individuals with Alzheimer's disease reside. As referenced, sixty-seven per cent of persons with Alzheimer's disease develop a 'psychotic' symptom (an hallucination or delirium) during the course of Alzheimer's disease. As described, more than 50% of patients with Alzheimer's disease demonstrate aggressive behavior, and nearly 20% physically assault their caregivers. Monias and Meier claim that "[n]oncognitive features of dementia may have a greater impact on caregiver burden than decrease in cognitive function or

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[502] Susan L.Mitchell, "A 93-Year-Old," 2329. Mitchell claims that "hospice eligibility for dementia is largely based on the Functional Assessment Staging (FAST) scale." According to Mitchell, "[t]his application of FAST has been criticized because the tool does not accurately predict 6 month survivaland because scoring requires that patients advance through the stages in a sequential fashion, which often does not occur."

[503] Desia and Grossberg, "Diagnosis and Treatment," 8.

[504] Ladislav Volicer," Palliative Medicine," 1383.

decrease in activities of daily living, . . . [and] [i]n fact, neurospsychiatric disturbances, particularly aggressive behavior and paranoia, increase the likelihood of nursing home placement more than decline in cognitive function." [505]

James Bernat adds that other "[s]pecific stresses on family caregivers that provoke institutionalization include nighttime awakening and wandering, suspiciousness, accusatory behavior, incontinence, and violence. Of these," in his opinion, "nighttime awakening is perhaps the most important." [506] Volicer suggests that it is perhaps the need for constant supervision that creates the greatest burden for caregivers:

> Functional dependence together with unsafe behavior and behavioral symptoms of dementia create a need for constant supervision that poses a great burden for the caregivers. Caregivers of individuals with dementia give up their vacation or hobbies more often, have less time for other family members, and report more work related difficulties than caregivers of individuals with physical impairments. [507]

Monias and Meier opine that "[c]aring for patients with dementing illnesses is physically, financially, and emotionally exhausting," [508] and there is much evidence to support that assessment. Sachs, Shega, and Cox-Hayley claim that Orly, et. al. found that compared with non-dementia caregivers, dementia caregivers reported more hours spent on care giving, more detrimental effects on employment, more emotional and physical strain, and a greater likelihood of suffering mental or physical health problems due to care giving." [509] Monias and Meier report

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[505] Monias and Meier, "Palliative Care," 9.

[506] James L. Bernat, *Ethical Issues in Neurology.* (Philadelphia, PA: Wolters Kluwer, 1994), 365.

[507] Ladislav Volicer," Palliative Medicine," 1383.

[508] Monias and Meier, "Palliative Care," 1.

[509] Sachs, Shega, and Deon Cox-Hayley. "Barriers to Excellent," 1059.

that "f]ifty percent of caregivers have financial difficulties and 66% have their own heath problems." [510] Steven Zarit informs that "[t[he chronic stress of assisting a relative with dementia can lead to changes in hormonal levels and immune system functioning, higher rates of cardiovascular disease and other medical illnesses and increased risk of mortality compared to age and gender matched controls." [511] Desia and Grossberg report that "[n]inety per cent are affected emotionally (frustrated, drained) and 66% have significant depression. . . [and that] [f]actors that create a 'breaking point' for caregivers include the amount of time spent caring for the patient with AD, loss of identity, patient misidentifications and clinical fluctuations, and the patient's nocturnal deterioration." [512]

Sachs, Shega and Cox-Hayley insightfully point out that "families caring for someone with dementia face additional conflict-provoking decisions over the course of the disease, including getting the patient to stop driving, taking over the management of finances and medications; and, in many cases, eventually relocating the patient to a relative's home or a nursing home." [513] (1060). It should not be forgotten that, as noted by Sachs, et. al. that "[c]aregivers may also feel unappreciated because patients may not be able to express appreciation or gratitude," [514] and "as increasing numbers of patients with dementia die in nursing homes" as claimed by Sachs, Shega,

[510] Monias and Meier, "Palliative Care," 1.

[511] Steven A. Zarit "Diagnosis and Management of Caregiver Burden in Dementia." In *Handbook of Clinical Neurology*, edited by Michael J. Aminoff, Francois Boller, and Dick F. Swaab, 100-106. (Edinburgh, Scotland: Elsevier, 2008), 102.

[512]Desia and Grossberg,"Diagnosis and Treatment," 8.

[513] Sachs, Shega, and Deon Cox-Hayley. "Barriers to Excellent," 1059.

[514] *Ibid*, 1059.

and Cox-Hayley, "usually without the benefit of hospice, families [of AD patients] rarely receive any kind of bereavement services" [515]

Finally, it cannot be overlooked that there are individual differences in the way different caregivers handle stress. According to Zarit, "[w]hile the disease creates conditions which can be experienced as stressful, the extent to which caregivers feel burdened by the demands placed on them varies considerably." [516] "Some people," in his estimation, "are overwhelmed by even minor changes in a relative and others manage without undue distress despite caring for someone with severe problems." [517]

As to whether some of the above mentioned burdens can be reduced, the answer is an emphatic "yes." Rabins reports that "[n]umerous studies demonstrate that caregivers benefit from emotional support and education." [518] Steven Zarit claims that "[i]n general, caregivers who engage the stressors they face in a more active way, planning and learning new strategies for responding to problems such as their relative's memory loss, and who are optimistic about the success of their efforts will experience lower levels of emotional distress." [519] "Assessment and management of the burdens that care giving imposes," in his view, "allow a family to give care for a longer time, if they choose, while reducing the risk of adverse effects on the caregiver's own health and well-being." [520] There are four general strategies for reducing caregiver burden: caregiver education, especially re: coping strategies, obtaining empathy and emotional support

[515] Sachs, Shega, and Deon Cox-Hayley. "Barriers to Excellent," 1059. The authors claims that '[b]ecause the nature of bereavement may be different in dementia, grieving at the time of diagnosis or when the patient no longer recognizes family, for example, grief and bereavement services may need to be restructured."

[516] Steven Zarit, "Diagnosis and Management," 101.

[517] *Ibid*.

[518] Peter V. Rabins, "Dementia and Alzheimer's Disease," 463.

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[519] Steven Zarit, "Diagnosis and Management," 102.

[520] *Ibid*, 101.

from counselors and support groups, taking advantage of available community resources, and institutionalizing the patient.

Not at all surprisingly, given the unprecedented access to information that helps to define the Information Age, caregivers want and expect to be educated about Alzheimer's disease. Zarit claims that "[c]aregivers have a myriad of questions about causes and treatment of the dementia. . .about resources available to help them. . . [and that] [a]nswering their questions thoroughly about diagnosis and treatment can be very helpful, even when the prospects for improvement are limited." [521] He reports that "[structured educational] programs have shown to be effective in increasing knowledge and coping skills and reducing depression." [522] He also notes that "[o]ne of the most critical areas that educational programs can address is helping caregivers understand why patients engage in dementia related behaviors," such as "why they ask the same question over and over again or make accusations that someone is stealing from them." [523],[524] He further notes that "[c]aregivers [perhaps most] often seek information about. . .legal and financial arrangements. . . [and] driving." [525] A list of books and other educational resources that address the reduction of care giver burden is provided in the Appendix (Number 9).

[521] *Ibid*, 103.

[522] *Ibid*, 103-4.

[523] Steven Zarit,"Diagnosis and Management," 104.

[524] *Ibid.* Zarit claims that understanding why patients engage in demtia related behaviors can benefit care givers in a number of ways: "Learning to recognize that altered behavior is due to the patient's underlying brain disease, and is not intentional, can be very helpful. Caregivers who can place behavior and memory problems in that perspective can often begin to make more adaptive and creative responses that relieve some of the stress they have been experiencing."

[525] *Ibid*, 104.

The Consensus Statement affirms that "[s]upport group participation will diminish caregiver distress and can help relieve feelings of anger, frustration, and guilt," [526] while Bernat reports that "[s]everal studies performed across different racial and ethnic groups showed that programs of caregiver counseling and support significantly delayed nursing home placement of patients with AD and improved patient and caregiver quality of life by preventing caregiver burnout and illnesses." [527] It seems likely that the gold standard for emotional support probably comes from fellow family members and friends, and Zarit confirms that "[t]he emotional help provided by relatives and friends is often critical for the caregiver's well-being." [528]

Caregivers can, if they so choose, arrange for a brief respite from their care giving duties, by paying a professional care giver to stand in for them for a morning afternoon, or even a full day in the home, or in the alternative, transporting the patient to a faculty where he/she can be remain for the day. None of these options is inexpensive, however, and as previously noted, are not reimbursed by government unless the patient is eligible for Medicaid. Nevertheless, depending on the community of residence, there are community resources that can help to reduce the burden of care giving, by providing adult day care, regular visits from social workers and home health agencies, or daily hot meals. Organizations that provide assistance or are, in the alternative, fully aware of other local organizations from which assistance can be obtained, are listed in the Appendix (Number 10).

The Alzheimer's Association of Greater Illinois reports that "[a]pproximately 90 per cent of persons who reach the late and final stages of dementia live in residential care facilities,

[526] American Association for Geriatric Psychiatry, et. al.,"Consensus Statement," 11.

[527] James L. Bernat, *Ethical Issues in Neurology*, 365.

[528] Steven Zarit, "Diagnosis and Mangement," 102.

primarily nursing homes," [529]. . . "more than two-thirds of nursing home residents have dementia, and more than half of residents in assisted living facilities have dementia." [530] It seems apparent from these statistics that most families choose to eventually institutionalize their demented loved one. Not only is such a decision undoubtedly extraordinarily painful for families, contrary to their expectations, institutionalization may not be as effective in relieving care giver stress as was anticipated.

Zarit claims that "[t]here are both practical and emotional reasons for taking a cautious approach toward. . .placement [of an AD patient into an institutional care facility." [531] He seems to indicate that burdens are not only not eliminated, and perhaps not even significantly reduced, they are instead, just shifted and transformed. [532] Zarit acknowledges that "[t]ere are reductions in care related stressors, such as feeling of overload." [533] Unfortunately, the cost for this relief is high, because, as noted previously, institutional care is expensive. The upshot may be that "out of sight is not out of mind" because caregivers continue to care deeply. According to Zarit, "they may be concerned with the quality of care and their own role in the nursing home, such as how often they should visit and what to do during visits." [534] He reports that it is apparently, "not uncommon for spouses to visit daily and to provide much of the ongoing care to their husband or wife." [535] "Not surprisingly," in his estimation, guilt is a common feeling after placement." [536]

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[529]The Alzheimer's Association of Greater Illinois, "Encouraging Comfort Care," 7.

[530] *Ibid*.

[531] Steven Zarit, "Diagnosis and Management,".105.

[532] *Ibid*.

[533] *Ibid*.

[534] *Ibid*.

[535] *Ibid*.

Chapter Three: Artificial Nutrition/Hydration, Terminal Dehydration, and Preemptive Palliative Sedation

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As discussed in the previous chapter, absent some intervening fatal injury or pathology, an individual diagnosed with Alzheimer's disease will ultimately be unwilling or unable, even with assistance, to eat and drink sufficiently to sustain his/her own life. Alzheimer's disease may destroy his/her ability to swallow without life-threatening aspiration of food and fluids into the lungs, or in the alternative, he/she may progressively lose most if not all of his/her desire, and/or physical ability, to eat and drink either because of the progression of the disease or simply as a result of the consequences of the natural shut down of bodily processes at the end of life.

Dysphagia

Dysphagia is a term used to describe the partial or complete inability to swallow normally, and although it is a function that is completely taken for granted by healthy individuals, as Jeffrey Palmer et. al. correctly observes, "[s]wallowing is a complex act that involves the coordinated activity of the mouth, pharynx, larynx, and esophagus." [537] Dysphagia can result from injury to the nerves and/or muscles essential to swallowing, but most often is a temporary or permanent consequence of injury to the portion of the brain that controls those nerves and muscles. Although it is certainly possible that dysphasia could be a consequence of aging alone,

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[536] *Ibid*.

[537] Jeffrey Palmer, Jennifer C. Drennan, and Mikoto Bara. "Evaluation and Treatment of Swallowing Impairments." *American Family Physician* 61, no. 8 (April 15, 2000): 2455.

Jennifer Horner et. al. maintain that "[Alzheimer's] patients show evidence of swallowing abnormality above and beyond that expected on the basis of aging alone," [538] and that '[n]o study to date shows that *aging alone* causes changes in swallowing of sufficient magnitude to effect discomfort, eating dependency, aspiration, malnutrition, or pneumonia." [539]

According to Gregory White et. al.,"[d]ysphagia can occur in the oropharyngeal or esophageal phases of swallowing. . . [and] 75% of cases of oropharyngeal dysphagia have a neurologic cause, such as stroke, dementia and Parkinson's disease." [540] They claim that "[d]ysphagia resulting from stroke is temporary in 90% of cases, whereas in patients with dementia or Parkinson syndromes it is part of a general decline." [541] In contrast, "esophageal dysphagia," in their view, "usually occurs as a result of an obstructive disorder." [542] Although there may have been an historic presumption that dysphagia is a phenomenon of *late stage* Alzheimer's, Ianessa Humbert, et. al. suggest that it begins much earlier in the progression of the disease: "Traditionally, dysphagia, aspiration, and aspiration pneumonia have been viewed as very late stage consequences of the disease. However, our videofluoroscopic findings and those of Priefer and Robbins in 1997 show that swallowing and self-feeding changes occur early on in the disease." [543]

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[538] Jennifer Horner, Mark J. Alberts, Deborah V. Dawson, and Gail M. Cook. "Swallowing in Alzheimer's Disease." *Alzheimer's Disease and Associated Disorders* 8, no. 3 (Fall 1994):187.

[539] *Ibid*, 185.

[540] Gregory White, Finian O'Rourke, Bin S. Ong, Dennis Cordato, and Daniel K.Y. Chan."Dysphagia: Causes, Assessment, Treatment, and Management." *Geriatrics* 63, no. 5 (May 2008): 15.

[541] *Ibid*, 15.

[542] *Ibid*.

[543] Ianessa Humbert, Donald G. McLaren, Kris Kosmatka, and Michelle Fitzgerald, et. al. "Early Deficits in Cortical Control of Swallowing in Alzheimer's Disease." *Journal of Alzheimer's Disease* 19, no. 4 (January 2010): 1194.
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Suspicions of dysphagia are easily confirmed with a videofleurographic swallowing study (VFSS), [544] which for Jeffrey Palmer et. al. is the "gold standard for evaluating the mechanism of swallowing." [545] In their view, the VFSS can not only be used as a diagnostic tool for dysphagia but also as a means of evaluating various means of mitigation:

> By testing various foods, it is possible to determine the effects of food consistency on swallowing. . . and make it possible to design an individualized diet. . . [In addition], it is also possible to test the effectiveness of compensatory measures designed to improve the pharyngeal clearance [such as] tucking the chin. . .holding the breath before swallowing. . . [and] turning the head. [546]

According to Palmer, et. al., "[o]ther maneuvers have been developed to improve the opening of the esophageal sphincter, increasing pharyngeal clearance and minimizing aspiration. . . includ[ing] altering the position of the head, neck and body relative to gravity, modifying the method of feeding or teaching the patient to voluntarily contract particular muscles during the act of swallowing." [547] Given, as pointed out in the previous chapter, that pneumonia is apparently the most frequent cause of death among those individuals afflicted with Alzheimer's disease, almost certainly a result of the aspiration of food and fluid into the lungs, it is not unreasonable to conclude that efforts at mitigation of dysphagia have met with only limited success.

Other Causes of Nutrition/Hydration Insufficiency

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[544] The patient is given food mixed with barium in order to make the food radiologicaly opaque and thus visible on the screen.

[545] Palmer, Drennan, and Bara, "Evaluation and Treatment," 2461

[546] *Ibid*, 2460.

[547] *Ibid*, 2461.

Unfortunately, Alzheimer's disease also has a profound impact on the desire for food and fluids that contributes to weight loss in many Alzheimer's patients. Karen Smith and Carol Greenwood's claim that "individuals with Alzheimer's disease consistently experience greater and more frequent weight loss than healthy, age-matched controls," [548] appears to accurately represent the consensus opinion, and there is no shortage of conjecture as to how the disease effectuates this result. Many Alzheimer's patients apparently eventually develop an indifference to food. Smith and Greenwood claim that "seniors with Alzheimer's disease are particularly susceptible to impairments in olfactory and taste reception, thereby reducing the pleasure and positive stimulation that promotes food ingestion." [549] Mark Deitweiler et. al. add that in Alzheimer's patients "barriers to eating [also] include reduced. . .vision. . touch. . .mouth apoxia," [550] and dysfunctional levels of neuropeptide Y and norepinephrine which help to regulate appetite. It is also noteworthy, especially for this inquiry, that Katherine Wasson, Helen Tate, and Carmel Hayes suggest that "[o]ther factors that may contribute to fluid refusal include [the] loss of thirst" [551] Wasson, Tate, and Hayes, as well as Deitweiler, et. al., [552] also list depression as a potential cause of a loss of appetite among Alzheimer's patients, while Smith and Greenwood maintain that the effects of medication in the weight loss of Alzheimer's patients should not be overlooked: "Many older adults with Alzheimer's disease take medications, mostly

[548] Karen L. Smith and Carol E. Greenwood. "Weight Loss and Nutritional Considerations in Alzheimer Disease." *Journal of Nutrition for the Elderly* 27, no. 3-4 (2008): 382.

[549] *Ibid*, 387.

[550] Mark Deitweiler, Kye Y. Kim, and Jim Bass. "Percutaneous Endoscopic Gastrostomy in Cognitively Impaired Older Adults: A Geropsychiatric Perspective." *American Journal of Alzheimer's Disease and Other Dementias* 19, no. 1 (January/February 2004): 24.

[551] Katherine Wasson, Katherine, Helen Tate, and Carmel Hayes. "Food Refusal and Dysphagia in Older People With Dementia: Ethical and Practical Issues." *International Journal of Palliative Nursing* 7, no. 10 (October 2001): 469.

[552] Deitweiler, Kim, and Bass, "Percutaneous Endoscopic Gastrostomy," 24.

for chronic conditions, which may have a variety of side-effects such as anorexia, nausea, vomiting, dry mouth, dysphasia, dysgeusia, and dysosmia that hinder their desire and/or ability to eat." [553]

Sadly, the impact of Alzheimer's disease extends beyond the suppression of the desire for food and fluids. Reduced cognitive capacity, evidenced especially in memory loss, the impairment of judgment, and the inability to focus on the task at hand, can profoundly impact eating and drinking. Alzheimer's patients may be incapable of understanding when to eat (or simply forget that they are hungry), [554] the importance and necessity of eating, or even whether they have already eaten. Wasson, Tate, and Hayes further claim that Alzheimer's patients may simply not be able to recognize food "as edible and therefore not respond when [food is] placed in front of him/her or in the mouth," [555] and that "[d]istractibility, reduced attention and concentration may also affect eating and drinking." [556],[557]

Alzheimer's disease related impairment of a patient's motor skills can not only create difficulty with the physical act of placing food in one's mouth, but also the ability to chew. Wasson, Tate, and Hayes point to an exorable decline in motor skill capacity:

> In the middle stages [of Alzheimer's disease], difficulty managing utensils often becomes evident as a result of, for example, agnosia, or dyspraxia. Food hoarding in the mouth and failure to chew sufficiently may also occur with a resultant risk of choking. In the end stages of dementia eating may become slower and food may remain in the mouth as chewing and swallowing are not initiated. Fluids may dribble from the patient's mouth

[553] Smith and Greenwood, "Weight Loss," 387.

[554] Wasson, Tate, and Hayes, "Food Refusal and Dysphagia," 469.

[555] *Ibid*.

[556] *Ibid*.

[557] *Ibid*

if they are not swallowed. [558]

Eventually, most Alzheimer's patients, provided they live long enough, are going to experience significant difficult in feeding themselves. Deitweiler et. al. claim that "[a]pproximately half of all cognitively impaired older adults may be unable to feed themselves within eight years of diagnosis." [559] The inability to feed oneself makes an Alzheimer patient caregiver dependent and if problems develop re: caregiver assisted feeding, nutrition and hydration can be compromised. According to Wasson, Tate, and Hayes, Andressen identified several causes for negative reactions in eating including fear or anxiety, unclear or complicated instructions, feelings of being rushed by the caregiver, and caregiver tension or impatience. In their view, "[w]hat appears as a refusal to eat may therefore be as a result of any or a combination of the above. . . [but] [w]hatever the cause(s) the result is usually that intake for nutrition and hydration is compromised." [560]

Finally, one or more of the above described factors may contribute to an Alzheimer's patient's simple refusal to eat or drink manifesting in either an unwillingness to open his/her mouth or a *refusal* to swallow and ejection of the contents of the mouth. Wasson, Tate, and Hayes claim that "Fernberg, et. al. found that most impairments [of the ability to swallow] was at the oral stage of the swallow, which is under *voluntary* (my emphasis) control." [561] According to Deitweiler et. al., "Michaelsson et. al. reported that 85 percent of institutionalized end-stage

[558] *Ibid.*

[559] Deitweiler, Kim, and Bass, "Percutaneous Endoscopic Gastrostomy," 24.

[560] Wasson, Tate, and Hayes, "Food Refusal and Dysphagia," 469.

[561] *Ibid*

dementia patients demonstrate refusal to eat." [562] It must be acknowledged that a number of strategies have been employed in an effort to mitigate the consequences of the Alzheimer's patient's loss of interest in food and/or physical inability to eat and drink, but it also seems clear that an inevitable reduction in the quantity of food and fluid consumed orally is likely unavoidable.

It should also not go unnoticed, as observed by Smith and Greenwood, that "food intake declines as a natural part of aging due to a reduction in appetite independent of the presence of Alzheimer's disease." [563] Accordingly, it may in certain circumstances be exceedingly difficult to determine how much of an Alzheimer's patient's slowly abating appetite is a result of the disease or simply a consequence of the natural process of aging. Smith and Greenwood insist that one's sense of both smell and taste diminish with advancing age: "Approximately 40% of all chemosensory (taste and smell) problems occur in persons aged 65 years and older." [564] Not only is food apparently not as appealing for seniors because of diminished taste and smell sensations, Smith and Greenwood also claim that the inability to experience taste sensation differences among various foods inexorably leads to the consumption of fewer overall calories: "Another sensory aspect of food intake—sensory specific satiety—may also decrease with aging." [565] Sensory-specific satiety is defined as the palatable response to food as a function of eating which leads to the tendency for variety in our diets.

[562] Deitweiler, Kim, and Bass, "Percutaneous Endoscopic Gastrostomy," 24

[563] Smith and Greenwood, "Weight Loss," 390.

[564] *Ibid*, 391.

[565] *Ibid*, 390.

Rolls and McDermott [566] found that "older persons were less likely to experience sensory-specific satiety than younger persons and, as a result, would likely to eat a more monotonous and lower calorie diet." Smith and Greenwood maintain that aging alters the manner in which the gastrointestinal system functions: "The elderly experience more rapid fundal emptying in the stomach due to decreased fundal capacity and, thus, earlier antral stretch and feelings of satiation. [567] Studies have also found that levels of cholecystokinin (CCK), a potent anorectic hormone, increase with aging." [568] In simpler terms, the elderly may experience a false sense of fullness, and stop eating and drink prematurely. Anyone who has witnessed the aging process of an older relative or friend is aware that there are other potential problems concomitant with growing older that impact both the desire for food and fluids and the ability to eat and drink. John Morely and Andrew Silver point to a number of issues, prominent among them depression, especially from bereavement, absence of socialization at meals, and the sheer physical difficulty encountered with eating and drinking.

Because the aging process alone, even when unaccompanied by dementia, creates a progressive loss of appetite, it has never been, from a historical standpoint, uncommon for aging individuals to simply eat and drink less and less until they stop eating and drinking altogether. In addition, others have stopped eating and drinking because they were either afflicted with pathologies that destroyed their ability to swallow, or aware that death was inevitable, simply refused to eat and drink because they no longer wanted, in their view, to inappropriately extend their lives. Obviously, the prolonged unwillingness or inability to eat and drink normally, even

[566] B. J. Rolls and T. M. McDermott. "Effects of Age on Sensory-Specific Satiety." *American Journal of Clinical Nutrition* 54, no. 6 (1991): 991.

[567] Smith and Greenwood, "Weight Loss," 391

[568] *Ibid*.

with assistance, short of some crude method of forcing food and water into an appropriate part of the body, has always had ultimately fatal consequences. Perhaps not surprisingly, given these consequences, there has historically been no shortage of efforts to artificially provide nutrition and hydration. [569]

Artificial Nutrition and Hydration

There are three general classifications of methods of artificially providing nutrition and hydration (ANH) to the human body. *Enteral* is the term used to describe methods that place nutrition and hydration into some portion of the digestive tract where they can be absorbed and utilized by the body. *Parenteral* describes those methods that bypass the digestive system and place nutrition and hydration directly into the blood stream. *Hypodermoclysis* (also known as interstitial or subcutaneous infusion) places primarily hydration, but also limited nutrition, under the skin where it can only be slowly absorbed by the body. Because all three methods require the transfer of nutrition and hydration through some form of tube, to make passage practical the nutrition is in liquid form. Although all three methods developed more or less independently, each required an awareness of human physiology and anatomy and/or a critical technological breakthrough.

Crude methods of enteral feeding may well nearly as old as man himself. Once the relationship between eating and drinking and sustaining life was understood it was only a matter of time before food and fluids were forced down the throat in a desperate attempt to circumvent

[569] John. Berkman,."Medically Assisted Nutrition and Hydration in Medicine and MoralTheology." In *Medicine, Health Care and Ethics: Catholic Voices, edited by* John F. Morris, 143-72. (Washington, DC: Catholic University of America, 2007), 149. John Berkman, quite correctly points out that "tube feeding is sometimes employed not because oral feeding is no longer physically possible but as a supplement to or improvement over oral feeding, and sometimes as a substitute for convenience rather than out of necessity."

an individual's unwillingness or inability to eat and drink normally. Laura Harkness' research reveals that, at least in terms of *recorded* history, "[e]nteral feeding has. . .its inception in ancient Egypt, when practitioners used enemas of wine, milk, whey, and wheat and barley broths." [570] [571] She reports that in 1598 "Capivacceus is reported to have used a hollow tube to put liquid down a patient's esophagus, [572] and Aquapendente, in 1617, fed through a nasopharyngeal tube." [573]

Until the early part of the 19th century all efforts at enteral feeding apparently involved the placement of food and fluids into the digestive tract via the esophagus or the rectum. According to David Major, "[t]he first of the 'modern' techniques, gastrostomy, (a surgical insertion of a tube through the abdominal wall into the stomach) was first proposed in 1837, first attempted on human beings in 1849, and first successfully performed in a human being in 1875." [574] Apparently, however, neither the use of gastrostomies (eventually referred to as G tubes) nor the older and bloodless gastrointestinal tube insertion through the nose or mouth was particularly common. Harkness claims that although "the intermittent use of upper gastrointestinal tubes continued during the 18th and 19th centuries. . .rectal feedings were the popular method of providing enteral feeding to patients." [575], [576], [577]

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[570] Laura Harkness."The History of Enteral Nutrition Therapy: From Raw Eggs and Nasal Tubes to Purified Amino Acids and Early Postoperative Jejunal Delivery." *Journal of the American Dietetic Association* 102, no. 3 (March 2002):399.

[571]John Berkman, "Medically Assisted Nutrition and Hydration," 146. John Berkman claims that "Greek physicians made extensive use of nutrient enemas, delivering various broths as well as wine, milk, and whey through this means."

[572] *Ibid.* John Berkman claims that "the earliest recorded use of a tube for feeding directly into the esophagus, stomach, or jejunem is in the fourteenth century."

[573] Laura Harkness, "The History of Enteral Nutrition," 399.

[574] David Major. "The Medical Procedures for Providing Food and Water: Indications and Effects." In *By No Extraordinary Means: The Choice to Forgo Life-Sustaining Food*, edited by Joanne Lynn, *21-8.* (Bloomington, IN: Indiana University Press, 1986), 23.

[575] Laura Harkness, "The History of Enteral Nutrition," 399

On the other hand, technology for gastrointestinal tube feeding, not only into the esophagus but deeper, into the stomach and even the first section of the small intestine (jejunum), may have benefited from the development of more flexible tubes and, in the opinion of Elizabeth Williams, repeated utilization in the force-feeding (gavage) of inmates of insane asylums, presumably incapable of understanding the life and death significance of eating and drinking, and even suffragettes on hunger strikes. [578] According to John Berkman, "such feedings were through tubes inserted through the mouth (orogastric feeding) or the nose (nasogastric feeding). . . [and][b]y the end of the nineteenth century pediatricians were advocating such feedings for premature infants, and for infants and children with diphtheria and other acute ailments." [579],[580] Nevertheless, despite what she describes as "clearly some early progress. . . regarding tube feeding," Nicole Phillips claims the preferred route for administering nutrition in the first 30 years of the 20th century was nutrient enemas." [581]

Eventually, however, sometime in the second third of the 20th century, gastrointestinal tube feeding through the esophagus overtook nutrient enemas as the preferred method of

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[576] David Major, "The Medical Procedures," 23. David Major claims that a major advancement in the efficacy of rectal feeding was provided by "John B. Murray (1857-1914). . .a surgeon of great fame at Northwestern University," whose method (sometime referred to as Murphy's drip or proctoclysis) according to Major, "involved the insertion of a rectal tube and administration of appropriate volumes of fluids and electrolytes at a constant enema drip" and with which "up to 24 liters a day of fluid could be administered, being absorbed readily into the mucosal surface of the large intestine"

[577] Laura Harkness, "The History of Enteral Nutrition," 400. Harkness' research revealed that "President Garfield was rectally infused with peptonized beef broth, beef peptonoid, and whiskey every 4 hours for most of the 79 days he lived after suffering a gunshot wound."

[578] Elizabeth Williams. "Gags, Funnels, and Tubes: Forced Feeding of the Insane and Suffragettes." *Endeavour* 32, no. 4 (December 2008): 139.

[579] John Berkman, "Medically Assisted Nutrition and Hydration," 146-7.

[580] It is noteworthy that Berkman makes no mention of gastrointestinal tube feeding for aging individuals no longer able or willing to eat and drink sufficiently to sustain their lives.

[581] Nicole Phillips. "Nasogastric Tubes: An Historical Context." *Medsburg Nursing* 15, no. 2 (April 2006): 85.

providing artificial nutrition and hydration, probably because as Phillips suggests, "developments in tube material with polyurethane ensure greater tolerance, patient comfort and tube longevity" In citing a circa 1930 training manual for American nurses that provided instructions for the insertion of a nasogastric tube, [582] Phillips reveals that the then existing protocol for gastrointestinal tube feeding was the insertion and removal of the tube each time nutrition or hydration was required. [583] The newer polyurethane tubes apparently permitted nasogstric tubes to remain in place, feeding after feeding, likely dramatically increasing their acceptance within professional medicine. There seems little doubt that gastrointestinal tube feeding through the esophagus continued to increase, but John Berkman cautions that "while alternatives to oral feeding were certainly employed in a large number of contexts in the first part of the twentieth century, their [clinical benefits] were not scientifically demonstrated [584] until the mid 1950's and their use did not become routine until the 1960's." [585] The issue, it seems, is determining with some measure of certainty the clinical circumstances in which tube feeding became, using Berkman's term, routine.

It is not difficult to understand why gastrointestinal tube continued to grow in acceptance and use as a modality for providing artificial nutrition and hydration for those individuals *temporarily* unable, because of illness, disease, trauma, or surgery, to eat and drink normally. Professional medicine made remarkable technological strides in the second half of the twentieth

[582] Nicole Phillips, "Nasogastric Tubes," 85-6. According to the nurse training manual referenced by Nicole Phillips, the possibility of a nasogastric tube being misplaced into the trachea rather than the esophagus is remote, both because the spasm of the epiglottis is too strong for the tube to pass into the trachea and the asphyxiating response of the patient is clear evidence that the tube is blocking the air passage."

[583] *Ibid.*

[584] One wonders how the clinical benefits of tube feeding could be scientifically demonstrated in this context only to be apparently scientifically demonstrated to be of little or no clinical benefit in the first decade of the twentieth century. The latest scientific evidence re: the clinical benefit of tube feeding is discussed in detail in chapter 5.

[585] John Berkman, "Medically Assisted Nutrition and Hydration," 148.

century. Not only did individuals who would, before 1940, have succumbed to heart disease, cancer, trauma, infection and a whole host of other maladies, survive, critical care medicine's dramatically increased technological capacity to sustain life in spite of respiratory, cardiac, renal, or blood chemistry dysfunction and sepsis, and to safely reduce consciousness for extended periods in what came to be called intensive care units, made artificial nutrition and hydration an issue for those *temporarily* unable to eat and drink normally. In simple terms, those who previously would have died *before* nutrition and hydration became an issue for them now lived long enough to at least potentially benefit from artificially provided nutrition and hydration. Of far greater significance re: nutrition and hydration issues at the end-of-life, particularly for this inquiry, is when, and especially why, gastrointestinal tube feeding made the leap from *temporary* use almost exclusively in critical care medicine to open-ended *long-term* use for end-of-life care of the terminally ill but not necessarily imminently dying, not only in hospitals but in long term nursing care facilities and eventually even private homes. Obviously, a principal reason was the expectation that gastrointestinal tube feeding would extend lives, but there is the distinct possibility that other influences also played a role.

It seems unreasonable to assume that when a terminally ill patient was unwilling or unable even with assistance to eat and drink sufficiently to sustain his/her life, *long-term* gastrointestinal tube feeding through the esophagus was immediately embraced by professional medicine of the 1930's, 40's and 50's, much less the American public, simply because it was an available modality that would extend lives. Doctors who practiced medicine in the United States during the first half of the twentieth century, as well as the American public, were arguably much more inclined not only to view the inability/ unwillingness of those nearing the end of their lives to eat and drink sufficiently to extend their lives as a natural consequence of the process of dying, but

to find little or no justification for prolonging that process in these circumstances. A physician's assessment that a terminally ill patient unwilling or unable even with assistance to eat and drink normally should receive only comfort care was seldom if ever second guessed, and in this era doctors had little or no fear of malpractice litigation from distraught relatives who concluded that all that could be done to sustain the life of their family member was *not* done. Individuals often died at home with family members serving as primary care givers, and not only was there in all likelihood a much greater acceptance of the ultimate inability to successfully sustain life by spoon feeding alone by those called upon to provide it day after day, grief was not accompanied by guilt because Momma or Poppa was not "farmed out" to strangers for care.

At some point, however, attitudes toward tube feeding at the end of life changed, not only for professional medicine but for the American public. It must be conceded that the development of the percutaneous endoscopic gastrostomy tube (PEG tube) first revealed in a medical journal article in 1980 played a role in this attitudinal change. The PEG tube dramatically changed tube feeding, providing significant advantages over the nasogastric and orogastric tube as well as the G tube. Guided down the throat into the stomach with the aid of an endoscope and slipped through the wall of the abdomen with but a minor incision, PEG tube insertion requires only moderate sedation of the patient, can be completed in less than twenty minutes, and leaves but a roughly three inch section of soft, flexible, plastic tubing protruding from the lower abdomen. Not only is the PEG almost always significantly more comfortable for the patient than the nasogastric or orogastric tube, it does not require the kind of surgery or anesthesia necessary for the insertion of a G tube. As much as the PEG tube may have contributed to the acceptance of tube feeding, however, it arguably was developed (1980) only after a significant attitudinal change toward tube feeding had already taken place.

It seems altogether possible that attitudinal change toward tube feeding at the end of life was even more reflective of changes in attitudes toward death, dying, and the capability of modern medicine to sustain life. Modern medicine's dramatic technological breakthroughs of the last half of the twentieth century not only gave professional medicine an unprecedented capacity for successfully addressing illness, disease, and injury, it raised medicine's own performance expectations. Not only did death become in some sense a failure for some doctors, a technological imperative began to impose an obligation to use whatever means was available to sustain life, solely because that means was at hand. The physician sons of the same doctors who earlier in the century had accepted the inability/ unwillingness of those nearing the end of their lives to eat and drink sufficiently to extend their lives as a natural consequence of the process of dying and found little or no justification for prolonging that process in these circumstances, chose instead to recommend tube feeding.

It is equally possible that the American public experienced its own attitudinal change toward death, dying, and the capability of modern medicine to sustain life, every bit as profound as that which may have been experienced by American professional medicine. As media accounts of the miracles wrought by modern medicine permeated the consciousness of the American public, expectations for the capability of professional medicine to sustain life inevitably rose correspondingly. As the right of a patient to make an informed choice or refusal of medical treatment gained legal acceptance, and health insurance became relatively commonplace, at least some patients and/or their families may have begun to feel a sense of entitlement to the best modern medicine could provide. With life expectancy continuing to increase, there was perhaps a reduced willingness to accept that "one's time had come at last" that may have been further fueled, at least in part, by an increasing fear of death over and above

that experienced by previous generations. This arguably inordinate fear may not only have been due to an inability or unwillingness to accept the concept of life after death as some Americans moved further and further away from embracing organized religion, the American public may have begun to experience a disassociation with death. Whereas most people had in the first half of the twentieth century died at home, with the body in the parlor at least for several days, often after being washed and dressed by family members themselves, it became more and more common for individuals to die in hospitals with the body whisked away and not to be seen again until a viewing in a coffin at a neighborhood funeral home. Death had arguably become, to the extent it could be, sanitized, yet more distant, mysterious, and threatening than ever. Given the expectations for professional medicine to sustain life, and the possible fear of as well as the disassociation with death, it is not at all unreasonable to suggest that at least some patients and their families chose to fight for every last breath with whatever means were available, including, but not limited to, tube feeding.

Still other influences may also have been of significance in changing the attitude toward gastrointestinal tube feeding at the end-of-life. The changing cultural mores that ultimately eliminated the coffin in the parlor in favor of the neighborhood funeral home also arguably ultimately granted permission to families to place their loved one in a nursing facility rather than providing end-of-life care at home. Nursing homes, dependent as they are on revenue, subject as they are to governmental regulation, and fearful as they are of litigation, not surprisingly have protocols that are much more accepting of tube feeding as an alternative to labor intensive and often unproductive hand feeding whenever a patient is unwilling or unable even with assistance to eat and drink sufficiently to sustain his/her life. Given the guilt that adult children can feel

because they have relinquished to nursing home personnel the care of Momma or Poppa, families may, as a result, be much more accepting of tube feeding.

Finally, professional medicine is today much more sensitive to the risk of medical malpractice litigation, even when groundless, and doctors are arguably much more inclined to recommend tube feeding, rather than face the possibility of angry, perhaps even guilt-ridden, family members, who conclude that Momma or Poppa was permitted to starve to death. Given all of the above, it should come as no surprise that tube feeding long ago made the leap from temporary use almost exclusively in critical care medicine to open-ended long term use for end-of-life care of the terminally ill, not only in hospitals but in long term nursing care facilities and even private homes.

Parenteral describes those methods of artificial nutrition and hydration that bypass the digestive system and place nutrition and hydration directly into the blood stream, and are used primarily when enteral methods are ineffective because of dysfunction of the digestive system. Not surprisingly, the capacity to provide parenteral nutrition and hydration occurred long after enteral nutrition and hydration methods were well established. The development of parenteral nutrition and hydration depended not only on the discovery of the circulatory system, but on the much more sophisticated assessment that blood carries both hydration and nutrition, the discovery of a means of accessing the blood stream intravenously, and most daunting of all, the development of a form of liquid nutrition directly usable by the human body without first being digested in the stomach and intestines. There is uncertainty as to when the first breakthrough assessment was made regarding the capacity of blood to carry both nutrition and hydration, but Ezra Steiger claims that the first effort at intravenous feeding occurred in the 1600's when "Sir

Christopher Wren infused wine and opium into the veins of dogs," [586] followed two centuries later by the adaption of the technology to humans, when "Dr. Latta described his experience with the use of an IV solution and the treatment of cholera in a letter to the Lancet in 1932. . . [where] he essentially gave the patient a saline solution that was invaluable in combating the great fluid losses associated with cholera." [587] For Steiger, "the modern day era of parenteral nutrition began in 1937, when Elman and Weiner, in the Journal of the American Medical Association reported on their experience with the use of carbohydrates and protein hydrolysates for intravenous feeding in a man." [588]

Laura Harkness claims "the first report of *long-term* (my emphasis) parenteral support being able to support life [occurred] [i]n 1968 [when] Dudrick et. al. reported the case of an infant sustained for 5 months on parenteral nutrition as her sole source of nutrition support." [589] [590] According to Kent Demaret, the problem Dudrick and his fellow physician-researchers eventually overcame was the *intravenous* delivery of a feeding mixture of sufficient nutritive value to sustain life long term. [591] In a 1978 interview by Demaret, Stanley Dudrick discussed the problems he and his colleagues eventually solved in their development of what Dudrick eventually christened total parenteral nutrition (TNP):

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[586] Ezra Steiger. "Tools for Living Better on Home IV and Tube Feedings." 1. http: www.oley.org/lifetime/95-052.html (accessed December, 10, 2010).

[587] *Ibid*.

[588] *Ibid*.

[589] Laura Harkness, "The History of Enteral Nutrition," 403.

[590] Eileen P. Flynn, *Issues in Health Care Ethics*. (Upper Saddle River, NJ: Prentice Hall, 2000), 13. According to Eileen Flynn, "Dudrick, adapted a technique developed by the French surgeon Aubaniac."

[591] Kent Demaret. "For Patients Who Can't Eat, Dr. Stanley Dudrick's Intravenous Feeding System." 1. http:www.people.com/people/archive/article/0,,20071854,00.html (accessed on April 1, 2011).

> We couldn't put it [a nutritive compound he developed to replace glucose] in through the arm because the mixture was too thick and produced problems in the small veins. We couldn't put it down with water either, because that produced edema, or excess fluid in the connective tissue. Then," Dudrick says, "we hit on the idea of putting it into larger veins [in the chest], where the blood flow is so great that the nutritional substances would be diluted and rushed throughout the body. [592]

In the four decades since its inception, total parenteral nutrition has gained widespread acceptance as an appropriate modality if and when enteral methods are not workable.

Finally, *hypodermoclysis* (also known as interstitial or subcutaneous infusion) describes those methods of artificial nutrition and hydration that place primarily hydration but also limited nutrition under the skin in subcutaneous tissue where it can be slowly absorbed by the body. There is uncertainty as to when the possibility of subcutaneous absorption of nutrition and hydration was first postulated, but according to David Major, the "development of the hypodermic syringe," obviously necessary for subcutaneous infusion, "is credited to a French surgeon named Pravez in 1851." [593] Yap, Tan, and Koo claim that hypodermoclysis was first used "in the 1940's in pediatric practice for dehydration, but became unpopular following anecdotal reports of shock caused by osmotic shifts." [594] They also suggest that a resurgence of the utilization of hypodermoclysis has taken place, beginning in the 1990's, "especially in non-emergency situations, [including] acute stroke, geriatric and terminally ill patients where venous access can be difficult." [595]

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[592] *Ibid*, 1.

[593] David Major, "The Medical Procesures," 22.

[594] L.K.P. Yap, S. H. Tan, and W. H. Koo. "Hypodermoclysis or Subcutaneous Infusion Revisited." *Singapore Medical Journal* 42, no. 11 (November 2001): 526.

[595] *Ibid*, 526.

Modern medicine has continued to refine these three general classifications of artificially delivering nutrition and hydration. Currently employed methods of enteral nutrition and hydration include, the G tube (gastrostomy), PEG tube (percutaneous endoscopic gastrostomy), the J tube (jejunsostomy, a G tube or PEG tube inserted into the jejunum, the second loop of the small intestine), the NG tube (nasogastric), and the orogastric tube. Only when a patient's digestive system is dysfunctional are parenteral methods of delivering nutrition apparently considered appropriate. Currently employed methods of parenteral nutrition and hydration include peripheral intravenous feeding, which can supply hydration but because of restrictions imposed by the size of peripheral veins only limited nutrition, and TPN (total parenteral nutrition or central intravenous feeding or hyperalimentation). Whereas intravenous hydration and nutrition usually require a nurse to start an IV and be available for observation, hypodermoclysis can, it is claimed, be accomplished at home by a family member with only minimal training.

Although all of the above described methods of artificial nutrition and hydration are capable of delivering both hydration and nutrition to an appropriate part of a patient's body, that capability is subject to three noteworthy qualifications. First, it must be emphasized that under certain circumstances a particular patient's body may be physiologically incapable of utilizing the nutrition, or even the hydration, provided. Second, under certain circumstances, especially at the end of life, artificially provided nutrition and/or hydration, although necessities of life, may also harm or impose a continuing burden on a patient. Third, each of the above described methods, because of the very nature of the method itself, can also harm or impose, in one form or another, a continuing burden on a patient. Burdens and benefits associated with each of these methods of providing artificial nutrition and hydration are thoroughly examined in chapter five.

As is certainly common knowledge, there are fatal consequences for the unwillingness or inability to eat and drink sufficiently to sustain one's life, absent the satisfactory utilization of one or more of these methods of providing ANH. What is less commonly understood, however, in such a circumstance, is that death ultimately results not from starvation, but from dehydration. What is even less commonly understood, especially by some advocates of an absolute obligation to utilize ANH, is that fatal, or as it is more commonly termed, terminal dehydration, is apparently vastly different experientially from the image in the minds of many Americans of someone dying of thirst in the dessert with sunken eyes and cracked, bleeding lips.

Terminal Dehydration

Admittedly, there is very little in American medical literature regarding death from either starvation or dehydration, but according to Dr. Robert Sullivan that absence is not at all surprising: "Reports of death associated with dehydration and starvation are uncommon in the medical literature that *focuses primarily on methods of successfully avoiding* such outcomes." [596] Nevertheless, although clearly counter-intuitive given the universal experience of thirst, there are assessments by a number of nurses and doctors, based on their own observations of and interaction with patients, as well as limited research, that suggest that, when appropriately managed, death from terminal dehydration can be virtually painless.

Linda Ganzini, and Elizabeth Goy et. al. surveyed Oregon hospice nurses and found that in the opinion of the majority of the nurses who responded to the survey, hospice patients who refused food and fluids had a good, if not a very good death:

[596] Robert Sullivan. "Accepting Death Without Artificial Nutrition and Hydration." *Journal of General Internal Medicine* 8, no. 4 (April 1993):221.

> We mailed a questionnaire to all nurses employed by hospice programs in Oregon. . . Of 429 eligible nurses, 307 (72 percent) returned the questionnaire, and 102 of the respondents (33 percent) reported that in the previous four years they had cared for a patient who deliberately hastened death by voluntary refusal of food and fluids. . .. On a scale from 0 (a very bad death) to 9 (a very good death), the median score for the quality of these deaths, as rated by the nurses, was 8. [597]

Registered nurses Phyllis Schmitz and Merry O'Brien, in observing the effects of dehydration on dying cancer patients, comment that "[i]nterestingly enough, our patients have not stated that they were thirsty but only that the mouth was dry, a symptom that can easily be relieved by local measures." [598]

Dr. J. Andrew Billings claims that "in [his] experience, thirst and dry mouth are the only seriously troubling and commonly encountered symptoms that can be attributed to dehydration in terminally ill patients," [599] and in James Hoeffler's view, "thirst [is] experienced in only a small percentage of dehydrating patients at the end of life." [600],[601] Dr. Louise A. Printz acknowledges

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Article II. [597] Linda Ganzini, Elizabeth R. Goy, Lois I. Miller, Theresa A. Harvath, and Ann Jackson, et. al. "Nurses' Experiences with Hospice Patients Who Refuse Food and Fluids to Hasten Death." *New England Journal of Medicine* 349, no. 4 (July 24, 2003): 359.

[598] Phyllis Schmitz and Merry O'Brien. "Observation on Nutrition and Hydration in Dying Cancer Patients." In *By No Extraordinary Means: the Choice to Forego Life-Sustaining Food and Water*, edited by Joanne Lynn, 29-38. (Bloomington, IN: Indiana University Press, 1989), 30.

[599] Andrew Billings. "Comfort Measures for the Terminally Ill: Is Dehydration Painful?" *Journal of the American Geriatrics Society* 33, no. 11 (November 1985): 809.

[600] James Hoeffler. "Making Decisions about Tube Feeding For Severely Demented Patients at the End of Life: Clinical, Legal, and Ethical Considerations." *Death Studies* 24, no. 3 (April/May 2000): 240.

[601] Leonard A. Sharzer. "Artificial Nutrition and Hydration: Revisiting the Dorff and Reisner *teshuvot"* *Conservative Judaism* 53, no. 2 (Winter 2001): 62.Leonard Scharzer, in what seems to be a decidedly minority opinion, appears to contradict Hoeffler, implying that dehydration *always* induces a noxious sensation of thirst: "[M]ost conscious patients with severe, end-stage debilitating diseases will actually not feel hungry and stop eating on their own. The same cannot be said for hydration. The symptom of thirst is powerful and exceedingly uncomfortable, and those same patients who stop eating will still continue to complain of thirst and want to drink."

the widespread misperception that the dying are hungry and thirsty: "[It] is assumed that dying patients must be hungry, probably because most do not eat or drink for some time. . . However, the assumption. . .that the dying must be hungry and thirsty, has not been proved. Indeed. . .the opposite is suspected by many who have worked closely with the dying." [602] She further claims that in her own "experience with dying patients who have not been medically hydrated [she] has been witnessing a peaceful, more comfortable death," [603] [and] has "also not observed true thirst as a result of lack of medical hydration in terminal patients, although [she has] observed dry mouth, which has been readily relieved by frequent sips of water." [604]

Physicians Robert McCann, William Hall, and Annmarie Groth-Juncker observed for a year the ten bed comfort care unit of a 471 bed long term care facility: [605] "Of the 32 patients monitored during the 12 months of study, 20 patients (63%) never experienced any hunger, while 11 patients (34%) had symptoms only initially. . . In all patients, symptoms of hunger, thirst, and dry mouth could be alleviated, usually with small amounts of food, fluids, and/or by the application of ice chips and lubrication of the lips." [606] They concluded that "[t]hose patients able to communicate consistently reaffirmed our hypothesis that lack of food and fluids sufficient to replete losses did not cause them suffering, as long as mouth care was provided and thirst alleviated with sips of water." [607] James Hoefler, citing numerous sources, maintains that

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[602] Louise A. Printz, "Terminal Dehydration, a Compassionate Treatment." *Archives of Internal Medicine* 152, (1999): 699.

[603] *Ibid.*

[604] *Ibid*, 700.

[605] Robert McCann, William Hall, and Annmarie Groth-Juncker. "Comfort Care forTerminally Ill Patients: The Appropriate Use of Nutrition and Hydration." *JAMA* 272, no. 16 (Oct. 26, 1994): 1263.

[606] *Ibid*.

[607] *Ibid*, 1265.

"[r]esearch on dehydration suggests that patients who stop taking in food and fluids slowly sink into a state of unconsciousness over the course of several days, and die peacefully after that." [608] "The process," according to Hoeffler, "is typically made without complaint of pain or discomfort as long as comfort care measures are continued." [609] Dr. Robert J. Sullivan, adds that "from the available data, it appears that systemic dehydration induces little pain or discomfort provided the mouth is kept moist." [610]

Finally, Hoefler claims that "[t]here is also historical precedent for allowing dehydration to hasten death [and that] [a]ccording to Shils, Olson, and Shike, dehydraton tended to be the direct cause of all 'natural' deaths (those not associated with violent trauma or acute infection) prior to the 1960's." [611] Even though a painless death from dehydration seems counter-intuitive given the universal experience with thirst and the visual image of a French Legionnaire or desert traveler apparently dying an agonizing death as he fruitlessly staggers through endless sand dunes in search of a water filled oasis, when one considers the family anecdotal accounts of the death of a grandfather/grandmother, or the media, biographical, or historical record of other individuals dying a peaceful and painless death as they simply "slipped away," the plausibility of the claim that terminal dehydration is virtually painless begins to gain considerable traction. The issue for this inquiry is whether a physiological explanation exists to provide scientific verification for such a claim.

There are several ways for the human body to dehydrate, only one of which results from the intentional total rejection of food and fluids, and Dr. Billings implies that *isotonic*

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[608] James Hoeffler. "Making Decisions about Tube Feeding." 240.

[609] *Ibid*.

[610] Robert Sullivan. "Accepting Death Without Artificial Nutrition and Hydration." 221.

[611] James Hoeffler. "Making Decisions about Tube Feeding." 239.

dehydration in which neither water nor salt are replaced as they are lost, produces especially benign effects on the human body. [612],[613],[614] Although when fluid loss exceeds fluid intake, absent a corrective rehydration, the human body almost immediately begins to both conserve and redistribute water internally to enable critical functions to continue unimpaired, [615] the *conscious* perception of the fluid imbalance and the body's internal adaptation to it is apparently confined to the mouth. According to Robert Orr, the conscious perception of "[d]ehydration [is] not perceived *anywhere in the body except the mouth* (my emphasis), and the mouth is easily treated with good nursing care." [616] In addition, it must be emphasized that when terminal dehydration results from a total fast, the body reacts not only to fluid insufficiency but also to nutritional insufficiency.

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[612] Andrew Billings. "Comfort Measures for the Terminally Ill," 808-810.

[613] *Ibid*, 808-809.. In addition to *isotonic* dehydration, Dr. Billings identifies two other forms, *hyponatremic* and *hypernatremic*. According to Billings, hyponatremic dehydration is produced when both salt and water are lost and although water is restored, sodium restoration is inadequate, resulting in weakness, apathy, lethargy, restlessness, confusion, delirium, stupor, coma, and seizures . *Hypernatremic* dehydration is produced when both salt and water lost and although sodium restoration is satisfactory water restoration is inadequate, resulting in mild confusion, progressing to obtundation and coma.

[614]The human body's attempt to regulate fluid levels is, if nothing else, exceedingly complex, directly dependent on the function and reactive capacity of a number of organs. Homeostasis is the term used to describe the effort of the body to regulate core body temperature and fluid levels in response to ambient external temperature, fluid intake and fluid losses. A number of organs have a role in homeostasis, including the kidneys, liver, and brain. The kidneys play an especially critical role in maintaining optimum fluid level, by not only adjusting the concentration of water in the blood stream, but also somewhat surprisingly, also changing sodium and ionization levels.

[615] E. Jequier and F. Constant. "Water as an Essential Nutrient: The Physiological Basis of Hydration." *European Journal of Clinical Nutrition* 64, no. 2 (February 2010): 117-118. In a 2010 article in the *European Journal of Clinical Nutrition,* Jequier and Constant provide an excellent description of the body's reaction to dehydration: "When water losses exceed water intake, the osmotic pressure of ECF [extra cellular fluid] increases. By activation of hypothalamic osmoreceptors, an antidiuretic hormone (ADH) is released from the posterior pituitary gland. Both the increased ECF osmotic pressure and ADH elicit the feeling of thirst. The receptors that elicit thirst have an osmotic threshold higher than the osmoreceptors involved in ADH release. Thus, ADH can act on the kidneys to increase water reabsorption before thirst is elicited. . . Thirst is triggered by an increase in plasma and ECF osmolarity, [and] by reductions in plasma volume. . . Kidneys are the main regulators of water losses. They have the unique property to modify the osmotic pressure of urine within a large range to respond to minute changes in plasma osmotic pressure."

[616] Robert Orr, "Just Put Me to Sleep….PLEASE! Ethical Issues in Palliative and 'Terminal' Sedation. *Loma Linda University Center for Christian Bioethics* 18, no. 2 (September 2002): 7.

Total fasting produces an apparent pain-relieving effect, and although it remains a matter of speculation as to the degree to which particular pain-reducing mechanisms contribute to this phenomenon, Dr. Sullivan is by no means alone in claiming that "[i]nstead of pain, food deprivation may induce analgesia." [617] It has apparently been well known, at least for most of the last century, that fasting produces not only anorexia (loss of appetite) but little apparent physical discomfort. According to Sullivan:

> Benedict's report of Mr. Levanzin's 31 day fast in 1915 revealed that total abstinence was tolerated without apparent physical discomfort, [618] Bloom's studies in the 1950's initiated the modern era of fasting to achieve therapeutic weight loss [when he] reported that his subjects experienced an absence of hunger and a sense of well-being, [619] [and] [r]esearch by Duncan et. al. confirmed these findings. [620]

During a total fast, the body apparently begins to burn fat. According to McCann, Hall, and Groth-Juncker, "[i]n previous studies of individuals without terminal illness who have voluntarily fasted, the long-term adaptation to starvation is that body fuel sources appear to be increasingly derived from fat metabolism." [621] From Dr. Sullivan's perception this adaptation makes perfect sense: "During starvation the body shifts its metabolic processes to rely on energy reserves in adipose tissue, presumably to protect protein integrity as long as possible." [622] McCann, Hall, and Groth-Juncker report that this "lipolysis ultimately leads to increased ketone

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[617] Robert Sullivan. "Accepting Death Without Artificial Nutrition and Hydration." 222.

[618] *Ibid*, 221.

[619] *Ibid*, 222.

[620] *Ibid.*

[621] McCann, Hall, and Groth-Juncker, "Comfort Care for Terminally Ill Patients," 1266.

[622] Robert Sullivan. "Accepting Death Without Artificial Nutrition and Hydration," 222.

production," [623] and Sullivan claims that "research by Duncan et. al.. . .suggested that the anorectic effect [of fasting] was due to ketonemia provoked by the fast, [624] and "[l]aboratory studies [provided confirmation." [625]

Dr. Louise Printz not only speculates that ketones produced during lipolysis, in addition to eliminating the sensation of hunger, also create an analgesic effect, [626] but that other pain-reducing mechanisms are activated by fasting, including the production of opiods, [627] and B-hydroxybutyrate." [628],[629] Ann Sutcliffe adds that as a result of *dehydration* induced electrolyte imbalance "[e]xtreme states of hypernatraemia (excessive sodium), hypercalcaemia (excessive calcium) and hypovolaemia (inadequate blood volume) may result in some degree of analgesia." [630] Hoeffler appears to claim that the analgesic effects of dehydration can be inferred from a reduction in the need for pain relieving medication: "Medical researchers and clinicians also

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[623] McCann, Hall, and Groth-Juncker, "Comfort Care for Terminally Ill Patients," 1266.

[624] *Ibid.*

[625] *Ibid.*

[626] Loiuse Printz, ""Is Withholding Hydration a Valid Comfort Measure in the Terminally Ill.?" *Geriatrics* 43, no. 11 (November 1988): 84. Dr. Louise Printz suggest that ketones may create a partial loss of sensation: "As for the decreased discomfort in the dehydrated patient who remains in a state of electrolyte balance, perhaps the ketones produced during calorie deprivation cause a partial loss of sensation. It has been shown that some ketones have an anesthetic effect on the squid axon."

[627] *Ibid*, 84-5. Dr. Louise Printz also suspects that extended fasting induces the body to increase the production of opiods: "Another possible etiology of decreased discomfort in these patients may be that in an advanced state of malnutrition and dehydration, pain relieving substances, possibly opioid peptides, are produced in increased quantity. Studies with rats have shown that food deprivation causes an increase in B-endorphin in the hypothalamus and plasma and that water deprivation causes an increase in dynorphin—an extremely powerful opiate—in the hypothalamus, but a decrease of it in the neurointermediate lobe of the pituitary. In humans, perhaps the state of fasting and water deprivation, or the state of fasting alone, leads to an increase of a specific compound, possibly an opioid, at a receptor site, causing some degree of analgesia."

[628] *Ibid*, 84-6

[629] *Ibid*, 84. Dr. Louise Printz claims that "lack of calorie intake leads to production of. . .b-hydroxybutyrate," and further claims that "[i]t has also been postulated that the brain metabolizes B-hydroxybutyrate to y-hydroxybutyrate, a substance with anesthetic properties."

[630] Ann Suttcliffe. "Terminal Dehydration." *Nursing Times* 90, no. 6 (February 1994): 61.

report that terminally ill patients who become dehydrated often report less pain and discomfort than patients receiving medical hydration, to the point where the dehydrated patients may require less analgesia than the hydrated group." [631] It does not seem at all unreasonable, as suggested by Sullivan, [632] among others, that fasting would accordingly produce a sense of euphoria.

As noted by Sutcliffe, total fasting apparently eventually destroys the body's capacity to maintain an appropriate electrolyte balance, and she further claims that, in addition to providing an analgesic effect, this resulting "electrolyte imbalance may serve as a natural anesthetic." [633],[634] In Robert Sullivan's view, severe electrolyte imbalance ultimately reduces consciousness:

> Following the cessation of fluid intake, hypernatremia develops slowly and induces few neurologic symptoms initially Worsening hypernatremia causes confusion, weakness, and lethargy, which eventually progresses to obtundation and coma. . . . Experience suggests that these patients slowly sink into unconsciousness over a period of time without complaint of pain or discomfort. [635]

Obviously, unconsciousness totally precludes the conscious perception of any form of suffering, but a reduced awareness of discomfort apparently begins even before consciousness is completely lost. Joyce Zerwekh suggests, quite correctly it seems, that "[a]s a patient's level of consciousness falls, his perception of suffering also decreases." [636] Dr. Billings agrees,

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[631] James Hoeffler. "Making Decisions about Tube Feeding," 241.

[632] Robert Sullivan. "Accepting Death Without Artificial Nutrition and Hydration," 222.

[633] Ann Suttcliffe. "Terminal Dehydration." *Nursing Times* 90, no. 6 (February 1994): 61.

[634] Joyce Zerwekh."The Dehydration Question." *Nursing* 13, no. 1 (January 1983): 48.

[635] Robert Sullivan. "Accepting Death Without Artificial Nutrition and Hydration," 221.

[636] Joyce Zerwekh."The Dehydration Question," 48.

commenting that "patients who become dehydrated may be too lethargic to be troubled by symptoms potentially produced by fluid deprivation." [637]

What is also clear from the available evidence is that whatever anorexic effects are experienced as a result of a total fast, these effects are lost once that fast is broken. Robert Sullivan claims that "[l]aboratory studies. . .show that hunger rapidly reappears when ketosis is relieved by ingesting small amounts of carbohydrate [638] [and that a] "controlled investigation by Keyes, et. al. duplicating famine conditions, revealed that hunger disappears with total starvation while semi-starvation makes food an omnipresent obsession. [639]

Although the principal benefits of total fasting are its anorectic, analgesic, and anesthetic effects, dehydration, according to James Hoeffler, produces other benefits that are worth noting: "Not only is symptom management relatively straightforward and effective, Schmitz and O'Brien, [640] found that dehydration actually reduces nausea, vomiting and abdominal pain. Sullivan [641] and Post [642] actually reported that dehydration reduces the diarrhea that is often suffered by dying patients. In addition, decreased urine output secondary to dehydration may decrease the incidence of urinary tract infection while it also lessens the need for bed pans,

[637] Andrew Billing, "Comfort Measures for the Terminally Ill," 808.

[638] McCann, Hall, and Groth-Juncker, "Comfort Care for Terminally Ill Patients," 1266. McCann, Hall and Juncker reach the same conclusion: "Anorexia is quickly reversed and replaced by hunger when subjects have access to even small amounts of carbohydrate, which quickly diminishes ketone production."

[639] Robert Sullivan, "Accepting Death Without Artificial Nutrition and Hydration," 222.

[640] Phyllis Schmitz and Merry O'Brien. "Observations on Nutrition and Hydration in Dying Cancer Patients." In J. Lynn *By No Extraordinary Means: The Choice to Forego Life-Sustaining Food and* Water, 29-38. (Bloomington, IN: University Press), 32.

[641] Robert Sullivan., "Accepting Death Without Artificial Nutrition and Hydration," 222.

[642] Stephen Post. "Nutrition, Hydration, and the Demented Elderly." *Journal of Medical Humanities* 11 (1990): 185.

precarious trips to the commode and catheterization, and lessens bedwetting episodes." [643] Hoeffler also maintains that dehydration reduces respiratory distress: "Pulmonary secretions also decrease with dehydration. This results in less coughing, less congestion, less gagging and choking, and less shortness of breath. Often the need for suctioning of congesting secretions is completely eliminated." [644] Finally, Hoeffler claims that "[d]ehydration also reduces swelling in the body, improving a patient's sense of well-being in general [and that] [r]educed swelling [may]also relieve pressure on tumors (if they exist), and that, too, may relieve some discomfort." [645], [646], [647]

Despite, however, the apparent benefits to a dying patient that accrue from a total fast, terminal dehydration is clearly not without its attendant complications, and it is important to be clear-eyed not only about the probability and severity of those complications but the efficacy of available forms of mitigation. As noted above, at least initially, the only conscious perception of dehydration is a sense of dryness in the mouth, and, in a small number of dehydrating patients at the end of life, thirst. [648] McCann, Hall, and Groth-Juncker are among a number of observers,

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[643] James Hoeffler.,"Making Decisions about Tube Feeding," 241.

[644] *Ibid.*

[645] *Ibid.*

[646] Schmitz and O'Brien, "Observations on Nutrition and Hydration," 30. The observations of registered nurses Phyllis Schmitz and Merry O'Brien of effects of dehydration on dying cancer patients are also worth noting: "As intake is spontaneously reduced by the patient, we have noted a reduction of nausea, vomiting, and abdominal pain, particularly where there is a bowel obstruction, liver disease, or malignant ascites. Lessened urinary output means fewer linen changes for incontinent patients and less frequent struggling with commode or bedpan for others. Pulmonary secretions decrease as patients allow themselves to become dehydrated, resulting in less coughing, less congestion, and less shortness of breath. With the decrease in mucus, there is less gagging and choking for those with difficulty swallowing and/or extreme weakness. Frequently, the need for oral-pharyngeal suctioning is eliminated."

[647] Joyce Zerwekh,"The Dehydration Question," 47. The observations of another registered nurse, Joyce Zerwekh, are also worth noting, on page 47 of her 1983 article in *Nursing*.

[648] Louise Printz, "Is Withholding Hydration a Valid Comfort Measure," 86. Specific to this inquiry, late stage Alzheimer's patients may require even less mitigation of the sensation of thirst. Dr. Louise Printz claims that "the

including Sullivan, [649] and Billings, [650] who claim that dry mouth can easily be satisfactorily addressed: "Ice chips, sips of liquid, hard candies, and mouth care (cleaning, swabbing, and application of lip moisteners) provided relief of dry mouth and thirst for varying periods of time. Some patients experienced relief for an hour while other remained symptom free for many hours." [651],[652] These same methods, according to Hoeffler, are equally efficacious in palliating thirst. [653] It is noteworthy that according to Dr. Billings, the amounts of oral fluid used to address the symptoms of both dry mouth and thirst are "too small to significantly reverse metabolic abnormalities." [654]

There remains some measure of uncertainty both as to the relationship between thirst and dry mouth and their respective etiologies. The sensation of thirst may be more a consequence of dry mouth than a result of dehydration and dry mouth itself may be attributable to causes

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voluntary intake of readily, available fluids [in the terminally ill] may be indicative of a disorder in thirst perception in the terminal state that protects the patient from significant discomfort."

[649] Robert Sullivan, "Accepting Death Without Artificial Nutrition and Hydration," 222 Sullivan reports that in his experience "[o]ne recurring physical complaint related to the absence of oral fluid intake is a dry mouth, which can be relieved with swabs, sips of fluid, or sucking on ice chips."

[650] Andrew Billings, "Comfort Measures for the Terminally Ill," 809. Billings claims that dry mouth can be addressed "oral fluid. . . or by maintaining moisture in the mouth with water, ice chips, or various forms of artificial saliva."

[651] McCann, Hall, and Groth-Juncker, "Comfort Care for Terminally Ill Patients," 1265.

[652] Joyce Zerwekh,"The Dehydration Question," 48-49. By far the most detailed description in the literature of the mitigation of the sensation of dry mouth through oral care is provided by registered nurse Joyce Zerwekh: "Avoid the drying effects of lemon and glycerin. Be certain your patient rinses often to replace the lost saliva. Use mouthwash, being careful to dilute it to the patient's need. Remove any debris in the patient's mouth by offering frequent peroxide and water rinses. (Here, too, the rinse should be diluted to the patient's particular tolerance. Brush the patient's tongue, gums, and teeth with a soft toothbrush—unless the patient indicates this causes him undue distress. Offer ice chips or small sips of favorite fluids, if the patient is conscious. If the patient experiences inflammation, use Benadryl and use a topical anesthetic to reduce pain. Once the microorganism causing the inflammation is identified, this can be counteracted with drug or antibiotic specific to that microorganism. Cover lips with Chap Stick, Vaseline, or other protective coating."

[653] James Hoeffler, "Making Decisions about Tube Feeding," 240.

[654] Andrew Billings, "Comfort Measures for the Terminally Ill," 809.

unrelated to dehydration. John Ellershaw, Jayne Sutcliffe, and Cicely Saunders report that "[t]he subjective sensation of thirst is evidently not solely dependent on level of hydration. . .[and] that patients who feel thirsty do so because they have a dry mouth." [655] In their view, "[s]ymptoms of respiratory tract secretions, thirst, and dry mouth are common in the dying patient, but these symptoms are not significantly related to the level of dehydration." [656]

Sutcliffe reports that 45% of patients admitted to a hospice complained of a dry mouth and a dry mouth ranked second in a distress score for patients with advanced cancer. [657] For Suttcliffe, "[t]hese findings reflect the fact that dry mouth is a common problem in cancer patients and is not related to dehydration but other causes such as drugs with anticholinergic side effects, candidiasis, local radiotherapy and mouth breathing." [658]

Additional complications attendant to terminal dehydration include nausea, lethargy/fatigue, and electrolyte imbalance. [659] Nausea is easily controlled by antiemetics, [660] and Billings claims that although "[b]edbound patients report primarily lethargy, drowsiness, and fatigue. . .these symptoms are rarely a source of much distress." [661],[662] According to Schmitz

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[655] John Ellershaw, Jane M. Sutcliffe, and Cicely M. Saunders. "Dehydration and the Dying Patient." Journal of Pain and Symptom Management 10, no. 3 (April 1995): 196.

[656] *Ibid*, 197.

[657] Joyce Sutcliffe, "Terminal Dehydration," 62.

[658] *Ibid.*

[659] Stephen Brooker. "Dehydration Before Death." *Nursing Times* 88, no. 2 (January 8, 1992): 61. Terminal dehydration, according to registered nurse, Stephen Brooker, produces other complications, including dry, inelastic skin, increased body temperature, and increased viscosity of secretions. Brooker recommends that dry, inelastic skin should be treated with soft mattresses, careful lifting and turns to prevent skin damage, and that great care should be exercised at IV sites, with no soap. Increased temperature, in his view, should be monitored as a possible indication of infection, but treated with cool wipes, cool drinks, light clothing and bed covers, and a fan. According to Brooker, increased viscosity of secretion should be treated with deep breathing/coughing exercises and physiotherapy if necessary/tolerated.

[660] Joyce Zerwekh, "The Dehydration Question," 48-49.

[661] Andrew Billings, "Comfort Measures for the Terminally Ill," 810.

and O'Brien, "sometimes the symptoms arising from electrolyte imbalances (especially hyperalcemia), such as twitching, muscle spasms, or altered states of consciousness, require treatment." [663] Schmitz and O'Brien, [664] Hoefler, [665] and Zerwekh, [666] all recommend treatment with antispasmodics and/or sedation.

Of great potential significance for patients experiencing terminal dehydration, as well as their families, is delirium. Soenke Boettger, Steven Passik, and William Breitbart describe delirium as a "neuropsychiatric disorder characterized by disturbances of consciousness, attention, cognition, and perception with an abrupt onset and fluctuating course." [667] Delirium is usually reversible, and can result from the development or worsening of many disorders. Boettger, Passik, and Breitbart report that "dementia is the leading risk factor for delirium, [that] two thirds of cases of delirium occur in the setting of dementia," [668] and that "[d]isturbance of level of consciousness (or arousal disturbance) is more severe in patients who have delirium superimposed on dementia compared to those who have delirium in the absence of dementia." [669] Dehydration is one cause of delirium and the sudden onset of delirium should accordingly be of

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[662] James Hoeffler. "Making Decisions about Tube Feeding," 241. James Hoeffler agrees, claiming that "lethargy/fatigue rarely creates much of a problem."

[663] Schmitz and O'Brien, "Observations on Nutrition and Hydration," 30.

[664] *Ibid*.

[665] James Hoeffler, "Making Decisions about Tube Feeding," 241.

[666] Joyce Zerwekh, "The Dehydration Question," 48.

[667] Soenke Boettger, Steven Passik, and William Breitbart. "Delirium Superimposed on Dementia Versus Delirium in the Absence of Dementia: Phenomenological Differences." *Palliative and Supportive Care* 7, no. 4 (December 2009): 495.

[668] *Ibid*, 495-6.

[669] *Ibid*, 499.

particular concern for the doctors, nurses, and care givers of late stage Alzheimer's patients experiencing terminal dehydration.

Delirium produced or aggravated by severe dehydration can presumably be mitigated or even eliminated with the intake of sufficient fluids, but it is uncertain how much fluid is necessary and whether that amount will extend the terminal dehydration process. Robin Fainsinger and Eduardo Bruera claim that "delirium is avoided with a small amount of fluids (1200 cc's a day)." [670] ,[671] Sedation is another potential method of addressing the impact of delirium on a dehydrating late stage Alzheimer's patient, but there is evidence that sedation can in certain circumstances actually worsen delirium, especially in the elderly.

There is no clear consensus as to how long terminal dehydration continues before death ensues. For Dr. Printz, " 3 to 10 days after the patient's last intake of fluid," [672] for Timothy Quill and Ira Byock, "several days to a few weeks," [673] and for James Hoefler, "anywhere from a couple of days to two-and-a-half weeks." [674] According to the survey referenced by Linda Ganzini, and Elizabeth Goy et. al " 85 percent of the patients died within 15 days after stopping food and fluids." [675] A number of variables influence the ultimate length of the dehydration process, including, according to Quill and Byock, the patient's disease burden and nutritional and

[670] Robin Fainsinger and Eduardo Bruera, "When to Treat Dehydration in a Terminally Ill Patient." *Support Care Cancer* 5, no. 3 (May 1977): 206.

[671] Approximately 40 fluid ounces.

[672] Louise Printz, "Terminal Dehydration," 699.

[673] Timothy E. Quill and Ira R. Byock, 410. Quill. Timothy E., and Ira R. Brock for the ACP-ASIM End of Life Care Consensus Panel. "Responding to Intractable Suffering: The Role of Terminal Sedation and Voluntary Refusal of Food and Fluids." *Annals of Internal Medicine* 132, no. 5 (March 7, 2000): 410.

[674] James Hoeffler,"Making Decisions about Tube Feeding," 240.

[675] Ganzini, Goy, Miller, Hoarvath, and Jackson, et. al.,"Nurses'Experience with Hospice Patients," 359.

metabolic state at the outset," [676] and apparently also the amount of stored fat in his/her body. As discussed above, and completely consistent with the common experience of dieters, fasting bodies metabolize fat. What the layperson, and likely even some physicians, fail to grasp, however, is that fat can be used by the human body as a source of fluids. Not only does Dr. Robert Sullivan claim that dehydrating bodies metabolize fat as a source of water, but that a body can *almost* satisfy its fluid needs from fat metabolism alone: "Laboratory studies have shown that urinary nitrogen excretion diminishes progressively with prolonged starvation. With a reduced urea load, there is little need for obligatory water excretion, and urine volume may fall to 200 ml. per day. Indeed, a fasting individual may have fluid requirements almost fully met by water produced through fat metabolism." In simple terms, the greater the stored fat in the body, the longer the process of terminal dehydration.

Specific to this inquiry, not only is a late stage Alzheimer's patient likely to possess less stored reserves of fat as a result of chronic loss of appetite, and/or physical ability to eat and drink, and/or dysphasia, he/she may also already severely dehydrated when the decision is made to reject artificial nutrition and hydration. According to E. Jequier, and F. Constant "[e]lderly individuals have a higher risk of developing dehydration than do adults." [677] In their view, "the diminution of the sensation of thirst the decreased ability to concentrate urine, the relative resistance of the kidney to ADH, the diminution of rennin activity and the low secretion of aldosterone, all increase the risk of dehydration." [678] As a consequence, although the overall length of terminal dehydration can be safely assessed as falling within a ten day to three week range, terminal dehydration in last stage Alzheimer's patients may be significantly faster.

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[676] Quill and Byock, "Responding to Intractable Suffering," 410.

[677] Jequier and Constant, "Water as an Essential Nutrient," 120.

[678] *Ibid*.

Absent the effect of another intervening lethal pathology, Robert Sullivan points to a number of potential causes of death due to terminal dehydration, that although producing little if any pain or extended suffering, are nonetheless fatal:

> In situations of extreme dehydration and starvation, several mechanisms are postulated to cause death. Neutropenia and a reduction in white cell function associated with protein deficit may permit the development of sepsis leading to death. Arrthythmias related to myocardial degeneration or to electrolyte imbalance [679] can cause cardiac arrest. Weakness from muscle protein catabolism may lead to inadequate clearing of chest secretions and subsequent pneumonia. Clouding of consciousness due to a hyperosmolar state can cause depressed respiration with aspiration and pneumonia. While discomfort is possible in each situation mentioned, none of these events is known to be associated with significant pain or prolonged suffering. [680]

Despite an awareness of anecdotal evidence buttressed by a scientific explanation of dehydration physiology, it may be exceedingly difficult to persuade patients or surrogate decision makers contemplating the rejection of artificial nutrition and hydration, as well as an individual diagnosed with Alzheimer's disease who wishes to express his/her preferences for future medical treatment in advance directives that, in the absence of nutrition and hydration, dehydration has fatal consequences long before starvation threatens life, and especially, that death from dehydration can be a virtually *physically* painless experience. Given the universal experience with hunger and thirst and the indelible image of the suffering endured by concentration camp internees and dessert wayfarers deprived of food and water respectively, this difficulty should come as no surprise. Perhaps equally problematic for patients and their families,

[679] Louise Printz, "Is Withholding Hydration a Valid Comfort Measure," 85. Dr. Louise Printz provides a more detailed description of the chemistry of electrolyte imbalance: "Lack of fluid intake, significant enough to lead to hypovolemia, causes the BUN to rise due to renal hypoperfusion. As hypovolemia progresses to the extreme state, tissue perfusion is eventually compromised and a lactic acidosis occurs. The now ischemic kidneys fail to excrete the excess acid. Hyperkalimia follows from the acute acidosis and renal failure."

[680] Robert Sullivan, "Accepting Death Without Artificial Nutrition and Hydration," 222.

however, is the absence of reassurance regarding other forms of distress that might possibly be experienced by an individual undergoing terminal dehydration, including psychological, emotional, and even existential suffering. As noted above, depending in significant part on a number of variables, the process of terminal dehydration can last as long as three weeks, and there can accordingly be a significant period of time within which non-physical forms of distress can occur.

Preemptive Palliative Sedation

Nevertheless, reassurance that the experience of terminal hydration will be entirely free of any form of pain or suffering, physically, psychologically, emotionally, or existentially, can be provided to a patient, and/or his family through the prudent application of preemptive palliative sedation, which when administered appropriately should permit a patient to more or less "sleep" through the entire dehydration process. Accordingly, in the circumstances specific to this inquiry, a choice can be made to request preemptive palliative sedation (PPS) once terminal dehydration has begun, in order to permit the Alzheimer's patient to rest comfortably until his/her body succumbs to dehydration and in so doing provide absolute assurance to him/her and his/her family from the moment a request for PPS is made in his/her advance directive(s), that if and when artificial nutrition and hydration (ANH) is rejected and dehydration begins, he/she will experience no suffering of any kind, not physical, psychological, emotional, or existential.
In the anticipated absence of any pain producing pathology unrelated to the unwillingness or inability, even with assistance, to eat and drink sufficiently to sustain life, what is desired in this circumstance is the minimal sedation possible to reduce the patient's consciousness only enough

to prevent the patient from experiencing *any* form of suffering. The Richmond Agitation-Sedation Scale (RASS) identifies 5 levels of sedation:

1 Drowsy: Not fully alert; but has sustained awakening to voice.
(eye opening and contact > ten seconds)

2 Light Sedation: Briefly awakens to voice.
(eye opening and contact < ten seconds)

3 Moderate Sedation: Movement or eye opening to voice.
(but no eye contact)

4 Deep Sedation: No response to voice, but movement or eye opening to physical stimulation.

5 Unarousable No response to voice or physical stimulation

Prolonged palliative sedation in this circumstance is not without risk, because life-threatening compromise of respiratory and cardiac function is *possible*, especially in the elderly, but three factors significantly reduce this risk. First, available evidence suggests that prolonged palliative sedation does *not* shorten lives, principally because of advances in sedation technology. Ronald Crawford and Raymond Gensinger claim that that improvements in sedation technology have made prolonged and uninterrupted sedation at the end-of-life, what is sometime referred to as terminal sedation, far less risky: "Terminal sedation is more easily managed today [2002] than a few years ago. Respiratory compromise is much less likely with newer agents (e.g. midazolam) than with the older, more sedating medications." [681] A plethora of studies, among them Muller-Busch, Anres, and Jehser, Stone , Phillips, et. al., Ventafridda, et. al., Chui, et. al., Vitetta, Kenner, and Sali, Morita, Tsunoda, et. al, Kohara, et. al, Waller and Bercovitch, et. al.,

[681] Ronald E. Cranford and Raymond Gensinger. "Hospital Policy on Terminal Sedation and Euthanasia." *HEC Forum* 14, no. 3 (September 2002): 262.

and Cowan and Palmer from countries all over the world have shown no difference in survival rates among those patients receiving sedation and those patients not receiving sedation.

According to Maureen Lynch, "the median time remaining until death after instituting palliative sedation is 1.3-3.2 days, and case reports have documented patients surviving *as long as 29 days* (my emphasis)." [682] Nigel Sykes and Andrew Thorns, in assessing the data from five studies reporting the use of sedation in relation to survival from admission to death for in-patient centres or from commencement of service involvement to death for [home] based teams, reach a similar conclusion:

> In each case survival of patients receiving sedation were not significantly different from that of patients who were not given sedatives, and in one case there was a difference in favor of sedation. Patients who received sedatives for over a week before death had better survival than those who did not receive sedation; patients who had only 2 or 3 days of sedatives has the same survival as those who never received sedation. [683]

Second, the lower the level of sedation the lower the risk, and in the circumstances specific to this inquiry what is desired is the minimal sedation possible, to reduce the patient's consciousness only enough to prevent the patient from experiencing *any* form of suffering. Mitigating somewhat the higher risk associated with sedating older patients, the elderly usually require a lower level of sedation to achieve the same results. Anesthesiologist Ronald Miller, writing in *Miller's Anesthesia*, reveals that "[i]n general, the elderly are more sensitive to

[682] Maureen Lynch. "Palliative Sedation." *Clinical Journal of Oncology Nursing* 7, no. 6 (May 22, 2003): 654.

[683] Nigel Sykes and Andrew Thornes."The Use of Opiods and Sedatives at the End of Life." *Lancet Oncology* 4, no. 5 (May 2003): 317.

anesthetic agents [and less] medication is usually required to achieve a desired clinical effect."[684]

Finally, sedation can, in the circumstances specific to this inquiry, be stopped and restarted if desirable, not only immediately reducing any risk from prolonged and uninterrupted sedation, but also providing windows of consciousness for possible reorientation to reduce or eliminate the onset of delirium and for family members to communicate with the dying patient. Interim or respite sedation has been championed by Paul Rousseau, and although his protocol is specific to deep sedation, it is obviously also applicable to minimal levels of sedation:

> Respite sedation is a form of palliative sedation in which patients are deeply sedated for a predetermined amount of time (usually 24 to 48 hours), and then reawakened to assess the extent of symptomatic improvement and the need for further sedation. Because many dying patients are afflicted with existential turmoil that engenders fear, fatigue, and insomnia, respite sedation may break a cycle of sleep deprivation and existential distress and allow such patients the opportunity to regain psychological strength and assuage the existential issues that precipitated the need for palliative sedation. Respite sedation also allows second-guessing and reassessment by health care providers, patients and family members, negating the sense of overwhelming finality and guilt that may occur with continuous deep sedation. [685]

Modern medicine has the undeniable technical capacity to safely and significantly ease, if not entirely eliminate, all forms of suffering in the ten days to three weeks before death from terminal dehydration, and absent unusual and unanticipated complications, is capable of doing so in a nursing facility or even a home care setting. The key is doing so *preemptively*, and in so doing providing absolute reassurance to Alzheimer's patients and their families, that the terminal dehydration resulting from the rejection of artificial nutrition and hydration will not produce

[684] Ronald D. Miller, ed. *Miller's Anesthesia*. (Philadelphia, PA: Elsevier/Churchill/Livingstone, 2005), 2445.

[685] Paul C. Rousseau..“Existential Distress and Palliative Sedation.” *Anesthesia and Analgesia* 101, no. 2 (August 2005): 611.

suffering of any kind: not physical, psychological, emotional, or existential. The promise that any and all suffering will be addressed as it is either *observed or reported* simply does not provide the same level of reassurance, especially with the impaired communication skills of a dehydrating patient with late stage Alzheimer's disease. It is accordingly not at all difficult to envision that preemptive palliative sedation will become a more and more requested modality at the end-of-life, especially with the terminal dehydration of a late stage Alzheimer's patient. Unfortunately, although modern medicine is certainly capable of using palliative sedation to reduce a patient's consciousness in order to address physical pain and other forms of suffering, it must be emphasized that American professional medicine is very conservative in assessing the appropriate circumstances for doing so. American professional medicine's protocol for palliative sedation, which it should be noted in advance, views palliative sedation as a method of last resort appropriate only after other consciousness preserving methods of alleviating physical pain and suffering have proved inadequate, is thoroughly examined in chapter eleven.

Chapter Four: Legal Authority to Reject Life-Sustaining Medical Treatment

This chapter asks, under what circumstances, if any, an individual possesses the requisite legal authority to *reject* a means of sustaining his/her life, including, but not limited to artificial nutrition and hydration (ANH), and he/she can make that rejection in advance, through the use of an advance directive(s), [686] in anticipation of loss of the requisite decisional capacity. [687],[688] Specific to the circumstances of this overall inquiry, particular focus will be placed on whether an Alzheimer's patient with decisional capacity possesses the requisite legal authority to reject ANH in advance, should he/she subsequently no longer be willing or able, even with assistance,

[686] Advance directive is a general term employed to describe those legal documents that permit individuals to provide written instructions re: their future medical treatment preferences (living will), and /or to appoint some other person to make medical treatment decisions on their behalf ("durable power of attorney for health care"), should illness or injury render them unable to do so through loss of consciousness or decisional capacity. Both forms of directives are discussed in detail in Chapter 12.

[687] As explained in greater detail later in this chapter, *decisional capacity* is a *medical* term and refers to an assessment made by a *physician* or other medical professional as to whether an individual is capable of giving informed consent for a particular medical treatment. *Competency* is a *legal* term and refers to an assessment made usually by a *judge* although in some instances by a *jury* as to whether an individual possesses decisional capacity, as a matter of law**.**

[688] Schwarz, Judith. "Exploring the Option of Voluntarily Stopping Eating and Drinking Within the Context of a Suffering Patient's Request for a Hastened Death." *Journal of Palliative Medicine* 10, no. 6 (2007): 1289. It must be noted that according to Judith Schwarz, even if an individual possesses the legal authority to reject a means of sustaining his/her life, a physician is under no obligation to continue his/her professional relationship with such a patient: "If a physician believes that it would be morally wrong to participate in the withdrawal of life-sustaining medical treatment because doing so under some circumstances would contribute to a 'self-killing,' the physician is not obligated to participate in a clinical practice that offends his/her personal conscience. However, the physician is required to inform the patient of his/her moral reservations, confirm the patient's right to make his or her own treatment choices, and facilitate transfer of the patient's care to another clinician who is able to support the patient's choice. Indeed, once the physician is assured that the patient's refusal of treatment is both informed and valid, if he or she continues in a therapeutic relationship with that patient, the clinician is morally required to honor the patient's decision to forego life-sustaining treatment, regardless of whether she or he approves of the decision or believes the patient's choice is good, bad, or wrong."

to eat and drink sufficiently to sustain his/her life and no longer possesses the requisite decisional capacity to make such a rejection.

Article II. Legal authority is obviously of enormous significance in insuring that an individual's decision to reject a means of sustaining his/her life will be honored. That the legal right to make such a rejection is recognized by the law effectively means that should the exercise of that right be resisted by an individual(s), such as a doctor or nurse, or an institution, such as a hospital or nursing home, that resistance is unlawful and subject to whatever law enforcement mechanisms are available. Generally speaking, awareness of the law is alone a sufficient deterrent to dissuade most medical professionals and medical institutions from resisting the exercise of a patient's legal right. What is probably underestimated, however, is the influence that the awareness of the law has on others, especially family and close friends, who might oppose a patient's decision to reject a means of sustaining his/her life and attempt either to persuade him/her to accept rather than reject the life-sustaining means or to override his/her previously made decision if and when he/she subsequently loses decisional capacity. In discussions re: the advisability of the rejection of a means of sustaining life, the awareness that an individual possesses the legal authority to do so often strengthens his/her argument *vis a vis* the objections and counter arguments of others. In addition, if a patient who has made a decision to reject a means of sustaining his life subsequently loses decisional capacity, even temporarily, he/she needs, at minimum, the acquiescence of others to prevent that means from being employed against his/her wishes. Those whose acquiescence is needed, whether family members or other surrogate decision makers, are much more likely to acquiesce to a patient's previously made decision to reject a means of sustaining his/her life, if they are aware that he/she possessed the requisite legal authority to do so.

Possible sources of legal authority under American law to reject a means of sustaining one's life and to make that rejection in advance, through an advance directive(s), include what is

termed the *common law*, [689] state legislation, state constitutions, federal legislation, the United States Constitution, as well as state and federal court rulings. State court rulings are a possible source of law because they review, interpret and apply common law, state legislation/constitutions, and when necessary federal legislation and the United States Constitution. Federal court rulings are likewise a possible source of law because they review, interpret, and apply the common law, state legislation and constitutions, federal legislation and the United States Constitution. Article VI, Clause 2 of the United States Constitution, sometimes referred to as the Supremacy Clause, declares that the United States Constitution, U.S. Treaties, and federal legislation is the supreme law of the land, [690] which means that when federal law and state law conflict and cannot be reconciled, federal law prevails.

Before examining these sources in depth it is important to be alert to the manner in which an individual's legal right to reject a means of sustaining his/her life might be *limited* by the law, including concerns about his/her decisional capacity to exercise such a choice, as well as the possibility that the interests of the state, and others, in the preservation of his/her life might, on balance, be assessed as trumping his/her right to refuse a means of extending his/her life. Because court rulings, by their very nature, are responsive to both constitutional and legislative changes, and legislation is, not infrequently, passed in response to a court ruling(s), neither legislation nor court rulings can be fully understood outside the context of the existing state of the law and prevailing legal, social, and political environment at the time they came into being. It

[689] For a definition of common law, see the Appendix (Number 11).

[690] United States Constitution Article VI, Clause 2: "The Constitution and the Laws of the United States which shall be made in pursuance thereof; and all treaties made, or which shall be made, under the authority of the United States, shall be the supreme law of the land; and the judges in every state shall be bound thereby, anything in the constitution or laws of any state to the contrary notwithstanding"

is, therefore, necessary not only to begin with our common law tradition, but to proceed chronologically, taking notice of relevant legislation and court rulings.

Historical Development

The legal authority under American law for an individual to reject a means of sustaining his/her life has its roots in English common law because the earliest American courts were comfortable in applying English common law precedents in settling legal disputes between individual Americans and between individual Americans and their local, state, and federal government even after the American revolution when there was no longer any obligation imposed by the "Crown" to do so. [691] English common law traditions were apparently clear and consistent in affirming that regardless of the known benefit of a particular means of sustaining life, such a means could not be imposed on an individual without his/her consent. According to Kenneth Vaux, "as early as [the court case entitled] *Slater v. Baker and Stapleton* [1767], [English] courts recognized that it was battery, assault, and trespass medically to treat a person over his objection." [692] Early in the last century, two American courts recognized and applied this common law tradition. In 1905, an Illinois appellate court in the case entitled *Pratt v. Davis* held that "[u]nder a free government at least, the free citizen's first and greatest right which underlies all others—the right to the inviolability of his person, in other words, his right to himself—is the subject of universal acquiescence, and this right necessarily forbids a physician. .

[691] Original pre-revolution courts in the American colonies were effectively English colonial courts and naturally applied Acts of Parliament and other sources of law from the mother country including the traditions of English common law. It should come as no surprise that when, after the American revolution, these courts became American courts that many American judges would choose to continue to apply English common law but substitute state and eventually federal law for Acts of Parliament and other sources of law from the mother country.

[692] Kenneth L. Vaux, *"Death Ethics: Religious and Cultural Values in Prolonging and Ending Life. (*Philadelphia, PA: Trinity Press International, 1992), 41.

. to violate without permission the bodily integrity of the patient by a major or capital operation" [693] Nine years later, the much esteemed and later U. S. Supreme Court justice Benjamin Cardozo, in a New York appellate court ruling in *Schloendorff v. Society of New York,* wrote that "[t]he root premise is the concept, fundamental in American jurisprudence, that "[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body." [694],[695],[696]

Despite the willingness of these, and undoubtedly other American courts in the first half of the 20th century, to affirm and apply the English common law right to refuse medical treatment, even life-sustaining medical treatment, it is likely that, for the most part, the average American patient was neither aware of nor had reason to exercise that right. Up until the 1960's, not only were American physicians apparently accustomed to making medical treatment decisions for their patients, patients were apparently comfortable with ceding to their physicians that decision making power. Patients' comfort with having their doctors make medical treatment decisions flowed from the apparent widespread public perception that, at least with regard to medical

[693] 118 Ill. App. 161 (1905) aff'd 224 Ill. 30, 79 N. E. 562 (1905).

[694] 211 N.Y. 125, 105 N. E. 92, 93 (1914).

[695] David F. Kelly. *Contemporary Catholic Health Care Ethics.* (Washington, DC: Georgetown University Press, 2004), 144. As David Kelly points out, although "[n]o one may touch me without my consent," there are [a]dmittedly. . . time(s) when I must give my consent, as to custom officials who search my person or police officers who arrest me, but these are rare exceptions and they are rather clear."

[696] Nancy M.P. King. *Making Sense of Advance Directives*. Boston, MA: Kluwer Academic Publishers, 1991), 37. Nancy King makes clear that consent cannot be assumed to extend, by implication, to treatment not expressly discussed by patient and physician: "According to the law of battery, it is the patient who initiates the physician-patient relationship, regardless of how the encounter has proceeded, the relationship can begin only when the patient consents to the physician's touch. Battery also makes clear that because it is the *touch* that is consented to, the patient's consent to the relationship does not automatically encompass all treatments. Each recommendation must be examined on its own terms; that first consent cannot reasonably be construed as consent to anything the physician recommends unless the patient understands it precisely that way." King cites *Pratt v. Davis*, but in addition, *Mohr* v. *Williams*, 1905. In Mohr v. Williams, the Minnesota Supreme Court ruled that consent to an operation on a patient's right ear could not be implied to be consent to an operation on his left ear. (104 N. W. 12 (Minnesota, 1905).

treatment decisions, doctors knew best, but there was almost certainly another major influence. Until well into the 20th century American medicine was not only limited in its overall capability to sustain life, it was almost totally unable to sustain a life with minimal function and/or poor overall quality.

This meant that with the exception of life-saving amputations and perhaps some other life-sustaining but function reducing surgeries there was very little downside risk, from a strictly reduced function/quality of life perspective, to accepting a possible means of sustaining one's life. If the method failed, death was the obvious result, and if the method worked, life was preserved. If, however, a patient's life was preserved, in all likelihood also retained was significant function and his/her overall quality of life. Modern medicine was, for the most part, not yet able to sustain the lives of those who were unable to breathe on their own, not yet able to sustain the lives of those who were unable to orally ingest nutrition and hydration, and absolutely unable to sustain the lives who permanently lost consciousness. There was, therefore, little chance that in accepting a means of sustaining his/her life that a patient or his/her surrogate was accepting continued biological existence with only minimal function/quality of life. Life tied to a mechanical ventilator was unheard of, tube feeding, though technologically possible, was viewed only as a temporary measure, and no one who permanently lost consciousness could be expected to survive very long.

For much of the first half of the century, with little, if any, downside risk, rejection of a means of sustaining one's life was simply not a particularly attractive option, even if a patient was aware of that option, which was probably unlikely. Physicians were probably not accustomed to sharing with their patients anything more than minimal, at best, information about diagnosis, and even less about a negative prognosis. Physicians, with at least some justification,

were not only doubtful that their patients could comprehend information disclosed to them re: diagnosis and prognosis, [697] but fearful that, even if they could comprehend, the value of that comprehension would be outweighed by the negative psychological/emotional consequences to the patient of a poor prognosis. [698]

This is not to say that potentially life-sustaining medical treatment was not rejected by physicians on behalf of their patients, it is simply that it was probably not all that unusual for patients and even patients' families not to be informed about how and why the attending physician made that decision. James Bernat seems to confirm as much, at least for demented patients, even after antibiotics were developed during World War II: "In the prior physician-centered era, it was a time-honored medical tradition to allow elderly demented patients to die by purposely not treating their infections or other potentially treatable conditions. It was in this context that Sir William Osler referred to pneumonia as 'the old man's friend." [699],[700],[701]

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[697] Mark A Hall, Mary Anne Bobinski, and David Orentlicher. *Bioethics and Public Health Law.* (New York, NY: Aspen Publishers, 2005), 153. Hall, Bobinski, and Orentilcher lend credence to a doctor's doubts that their patients, especially their most seriously ill patients, are capable of comprehending information disclosed about their diagnosis and prognosis: "There are a number of explanations for the gap between disclosure and comprehension/retention. Patients are often sick or emotionally vulnerable at the time of the disclosure; information may be presented in a highly technical and incomprehensible fashion; patients may not feel able to ask important follow-up questions."

[698]Nancy M.P. King, *Making Sense*, 44. Nancy King suggests yet another reason why physicians were historically reluctant to disclose information to their patients re: their diagnosis and prognosis: "Before the nineteenth century, truth telling generally was viewed by physicians as counterproductive, largely because, in what was considered a highly competitive atmosphere, patients were accustomed to doctor shopping according to whether they like what they heard. Because therapeutic alternatives were few, diagnosis and prognosis were all-important, and accuracy warred with optimism as the approach most likely to help patients."

[699] James. L. Bernat. "Ethical Issues in the Care of the Patient with Dementia." In *Handbook of Clinical Neurology*, edited by Michael J. Aminoff, Francois Boller, and Dick F. Swaab, 121-36. (Edinburgh, Scotland: Elsevier, 2008), 129.

[700] *Ibid.* According to Bernat, "[t]he practice remained covert until the courageous report in 1979 by Brown and Thompson of a cohort of demented nursing home patients in whom physicians decided not to evaluate or treat fevers in 43%, of whom 59% died as a result."

[701] It should also be emphasized that patients who made the decision that they were no longer willing to oppose the trajectory of a particularly debilitating and irreversible illness, disease, or injury were not totally bereft of options. They could if they so chose simply refuse to eat and drink.

As the decade of the 1960's began to unfold, however, change was is in the wind, and it can be attributed, in large part, to five separate though related developments. First, more and more American patients apparently demanded the right to make medical treatment decisions for themselves based on a growing sense of an individual's right of self-determination in all things, including but not limited to, medical care. Second, despite an unparalleled, veritable explosion of the technological capability of modern medicine to sustain lives, as well as the widespread public awareness of that technological capability, the utilization of an almost certain means of sustaining life, became, in certain circumstances, of questionable appropriateness.

Arthur Derse reports that, at least initially, questions of the appropriateness of potentially life-sustaining medical treatment focused on cardiopulmonary ventilation [CPR] and mechanical ventilation:

> CPR was initially developed for use in reversible cardiac disease, and the universal application of CPR to all patients in cardiac arrest resulted in ethical quandaries. Analysis of patient outcomes show[ed] that only a minority of patients would survive the attempt at resuscitation, and. . . [t]he majority [of those] would die in hospital, often after long periods of unresponsiveness. Do-not-resuscitate (DNR) orders were developed to distinguish those for whom resuscitation should not be attempted, either on the basis of patient desires or expected medical ineffectiveness. [702]

"Courts," according to Derse, "have upheld the validity of DNR orders, and DNR orders have achieved widespread acceptance." [703] Derse further suggests that the mechanical ventilators provided another similar ethical dilemma:

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[702] Arthur Derse. "Limitation of Treatment at the End-of-Life: Withholding and Withdrawal." *Clinics in Geriatric Medicine* 21, no. 1 (February 2005): 227.

[703] *Ibid.*

> The use of ventilators. . .gave rise to the phenomenon of patients who could not be weaned from them. These patients ranged in neurological status from full conscious to absent brain activity. One of the first ethical dilemmas of this technology was whether to continue ventilation for patients whose brain and brain stem were not functioning, but whose heart continued to beat. . . The recognition of ventilation as a technological treatment that may be withdrawn was an early consensus in ethical and legal analysis. [704]

In contrast to the past, here at last were clear and significant down side risks to the utilization of life-sustaining medical treatment and the American public was slowly but surely [705] becoming fully aware of those risks. One could have one's life-sustained but it might come at a significant cost, including having one's heart restarted over and over again, being permanently bedridden and dependent for breath on a mechanical ventilator, and finally being only biological alive, without movement, consciousness, or apparently any cognitive function whatsoever, dependent for hydration and nutrition on a feeding tube.

Third, American physicians were no longer viewed in quite the same way by the American public. Historically, Americans had, at least arguably, unqualified faith and trust in their family doctor's wisdom and judgment. Now, according to Hall, Bobinski, and Orentilicher, that relationship had undergone a significant alteration: "A wide range of factors—perhaps among them the anti-establishment views of the 1960s, the consumer movement of the 1970s, the startling advances and lingering failures of medical progress, and the expansion of specialties such as 'bioethics' and 'health law'—. . .combined to change the authority and supremacy of the physician."

Four, the eventual, virtually universal, acceptance by American professional medicine of

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[704] *Ibid.*

[705] Hall, Bobinski, and Orentilicher, "Bioethics and Public Health Law," 149.

the necessity of obtaining informed consent from their patients before proceeding with medical treatment made patients aware, perhaps in many instances for the first time, that they possessed the right to say "Thanks, but no thanks," to life-sustaining medical treatment. Not only were doctors aware of the necessity of obtaining a patient's signature on a consent form, they knew they were also obliged to *justify* to that patient the utilization of a means of sustaining his/her life with full disclosure of possible and probable risks and consequences. Thanks to the necessity of obtaining their informed consent, American patients, or their surrogates, became participants in discussions re: their diagnosis and prognosis and much more likely to reject life-sustaining treatment that in their assessment imposed foreseeable harm(s) and/or burden(s) that were, on balance, disproportionate to its foreseeable benefit(s).

Finally, Americans denied the right to reject life-sustaining medical treatment by doctors and/or hospitals, began to petition American courts for enforcement of that right, and not only found those courts, including the United States Supreme Court, for the most part receptive to those pleas, but also sympathetic state legislatures, as well as the United States Congress. What follows is a chronological examination of the assertion of the legal right to reject life-sustaining medical treatment, which although by no means exhaustive as to court rulings or legislation, does provide a broad overview, not only of the ultimate affirmation of that right in American law, but the limitations imposed by state and federal courts, and state legislatures, on the exercise of that right. To simplify the analysis, the relevant facts of the court rulings, when pertinent to the discussion, can be found in an accompanying footnote.

Further Development in the Last Half-Century

Reflective of the changes taking place as the decade of the 1960's began, the Kansas Supreme Court, in *Natanson v. Kline,* [706] reversed and remanded for new trial a lower court ruling denying Irma Natanson damages in her malpractice claim against her physician, Kline, and St. Francis hospital because of an alleged *negligent* failure to adequately *disclose* the risks of radiation as a treatment for cancer. The *Kansas* Supreme Court ruling was significant for three reasons. First, the court affirmed that Natanson possessed the legal authority to reject a means of sustaining her life: "Anglo-American law starts with the premise of through-going self-determination. It follows that each man is considered to be master of his own body, and he may, if he be of sound mind, expressly prohibit the performance of life-saving surgery, or other medical treatment." [707] Second, and of perhaps even greater significance, whereas a patient's legal right to refuse medical treatment under American law was presumably based on *criminal battery*, i.e. a non-consensual touching by a physician, the court permitted Natanson to pursue a *civil negligence* claim against her doctor and hospital based *not* on the failure to skillfully perform a medical treatment but on the *failure to adequately disclose the risks* of that treatment. [708]

Finally, whereas heretofore American law had imposed upon a doctor a *negative obligation* to refrain from treating a patient against his/her wishes, as has had been the case in *Schloendorff v. Society of New York* where Schloendorff had consented to exploratory surgery but withheld consent for the removal of a tumor, which her doctor ignored, the Kansas Supreme

[706] 180 Kansas 393 350 P. 2nd, 1093.

[707] *Ibid*, 410.

[708] It is important to note the distinction between the claim that a physician performed a medical treatment negligently, which had previously although probably infrequently made, and what Natanson alleged, that her doctors and hospital negligently failed to disclose the risk of a medical treatment even if it was performed skillfully.

Court, citing *Salgo v. Leland Stanford Etc. Board of Trustees* [709] held that a physician had an *affirmative obligation* to adequately explain the pros and cons of a proposed treatment lest a patient's right to accept or reject potentially life-sustaining medical treatment be effectively denied because of the inadequacy of information upon which to reach this decision:

> In considering the obligation of a physician to disclose and explain to the patient in language as simple as necessary the nature of the ailment, the nature of the proposed treatment, the probability of success or of alternatives, and perhaps the risks of unfortunate results and unforeseen conditions within the body, we do not think the administration of such an obligation by imposing liability for malpractice if the treatment were administered without such explanation where explanation could reasonably be made, presents any insurmountable obstacles. [710]

Eleven years later, in *Cobbs v. Grant* [711] the *California* Supreme Court reached a similar result, reversing and remanding for new trial a medical malpractice claim by Cobbs against his doctor, and in so doing declaring evidence produced at trial legally insufficient to support the claim that the physician Grant was negligent in the performance of an operation, but requiring a new trial based on Cobb's alternative claim that Grant negligently failed to obtain Cobb's informed consent to the operation and providing a suggestion as to how the trial court might reconsider that issue:

> A medical doctor, being the expert, appreciates the risks inherent in the procedure he is prescribing, the risks of the decision not to undergo the treatment, and the probability to a successful outcome of the treatment. . .

Article III. [709] 154 Cal.App.2d 560 (1957) 317 P.2d 170.

[710] 180 Kansas 393 350 P. 2nd, 410.

[711] 104 Cal Rptr. 505, 502 P. 2nd. 1 (1972).

> The weighing of those risks against the individual fears and hopes of the patient is not [however] an expert skill. Such evaluation and decision is a non-medical judgment reserved to the patient alone. A patient should be denied the opportunity to weigh the risks only. . .where there is an emergency or the patient is a child or incompetent. [712]

That same year, a *federal* appeals court in *Canterbury v. Spence* [713] not only reaffirmed a patient's legal right of self determination re: medical treatment, but also predicated the authentic exercise of a decision to accept or reject a treatment on receiving adequate information as to possible outcomes and available options: "The root premise is the concept, fundamental in American jurisprudence, that "[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body. . ." [714] "True consent to what happens to one's self is the informed exercise of a choice, and that entails an opportunity to evaluate knowledgeably the options available and the risks attendant upon each. . . It is also clear that the consent, to be efficacious, must be free from imposition upon the patient." [715]

As important as these three court rulings were in confirming not only the right to reject medical treatment but the right to be given adequate information upon which to base that decision, these judicial cases involved patients still considered medically and legally capable of making a decision re: medical care entirely on their own, in circumstances in which the rejection of the life-sustaining medical treatment in question was not anticipated to result in virtually certain and almost immediate death. In contrast, the first genuine landmark case in the

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[712] *Ibid.*

[713] 464 F. 2nd 772 (D. C. circuit) cert denied 409 U.S. 1064 (1972) It is important to note that this decision was made by the U. S. Court of Appeals for the D. C. circuit, and appeal to the United States Supreme Court through what is termed a writ of *certiorari* was denied by the Supreme Court. Circuit Court rulings of one of thirteen circuits are not of binding authority for the other circuits, but are supposed to have what has been called persuasive authority.

[714]Here citing Schloendorff v. Society of New York

[715] *Ibid.*

advancement of the right of an individual, including an individual no longer considered medically and legally capable of making a decision re: medical care entirely on his/her own, in circumstances in which the rejection of the life-sustaining medical treatment in question could be anticipated to result in virtually certain and almost immediate death, to refuse *life-sustaining* medical treatment, occurred as a result of a misfortune that befell young Karen Quinlan.

Quinlan

In April of 1975, 21 year old Quinlan, for still undetermined reasons, stopped breathing for two fifteen minute periods after returning home from having a couple of cocktails at a local bar, went to sleep and never regained consciousness. She fell into what expert physicians who examined her described as a persistent vegetative state (PVS). She was placed on a mechanical breathing machine (ventilator) and given artificial nutrition and hydration (ANH). When it became clear to him that she had no chance of recovery, Quinlan's father petitioned a New Jersey Superior court to appoint him as her legal guardian with the authority to order that the ventilator be removed. His petition was opposed by her doctors, hospital, county prosecutors, the state of New Jersey, and the attorney appointed by the court to represent her legal interests in this proceeding. The Superior court denied her father's petition, and he appealed to the *New Jersey* Supreme Court. The New Jersey Supreme Court ruling in *In the Matter of Karen Quinlan* [716] not only elicited seemingly equal measures of approval and outrage from observes and pundits but, at minimum, awakened Americans to the ethical quandaries that arise in sustaining the lives of those patients possessing only minimal function/quality of life.

The New Jersey Supreme Court reversed the lower court and in so doing articulated a

[716] 355 A. 2nd 647 (N. J. 1976).

Constitutional basis for the right to reject a means of sustaining one's life that is worthy of quoting at length:

> We have no hesitancy in deciding. . .that no external compelling interest of the state could compel Karen to endure the unendurable, only to vegetate a few measurable months with no realistic possibility of returning to any semblance of cognitive or sapient life. . . Although the Constitution does not explicitly mention a right of privacy, [United States] Supreme Court decisions have recognized that a right of privacy exists and that certain areas of privacy are guaranteed under the Constitution. . . The Court in *Griswold* [*v. Connecticut*] found that the unwritten constitutional right of privacy to exist in the penumbra of specific guarantees in the Bill of Rights 'formed by emanations from those guarantees that help to give them life and substance.' Presumably this right is broad enough to encompass a patient's decision to decline medical treatment under certain circumstances, in much the same way as it is broad enough to encompass a woman's decision to terminate pregnancy under certain conditions. . . The claimed interest of the state in this case are essentially the preservation and sanctity of human life and defense of the right of the physician to administer medical treatment according to his best judgment. . . We think that the state's interest *contra* weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims"

Karen Quinlan's ventilator was disconnected, but ironically she lived another ten years sustained by tube feeding, the appropriateness of which was not challenged by her father. It is important to note that the New Jersey Supreme Court's decision, despite upholding a individual's right to reject a means of sustaining his/her life on constitutional grounds, seemed to leave open the possibility that in circumstances in which a patient had a better prognosis and/or the medical treatment in question was considered less invasive, the state's interest in preserving life might trump that patient's right to reject that specific medical treatment in those particular circumstances.

There can be little doubt that because of the *Quinlan* litigation many Americans, perhaps for the very first time, were made aware of certain end-of-life medical treatment realities. These

included the awareness that despite the loss of consciousness and/or only minimal function, modern medicine had the technological capability of sustaining one's life, perhaps almost indefinitely, and the further awareness that if one lost consciousness and/or was no longer considered medically and legally capable of making one's own medical decisions, one possible result was someone else making medical treatment decisions on one's behalf that might not necessarily correspond to one's own wishes in those particular circumstances. Accordingly, it is not in the least surprising that because of the *Quinlan* litigation, in Gregory Pence's view, American opinion changed:

> [I]nterest grew in creating for oneself, while still conscious and considered medically and legally capable of making one's own medical decisions, an *advance directive(s)* that either made one's future treatment wishes known (living will), or appointed someone in particular to make those decisions on one's behalf (durable power of attorney) if and when the necessity of making those decisions arose.[717]

Americans turned to their respective state legislatures for the legal authority to create advance directives, and although there was apparently great initial opposition, even after the *Quinlan* decision, from conservatives and various religious organizations, advocates of advance directives ultimately prevailed. The first such state advance directive legislation was the California Natural Death Act in 1976. [718] Slowly but surely other states followed, [719] but not without a struggle. [720] It is worth noting that this new legislation was probably a product of

[717] Gregory E. Pence. *Classic Cases in Medical Ethics*. (New York, NY: McGraw Hill Higher Education, 2007), 52.

[718] For a brief history of the California Death Act, see the Appendix (Number 12).

[719] Pence, Gregory Pence. "Classic Cases." 52. Gregory Pence reports that " [b]y 1990, 43 states had statutes recognizing some version of advance directives."

[720] Filene, Peter G. Filene, "In the Arms," 105. As Filene points out, from the initial introduction of what ultimately became the California Natural Death Act in 1974 to its final passage in 1976, "fifteen legislatures had

compromise between proponents and their opposition, and was accordingly by no means the affirmation of a *totally unfettered* right to refuse life-sustaining medical treatment regardless of attendant circumstances. [721] The California Natural Death Act, for example, although affirming the right to make life-sustaining medical treatment decisions in advance should one be no longer able to communicate their contemporaneous views, nevertheless required a second physician to certify that the patient, whose advance directive(s) was at issue, was *terminally* ill.

It should not escape attention that although the New Jersey Supreme Court in *Quinlan* permitted Karen Quinlan's father to make a decision on her behalf as her legal guardian, based at least ostensibly on what available evidence showed that *she would have chosen for herself were she able to do* so, it was apparently important to the Court to satisfy itself as to the reasonableness of such a decision under the circumstances, noting that a majority of person similarly situated would make the same decision:

> The only practical way to prevent destruction of [Karen's] right [to terminate her vegetative existence] is to permit the guardian and family of Karen to render their best judgment. . .as to *whether she would exercise it in these circumstances.* (my emphasis). If their conclusion is in the affirmative this decision should be accepted by a society the overwhelming majority of whose members would, we think, in similar circumstances, exercise such a choice in the same way for themselves or for those closest to them. [722]

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rejected living will bills."

[721] Norman Cantor. "*Advance Directives and the Pursuit of Death with Dignity.* (Bloomington, IN: Indiana University Press, 1993), 34. According to Norman Cantor, living-will statutes not only gave binding legal authority to prior instructions re: future medical treatment of a now incompetent individual, but reassured those professionals acquiescing to these wishes reassurance as to their criminal and civil liability: "In the many states where the judiciary had not addressed the issue, living-will statutes removed any legal cloud over the concept of future-oriented autonomy. The legislation clarified that a now incompetent patient's prior instructions could and should be given binding force. It also clarified that medical compliance with a living will would not be deemed assistance to suicide or any other impropriety. Indeed, health-care providers were assured by the legislature that good faith compliance with a living will would immunize providers from legal liability."

[722] In Re : the Matter of Karen Quinlan, 355 A. 2nd 647 (N. J. 1976) 41-2.

This seems to suggest that this particular Court was not yet ready to affirm the right of a patient, no longer considered medically and legally capable of making a decision, to reject life-sustaining medical treatment if that decision was other than what a reasonable person would decide in similar circumstances.

A year later, however, in *Superintendent of Belchertown State School v. Saikewicz*, [723] [724] the Massachusetts Supreme Judicial Court seemed willing to affirm the appropriateness of an incompetent patient's court appointed guardian's rejection of life-sustaining medical treatment made on that patient's behalf, based solely on what was determined that patient would have decided for himself were he/she still able to do so, without regard to what other similarly situated persons would decide:

> The [*Quinlan*] court's observation that most people in like circumstances would choose a natural death does not, we believe, detract or modify the central concern that the guardian's decision conform, to the extent possible, to the decision that would have been made by Karen Quinlan herself. . . Evidence that most people choose to accept the rigors of chemotherapy has no direct bearing on the likely choice that Joseph Saikewicz would have made. . . [T]he decision in cases such as this should be that which would be made by the incompetent person, if that person were competent, but taking into account the present and future incompetency of the individual. [725] [726]

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[723] 373 Mass 728, 370 N.E. 2nd 417 (1977).

[724] Saikewicz, a severely mentally retarded 67 year old resident of the Belchertown state school for the retarded, was diagnosed with incurable leukemia, and chemotherapy was assessed as most efficacious means of treatment. Jones, superintendant of the School, petitioned a Massachusetts probate court for the appointment of a guardian for Saikewicz with the intention of having the guardian reject, on Saikewicz's behalf, the chemotherapy. The judge of the probate court appointed a guardian and ultimately entered a judgment essentially in agreement with the guardian's recommendation and the testimony of two physicians, that the limited benefit, if any, that Saikewicz might receive from the chemotherapy was outweighed by accompanying pain, made especially egregious because of his inability to understand its purpose. Because of the nature of the case, the Massachusetts Supreme Judicial Court granted an expedited appeal.

[725]373 Mass 728, 370 N.E. 2nd 417 (1977). 749-53.

[726] It should not be overlooked that the Saikewicz court also affirmed the right of an incompetent person to reject life-sustaining medical treatment and in so doing suggested that although the State has an obligation to protect

The *Saikewicz* decision is thus of significance not only because of its insistence on sole reliance of what an incompetent person would have decided re: life-sustaining medical treatment if he/she retained the medical/legal capability of doing so, but, of particular importance to the specifics of this inquiry, because it also recognized that burdens of life-sustaining medical treatment can be especially egregious for the incompetent person because of his/her inability to understand its purpose and justification, and this inability to understand must be taken into account in the effort to discern what the incompetent would have decided had he/she knowledge of his/her present incompetency as well as the capability of making his/her own decision.

In 1978, one of the New Jersey superior courts, in *In re: Quackenbush* [727] attempted to apply the N. J. Supreme Court's ruling in *Quinlan* to its determination of whether Quackenbush, a 72 year old with gangrenous legs, could be prevented from rejecting a life-saving amputation. Although only a lower court ruling, the *Quackenbush* decision is of significance because Quackenbush was *not terminally ill or in a PVS*, and therefore might be expected to live a number of additional years if he consented to a surgery with a high probability of success. In what can be viewed as another small step toward the establishment of an unconditional right to reject life-sustaining medical treatment, the court held that state's interest in preserving life could not overcome Quackenbush's right to decide his own future:

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a patient's best interests, that obligation must yield to that patient's right of self-determination: "[W]e recognize a general right in all persons to refuse medical treatment in appropriate circumstances. The recognition of that right must extend to the case of an incompetent, as well as a competent patient, because the value of human dignity extends to both. This is not to deny that the State has a traditional power and responsibility, under the doctrine of *parens patriae* [Latin for parent of the nation], to care for and protect the 'best interests' of the incompetent person. . . . If a competent person faced with death may choose to decline treatment which not only will not cure the person but which substantially may increase suffering in exchange for a possible yet brief prolongation of life, it cannot be said that it is always in the 'best interests' of the ward to require submission to such treatment" (745-7)

[727] 156 N.J. Super. 282.

> The extent of the bodily invasion required to overcome the State's interest is not defined in *Quinlan.* Further, there is a suggestion of a need for a combination of significant bodily invasion *and* a dim prognosis before the individual's right of privacy overcomes the State's interest in preservation of life. . .[T]he extensive bodily invasion involved here — the amputation of both legs above the knee and possibly the amputation of both legs entirely — is sufficient to make the State's interest in the preservation of life give way to Robert Quackenbush's right of privacy to decide his own future *regardless of the absence of a dim prognosis* (my emphasis). [728] [729]

State and federal courts were not the only source of affirmation of the right to refuse medical treatment. According to George Annas and Leonard Glantz:

> [Although a] few states adopted the durable power of attorney strategy early . . . it was not until 1979 when the National Conference of Commissioners on Uniform State Laws included the 'Uniform Durable Power of Attorney Act' in the provisions of the Uniform Probate Code that large numbers of states began to adopt language identical or similar to that asset forth in Section 5-501 et. seq. of the Uniform Probate Code. [730]

In a court case indicative of what may well have been a widespread fear during this time period of both civil liability and criminal prosecution on the part of physicians and hospitals for acquiescence to the rejection of life-sustaining medical treatment, and uncertainty on the part of state attorneys as to whether withdrawing life-sustaining medical treatment was a criminal act, Abe Perlmutter, a totally competent 73 year old with Lou Gehrig's Disease, wanted, with his family's concurrence, the ventilator keeping him alive disconnected. Apparently fearing civil

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[728] *Ibid.*

[729] For other early judicial decisions dealing with patients who were neither terminally ill or in a PVS, see *Lane v. Candura* 376 N.E. 2nd 1232 (Mass App. 1978, *Bartling v. Superior Court*, 209 Cal Reporter 220 (Cal. App. 2 Dist 1984).

[730] George Annas and Leonard Glantz, "The Right of Elderly People to Refuse Life-sustaining Treatment." *Milbank Quarterly* 64, Supp. 2 (1986): 137.

liability, Perlmutter's physician and the hospital where he had been admitted both refused. In *Satz v. Perlmutter*, a Florida Court of Appeals [731] as well as the Florida Supreme Court [732] affirmed a lower court ruling enjoining Perlmutter's doctor and hospital from opposing the removal of his ventilator, and rejected the claim of the state of Florida that termination of life-sustaining treatment, whether by the patient, his/her family, or medical personnel was either murder or manslaughter under Florida law. In so ruling, the Florida Court of Appeals reached a significant conclusion:

> Abe Permutter should be allowed to make his choice to die with dignity, notwithstanding over a dozen legislative failures in this state to adopt suitable legislation in this field. It is all very convenient to insist on continuing Mr. Perlmutter's life so that there can be no question of foul play, no resulting civil liability, and no possible trespass on medical ethics. However, it is quite another matter to do so at the patient's sole expense and against his competent will. . . Such a course of conduct invades the patient's constitutional right of privacy, removes his freedom of choice and invades his right to self-determine. [733]

Just five years later, in 1983, whether the rejection of life-sustaining medical treatment was a criminal act remained unsettled in the state of California. California prosecutors brought murder charges against doctors for disconnecting a ventilator and removing the feeding tube for even though they did so at behest of the family of the patient, Clarence Hebert, who had lapsed into a PVS. In *Barber v. Superior Court*, [734] the Appellant court reversed a Superior court ruling that

[731] 362 So. 2d 160 (1978).

[732] 379 So. 2nd 359 (Fla. 1980).

[733] *Ibid.* 164.

[734] 195 California Reporter 478 (Ct. App. 1983.

had overturned a magistrate's ruling ordering the charges dismissed. [735],[736]

The New Jersey Supreme Court's 1985 ruling in *In re: Conroy,*[737],[738] is of significance for several reasons. First, the Court's ruling was the first from a state's highest court that permitted the withdrawal of a *feeding tube* from a patient lacking decisional capacity. Second, in affirming a patient's right to reject life-sustaining medical treatment the Court nonetheless held that this right was not absolute; identifying, discussing, yet finding inapplicable in the circumstances at hand, four different state interests in sustaining a patient's life that could perhaps, in other circumstances, arguably limit that right: preserving life, preventing suicide, safeguarding the integrity of the medical profession, and protecting innocent third parties [739] Finally, the Court identified and discussed three methods of legal justification for the rejection life-sustaining medical treatment on behalf of an incompetent patient. First, a purely *subjective* test, applicable *only* when *sufficient* evidence exists that the patient, if he/she was still medically and legally capable of making that decision, would reject the treatment, and considered legitimate *without* any reassurance that a reasonable person would have made the same choice under similar

[735] Hall, Bobinski, and Orentilicher, "Bioethics and Public Health Law," 246. According to Hall, Bobinski, and Orentilicher, "[no] physician has suffered civil or criminal liability for withdrawing life-sustaining treatment at the request of a patient or a patient's family."

[736]Barber v. Superior Court of Los Angeles County 147 Cal App 3rd 1006 (1983). The Barber court may have been one of the first to find no difference of significance between withdrawal and withholding of life-sustaining medical treatment: "Even though these life support devices are, to a degree, "self-propelled," each pulsation of the respirator or each drop of fluid introduced into the patient's body by intravenous feeding devices is comparable to a manually administered injection or item of medication. Hence "disconnecting" of the mechanical devices is comparable to withholding the manually administered injection or medication."

[737] 486 A. 2nd 1209 (N. J. 1985)

[738] Conroy's guardian petitioned a trial court for permission to discontinue her feeding tube. Her trial court appointed guardian opposed the petition. The trial court granted the petition but on appeal the intermediate court reversed. The New Jersey Supreme court reversed, affirming the trial courts initial ruling and the feeding tube was removed.

[739] The majority opinion in *Conroy* is of no little historic significance. The most important portion of the opinion is quoted in the Appendix (Number 13).

circumstances. [740] Second, a *limited objective* test:

> [Applicable when] there is *some* (my emphasis) trustworthy evidence that the patient would have refused the treatment, and the [surrogate] decsionmaker is satisfied that it is clear that the burdens of the patient's continued life with the treatment outweigh the benefits of that life for him . . . the patient is suffering, and will continue to suffer throughout the expected duration of his life, unavoidable pain, and that the net burdens of his prolonged life. . .markedly outweigh any physical pleasure, emotional enjoyment, or intellectual satisfaction that the patient may still be able to derive from life. [741]

Finally a *pure-objective* test, applicable when "the net burdens of the patient's life with the treatment. . .clearly and markedly outweigh the benefits that the patient derives from life. . . [and] [f]urther, the recurring, unavoidable, and severe pain of the patient's life with the treatment [are] such that the effect of administering the life-sustaining treatment would be inhumane." [742] Ironically, the Court found that evidence presented at the trial court was legally insufficient to satisfy any of the three tests. Claire Conroy had unfortunately died before the court's ruling, but had she lived, according to Hall, Bobinski, and Orentlicher, "the court would have instructed her guardian to find out more about her prior preferences and the benefits and burdens of her life before deciding whether any of the three standards for withdrawing treatment were satisfied." [743]

In 1983 Elizabeth Bouvia, a 25 year old legally competent woman with severe cerebral palsy sought a court order to stop her from being force fed through a feeding tube against her

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[740] In re: Conroy 486 A. 2nd. 1209 (N. J. 1985). It is worth noting that in articulating this subjective test, the *Conroy* court dismissed any litmus test reference to what a reasonable person might have decided under similar circumstances: "the question is not what a reasonable or average person would have chosen to do under the circumstances but what the particular patient would have done if able to choose for himself."

[741] In re: Conroy. 486 A. 2nd 1209 (N. J. 1985).

[742] *Ibid.*

[743] Hall, Bobinski, and Orentilicher, "Bioethics and Public Health Law," 259.

will. The court refused based, on what Judge Hews claimed was the probable effect on others of allowing her to starve including "the profound effect on the medical staff, nurses, and administration of the hospital" and the devastating effect on other. . . physically handicapped persons." [744] Bouvia eventually petitioned another court and was again denied. This time, however, she appealed that ruling, and in 1986 a California Court of Appeals, in *Bouvia v. Superior Court*, [745] reversed the lower court ruling, acknowledging her right to refuse life-sustaining medical treatment *despite* the awareness that she was *not* terminally ill:

> If her right to choose may not be exercised because there remains in her, in the opinion of the court, a physician or some committee, a certain arbitrary number of years, months , or days, her right will have lost its value and meaning. Who shall say what the minimum amount of available life must be? Does it matter if it be 15 or 20 years, 15 or 20 months, 15 or 20 days, if such life has been physically destroyed and all its quality, dignity, and purpose gone? As in all matters lines must be drawn at some point, somewhere, but that decision must ultimately belong to one whose life is at issue. [746]

That same year, the Massachusetts Supreme Judicial Court, in *Brophy v. New England Sinai Hospital, Inc.* affirmed a trial court's acceptance of evidence provided by Paul Brophy's wife that her husband, now in a PVS as a result of an aneurysm, and dependent for nutrition and hydration on a feeding tube, would not have wanted to be kept alive under these circumstances. A Massachusetts Appeals Court had reversed the lower court, holding that that state's interest in preserving life trumped Brophy's right to refuse life-sustaining medical treatment. The Massachusetts Supreme Judicial Court reversed the appellate court, ruling that Brophy's right to

[744] *Bouvia v. County of Riverside*, California Superior Court, December 16, 1983.

[745] 225 Cal. Reptr, 297 304-5 (Cal Ct. App. 1986).

[746] *Ibid.*

self determination overrode the state of Massachusetts's interest in maintaining his life.

It is important to note that in *Brophy* the Massachusetts's Supreme Judicial Court permitted the rejection of *tube feeding* on behalf of a patient without decisional capacity, Paul Brophy, who prior to the loss of competence had expressed a preference for rejecting under certain circumstances life-sustaining medical treatment, *without specifically mentioning tube-feeding* as a treatment that he, Brophy, would choose to reject. In 1988, however, a New York Court of Appeals, in *In re: O'Connor,* [747] reached a different result. Mary O'Connor had suffered a series of severe strokes and needed a feeding tube to sustain her life. Prior to the strokes she had indicated to her daughters that if ever she had no hope of recovery from an illness she did not want to receive life-sustaining medical treatment, but *never specifically mentioned tube feeding*. Her daughters sought to remove her feeding tube. The New York Court of Appeals ultimately refused their request because Mary O'Connor's previous rejection of life sustaining medical treatment was not specific to tube feeding and thus, in their view, the evidence presented was not *clear and convincing* of what her decision would have been had she been medically and legally capable of making her own decision.

A year earlier the New Jersey Supreme Judicial Court had also ruled that prior statements of a now incompetent patient re: the rejection of *tube feeding* failed to meet the *clear and convincing* evidence standard. *In re: Jobes,* [748] 31 year old Nancy Jobes had fallen into a PVS after unsuccessful surgery following a serious automobile accident, and subsequently required tube feeding to sustain her life. Her family sought to have her feeding tube removed and along with close friends offered testimony that if competent Nancy would have refused *tube feeding*.

[747] 71 N.Y. 2nd 517, 1988.

[748] 529 A.2nd 434, 437 (N.J. 1987).

Pointing to the insufficiency of the evidence, [749] the New Jersey Supreme Judicial Court ruled:

> [A]lthough there is some 'trustworthy' evidence that Mrs. Jobes, if competent, would want the [feeding tube] removed, it is not sufficiently 'clear and convincing' to satisfy the subjective test. Therefore, we must determine the guidelines and procedures under which life-sustaining medical treatment may be withdrawn from a patient like Mrs. Jobes when there is no clear and convincing proof of her attitude toward such treatment. [750]

Unlike, however, the result reached by the New York Court of Appeals, in *In re: O'Connor,* the New Jersey Supreme Judicial Court, subject to medical testimony that she would never recover to a "cognitive, sapient state," affirmed the lower court's rejection of tube feeding on Nancy Jobes's behalf, based on the limited objective standard it had articulated in *Conroy*. [751]

Up until 1990, with the exception of a *federal* appeals court decision in *Canterbury v. Spence*, which it may be recalled the U.S. Supreme Court refused to review on a writ of *certiorari*, there had been little or no indication from federal jurists as to how the federal courts might respond to a petition to affirm an individual's legal authority to reject a means of sustaining his/her life. Higher courts in Missouri, California, New Jersey, Kansas, Massachusetts, and Florida had generally affirmed, with limitations, that right, but these rulings

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[749] *In re: Jobes*, 529 A.2nd 434, 437 (N.J. 1987). "In *Conroy* and *Peter* we have described the type of evidence that can establish a person's medical preferences under the 'subjective test.' We have explained that the probative value of prior statement offered to prove a patient's inclination for or against medical treatment depends on their specificity, their 'remoteness, consistency, and thoughtfulness. . . [,] and the maturity of the person at the time of the statements…." *Conroy*, 486 A. 2nd at 1230. All of the statements about life-support that were attributed to Mrs. Jobes were remote, general, spontaneous, and made in casual circumstances. Indeed they track the examples of evidence we have explicitly characterized as unreliable"

[750] *Ibid*.

[751] *McKay v. Bergstedt*, 801 P. 2nd. 617 (Nev. 1990). Also worthy of note is the Nevada Supreme Court's 1990 ruling in *McKay v. Bergstedt*. Bergstedt was a 31 year old *totally competent* quadriplegic, ventilator dependent since a swimming accident at age 10. After 21 years he finally sought a court order to disconnect the ventilator. The Nevada Supreme Court found that the patient's right to treatment, even life-sustaining treatment, trumped the state of Nevada's interest in preserving life "attach[ing] great significance to the quality of Kenneth [Bergstedt's] life as he perceived it under the particular circumstances that were afflicting him"

were binding precedent only for the those living within these individual state's geographic boundaries, with only persuasive authority, at best, for the other jurisdictions. That all changed with the U. S. Supreme Court's ruling in *Cruzan v. Director, Missouri Department of Health*, [752] a second landmark decision in the affirmation of the legal authority under American law to reject a means of sustaining one's life.

Cruzan

Twenty -four year old Nancy Cruzan had been in a serious accident, thrown from her automobile and discovered laying face down in a ditch without detectable pulse or respiration. Although heartbeat and breathing were restored, it was estimated that she was deprived of oxygen for perhaps as long as 15 minutes. After being in a coma for three weeks her condition improved sufficiently to permit the oral ingestion of some nutrition, but she was ultimately given a feeding tube for nutrition and hydration. After it became clear that she would not emerge from a persistent vegetative state, her parents asked that her tube be removed and she be permitted to die, but the hospital where she had been admitted refused to do so without a court order. A Missouri trial court granted her parent's request for a court order, but on appeal the Missouri Supreme Court reversed the trial court. The Supreme Court granted a writ of *certiorari*, ultimately overturning the ruling of the Missouri Supreme Court.

The U. S. Supreme Court's ruling in *Cruzan* is of significance for six reasons: First, the United States Supreme Court is the ultimate authority on rights granted by the U. S. Constitution, and subject to amendment of the Constitution itself, the final word of the parameters of those rights. Unlike state Supreme Court rulings and even the decisions of lower federal courts, U. S.

[752] 497 U. S. 261 (1990).

Supreme Court rulings are the law of the land, applying to the entire country. Second, the Court held that an individual's right to reject medical treatment, even life-sustaining medical treatment, was rooted not only in the common law but in a liberty interest guaranteed by the fourteenth amendment of the United States Constitution.[753],[754]

Third, the Court assumed, for the purpose of this case, that among the liberties guaranteed by the Constitution is the liberty to refuse *all* forms of medical treatment, specifically including life-sustaining *nutrition and hydration*. [755] Fourth, the Court acknowledged that even if a constitutional right to liberty exists, that right is *not* absolute, but must be balanced by a state's interest in limiting under certain circumstances an individual's exercise of that right. [756] Fifth, the Court held that a state may, *if it so chooses*, limit the exercise of the right to reject life-sustaining medical treatment, including nutrition and hydration, made by a surrogate *on behalf of* a now *incompetent* person, by insisting on *clear and convincing* [757] evidence that the rejection conforms to the wishes expressed by the now incompetent person while he/she was still competent. [758]

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[753] *Cruzan v. Director, Missouri Department of Health* 497 U. S. 261 (1990). Chief Justice Rehnquist authored the majority opinion in Cruzan, significant parts of which are worth quoting at some length, as provided in the Appendix (Number 14).

[754] A closer look at the Fourteenth Amendment, and how it has been interpreted, is provided in the Appendix (Number 15).

[755] *Cruzan v. Director, Missouri Department of Health* 497 U. S. 261 (1990). Chief Justice Rehnquist, again for the majority: " [F]or purposes of this case, we assume that the United States Constitution would grant a competent person a constitutionally protected right to refuse lifesaving hydration and nutrition."

[756] *Cruzan v. Director, Missouri Department of Health* 497 U. S. 261 (1990). Chief Justice Rehnquist, again for the majority: "But determining that a person has a 'liberty interest' under the due process clause does not end the inquiry, 'whether respondent's constitutional rights have been violated must be determined by balancing his liberty interests against the state's interests.' *Youngberg v. Romero*, 457 U.S. 307, 321 (1982)."

(i) [757] Clear and convincing evidence and a preponderance of the evidence are both standards for evidence used in civil cases. A preponderance of the evidence is the applicable standard in most civil cases and simply means that a judge or jury believes it to be more likely than not. Clear and convincing evidence, on the other hand, is a much higher standard, and when applied simply means that more likely than not is insufficient, and to meet the evidentiary burden demanded by this standard, a judge or jury must have a firm belief or strong conviction of truth.

[758] Another especially significant portion of Justice Rehnquists' majority opinion is provided in the Appendix

Finally, Justice O'Connor, in a concurring opinion, seemed to suggest that the Constitution *might* require a state to accept the appointment of a *durable power of attorney* to protect an individual's liberty interest in refusing medical treatment, [759] and Justice Brennan, writing in dissent, commented that "the court did not specifically define what kind of evidence it would consider *clear and convincing* evidence, but in general discussion suggested that only a living will or equivalently formal directive from the patient when competent would meet this standard." [760]

Not unexpectedly, especially given that the issues brought before the Court were highly controversial, and this was the highest court in the land's first straightforward consideration of those issues, there was immediate reaction to *Cruzan*. First, there was at least some initial concern that the *Cruzan* majority, rather than simply affirming in unequivocal language that the Constitution granted an individual the right to reject life-sustaining medical treatment, had instead *assumed* the existence of that right. [761] Second, legal scholars and other knowledgeable observers were not only fully cognizant that the Fourteenth Amendment of the United States

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(Number 16).

[759] *Cruzan v. Director, Missouri Department of Health* 497 U. S. 261 (1990). Justice O'Connor, in a concurring opinion, wrote in part: I also write separately to emphasize that the Court does not today decide the issue whether a State must also give effect to the decisions of a surrogate decisionmaker. *See ante* at **497 U.S. 287**"]287, n. 12. In my view, such a duty may well be constitutionally required to protect the patient's liberty interest in refusing medical treatment. Few individuals provide explicit oral or written instructions regarding their intent to refuse medical treatment should they become incompetent.[n1] **[p290]** States which decline to consider any evidence other than such instructions may frequently fail to honor a patient's intent. Such failures might be avoided if the State considered an equally probative source of evidence: the patient's appointment of a proxy to make health care decisions on her behalf."

[760] *Cruzan v. Director, Missouri Department of Health* 497 U. S. 261 (1990). Neither Justice O'Connor's concurring opinion nor Justice Brennan's dissenting opinion are in the least legally binding as precedent on the Supreme Court in subsequent cases or even on lower federal courts or state courts. Nevertheless, they arguably have persuasive value because they are an indication of how a justice is thinking on a particular issue and can arguably, at least, give court observers and even the general public some idea of how the Court could rule if and when it hears subsequent cases re: similar subject matter.

[761] Hall, Bobinski, and Orentilicher, "Bioethics and Public Health Law," 235. According to Hall, Bobinski, and Orentilicher, although "the *Cruzan* majority only assumed for the purposes of the case that individuals enjoy a constitutional right to refuse life-sustaining treatment. . . [n]evertheless, the decision has been read by courts as establishing such a right."

Constitution protects individuals against action by *government entities and their employees* and not the actions of physicians in private practice or those employed by private hospitals, but were also aware, as pointed out by Hall, Bobinski, and Orentilicher, that Nancy Cruzan "was being treated in a state rehabilitation facility, so the Supreme Court did not have to worry whether the state action requirement of the Fourteenth Amendment was satisfied." [762] There was accordingly, some measure of uncertainty, at least initially, as to whether the *Cruzan* decision would prevent doctors and hospitals *unaffiliated with federal or state governments* from refusing to honor a patient's decision to reject life-sustaining medical treatment.

Third, and of perhaps greater significance, there was apparently widespread awareness that, post *Cruzan*, a state's Constitutionally valid requirement of clear and convincing evidence that the rejection of life-sustaining medical treatment made on behalf of an incompetent patient conformed to the wishes expressed by the now incompetent person while he/she was still competent, could conceivably defeat an individual's right to reject a means of sustaining his/her life, *unless* as intimated by Justices O'Connor and Brennan, an individual, while still competent, appointed a durable power of attorney and/or executed a living will. According to Peter Filene, the official response to this awareness was almost immediate:

> A month after the. . .*Cruzan* ruling. . .U. S. Senator John Danforth—from the Cruzan's home state of Missouri—took action. He introduced the Patient Self Determination Act. . .Congress passed the bill easily while various state legislatures amended their living will statutes to permit withdrawal of life-support (including food and water) from PVS patients and to authorize a durable power of attorney. [763] [764],

[762] Hall, Bobinski, and Orentilicher, "Bioethics and Public Health Law,"236.

[763] Peter Filene, "In the Arms," 35.

[764] Howard Brody, Laura D. Hermer, Larrry D. Scott, L. Lee Grumbles, Julie Kutac and Susan D. McGammon. Unpublished first rough draft of article that was later published as "Artificial Nutrtion and Hydration: The Evolution of Ethics, Evidence and Policy." *Journal of General Internal Medicine* 26, no. 9 (September 2011): 1053-8.

The obligations imposed by the Patient Self Determination Act, effective in December of 1991, were entirely procedural in nature. The PSDA requires hospitals, extended care facilities, such as nursing homes, and other health care organizations, such as hospices, *receiving Medicare or Medicare funding,* to inform individuals on admission/acceptance about applicable state law and the institution/organization's policy re: accepting/rejecting treatment, and to ask if the individual has executed an advance directive. If the individual has brought with him/her a copy of his/her advance directive it must be placed in his/her medical file. If no copy is readily available, some effort must be made to secure a copy. Admission/acceptance cannot be conditioned on whether a patient does or does not have an advance directive.

Of even greater importance, however, than the passage of the Patient Self Determination Act, or even the revision of state advance directive statutes, was the additional impetus that *Cruzan* likely gave individuals to execute living wills and/or forms designating a durable power of attorney for health care. Many Americans were no doubt appalled that nutrition and hydration could be legally withdrawn from a helpless woman who had never unequivocally said she would choose death over life if and when she fell into a permanent vegetative state. Countless other Americans, however, likely feared that *absent* an unequivocal declaration from them, in the form of a living will or durable power of attorney, that if and when they lapsed into a PVS they

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Brody, et. al. suggested that Cruzan Court's classification of ANH as simply another from of medical treatmen may have had an especially significant impact on the revision of state advance directive statutes: "Statutes enacted prior to 2005 generally fell into two categories. The law might distinguish between ANH and other forms of life-prolonging therapy such as ventilators, and require additional restrictions or safeguards for the refusal of ANH. Alternatively, the law might consider all forms of life-prolonging therapy together and give general procedures by which patients and/or surrogates might request or refuse any such treatment. Following the U.S. Supreme Court *Cruzan* decision in 1990, which incorporated the key assumption that ANH should be viewed as no different from any other form of therapy, there was some tendency for state advance directive laws to follow the lead of the Court and treat all treatment decisions as falling into a single category."

wanted all life sustaining-medical treatment withdrawn, that their families might be unable to agree as to the proper course of action, and even if in accord, might be prevented by state legislation from rejecting, on their loved one's behalf, life-sustaining treatment, including tube feeding.

Before examining state court decisions post *Cruzan*, it is important to note that *Cruzan* does *not* limit an individual with decisional capacity's right to refuse life-sustaining medical treatment. In addition, *Cruzan* does *not require* a state to insist on *clear and convincing* evidence that the rejection of life-sustaining medical treatment conforms to the wishes expressed by a now incompetent individual while he/she was still competent. It merely acknowledges that a state may do so, if it so chooses, without violating that individual's constitutionally guaranteed liberty interest in refusing life-sustaining medical treatment.

In *In re: Martin* [765] Michael Martin suffered brain damage in an automobile accident and, although neither in a PVS or considered terminally ill, required tube-feeding to sustain his life. Although he retained a very limited ability to communicate he was no longer considered medically or legally capable of making his own decision to reject tube-feeding. In seeking authority from a Michigan trial court to discontinue tube feeding his wife testified that Michael had told her repeatedly, and as recently as one month before his accident, that he did not want to be dependent on machines to stay alive. The Michigan Supreme Court ultimately ruled that *her testimony*, apparently contradicted by the testimony of friends and co-workers, was *not* clear *and convincing* evidence that if confronted with his present condition Michael Martin would have wanted tube feeding withheld/withdrawn, holding that prior *oral* statements are sufficiently clear and convincing evidence to justify withdrawal of treatment "only when the patient's prior

[765] 538 N. W. 2nd. 399, 411 (Michigan, 1991).

statements clearly illustrate a serious, well thought out, consistent decision to refuse treatment under these exact circumstances or circumstances highly similar to the current situation." [766]

Glucksberg

Seven years after *Cruzan,* the U. S. Supreme Court again addressed an individual's right to end-of-life self-determination, in *Washington v. Glucksberg.* [767] Dr. Glucksberg and three other Washington physicians claimed that they were willing to assist suffering, terminally ill patients with suicide but were *unconstitutionally* prohibited from doing so by the state of Washington's legislative prohibition against knowingly causing or aiding another to attempt suicide. A federal district court struck down the Washington law, ruling that it unconstitutionally placed an undue burden on the constitutionally protected exercise of a terminally ill, yet still competent, adult's liberty interest in rejecting a means of sustaining his/her own life. A three judge *panel* of the U. S. 9th Circuit Court of Appeals, reversed the District Court, but the full 9th circuit reversed its panel. The U. S. Supreme Court granted a writ of *certiorari*.

In a majority opinion written by Chief Justice Rehnquist, the Court not only reaffirmed its assumption in *Cruzan* that the Fourteenth amendment of the U. S. Constitution protects an individual's right to reject life-sustaining medical treatment, [768] but distinguished a constitutionally protected liberty interest in refusing life-sustaining medical treatment from a right to assistance in committing suicide. The Court held that the latter right was not among

[766] *Ibid.*

[767] 521 U. S. 702 (1997).

[768] Washington v. Glucksberg, 521 U. S. 702 (1997). Chief Justice Rehnquist, for the majority: "We have also assumed, and strongly suggested, that the due process clause protects the traditional right to refuse unwanted lifesaving medical treatment. *Cruzan*, 497 U.S. at 278-9. . . Given the common-law rule that forced medication was a battery, and the long tradition of protecting the decision to refuse unwanted medical treatment, our assumption [in *Cruzan*] was entirely consistent with the nation's history and constitutional traditions."

those fundamental liberty interests guaranteed by the Constitution and protected by the Fourteenth amendment, not only because of the nation's historic repugnance for suicide, [769] and the requirement that in order to be deemed fundamental a liberty interest must be so ingrained in our country's history, traditions, and understanding of liberty that to deny its existence would place both liberty and justice at risk, [770] but also because of the nation's highest court historic unwillingness to further extend the range of rights protected by the Fourteenth amendment and in so doing preempt public debate and legislative action. [771] Finally, the *Glucksberg* Court held that the state of Washington's legislation banning assisted suicide was a constitutionally permissible exercise of a state's fundamental governmental interest. [772]

Vacco

During the same term in which the Supreme Court issued the Glucksberg opinion, the Court also decided Vacco v. Quill. [773] It is a crime in the state of New York to commit suicide or to assist someone else in their suicide, but it is not a crime to refuse life-sustaining medical

[769] The Glucksberg majority's understanding of the nation's historic repugnance for suicide is provided in the Appendix (Number 17).

[770] The Glucksberg's majority's understanding of the relationship between substantive due process and an individual's liberty interest is provided in the Appendix (Number 18).

[771] Washington v. Glucksberg, 521 U. S. 702 (1997). Chief Justice Rehnquist, for the majority: "We 'have always been reluctant to expand the concept of substantive due process because guideposts for responsible decision-making in this uncharted area are scarce and open-ended.' *Collins*, 503 U.S. at 125. By extending constitutional protection to an asserted right or liberty interest, we, to a great extent, place the matter outside the arena of public debate and legislative action. "

[772] Washington v. Glucksberg, 521 U. S. 702 (1997). Chief Justice Rehnquist, for the majority: The Constitution also requires, however, that Washington's assisted-suicide ban be rationally related to legitimate government interests. This requirement is unquestionably met here. . . First, Washington has an 'unqualified interest in protecting human life.'. . Relatedly, all admit that suicide is a serious public health problem, especially among persons in vulnerable communities. . . Finally, the state may fear that permitting assisted suicide will start it down the path to voluntary and perhaps even involuntary euthanasia."

[773] 521 U.S. 793 (1997).

treatment. Timothy Quill and two other doctors practicing in the state of New York along with three gravely ill patients claimed that the state of New York, in prohibiting doctors from prescribing lethal medication for mentally competent patients suffering in great pain who wish to take their own lives, deprived the patients of the *equal protection* of the law guaranteed by the Fourteen Amendment of the U. S. Constitution. A federal District Court denied the claim, but the U. S. Second Circuit Court of Appeals reversed the District Court. The U. S. Supreme Court reversed the Second Circuit Court ruling and in so doing again distinguished, on the basis of causation and intent, the refusal of life-sustaining medical treatment from receiving assistance in committing suicide. In essence, the *Vacco* Court reasoned that whereas an individual committing suicide with the assistance of a lethal injection administered by a physician, *intends* to cause his/her own death by means of the injection, an individual rejecting a means of sustaining his/her life *may* do so not to end his/her life but to avoid the harm(s)/burden(s) imposed by the treatment, and if his/her death does result it is not caused by the rejection of the medical treatment but by an underlying fatal pathology. [774] The *Vacco* ruling is also of significance because of the concurring opinion written by Justice Sandra O'Connor that at least arguably provided some measure of federal judicial support [775] for the legal authority to utilize methods of pain control, including palliative sedation, to alleviate a patient's suffering even though their use might unintentionally cause unconsciousness and even death.[776],[777]

[774] The *Vacco* court's affirmation of a distinction between assisting suicide and withdrawing/withholding life-sustaining treatment is provided in the Appendix (Number 19).

[775] Once again, as was true with Justice O'Connor's concurring opinion in *Cruzan*, Justice O'Connor's concurring opinion here in Vacco has no binding precedential value. It does, however, give, at the very least, an indication of how one and perhaps even more justices are thinking re: a particular issue.

[776] *Vacco v. Quill* 521 U.S. 793 (1997). Justice O'Connor, concurring opinion:The parties and *amici* [friend of the court] agree that in these states [New York and Washington] a patient who is suffering from a terminal illness and who is experiencing great pain has no legal barrier to obtaining medication, from qualified physicians, to alleviate suffering, even to the point of causing unconsciousness and hastening death."

As noted above, there was undoubtedly some measure of uncertainty as to whether the *Cruzan* decision would prevent doctors and hospitals *unaffiliated with federal or state governments* from refusing to honor a patient's decision to reject life-sustaining medical treatment. Whatever anxiety that existed immediately following the *Cruzan* decision was hardly dispelled in *Klaxan v. Crozer-Chester Medical Center*, [778] heard in a federal district court in the eastern district of Pennsylvania. Dr Klavan had a living will that rejected extraordinary methods of preserving his life. He was resuscitated in the emergency room of Crozer-Chester Medical Center, and the hospital was subsequently made aware of the provisions of his living will. Nevertheless, he was again resuscitated. The Federal district court rejected a claim filed on his behalf that Crozer-Chester Medical Center was a state actor under the Fourteenth amendment of the U. S. Constitution, and was accordingly prohibited under *Cruzan* from denying Dr. Klaxan's constitutionally guaranteed liberty interest in rejecting life-sustaining medical treatment. The Klaxan court ruled that because Crozer-Chester Medical Center was a private hospital, necessary state action was lacking.

In 2001, the California Supreme Court, in *Wendland v. Wendland* [779] applied *Cruzan's* clear and convincing evidentiary standard to a case involving the rejection of tube feeding made on behalf of an incompetent patient. Wendland, who had no advance directive of any kind, suffered brain damage and paralysis as a result of an auto accident, requiring tube feeding to sustain his life, but was neither terminally ill nor in a PVS. Family members were split as to their respective understanding of his expressed wishes before his accident re: life-sustaining

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[777] 2 footnotes from Justice Rehnquists's majority opinion that at least arguably provided persuasive judicial support for palliative sedation are provided in the Appendix (Number 20).

[778] 60 F. Supp. 2nd. 436 (E. D. Pa. 1999).

[779] 28 P. 3rd 151 (CA 2001).

medical treatment. Two California lower courts refused to allow his feeding-tube to be withdrawn because they each determined that there was neither clear nor convincing evidence that he would have wanted the feeding tube removed, nor could the removal of the feeding tube be assessed as being in his objective best interests. The California Supreme Court affirmed the lower courts, holding that *less* than clear and convincing evidence *could be sufficient* to support a finding that a now incompetent patient had, while still competent, expressed a determination to refuse life-sustaining medical treatment, if and when he was ever severely debilitated, but only if that patient was terminally ill or had lapsed into a PVS. Wendland, on the other hand, was neither terminally ill or in a PVS, and an assessment could be made that the tube-feeding was in his objective best interests.

There can be little doubt that the very public controversies surrounding the long ordeals of the Quinlan and Cruzan families were both extremely painful episodes in late twentieth-century American domestic history. Although it must be conceded that public consciousness of end-of-life moral and legal issues was undoubtedly raised, the average American had seen and heard enough public name-calling, talk-radio and television recriminations, candlelight prayer vigils, and man-in-the-street expressions of overall angst, to last a lifetime. It seemed inconceivable that once the reaction to the Supreme Court's decision in *Cruzan* had at last died down that the country would have to endure all of this all over again, but this is precisely what happened as a result of another protracted and very public family ordeal, this time suffered by the family of Teri Schindler Schiavo.

Schiavo

In February of 1990 Teri Schiavo suffered a cardiac arrest, perhaps as a result of

complications from an eating disorder and, because of the prolonged loss of oxygen to her brain, fell into a deep coma. Tube-feeding was used to sustain her life. Within roughly two months she was diagnosed as being in a persistent vegetative state (PVS). In 1998, after eight years in a PVS and dependent for life on artificial nutrition and hydration provided through a feeding tube, her husband, Michael Schiavo, petitioned a Florida trial court to order her feeding tube withdrawn. At this point there was probably very little public attention given to the trial court preceding, until it was discovered that Teri's parents, Bob and Mary Schindler, opposed Michael Schiavo's petition.

In contrast to Joe and Julia Quinlan, and Lester and Joyce Cruzan, who had each sought through the courts the legal right to reject, on their unmarried daughter's behalf, medical treatment that was sustaining her life, Bob and Mary Schindler emphatically and emotionally not only insisted that their daughter not, in their view, be starved to death, but be returned to their loving care. Adding fuel to the fire of concern that a grave injustice was taking place arose when doubts began to be expressed as to whether Michael Schiavo was acting in Teri's interests or in his own. Although Michael had steadfastly maintained that he was only following what he knew to be Teri's expressed wishes re: life-sustaining medical treatment if and when she was totally incapacitated with no hope of recovery, doubts of his sincerity persisted and, if anything, grew as more of his private life, post Teri's incapacity, was revealed. Five years after Terri was diagnosed as being in a PVS, Michael had moved in with another woman and fathered two children. Allegations also surfaced about how Michael had spent a 1 million dollar medical malpractice settlement that, it was claimed, was totally expended at the time he filed the petition with the trial court. Here then, at least from the perspective of many of those who opposed the removal of Terri Schiavo's feeding tube, were a tearful and distraught mother and father asking

only for the opportunity to take their "little girl" home and care for her at their own expense until her natural death, over the objections of someone they considered to be only her *former* husband who had abandoned her for another woman and now wanted to starve her to death so he could get on with his own life.

Two Florida lower courts ruled in favor of Michael Schiavo finding clear and convincing evidence that were Teri able to decide for herself she would reject tube feeding. The Florida Supreme Court declined to review the lower court rulings. Bob and Mary Schindler again petitioned a court to override the previous court rulings. This court also refused and the Florida Supreme Court again declined to review. In 2003 the Florida legislature passed special legislation authorizing Florida Governor Jeb Bush to order the feeding tube reinserted. In 2004 the Florida Supreme Court ruled that legislation unconstitutional. [780] The U.S. Supreme Court refused to grant a writ of *certiorari*. The Republican majority in the U. S. Congress passed a law authorizing federal court jurisdiction in the matter. A Florida District Court left undisturbed the previous court rulings authorizing the removal of her feeding tube, which was removed in March of 2005. Terri Shiavo died thirteen days later.

Among the most unfortunate aspects of the Schaivo affair were the broad dissemination and generally uncritical acceptance of misinformation concerning Teri Schiavo's physical and mental condition and manner of death, the unseemly politicizing of the legal process, and the way in which the largely unfounded fear that other "defenseless incompetents who wanted to live would be cruelly starved to death" may have influenced state legislators to revise advance directive legislation to prevent such "barbaric practices" from occurring again.

[780] Bush v. Schiavo. WL 2109983 (Florida 2004).

Thanks in large part to statements attributed to her parents and what can only be described as general public ignorance about the physiology of terminal dehydration, the public was, for the most part, badly misinformed about Teri Schiavo's physical and mental condition and manner of death. There can be no question that Bob and Mary Schindler loved their daughter very much, and they no doubt were completely truthful when they allegedly claimed that she not only had some awareness of her environment and especially their physical presence but was able to communicate with them on some minimal level. They were apparently so certain that they attempted to prove their claims with video evidence.

The widespread perception among the general public, reinforced by photographs from the concentration camps of the Holocuast, is that deprived of food and water, humans slowly and painfully starve to death. Accordingly, many Americans probably concluded that Teri starved to death, and likely suffered as she died. John R. Thogmartin, a Florida pathologist, conducted an autopsy soon after Teri Schiavo's death, and Stephen J. Nelson, a neuropathologist in Winter Haven, reviewed the findings. The autopsy results showed that she had suffered irreversible brain damage, that her brain was scarred, discolored, shriveled to half its size, and had suffered damage to all of its regions, including the one responsible for vision. Her blood chemistry showed signs of severe dehydration and she had definitely not "starved to death." [781] The autopsy findings are clearly inconsistent with the Schindler's perception that Teri was aware of her environment, and the contention that she starved to death. The autopsy indicated that she died from the effects of terminal dehydration, which as discussed in some detail in the previous chapter, does not, especially at the end-of-life, necessarily involve significant personal

[781] Actual autopsy: http://euthanasia.procon.org/sourcefiles/SchiavoAutopsy.pdf. See also http:www.washingtonpost.com/wp-dyn/content/article/2005/06/15…

discomfort. Even more reassuring to those who feared that Teri suffered as she died; the perception of pain was not possible given the extent of her brain damage.

Whether certain politicians acted out of genuine conviction and compassion or politicized the ordeal of the Schiavo/Schindler family for political gain is an issue that can easily be colored by where one falls on the national political spectrum. Nevertheless, some of the public statements made by then House Majority Leader Tom Delay (R-Texas), seem to be at considerable variance with the autopsy results and how medical science understands a persistent vegetative state:

> A death row inmate has more of a process to go through than Teri Schiavo does." "All we are doing in Congress is giving Terri Schiavo an opportunity to come to the federal courts and review what this judge in Florida has been doing, and he's been trying to kill Teri for 4 1/2 years." [782] "[Schiavo] talks and she laughs and she expresses happiness and discomfort" [She is] [u]nable to speak because "she has not been afforded any speech therapy, none. [783]

That a strong majority of Americans had suspicions about the motivation of various politicians was borne out by the results of a CBS news poll: "While both Republicans and Democrats claim that they acted purely out of principle, 74 percent of Americans believe the president and the Congress were motivated by politics rather than concern for Schaivo." [784]

Finally, the largely unfounded fear that other "defenseless incompetents who wanted to live would be cruelly starved to death" may have influenced state legislators to revise advance

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[782] http://abcnews.go.com/GMA/Schiavo/story?id=595905&page=2

[783] http:www.washingtonpost.com/wp-dyn/content/article/2005/06/15…

[784] http://www.cbsnews.com/stories/2005/03/25/opinion/lynch/main68...

directive legislation in an effort to prevent such "barbaric practices" from occurring again. Unfortunately, as noted by Howard Brody, et. al., there was an overreaction:

> Proposals for legal action to restrict the rights of patients and surrogates to withdraw or withhold ANH. . .went well beyond the population afflicted by the vegetative state. . . [including]. . .[a] new legal method of restricting the rights of a patient or surrogate to refuse ANH. . .so-called "conscience" legislation, permitting health care providers to refuse to provide any services to which they have moral or religious objections.[785]

Although the legal right of a physician to decline to treat a patient, while insuring that alternate but comparable professional treatment was at hand, was well established, "conscience legislation" made refusal of life-sustaining medical treatment more difficult for individuals who had established a relationship with a doctor unwilling to acquiesce to their decision.

Remaining Uncertainty

Although the United States Supreme Court has clearly affirmed an individual's legal right to reject life-sustaining medical treatment, there is nevertheless some measure of uncertainty, even post *Shiavo,* regarding the source(s) of that right and the circumstances in which it can be exercised. According to Hall, Bobinski, and Orentlicher there has been a noticeable judicial shift:

> In the early cases that recognized a right to refuse treatment, courts rested that right on two individual interests: the common law right to be free of nonconsensual bodily invasion (i.e. the right to informed consent) and the

[785] Brody, Hermer, Scott, Grumbles, Kutac and McGammon. Unpublished first draft of article that was later published as "Artificial Nutrtion and Hydration: The Evolution of Ethics, Evidence and Policy." *Journal of General Internal Medicine* 26, no. 9 (September, 2011): 1053-8. Brody, et. al. suggested that although "[t]hese are primarily aimed at providing reproductive services such as abortion and emergency contraception[,]. . . many laws are so broadly written that they would include end-of-life care decisions, and would allow a provider to refuse to implement a treatment refusal as well as to refuse to provide a treatment that is requested."

> substantive [Constitutional] right to make decisions of critical importance to one's destiny (i.e. the right to privacy). As the U. S. Supreme Court began to narrow the reach of the right of privacy, state courts relied more heavily on common law principles of informed consent to find a right to refuse treatment. [786]

The *Cruzan* court, although acknowledging the common law right to reject a nonconsensual touching, affirmed the right to reject life-sustaining medical treatment based primarily on a liberty interest guaranteed by the Fourteenth amendment of the United States Constitution. Post *Cruzan*, as noted by Hall, Bobinski, and Orentlicher, "[courts began to again rely] on substantive due process rights, although now framed as a liberty interest rather than a privacy right." [787]

Three remaining issues raise at least a measure of uncertainty. First, if the source of the right to reject life-sustaining medical treatment is a liberty interest constitutionally guaranteed by the Fourteenth amendment, the question arises as to whether doctors in private practice or private hospitals are *constitutionally* barred from refusing to honor an individual's decision to reject life-sustaining medical treatment. The U. S. Constitution was written to protect individuals from their governments, not only federal, but state and local as well. Accordingly, courts have applied the Constitution only to *government* infringements of constitutionally guaranteed rights, insisting on evidence of what has been termed *state action* before providing a legal remedy. Patrick Webster claims that "[t]ime has shown that the majority of attempts to attempt to invoke the rights recognized in *Cruzan* are tossed back to state courts, since rarely is the defendant in such a case deemed to be a 'state actor' for Fourteenth Amendment purposes." [788] Obviously, direct action by government officials and government employees is state action, but despite Webster's

[786] Hall, Bobinski, and Orentilicher, "Bioethics and Public Health Law," 235.

[787] *Ibid*.

[788] Patrick Webster. "Enforcement Problems Arising From Conflicting Views of Living Wills in the Legal, Medical, and Patient Communities." *University of Pittsburg Law Review* 62, no. 4 (Summer 2001): 794.

claim, some courts have apparently been comfortable finding state action when private individuals, organizations, and business entities have a financial relationship with government through contract, tax subsidy, and the like. In addition, Hall, Bobinski, and Orentelicher et. al. suggest that "[m]ost likely, state action has not been viewed as an issue in treatment withdrawal cases both because state common law grounds are available to justify withdrawal and because state courts recognize that the state is doing more than refusing to intervene but is also using the threat of criminal liability to effectively force the physician or hospital to treat." [789]

Nevertheless, it is by no means certain that a court will find state action when a physician in private practice or a private hospital has no financial relationship of any kind with government. It must also be noted, as pointed out above, that certain states have enacted "conscience" legislation that permits health care providers to severe the professional relationship with a patient whose preferences re: the acceptance or rejection of medical treatment the provider finds objectionable on moral or religious grounds.

Second, if the source of the right to reject life-sustaining medical treatment is the common law, there is uncertainty as to whether this common law right is subject to limitation by a state, and if so, the extent to which the right can be limited either procedurally or substantively. Because a common right is independent of the U. S. Constitution, there is no need to show state action, and a doctor in private practice or a private hospital are both thus prohibited by common law from refusing to honor an individual's decision to reject life-sustaining medical treatment. There is at least some uncertainty, however, as to whether a court would accept that line of reasoning.

Third, as pointed out by Hall, Bobinski, and Orentlicher, the right of a patient possessing, from a legal standpoint, decisional capacity to reject life-sustaining medical treatment appears to

[789] Hall, Bobinski, and Orentilicher, "Bioethics and Public Health Law," 236.

have grown in overall judicial acceptance, so much so that it can be assessed, at least arguably, as virtually unlimited:

> As case law has developed, courts have seemingly abandoned any effort to balance the individual's right to refuse treatment with the state's interest in preserving life, [790] almost without exception permitting *competent* [my emphasis] patients to refuse life-sustaining treatment. In the early cases . . . the courts had suggested that the right to refuse life-sustaining treatment was a right that existed when life could be prolonged only a short time, with a poor quality of life and at considerable cost to the patient (with cost being measured in terms of pain, other suffering, and economic burden). However, recent cases have not so limited the right. [791]

This apparently includes a decision to refuse life-sustaining treatment by women who have young children [792] or who are pregnant. [793] Especially worthy of note is the apparent willingness to recognize an individual with decisional capacity's right to reject life-sustaining medical treatment for reasons of his/her own, including his/her assessment of functional incapacity/quality of life. [794]

Nevertheless, it is also quite clear that *Cruzan* strongly suggested that states may limit the exercise of the constitutionally guaranteed liberty interest in rejecting life-sustaining medical treatment made on behalf of a now *incompetent* (lacking, from a legal standpoint, decisional

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[791] Hall, Bobinski, and Orentilicher, "Bioethics and Public Health Law," 239.

[792] Hall, Bobinski, and Orentilicher, "Bioethics and Public Health Law," 24. Bobinski, and Orentilicher report that "[i]n more recent cases, courts have generally recognized a patient's right to refuse life-sustaining treatment even though the patient has young children."

[793] Kelly, David F. Kelly, *Contemporary Catholic*, 258. According to David Kelly, [s]ome courts and some state laws have made an exception for a pregnant woman, but this issue is very controversial, and courts often allow the woman and the fetus to die if the woman refuses treatment."

[794] Hall, Bobinski, and Orentilicher, "Bioethics and Public Health Law," 24. In Hall, Bobinski, and Orentilicher's opinion, the "nearly unlimited recognition of a right to refuse life-sustaining treatment means that the courts have not distinguished between patients who refuse treatment because the treatment itself is not desired and patients who refuse treatment because their life with treatment has become undesirable."

capacity) individual, to only those circumstances in which *clear and convincing* evidence is adduced that the refusal of the life-sustaining medical treatment represents a decision that the individual would have made on his/her own behalf if aware of his/her present diagnosis/prognosis/treatment options and still competent to make a decision on his/her own behalf. What remains uncertain is whether a state can constitutionally limit the exercise of the right to refuse life-sustaining medical treatment, especially ANH, made on behalf of an individual without decisional capacity, to *only* those instances where the individual is assessed as being either terminally ill or in a persistent vegetative state. Stated differently, a measure of uncertainty persists as to whether a state can prevent the refusal of life-sustaining medical treatment made on behalf of an individual without decisional capacity when that individual has *not* been diagnosed as being terminally ill, or in a PVS, and is instead in the end stage of a disease, such as dementia, but where life expectancy cannot be accurately quantified.

All fifty states have advance directive statutes authorizing either a living will or the designation of an appointee given a durable power of attorney, with almost all states having both. It is important to recall from the above discussion re: judicial decisions that the common law, state constitutions, and the U. S. Constitution, are all potential sources of an individual's legal authority to reject life-sustaining medical treatment. State advance directive statutes are nevertheless of significance, however, because they describe at least *one* potential method of exercising the right to reject life-sustaining medical treatment, and according to Alan Meisel, confer immunity "for individual and institutional health care [professionals] who rely on advance directives. . . [if they observe the] procedures which must be followed if statutory immunity is to be available." [795]

[795] Alan Meisel. "Barriers to Forgoing Nutrition and Hydration in Nursing Homes." *American Journal of Law and Medicine* 21, no. 4 (1995): 356.

In Carol Sieger, James Arnold, and Judith Ahronheim's experience, "advance directive legislation is often mistakenly perceived as establishing the only permissible mechanism for determining decision-making standards and procedures." [796],[797] This may," in their view, "be because of the seeming straightforwardness of the statutes and the promise of provider immunity. . . [but] most advance directive statutes, and decisions by some courts, clarify that these statutory provisions are cumulative with existing law and should not preempt common law rights and prerogatives." [798],[799] Sieger, Arnold, and Ahronheim's 2005 article in the *Journal of the American Geriatrics Society* [800] revealed that although a number of states had advance directive legislation that, as of December 31, 2000, had imposed *procedural* limitations on an individual's right to refuse artificial nutrition and hydration once decisional capacity/competency had been lost, five different states had advance directive legislation that *substantively* limited that right. Procedural limitations can presumably be overcome with appropriate advance planning, but substantive limitations are obviously another matter altogether. Under the Arizona [801] and

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[796] Carol E. Sieger, Jason F. Arnold, and Judith C. Ahronheim. "Refusing Artificial Nutrition and Hydration: Does Statutory Law Send the Wrong Message" *Journal of the American Geriatrics Society* 50, no. 3 (April 2002): 547.

[797] Kelly, David F., *Contemporary Catholic*, 174. David Kelly seems to suggest that advance directive legislation should make clear that it has a cumulative effect, authorizing a specific but by no means exclusive method of rejecting, *in advance*, a means of sustaining one's life, *in addition to*, methods available from the common law: "[I]f the state law is clear that the legislation is cumulative [only an addition to the rights people already have], then people can still make their wishes know in other ways as well, by telling their families or writing their wishes down in another document."

[798] Sieger, Arnold, and Ahronheim, "Refusing Artificial Nutrition and Hydration," 547.

[799] Here citing Va. Code 54.1-2992; Ga. Code Ann 31-32-11 (a); DeGrella v. Elston, 858 S. W. 2d 698, 706-07 (Ky.-1993); In re: Gardener, 534 A. 2d. 947, 952 (Me. 1987).

[800] Sieger, Arnold, and Ahronheim, "Refusing Artificial Nutrition and Hydration," 547.

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[801]Living Wills and Health Care Directives Act, Arizona Revised Statutes Ann, 36-3201-36-3262

Missouri [802]statutes, refusal of ANH was simply not permitted. Kentucky [803] and Ohio statutes [804] insisted that a patient be terminally ill or in a PVS before ANH could be refused. Under the Illinois statute [805] refusal of ANH was not permitted if death would result from starvation or dehydration. Four months after Terri Schiavo's death, Idaho enacted a statute [806] that mandated certain comfort care measures, including "reasonable efforts to *offer food and fluids orally* (my emphasis)," [807] for "patient[s] for whom artificial life-sustaining procedures or artificially administered nutrition and hydration are withheld or withdrawn." [808]

Any state statute that *substantively* limits an individual's right to refuse life-sustaining medical treatment, including but not limited to ANH, would appear to not only be constitutionally invalid, but inappropriately deny a right established in common law. As discussed above, *Cruzan* permits but does not require states to limit the exercise of the right to reject life-sustaining medical treatment, including nutrition and hydration, made by a now *incompetent* person, by insisting on *clear and convincing* evidence that the rejection conforms to the wishes expressed by the now incompetent person while he/she was still competent.

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[802] Missouri Life Support Declarations Act, Mo. Ann. Stat. 459.010 to 459.055
Durable Power of Attorney for Health Care, Mo. Ann. Stat. 404.800 to 404.872

[803]Living Will Directives Act. Ky. Rev. Stat Ann. 311.621 to 311.644 "ANH may be withheld from a patient only where (1) death is imminent within days; (2) patient is in PVS and has specifically authorized withdrawal or refusal of ANH under that circumstance; (3) ANH can't be physically assimilated by patient; or (4) where the burdens of ANH for the patient outweigh the benefits."

[804] Modified Uniform Rights of the Terminally Ill Act. Ohio Rev. Code Ann. 2133.01 to 2133.15
Power of Attorney for Health Care Act Ohio Rev. Code Ann. 1337.11 to 1337.17

[805] Living Wills Act,. Ill. Comp. Stat. Ann. Ch. 755 35/1 to 35/10
Powers of Attorney for Health Care Act, Ill. Comp. Stat. Ann. Ch. 755 45/4-1 to 45/4-12
Health Care Surrogate Act Ill. Comp. Stat. Ann. Ch. 755 40/1 to 40/55.

[806]Natural Death Act Idaho Code 39-4501 to 39-4509

[807] Natural Death Act Idaho Code 39-4502 (5)(b)

[808] Natural Death Act Idaho Code 39-4514 (3)

Accordingly, some states apply a far less demanding preponderance of evidence standard rather than clear and convincing evidence standard. Those states that have written legislation applying the clear and convincing evidence standard would seem to unquestionably be within U. S. Constitutional limits. Conversely, however, state legislation that *substantively* restricts that individual's right to reject life-sustaining medical treatment, especially ANH, would appear to, at least arguably, exceed what the U. S. Supreme Court in *Cruzan, Glucksberg,* and *Vacco* expressly permitted a state to do in protecting state interest in preserving life, preventing suicide, safeguarding the integrity of the medical profession, and/or protecting innocent third parties. [809]

In addition, the right to refuse nonconsensual touching is well established in the common law as is, according to Norman Cantor, "broad common law acceptance of prospective autonomy," [810] which presumably means that there was no restriction at common law that limited prospective autonomy to *only* the terminally ill. Nancy M. P. King implies that it is within a state legislature's authority to limit common law rights, but "in order to narrow the common law in this area, where it is deeply rooted and of long standing, states must be explicit

[809] The *Vacco* court distinguished, on the basis of causation and inference of intent, the refusal of life-sustaining medical treatment from receiving assistance in committing suicide when a patient assesses the foreseeable harm and/or continuing burden of a particular life-sustaining treatment to be on balance disproportionate to its foreseeable benefit(s). State legislation requiring a patient to be terminally ill or in a PVS or permanent coma in order for such a burden/benefit assessment to be considered legitimate fail to take into account that a patient may not be terminally ill in that his/her death is not expected within six months yet still make a legitimate assessment that a particular medical treatment has a foreseeable harm or continuing burden that is disproportionate to its foreseeable benefit and must therefore be rejected even though death will occur as a result. Such a patient is choosing death rather than continued life when continued life is possible only by accepting a significant foreseeable harm(s) and/or continuing burden(s). In addition, under certain circumstances, the foreseeable burdens associated with ANH can be reasonably assessed as disproportionate to its foreseeable benefit(s). State legislation that prohibits the cause of death from the rejection of life-sustaining medical treatment from being starvation or dehydration ignore the *Vacco* court's acceptance that the cause of death when ANH is rejected is not starvation/dehydration but the underlying pathology that made ANH necessary. In certain states, the state legislature's fear of suicide is being permitted to deny a patient's right to reject life-sustaining medical treatment when his/her intent is not suicide but avoidance of a significant harm(s) and/or burden(s). Such legislation would appear to be of doubtful Constitutional validity.

[810] Norman Cantor, *Advance Directives and the Pursuit,* 35

in their intent and persuasive in their reasoning, and must not exceed the limitations posed by the Constitution." [811]

Fortunately, it appears that of the above mentioned six states, several have amended their advance directive statutes. Arizona law appears to have been amended to permit the refusal of artificial nutrition and hydration but only if one is considered terminally ill, in a permanent coma, or a PVS. [812] Missouri's current legislation still prohibits the use of a living will to refuse ANH, but now permits refusal through the use of a durable power of attorney. Kentucky's recent (2010) revision of its advance directive legislation now permits a living will to direct that life-prolonging treatment, including ANH, can be withheld or withdrawn without meaningful substantive restriction[813] Much like Missouri, the current Illinois legislation appears to restrict the use of a living will to circumstances where a patient is not only terminally ill but for whom death is considered imminent, but permits the use of a power of attorney to reject life-sustaining medical treatment without meaningful substantive restriction. [814] Under current Ohio law, an individual must still be in a terminal condition or in a PVS in order for his/her living will or durable power of attorney to be used as legal authority to reject life-sustaining medical treatment. [815]

Although it is possible that the Arizona, Ohio, and Idaho advance directive statutes, which appear to substantively limit the right to reject life-sustaining medical treatment once decisional

[811] Nancy M. P. King, *Making Sense*, 99..

[812] Arizona's current advance directive legislation is provided in the Appendix (Number 21).

[813] A portion of Kentucky's current living will legislation is provided in the Appendix (Number 22).

[814] Portions of Illinois' current living will and power of attorney legislation is provided in the Appendix (Number 23).

[815] Portions of Ohio's current living will and power of attorney legislation is provided in the Appendix (Number 24).

capacity is lost, might not withstand a constitutional challenge, until a successful constitutional challenge is made in a court of appropriate jurisdiction, or the legislation is amended or repealed, it must be observed, at least in those states. Arizona and Ohio law present particular, but probably not insurmountable, challenges for individuals suffering in the end stage of a disease, such as dementia, but where life expectancy cannot be accurately quantified. [816]

Clearly, not only does advance directive legislation vary from state to state, there is some ambiguity in at least some of the state legislation, and as will be discussed in detail in Chapter 12, an individual who has decided to reject ANH under particular end-of-life circumstances, and wants to protect and preserve his/her right to do so in anticipation of the loss of decisional capacity, *should* execute appropriate advance directives with full awareness of the applicable state law, as understood by legal counsel fully versed in health law, not only where he/she currently resides, but, in addition, where he/she might be transported for medical treatment and/or extended care. Although legal authority for refusing ANH is provided constitutionally, and by the common law, independent of the particular provisions of state advance directive statutes, as pointed out by Sieger, Arnold, and Ahronheim, "it is likely that healthcare providers and even many attorneys do not always understand the intricacies of the law in certain states." [817] It seems clear, therefore, that the most prudent course of action is to proceed with appropriate advance planning in full compliance with state statutory provisions, to the extent possible to do so without *substantively* sacrificing one's right to refuse a means of sustaining one's life.

[816] Obviously, much will depend on the patient's prognosis at the time life-sustaining medical treatment, including ANH, is withdrawn or withheld. The question posed for this inquiry assumes that ANH would be withheld when a late stage Alzheimer's patient is unwilling or unable, even with assistance, to eat and drink in sufficient quantity to sustain his/her life. It is likely, though by no means certain, that at this juncture the patient would be assessed as terminally ill. As discussed in Chapter 12, once diagnosed with Alzheimer's disease, much of the uncertainty can be eliminated by meeting with one's doctor and one's lawyer, before one loses decisional capacity, to discuss the best method of effectuating one's medical treatment preferences. This can be accomplished, even in Arizona and Ohio, provided one chooses his/her doctor and lawyer, wisely.

[817]Sieger, Arnold, and Ahronheim, "Refusing Artificial Nutrtion and Hydration. 547.

Current State of the Law

Having examined relevant parts of the U. S. Constitution, federal and state court decisions and state legislation, it is at last appropriate to summarize the current state of American law:

American doctors are prohibited by law from treating a patient without his/her consent.

Article III. ***American doctors are required by law to inform a patient, without intimidation or deception, about his/her diagnosis, prognosis, available options for treatment, and the foreseeable benefit(s) and harm(s)/burden(s) of that treatment so that the consent necessary for that treatment is informed consent.***

James Bernat insists that informed consent is predicated on an ongoing conversation between doctor and patient, and not simply a signature on a consent form:

> The amount of information a physician must explain to a patient or surrogate is that amount a reasonable person would need to make the decision in question. Generally, patients need to know their diagnosis, prognosis, treatment choices, and their probable outcomes. Consent is best conceptualized as a process and not an event. It is not a signature on a consent form. Rather, consent is a dialogue that evolves over time in which physicians educate patients or surrogates and agreement on treatment is reached. A patient's written consent is merely the evidence of the preceding consent conversation. [818]

Bernat also notes that informed consent is impossible in a coercive or intentionally deceptive environment: "Consent requires an absence of coercion to become valid. It is coercive to threaten patients or surrogates with abandonment or to exaggerate the benefits of following the

[818] James Bernat, *Ethical Issues*, 122..

recommended therapy or risk of not doing so." [819], [820], [821]

In the United States, an adult patient with decisional capacity possesses the legal authority to reject life-sustaining medical treatment, including, but not limited to, artificial nutrition and hydration, subject only to constitutionally valid procedural or substantive limitations on that authority imposed by state legislation, currently in force only in a handful of states.

Decisional capacity is a *medical* term and refers to an assessment made by a *physician* or other medical professional that a patient is capable (or incapable) of giving informed consent for a particular medical treatment. An individual is presumed to possess decisional capacity until determined otherwise. According to the *Hastings Center Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying*, decisional capacity is not only task specific but time and circumstance dependent:

> Capacity is not an all-or-nothing matter; there is a spectrum of abilities, and capacity can fluctuate over time and in different circumstances. . . In determining capacity, careful attention must be paid to the timing of the determination and the setting in which it is to be made." [822] "[A] patient's capacity need not be perfect or unaffected to be adequate for the decision at hand." [823] "Some people have the capacity to make one choice but not another. [824]

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[819] *Ibid*, 122.

[820] Peter Shuck claims that three different conceptions of informed consent are identifiable. See the Appendix (Number 25).

[821] Hall, Bobinski, and Orentilicher, "Bioethics and Public Health Law," Hall, Bobinski, and Orentilicher claim that uncertainty as to what constitutes informed consent is manifested in the different standards that courts and legislatures have used in applying this principle to the practice of medicine in the United States. For a discussion of different standards for assessing informed consent, see the Appendix (Number 26).

[822]Hastings Center. *Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying.* (Briarcliff Manor, NY: Hastings Center, 1987), 133.

[823] *Ibid.*

[824] *Ibid*, 23.

Once an assessment is made that an individual has insufficient decisional capacity to make a necessary decision regarding a particular medical treatment, the *Hastings Center Guidelines* insist that the medical professional who made that assessment has an obligation to make an effort to restore, if at all possible, that capacity: "Once the responsible health care professional determines that the patient lacks decisional capacity, the professional should assess whether there are ways to restore capacity. In some cases, lack of capacity may have a reversible cause, such as overmedication, pain, dehydration, or metabolic abnormalities." [825],[826] Virtually all assessments of an individual's *decisional capacity* to accept or reject a particular medical treatment, even life-sustaining medical treatment, are made by physicians, often in consultation with family. [827] Only rarely is a court asked to make a determination of decisional capacity as a matter of law, in a competency hearing.

Competency is a *legal* term and refers to an assessment made usually by a *judge* although in some instances by a *jury* as to whether an individual possesses decisional capacity, as a matter of law. According to the *Hastings Center Guidelines*, "[a] person can be legally competent and nonetheless lack the capacity to make a particular [medical] treatment decision. . .[while]

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[825] *Ibid*.

[826] Allen Buchanan and Dan W. Brock. *Deciding For Others: The Ethics of Surrogate Decision Making.* (New York, NY: Cambridge University Press, 1989), 81. Buchanan and Brock add that the attending physician's responsibility for making every reasonable effort to maximize the patient's competence includes "appropriate control of medications. . . [and] improving the patient's ability to communicate through the use of special techniques or equipment where appropriate."

[827] Buchanan and Brock, *Deciding For Others: The Ethics*, 271. Buchanan and Brock suggest that decisional capacity is usually an informal assessment: "It is generally agreed. . .that by far the large majority of all determinations of incompetence in the elderly are made informally. In many cases, other people—spouses, family members, nursing home personnel, physicians, family members or neighbors—simply decide that an elderly person is no longer able to make his or her own medical decisions or to manage financial affairs, without any formal procedure and without any explicit declaration of incompetence being made, even to the elderly individual him--or herself."

[c]onversely, a person who has been declared legally incompetent for other purposes (such as financial decisions) may still possess the capacity to make a treatment decision." [828] George Annas and Leonard H. Glantz not only claim that "American law properly presumes that every competent adult is at liberty to consent to or refuse *any* proposed medical treatment or intervention. . . [but that] a further legal presumption is that all adults *are* competent, and the burden of proof is on those who would declare them incompetent." [829]

It is important to note that the standard for determining decisional capacity is the same whether the assessment is made by a doctor or a judge/jury. Unfortunately, there is apparently no universal agreement on that standard. Joe and Sander Welie report that "[t]here is little consensus in the scientific literature and even less among clinicians and in the law as to what competence exactly means, let alone how it can be diagnosed reliably." [830] As a consequence, Daniel Marson, et. al. lament that "because "[n]o widely accepted standardized instruments exist for competency assessment. . .[and] competency assessment training has been [un]available to physicians. . .physician competency evaluation has been a subjective and even idiosyncratic process." [831],[832]

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[828] Hastings Center. *Guidelines on the Termination of Life-Sustaining Treatment*, 132.

[829] Annas and Glantz, "The Right of Elderly People," 111.

[830] Joe V. M. Welie and Sander P.K. Welie. "Is Incompetence the Exception or the Rule." *Medicine, Healthcare and Philosophy 4, no. 2* (May 2001): 127.

[831] Daniel Marson, Frederick A. Schmitt, Kellie K. Ingram, and Lindy E. Harrell. "Determining the Competency of Alzheimer Patients to Consent to Treatment and Research." *Alzheimer Disease and Associated Disorders* 8, Supp. 4 (Winter 1994): 5.

[832] Buchanan and Brock, *Deciding for Others, The Ethics*, 74. In contrast, Buchanan and Brock are not apparently dismayed by the absence of a universally acknowledged standard for determining decisional capacity: "The fact that no one has proposed a single unified scale or numerical measure of competence applicable to every decision and decision-maker does not indicate, however, that judgments of competence rest on nothing more than intuitive criteria. Instead, the lack of such a scale merely reflects the reality that competence involves too complex a meshing of various capabilities and skills of each patient and the demands of a specific situation to yield a single, unified, formal summary."

Richard Frierson and Katherine Jacoby claim that the medical standard to be applied by a doctor in determining a patient's decisional capacity in a particular state is the same as that state's *legal* standard for assessing decisional capacity in a competency hearing in a court of law: "Each jurisdiction in the USA has its own legal criteria for the determination of competence, and before performing a capacity evaluation the physician should become familiar with the standards in their jurisdiction." [833] Frierson and Jacoby maintain that there are four abilities that determine decisional capacity regardless of whether the specific capacity at issue is managing one's financial affairs or giving informed consent for medical treatment: "(1) the ability to communicate a choice, (2) the ability to understand the factual information that is pertinent to the decision, (3) the ability to appreciate the importance of those facts as applied to one's own circumstances, and (4) the ability to reach a final decision in a logical manner." [834],[835],[836],[837]

There are two rather disconcerting aspects of the medical assessment of decisional capacity. First, as pointed out by Frierson and Jacoby, "[t]he threshold for competence and the degree of cognitive abilities required in the informed consent process is variable and partly dependent on the risk of the procedure; it is higher for low-benefit, high-risk treatments and lower for high-benefit, low-risk treatments." [838] A higher threshold of decisional capacity for

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[833] Richard L. Frierson and Katherine A. Jacoby. "Legal Aspects of Dementia." In *Handbook of Clinical Neurology*, edited by Michael J. Aminoff, Francois Boller, and Dick F. Swaab, 113-119. (Edinburgh, Scotland: Elsevier, 2008), 114.

[834] *Ibid*.

[835] Marson, Schmidt, Ingram, and Harrell suggest that there are a number of legal strategies for assessing decisional capacity to give informed consent. See the Appendix (Number 27).

[836] Arthur Derse proposes a slightly different model for determining decisional capacity to give informed consent. See the Appendix (Number 28).

[837] The Hastings Center has its own definition of decision making capacity. See the Appendix (Number 29).

[838] Frierson and Jacoby, "Legal Aspects of Dementia," 114.

higher risk procedures clearly raises a doctor's comfort level, but why should the standard change? An individual either has decisional capacity or he/she does not. Rather than changing the standard, a second or even third assessment of decisional capacity by different physicians employing the same standard would seem to provide comfort without doing unnecessary violence to the standard.

Second, as surmised by Allen Buchanan and Dan Brock, "[a] common criticism of the way physicians actually practice, often noted with some cynicism, is that patients' competence is rarely questioned until they refuse to consent to a physician's recommendations for treatment." [839] In their view:

> [Although] some treatment refusal does reasonably raise the question of a patient's competence in a way that acceptance does not. .. a disagreement with the physician's recommendation or refusal of a treatment recommendation is *no basis whatsoever* for a finding of incompetence. . . The competence evaluation . . . should address the *process* of understanding and reasoning of the patient, not the *content* of his decision. [840]

Of particular significance for this inquiry, Daniel Marson, et. al. insist that "[a] diagnosis of dementia is not synonymous with incompetency." [841] In their view, "[n]europsychological and mental status test measures cannot decide issues of capacity to consent. . . [for] [w]hile such tests are important for diagnosing AD [Alzheimer's disease] and for measuring levels of cognitive impairment, they cannot by themselves be determinative of competency." [842] Despite the inexorable cognitive decline associated with dementia, decisional capacity apparently remains

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[839] Buchanan and Brock, *Deciding for Others, The Ethics*, 58.

[840] *Ibid.*

[841] Marson, Schmidt, Ingram, and Harrell , "Determining the Competency," 10.

[842] *Ibid*, 10.

dynamic. Greg Sachs and Christine Cassell point out that "in the early phase of dementia. . . [a] physician may discover that [a patient] cannot manage her own finances, but. . .still may be able to state what [he]/she believes about life-sustaining therapies if [he]/she were to fall critically ill or whom [he]/she trusts to make such decisions for her." [843] In their view, "physicians periodically need to evaluate demented patient's decision-making capacities as patients' cognitive abilities decline." [844] It seems apparent that determining decisional capacity for patients in the very early or very late stages of dementia is not the problem. In a study, with an admittedly small sample size, Marson, et. al. found that "even experienced physicians can frequently disagree in their competency assessments of AD patients. . . for [w]hile such physicians showed very good judgment agreement for normal elderly, very mild and severe AD patients, they demonstrated much less agreement for cases of mild to moderate dementia." [845]

Finally, a doctor or other medical professional's assessment of an individual's decisional capacity is by no means legally binding. When a patient and/or his family disagrees with the doctor's assessment, or disagree among themselves, the *Hastings Center Guidelines* maintain that "[t]he patient and involved others should be able to challenge a determination that the patient lacks decision-making capacity, pursuing the challenge through the institutional ethics committee or other institutional mechanism for advising on ethical issues, and through judicial review if necessary." [846]

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[843] Greg A. Sachs and Christine K. Cassell. "Ethical Aspects of Dementia." *Neurologic Clinics* 7, no. 4 (1989): 848.

[844] *Ibid.*

[845] Marson, Schmidt, Ingram, and Harrell , "Determining the Competency," 12.

[846] Hastings Center, *Guidelines on the Termination of Life-Sustaining Treatment,* 31.

Subject to certain constitutionally valid procedural or substantive limitations and/or evidentiary standards imposed by individual states re: the determination of his/her previously expressed or implied intention, an adult with decisional capacity, in anticipation of the possible loss of that capacity, possesses the legal authority to refuse, in advance, life-sustaining medical treatment, including artificial nutrition and hydration.

The best method of making an advance decision to reject life-sustaining medical treatment is to do so expressly, in writing, and in conformance with the requirements of the advance directive legislation in the state where one resides or could conceivably be transported for medical treatment or extended care. [847]

In the absence of an advance directives(s) clearly and unequivocally rejecting life-sustaining medical treatment, once an adult's decisional capacity is lost, medical treatment decisions will be made on his/her behalf that may not correspond to what he/she would have chosen if he/she still retained decisional capacity and was fully aware of his/her present condition/diagnosis/prognosis and treatment options.

In the absence of an advance directive(s) clearly and unequivocally giving or denying consent for a particular medical treatment, an individual assessed as lacking sufficient decisional capacity cannot receive that treatment or have it withdrawn if underway at the time decisional capacity is lost, unless and until someone acknowledged to have the authority to do so on this individual's

[847] Norman Cantor points out the possibility that someone who has created an advance directive can subsequently change his/her mind. See the Appendix (Number 30).

behalf, accepts or rejects the treatment [848] James Bernat informs that the requisite authority to provide consent to medical treatment on someone else's behalf is usually, but not always, provided by state statute: "In situations in which an incapacitated patient did not formally designate a heath care agent, many jurisdictions, by statute, provide an automatic appointment of an agent from an ordered list of close relatives." [849]

According to Alan Meisel, "[t]he basis for presuming that family members speak for patients is not the degree of relationship per se but the assumption that family members know the wishes of the patient." [850] Bernat claims that "[i]n jurisdictions without such laws, no legally authorized surrogate exists. . . [and] [i]n practice, and by common law, the nuclear family becomes a joint surrogate by default." [851] Needless to say, end-of-life health care crisises especially when a patient is no longer able to speak for himself/herself can divide even the closest families, and Bernat is well aware that informal surrogacy is sometimes not acceptable to all parties:

> [I]nformal surrogacy arrangement works only so long as the family members are in agreement about treatment decisions and are making decisions that appear to represent what the patient would want or are in the patient's best interest. In the face of an intractable disagreement that cannot be resolved

[848] In circumstances where a patient lacks sufficient decisional capacity to consent to a particular medical treatment or the withdrawal of a treatment already underway at the time decisional capacity is lost, but has executed a living will *clearly and unequivocally* giving or denying consent for the particular medical treatment for which a decision is necessary, in the absence of a family member that could conceivably serve as a surrogate, the attending physician may, if he/she so chooses, accept the advance directive as the requisite legal authorization for acceptance/refusal of treatment without seeking the legal appointment of a surrogate to act on this patient's behalf. It is, however, much more likely that even when a patient has a living will a family member is going to serve as an informal surrogate and use the living will as a guide to consenting or rejecting, on the patient's behalf to particular medical treatment.

[849] James Bernat, "Ethical Issues in the Care," 122.

[850] Alan Meisel. "The Legal Consensus About Forgoing Life-Sustaining Treatment: Its Status and Prospects." *Kennedy Institute of Ethics Journal* 2, no. 4 (March 1992): 321.

[851] James Bernat, "Ethical Issues in the Care," 122.

> by the intervention of a hospital ethics committee or other mediation, or given evidence of non-altruistic decision-making, it may become necessary for a judge to appoint a guardian who is legally authorized to speak for the patient. [852]

Failure to designate, in writing, one's choice of a surrogate to make medical treatment decisions on one's behalf, if and when one loses decisional capacity, obviously means that a surrogate may be designated that is not necessarily who one would have chosen. This is not always a problem, because family members, especially spouses, are usually the statutorily designated surrogates. On the other hand, spouses can sometimes have great difficulty following what they know with certainty to be their husband or wife's preference to refuse, under certain circumstances, life-sustaining medical treatment.

What should be even more frightening, however, for those individuals unwilling or unable to plan for the possibility of the loss of their decisional capacity, is that in the absence of an advance directive or other evidence of one's medical treatment preferences, a surrogate may intentionally or unwittingly consent to medical treatment under circumstances that a now decisionally incapacitated patient would absolutely reject if he/she was aware of the circumstances and still possessed the decisional capacity to make his/her own decision. As noted and examined above in the discussion of court rulings, there are three generally accepted legal standards for a surrogate to use in making a medical treatment decision on another's behalf.

Legal Standards for Making Medical Treatment Decisions on Another's Behalf

Bernat informs that "[t]he highest standard is to follow the expressed wishes of the patient

[852] *Ibid.*

if the patient has made these wishes known through written or oral advance directives," [853] what is often termed the *subjective* standard. According to Alan Meisel, "[a]ll courts agree that it is best in making decisions for incompetent patients that surrogates be guided by a 'subjective' standard, which requires that any instructions the patient gave before losing decision making capacity about what kind of treatment he did or did not want should guide decision-making." [854] This makes perfect sense from a legal standpoint because the legal authority to reject a means of sustaining an individual's life is vested in that individual alone if he/she has decisional capacity. If sufficient evidence can be adduced as to his/her medical treatment preferences under existing circumstances, it is his/her right to accept or reject medical treatment and no one else's. It would be a great injustice to deny that right, especially in instances where he/she has made his/her wishes re: medical treatment unequivocally clear, simply because he/she has lost decisional capacity.

In Meisel's view, "[i]f the subjective standard cannot be applied because such information about the patient's treatment preferences is not available or does not meet the high level of proof necessary to meet the subjective standard, the consensus holds that the surrogate should attempt to apply the 'substituted judgment' standard." [855] For Bernat, the task in applying the substituted judgment standard is to "attempt to reproduce the exact decision the patient would have made by applying the patient's known values and preferences to the present clinical situation and execute a substituted judgment." [856] This standard also seems to make legal sense because it permits a reasonable inference to be made as to what the patient would have expressed, verbally or in

[853] *Ibid.*

[854] Alan Meisel, "The Legal Consensus," 322.

[855] *Ibid*.

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[856] James Bernat, "Ethical Issues in the Care," 122.

writing, had he/she chosen, or been given an opportunity, to do so.

Once again, it seems unjust to deny an individual the right to accept/reject medical treatment, if it can be determined, with a reasonable degree of certainty, what he/she would choose to do or not do in the present circumstances, simply because he/she lost decisional capacity without first expressing, verbally or in writing, his/her acceptance or rejection of a particular medical treatment in the circumstances that have arisen. On the other hand, Allen Buchanan and Dan Brock are apparently not persuaded as to the wisdom of inferring a deliberate choice from a value or preferences: "[E]vidence concerning *preferences* does not have the same moral weight as evidence about a *deliberate choice*. A deliberate choice is an *act of will*; a preference is merely a pro-attitude, a desire to have one thing rather than something else." [857] Obviously the application of the substituted judgment standard necessitates a discussion with the patient's family and even close friends and confidants, and although there is a chance that they may unwittingly or even intentionally misrepresent the patient's values and general preferences to suit their own purposes, it seems completely appropriate to attempt to make a reasonable attempt to effectuate a now decisionally incapacitated patient's will, even in the absence of a verbal or written expression of that will.

In the absence of sufficient evidence not only of verbal or written expressions of the patient's wishes re: particular medical treatment but also of his/her values and general preferences, a third standard can be used by a surrogate to provide consent or rejection of medical treatment. According to Bernat, "[i]f the patient's values and preferences are unknown, the surrogate should attempt to balance the benefits to the patient of the proposed therapy against

[857] Buchanan and Brock, *Deciding for Others, The Ethics*, 71.

its burdens and determine which course of action lies in the patient's best interests." [858] The acceptance of this standard is based on the acknowledgment that although the right to accept or reject medical treatment is legally vested in the individual and can, if and when decisional capacity is lost, be made on his/her behalf based on his/her expressed or even implied will, in the absence of sufficient evidence of his/her will, medical treatment decisions still must be made. The *best interests* standard is a logical attempt to make a decision on behalf of a decisional incapacitated individual based upon what a reasonable person would choose to do in the situation at hand, given his/her present physical condition/diagnosis/prognosis and the expected outcomes of alternative methods of treatment or non-treatment.

The best defense of the application of this standard is that like it or not a medical treatment decision(s) must be made, and there does not appear to be any better alternative at hand. Having said that, however, it is equally clear that the *best interest* standard is fraught with potential for abuse from two entirely different groups. Ironically, there is an obvious temptation for both groups, although for very different reasons, to argue that available evidence is insufficient to permit an application of either the subjective or substituted judgment standards and best interests must prevail.

The first group is those interested parties, whether family members, friends, or medical professionals, who could potentially use the *best interests* standard as a means to ignore at least some available evidence that an individual would *probably* want to accept life-sustaining medical treatment in the circumstances at hand. It is with this first group in mind that Bernat cautions that "[p]hysicians should approach best interests judgments only as a last resort and always with caution and humility because of the tendency for healthy physicians and surrogates

[858] James Bernat, "Ethical Issues in the Care," 122.

to unjustifiably devalue the quality of life of elderly and disabled patients." [859]

The second group is composed of family members, friends, and medical professionals who could potentially use the *best interests* standard as a means to override at least some available evidence that an individual would *probably* want to reject life-sustaining medical treatment if the circumstances at hand. This group consists of those, for reasons of their own, who firmly believe that they know what is best for a decsionally incapacitated patient, and despite his/her minimal functional capacity/quality of life *must* accept artificial nutrition and hydration, mechanical ventilation, or some other form of life-sustaining medical treatment. Representative of this second group is, at least arguably, David F. Kelly, who claims that the objective best interests of a patient can never be ignored: "I have argued that in daily hospital practice the pure subjective standard is seldom available. I am therefore convinced that in almost all cases the objective best interests of the patient must be considered. Thus, *in almost all cases, surrogates may not legally or ethically choose to reject treatment that is in the objective best interests of the patient.*" [860] Once again, and as discussed in detail in chapter 12, having been diagnosed with Alzheimer's disease, or any other ultimately terminal disease, if one desires to have one's will re: medical care ultimately prevail against all who might oppose it, it is critically important to create not only a disease specific living will, but to designate a surrogate and write a statement of one's personal values.

It must be emphasized that there can be no assurance that a surrogate, especially a surrogate that one did not expressly choose and instruct as to one's medical treatment decisions/preferences, is going to be aware of these three standards much less consider himself/herself legally or ethically bound to apply them, which is again the risk of not using

[859] *Ibid*.

[860] David F. Kelly, *Contemporary Catholic*, 157.

appropriate advance directives to designate and instruct a surrogate of one's own choosing. The ethical basis on which a surrogate makes a medical treatment decision will be determined, at least in part, on the acquiescence of the attending physician and other interested parties, especially other family members. If they are unwilling to mount an ethical challenge to a surrogate's decision, the surrogate can, if he/she so chooses, effectively ignore what he/she believes to be the medical treatment decisions/preferences of the decsionally incapacitated patient.

Whether a surrogate is going to consider himself/herself legally bound to apply these standards will be determined, in large part, by the manner in which his/her appointment was made. A surrogate appointed by court order is, in all likelihood, going to have his/her decisions scrutinized by that court. Surrogate decisions that are legally challenged by interested parties are also going to obviously receive court scrutiny. Absent a legal challenge, however, a surrogate appointed by statute or informally accepted by the attending physician can, if he/she so chooses, either effectively ignore what he/she believes to be the medical treatment preferences of the decsionally incapacitated patient, or conversely accept evidence of a preference to reject life-sustaining treatment that a court might find legally insufficient.

Finally, it seems reasonably clear that there is no legal impediment to preemptive palliative sedation, so long as a reasonable inference is possible, given the manner in which sedation is administered, that the intention of the sedation is to prevent even the possibility of suffering rather than to cause death. Preemptive palliative sedation that renders a patient unable to eat and drink in circumstances where ANH is withheld or withdrawn is also firmly within treatment permissible under American law, provided that the rejection of ANH is made with requisite legal

authority, and a reasonable inference is again possible that the intention of the sedation is to prevent even the possibility of suffering rather than to cause death.

Chapter Five: Moral Authority to Reject Artificial Nutrition and Hydration

The previous chapter confirmed that, in the United States, an adult with decisional capacity possesses the legal authority to reject life-sustaining medical treatment, including, but not limited to, artificial nutrition and hydration (ANH), subject only to Constitutionally valid procedural or substantive limitations on that authority by state legislation. In addition to these and other Constitutionally valid procedural or substantive limitations and/or evidentiary standards re: the determination of his/her previously expressed or implied intention, all imposed by particular state legislation, an adult with decisional capacity can, in anticipation of the possible loss of that capacity, refuse, in advance, life-sustaining medical treatment, including ANH, through the use of an advance directive(s). That he/she possesses the legal authority to reject a means of sustaining his/her life does not, however, necessarily mean that he/she also possesses the moral authority to do so. [861] Although it can be asked, with at least some

[861] Historically, and as will be discussed in detail in chapters 7, 8, 9, and 10, there has been general, although by no means universal, agreement, at least in the western world, that despite the acknowledgement that human life has absolute sanctity and enormous intrinsic value, that under certain very narrowly defined circumstances, an individual possesses the moral authority to sacrifice his/her life, if confronted with a circumstance where it is otherwise impossible to preserve something considered even more valuable, including, but not limited to, his/her relationship with God, the defense of his/her country, and the life of another, especially his/her family, neighbors, and friends. Nevertheless, there has been far less discussion, much less agreement, as to whether there are any circumstances whatsoever in which an individual possesses the moral authority to reject a means of sustaining his/her life, including food and water.

Until the availability of effective long term artificially provided nutrition and hydration (ANH) became widespread, not only was moral authority for the rejection of ANH not an issue, neither was the moral authority for the refusal of food and water. Throughout the millennia, at least some individuals, still conscious, fully cognizant or merely suspicious of the terminal character of their own illness, disease, or injury, and still capable of orally ingesting food and water, have chosen to reject both in order to no longer oppose the dying process. Provided that these individuals quietly and privately refused food and drink without revealing their intention, it seems quite probable that their actions were perceived as a natural part of the dying process rather than a form of suicide, and

justification, why moral authority is of any consequence whatsoever, so long as legal authority exists, the assessment that one possesses moral authority for a particular action or course of conduct can nevertheless be of great significance.

Many, although certainly not all, individuals need some form of reassurance that in making significant decisions, especially those decisions involving life and death, that they are doing the "right thing." Awareness that one has the requisite legal authority may not in and of itself provide that reassurance. Federal law, for example, grants legal authority, [862] at least under certain circumstances, for abortion, but for a significant segment of American society, the moral authority for such an action is entirely absent. Accordingly, many individuals contemplating whether they would, under certain circumstances, reject a means of sustaining their own lives,

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they and their families thus escaped not only the opprobrium surrounding suicide but any form of formal or even informal legal or religious sanction. Even, however, if an individual chose to make known his/her intention of no longer opposing the dying process it was far from certain that his decision would be characterized as a form of suicide. Whether the refusal of food and water was so characterized depended in large part on observers' perception of the patient's proximity to death and the ultimate cause of death. The closer the perceived proximity to death, the less likely that the refusal of food and water was viewed as a form of suicide.

Within the last four decades, however, thanks to modern medicine's capability of providing some form of artificial nutrition and hydration in virtually all circumstances, ANH issues have arisen for those unwilling or unable to ingest food or fluids, and have become more and more emotional, contentious, and divisive. Widespread public awareness of issues regarding ANH for the permanently unconscious has attracted greater scrutiny to instances where a individual with an illness, disease, or injury thought to be inexorably fatal, who nonetheless is fully conscious yet unwilling or incapable of ingesting fluids, chooses to refuse artificial nutrition and hydration. Dramatically increasing transparency is modern medicine's capability of determining a cause of death in such a circumstance. Whereas historically it was difficult to determine the cause of death of an individual with an illness, disease, or injury thought to be terminal who refused food and water, today the physiology and trajectory of death from terminal dehydration is well known. Although all doubt has by no means been removed, there is much greater certainty in many instances. As a result, it is today, in marked contrast to the past, much more difficult to exonerate an individual from what might otherwise be viewed as a form of voluntary passive euthanasia by giving him/her the benefit of the doubt as to whether death resulted from terminal dehydration, or some other cause.

Adding "fuel to the fire" is the argument made by critics of withdrawal or withholding of artificial nutrition and hydration, that ANH is simple, inexpensive, and almost totally innocuous, and to deny it to those incapable of ingesting food and fluid normally, especially from those incapable of making an informed choice re: ANH, is to slowly and painfully *starve* an unwilling, totally defenseless person to death. Against this backdrop is a seemingly ever increasing insistence by individuals, particularly Americans, that their personal autonomy be respected, especially with regard to their own bodies and their right to choose whether they wish to prolong lives that they evaluate as no longer worth living. It is hardly surprising; therefore, that whether an individual possesses the moral authority to reject ANH continues to command a great deal of attention.

[862] Effectively by preventing states from prohibiting almost all abortions.

including, but not limited to, artificial nutrition and hydration, want to know whether they possess the requisite moral authority to do so.

In addition, legal authority alone, without corresponding moral authority, may not be sufficient to insure that an individual's decision to reject a means of sustaining his/her life will be honored, especially if he/she subsequently loses consciousness or decisional capacity, or otherwise provides those who oppose such a decision an opportunity to ignore or overturn it. As long as an individual's consciousness and decisional capacity both remain unimpaired, there is a much greater probability that his/her rejection of artificial nutrition and hydration will be honored. If, on the other hand, either decisional capacity or consciousness is lost, even temporarily, an individual determined to reject artificial nutrition and hydration requires, at minimum, the acquiescence of others. Those whose acquiescence is needed, whether legally designated surrogate decision makers, care givers, attending medical personnel or even family members, are much more likely to acquiesce to the decision to reject ANH if they are persuaded that the decision-maker possessed both the legal *and* moral authority to do so at the time the decision was made, *especially* when they *disagree* with that decision. Accordingly, this chapter examines whether an individual has the *moral* authority to reject a means of sustaining his/her life, including, but not limited to, artificial nutrition and hydration, especially in the circumstances specific to this inquiry, and does so from an exclusively *secular* perspective. Whether an individual possesses the requisite moral authority to reject a method of sustaining his/her life as determined from a *religious* perspective, is examined in chapters 6, 7, 8, and 9. Whether an individual has the moral authority to reject a life-sustaining means through the use of an advance directive(s) is the focus of the following chapter.

Although there are those who might claim that each and every individual is entitled to his/her own exclusive and entirely subjective determination of "right and wrong," granting to him/her the moral authority to do whatever he/she determines to be "right," the vast majority of those living in the second decade of the twenty-first century would, in all likelihood, reject such a claim. Unfortunately, there is much less agreement as to how moral authority, for a particular action or course of conduct in a given circumstance, should be ultimately determined. Nevertheless, as will be seen as this chapter unfolds, whether or not an individual possesses the moral authority to reject a means of sustaining his/her life, including, but not limited to, artificial nutrition and hydration (ANH), is determined in significant part by the relative weight given to one or more of the following five moral principles:

1 Respect for individual personal autonomy.
In simplest terms, your body, your life, and therefore your right to accept or reject a means of sustaining your life.

2. Respect for the sanctity and, at least arguably, enormous intrinsic value of human life.
Certain moral imperatives are imposed by respect for the sanctity and intrinsic worth of human life, including not only the prohibition of suicide, but the obligation to preserve, extend, and sustain one's life.

3. Respect for the sanctity and intrinsic value of human life does not impose an obligation to use a means of sustaining life that imposes a foreseeable harm(s) or a continuing burden(s) disproportionate to the foreseeable benefit provided.
The obligation to use a means of sustaining a patient's life imposed out of respect for the sanctity and enormous intrinsic value of human life is *not unlimited*, not only because there are other human goods that have legitimate and significant value, including, but not limited to, human dignity, individual personal autonomy, and the well being of others, but also because a patient and/or his/her family/caregivers, community, and even society as a whole have *limited* physical, financial, psychological, emotional, and spiritual resources. The utilization of a means of sustaining a patient's life has foreseeable consequences for him/her, his/her family/caregivers/community, as well as society as a whole, especially as to the utilization of those resources and necessitates a balancing of the foreseeable harm(s) and continuing burden(s) imposed by that means against the foreseeable benefit(s) provided by that means. [863]

[863] When an exception to the *obligation* to utilize a means of sustaining life is based on the assessment that foreseeable harm(s)/burden(s) imposed by that means are, on balance, disproportionate to the foreseeable benefit(s) provided thereby, the foreseeable *consequences* of the utilization of that means is overriding the obligation, arising out of respect for the sanctity and intrinsic value of human life, to sustain human life. Obviously the inherent

4. A distinction can be drawn between shortening the life of an individual without a potentially fatal pathology or whose otherwise fatal pathology can be effectively treated and death thus forestalled, perhaps almost indefinitely, and no longer prolonging the unpreventable death of an individual who has an incurable fatal pathology that significantly reduces his/her life expectancy. The existence of an incurable fatal pathology lends greater plausibility to the inference that the rejection of a means of sustaining life reflects an intention to no longer prolong the dying process rather than an intention to kill.

5. Because food and water not only have enormous symbolic significance but all human life is physiologically impossible in their extended absence, there is, accordingly, a higher standard of obligation to utilize nutrition and hydration in all its forms, natural and artificial, to sustain life.

Each of the following four general analytical methods for making a determination as to whether an individual possesses the moral authority to reject a means of sustaining his/her life, including ANH, are based on the application of at least one of the above described moral principles and are therefore, at minimum, worthy of respect, if not concurrence. [864] Of the four general analytical methods, two are, at least arguably, extreme positions, while the other two are much more moderate. Not surprisingly, the two moderate positions, though fundamentally different, are firmly within the American mainstream, while the two extreme positions are embraced by distinctive yet, at least mathematically, less significant groups of Americans. Because the two extreme positions privilege one of the moral principles over all the others, and are accordingly completely straightforward, it is useful to examine these first before proceeding to the much more moderate, yet complex, analytical methods.

Vitalism

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weakness in any attempt to foresee the consequences of the decision to accept or reject a means of sustaining life is that the consequences of that decision, both short and long term, are *not* entirely foreseeable. Nevertheless, as will be discussed in greater detail in Chapter 6, the inability to foresee the future with total accuracy is not fatal to the right to do so.

[864] A general history of the debate over whether an individual possesses the moral authority to reject a means of sustaining his/her own life is provided in the chapter on Roman Catholicism.

The first analytical method is sometimes described as vitalism, and effectively privileges the moral imperatives imposed by respect for the absolute sanctity and enormous intrinsic worth of human life to preserve, extend, and sustain one's life over the other four moral principles. In so doing, vitalism effectively imposes an exceptionless obligation to fight for every last breath with whatever means are available, regardless of the foreseeable consequences of the utilization of a particular means of sustaining life to the patient and his/her family/caregivers/community, as well as society as a whole, regardless of the patient's prognosis or proximity to death, and regardless of whether that patient or his/her designated surrogate decision-maker wishes to make an informed and autonomous rejection of that means. Vitalism draws no distinction between nutrition and hydration and other means of sustaining life, imposing an absolute, exceptionless obligation to utilize *all* means that are available. For the vitalist, no one, under any circumstances whatsoever, not even in the circumstances specific to this inquiry, possesses the moral authority to reject a means of sustaining his/her own life, including but not limited to artificial nutrition and hydration. The strength of vitalism is that human life is preserved at all costs. The obvious weakness of vitalism is that those costs can be enormous, imposing on a patient, his/her family/caregivers, and even, in extreme circumstances, an entire community or even society as a whole, significant burdens.

Totally Unrestricted Individual Personal Autonomy

In stark contrast, the second analytical method privileges individual personal autonomy over the other four moral principles. In so doing, this method affirms an individual's *totally unfettered* right to autonomously reject a means of sustaining his/her life, *despite* the moral imperatives imposed by respect for the sanctity and intrinsic worth of life to preserve, extend,

and sustain his/her life, regardless of the foreseeable consequences of the rejection of that means to him/her and his/her family/caregivers/community or society as a whole, regardless of his/her prognosis or proximity to death, and regardless of whether the means in question is any form of natural or artificial nutrition and hydration, and/or sustains life by forestalling the effects of the fatal pathology from which death has been assessed to be both unpreventable and likely to occur within a reasonably short span of time. For the advocate of totally unbridled individual personal autonomy, in *all* circumstances, including the circumstances specific to this inquiry, an individual possesses the absolute and unquestionable moral authority to reject a means of sustaining his/her own life, including, but not limited to, ANH. The strength of unbridled individual personal autonomy is that self determination reigns supreme and as a consequence, a competent adult and/or those acting at his/her behest can make decisions regarding the acceptance or rejection of a means of sustaining his/her life *totally without restraint*. The weakness of unbridled individual personal autonomy is that an individual's autonomous rejection of a means of sustaining his/her life can not only be a form of passive euthanasia but impose significant burdens on his/her family and caregivers, especially if he/she is relatively young, otherwise in good health, and with a correspondingly long life expectancy if a potentially fatal but nonetheless treatable illness, disease, or injury is appropriately addressed. [865]

[865] Bruce Jennings "Autonomy." In *The Oxford Handbook of Bioethics.* Edited byBonnie Steinbock, 72-89. (Oxford, UK: Oxford University Press, 2007), 80, 81. Needless to say, totally unfettered individual personal autonomy is anathema to anyone who supports limits on one's right to refuse to prevent preventable harm to oneself, especially when the decision to reject a means of sustaining one's life produces a result that from a third-party perspective is particularly egregious. Although a particular personality profile can probably be attributed to those who insist on their unfettered right to make choices regarding their bodies and lives, it must be noted, that the exercise of individual personal autonomy does not, in and of itself, insure that in exercising that right an individual is necessarily irrational, self-indulgent, or completely motivated by ego or self-aggrandizement. That an individual insists on the unfettered right to freely make choices regarding his/her body and life does not exclude the possibility that those choices can be altruistic, unselfish, and other directed. Bruce Jennings makes a particularly persuasive defense of the ethic of individual personal autonomy: "Autonomy is not an ethic of selfishness, nor is self-indulgence the same as rational self-fulfillment. Autonomy means freedom from outside restraint and the freedom to live one's own life in one's own way. . . Nothing in these notions necessitates selfishness or egoism. Self-determining conduct need not be exclusively self-serving. Being the author of your own life says nothing per se

Obviously, these first two analytical methods are extreme, to say the least, and it is not at all surprising that the American mainstream has been unwilling to embrace either position. Nevertheless, it is certainly possible to encounter individuals who consider themselves wholeheartedly vitalists or champions of the right to totally unrestricted individual personal autonomy and self-determination with regard to one's own body and life. In addition, because morality authority is not determined mathematically, it cannot be said with absolute certainty that the right to personal autonomy and self-determination does not *alone* legitimately and authentically provide an adult with decisional capacity the requisite moral authority to reject *all* means of sustaining his/her life regardless of the circumstances or ultimate consequences, or conversely that respect for the sanctity and intrinsic worth of human life does not categorically *deny* to an adult with decisional capacity the moral authority to reject under *any* circumstances whatsoever, including the circumstances specific to this inquiry, *any* means of sustaining his/her life.

Somewhere between the two extreme positions are to be found two much more moderate positions arising from analytical methods that can be accurately characterized as *inclusionary* and *exclusionary* respectively. Virtually all American secular moralists, medical ethicists, and the overwhelming majority of the American mainstream embrace one of these two positions and because the exclusionary analytical method can be viewed as a conditional acceptance of the inclusionary analytical method, albeit with significant qualifications, it seems appropriate to first examine the inclusionary analytical method.

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about the moral contents of that life." Jennings also challenges the notion that individual personal autonomy belongs only to those who have somehow earned that right. "Autonomy allows one person to demand respect from another as a matter of right. . . just because one is a person, an adult human being, a first-class member of the moral community. . . Self-sovereignty in the moral realm; the right to live your own life in your own way as long as you do others no harm; being true to yourself above all—these notions are at the core of individualism, authenticity, moral freedom, and autonomy, if not as all professional philosophers would define them, then at least as many ordinary people define them in their own social and self-consciousness."

Inclusionary Analytical Method

The inclusionary analytical method simultaneously affirms *both* the moral imperatives arising out of respect for the sanctity and intrinsic worth of human life and the right of individual personal autonomy, but holds that neither the obligation to sustain life nor the autonomous right to reject a means of sustaining life are *unlimited*. The autonomous right to reject a means of sustaining one's life is *limited* to those means whose foreseeable harm(s) and/or continuing burden(s) is, on balance, disproportionate to the foreseeable benefit(s), if any, provided thereby. [866] The obligation to utilize a means of sustaining one's life is correspondingly limited to those means that do *not* impose a foreseeable harm(s) and/or continuing burden(s) that is, on balance, disproportionate to its foreseeable benefit(s). [867]

This inclusionary analytical method is, at least arguably, the method preferred by most Americans because it permits the determination of whether an individual possesses the moral authority to reject a means of sustaining his/her life, including ANH, to be made based on an

[866] Autonomy is nevertheless affirmed because one is permitted to subjectively identify, assign a relative weight, and balance foreseeable harm(s)/burden(s) and benefit(s), and given wide discretion in doing so.

[867] Notably, the inclusionary analytical method does *not* directly address a distinction between shortening life and no longer opposing death by further restricting the autonomous right to reject a means of sustaining one's life not only to those means whose foreseeable harm(s) and/or continuing burden(s) are disproportionate, on balance, to its foreseeable benefit(s) but to circumstances where the individual exercising his/her right of self determination has an incurable fatal pathology that significantly reduces his/her life expectancy to some arbitrary maximum. Instead, it is apparently assumed that whether or not one has an untreatable fatal pathology that reduces one's life expectancy will be given appropriate weight in a very inclusive assessment of foreseeable harm(s) and/or continuing burden(s) imposed, and foreseeable benefit(s) provided, by a means of sustaining life. This analytical method also does not directly address whether the symbolic significance and physiological necessity of food and water imposes a higher standard of obligation for the utilization of nutrition and hydration in all its forms than the standard of obligation imposed by respect for the sanctity and intrinsic value of life. Instead, it is apparently assumed that if artificial nutrition and hydration is the life-sustaining means being evaluated that the standard of obligation for its utilization will be appropriately reflected in the extent to which harm(s) and/or burden(s) must exceed benefit(s) in order to be considered, on balance, disproportionate. Finally, re: the rejection of ANH, this method does directly address whether a fatal pathology has destroyed the patient's appetite and/or his/her ability to swallow.

assessment of foreseeable [868] harm(s)/burden(s) and benefit(s) that *includes everything* that can even remotely be considered a foreseeable harm/burden or benefit. This method is familiar to and comfortable for most Americans because it parallels the totally inclusionary way many Americans solve problems and decide on a course of action. There is no obligation to utilize a means of sustaining life that doesn't work or does more harm than good, and *nothing* is peremptorily excluded as irrelevant or prejudicial in making that determination unless the individual making the determination chooses to do so. This means that a *very* broad assessment of foreseeable harm(s)/burden(s) and benefit(s) is permitted that includes not only *all* harm(s)/burden(s) imposed on, but *all* benefit(s) provided to, the patient, but his/her family, caregivers, community, and even society as a whole.

Especially noteworthy is that the inclusionary analytical method permits a patient's body's functional incapacity; as well as what is sometimes referred to as his/her quality of life, to legitimately be considered as either a burden imposed or a diminution of the benefit provided by a means of sustaining his/her life because of the inability of that means to restore that functional capacity/quality of life. Particularly revealing in this regard is the application of this inclusionary analytical method in the determination of whether there is moral authority to reject a means of sustaining the life of patient in a persistent vegetative state (PVS). Because functional incapacity and quality of life can be legitimately assessed either as a burden imposed or a diminution of the benefit provided by a means of sustaining the life of an individual in a PVS, the assessment can be made that a means of sustaining his/her life, including but not limited to ANH, that is incapable or restoring his/her body's functional capacity/quality of life, imposes

[868] It should be noted that an accurate assessment of foreseeable benefit(s) and harm(s)/burden(s) is heavily dependent not only on their possibility but their probability, and necessitates an identification of the degrees of *possible* foreseeable benefit(s) respectively enhanced or diminished relative to its probability and appropriately assigned a moral weight balanced against the results of an identical assessment of foreseeable harm(s) and/or burden(s).

burden(s), that are, on balance, disproportionate to its benefit(s), and that there is, therefore, moral authority to reject this means. Significantly, such an assessment could presumably be considered legitimate even without any consideration of foreseeable harm(s) and/or burden(s) directly imposed by this means or whether this means has the capability, given the PVS patient's condition, of actually sustaining his/her life.

The application of this inclusionary analytical method to the circumstances specific to this inquiry raises the issue of whether the extremely low functional capacity and quality of life of an individual in the *late stages* of Alzheimer's disease, although, in all likelihood, by no means as low as that of a patient in a PVS, can nonetheless justify the assessment that the burden(s) of ANH are, on balance, disproportionate to its benefit(s). It seems clear that the *very broad* assessment of foreseeable harm(s)/burden(s) and benefit(s) permitted by the inclusionary analytical method permits such an assessment. Especially noteworthy is that such an assessment is apparently considered legitimate even without any consideration of other foreseeable harm(s) and/or burden(s) directly imposed by ANH or whether ANH has the capability, given the late-stage Alzheimer's patient's condition, of actually sustaining his/her life. [869]

The strength of the inclusionary analytical method is that because it excludes nothing, one is able to see the "whole picture" and decide for oneself how to identify, assign a relative weight, and balance the foreseeable harm(s), burden(s), and benefit(s) of a means of sustaining one's life. The source of its strength is, however, also the source of its arguable weakness, at least from the standpoint of those observers critical of totally unbridled personal autonomy, because the inclusionary analytical method permits an individual or his/her surrogate's entirely subjective

[869] It is, on the other hand, quite possible that one can in good faith apply this inclusionary analytical method and make the assessment that foreseeable harm(s) and/or burden(s) are disproportionate to benefit(s) based entirely on the harm(s)/burden(s) *imposed directly* by the means, without regard to the inability of the means to restore the body's functional incapacity. This possibility can be seen in the circumstances specific to this inquiry.

assessment of his/her functional incapacity and/or quality of his/her life to potentially trump all else. The ability to do so, it can be argued, can effectively eviscerate the check on personal autonomy flowing out of the requirement that foreseeable harm(s)/burden(s) be, on balance, disproportionate to foreseeable benefit(s) because it allows autonomy to "put its thumb on the balancing scale" in assigning an inordinate and thus arguably illegitimate weight to functional incapacity and/or quality of life.

The inclusionary analytical method is preferred by a majority of those Americans that are either *unaware* that the rejection of a means of sustaining life can be a form of passive euthanasia, or *unconcerned* about that possibility, either because they are capable, at least to their own satisfaction, of *distinguishing*, in their particular circumstances, the rejection of a means of sustaining life from passive euthanasia, or in the alternative, capable of somehow *justifying*, again to their own satisfaction, what they acknowledge to be passive euthanasia. Despite the *possibility* that the *very broad* assessment of harm(s)/burden(s) and benefit(s) permitted by this inclusionary method *can* be used to countenance what the exclusionary analytical method considers passive euthanasia, it cannot be said, with assurance, that this inclusionary analytical method does not *alone* legitimately and authentically provide a competent adult with the requisite moral authority to reject a means of sustaining his/her life, including ANH, that he/she assesses as imposing harm(s) and/or burden(s) disproportionate, on balance, to the benefit(s), if any, provided thereby, including, but by no means limited to, in the circumstances specific to this inquiry.

Exclusionary Analytical Method

As discussed, a fourth and final *exclusionary* analytical method can be viewed as a conditional acceptance of the above described inclusionary analytical method subject to several *significant* qualifications imposed because of the fear that the rejection of a means of sustaining life can be a form of passive euthanasia. The balance of this chapter examines these qualifications, their apparent justification, and the application of this final method to the determination of whether a competent adult possesses the moral authority to reject a means of sustaining his/her life, including, but not limited to, ANH, especially in the circumstances specific to this inquiry.

The most significant qualification to the *inclusionary* analytical method imposed by the *exclusionary* analytical method is the requirement that foreseeable harm(s)/burden(s) assessed in the process of balancing foreseeable harm(s)/burden(s) against foreseeable benefit(s) is restricted to *only* that harm(s) and/or continuing burden(s) *directly imposed by the means* of sustaining life being evaluated, and nothing else. It is apparently considered legitimate to assess the harm(s) and/or continuing burden(s) imposed by the means on the patient, on a patient's family/caregivers, and even, under extreme circumstances, society as a whole, but *only* the harm(s) and/or burden(s) *directly* imposed, *as strictly interpreted, by the means itself*. All other foreseeable burdens, especially the burdens imposed by the *continued existence of the patient*, on the patient, his/her family/caregivers, and society as a whole, including the burden(s) imposed by

the patient's underlying illness/disease/injury and/or resultant functional incapacity and/or poor quality of life, are *absolutely* excluded. [870]

The rationale for the exclusion is perfectly clear. The apparent justification for the rejection of a means of sustaining life, even though death follows, is based on the assessment that foreseeable harm(s) and continuing burdens(s) *imposed by the means itself* are disproportionate, on balance, to the foreseeable benefit(s) provided and the critically important *inferred* intent in rejecting this means is to avoid the foreseeable harm(s) and/or continuing burden(s) with the regrettable but completely unintended consequence that death *may* also foreseeably result. If on the other hand, foreseeable harm(s) and/or burden(s) that are assessed as disproportionate, on balance, to the benefit(s) are *also* those harm(s) and/or continuing burden(s) *imposed by the continued existence of the patient*, the inferable intent is that the rejection of this means is *not* only to avoid the harm(s) and/or burden(s) imposed by the means *itself*, if any, but to avoid the burden(s) imposed by the continued existence of the patient by ending his/her life. Avoidance of the burden(s) imposed by the continued existence of the patient is held to be a form of passive euthanasia, the intentional indirect killing of an innocent person.

A related but nonetheless significant qualification to the *inclusionary* analytical method imposed by the *exclusionary* method is the requirement that in assigning a relative weight to a foreseeable benefit of a means of sustaining life, the evaluation is restricted *only* to what the means in question is *designed and capable* of providing, and *not*, in addition, its ability to restore

[870] It should be noted that inevitable questions arise concerning the nuances of the assessment of foreseeable burdens, including but not limited to the following:
1. Must the assessment of burden(s) focus exclusively on the burden resulting from the medical treatment being evaluated or may cumulative burdens imposed by other ongoing medical treatments be legitimately considered? For example, a patient with lung cancer who is undergoing chemotherapy needs dialysis. In assessing the burden(s) of dialysis may the burden of chemotherapy be considered?
2. If financial cost can be legitimately considered in the assessment of the burden(s) imposed by a medical treatment, must the assessment of cost focus exclusively on the cost of the medical treatment being evaluated, or may the cumulative cost of all treatment be considered including the cost of supervision for those whose incapacity requires some form of 24 hour observation?

a patient's functional capacity/quality of life. By way of example, artificial nutrition and hydration is designed and capable *only* of providing nutrition and hydration and under no circumstances can be expected to restore a patient's body's lost cognitive functional capacity/quality of life. Accordingly, it is considered inappropriate to devalue the benefit provided by ANH based on its inability to restore a patient's functional capacity and/or quality of life lost as a result of injury, illness, or disease. The rationale for this restriction is also clear. If the foreseeable benefit(s) of a means of sustaining the life of an individual whose body has lost significant functional capacity/quality of life is evaluated by that standard, most, if not all means of sustaining life, including ANH, will be assessed as providing an insufficient benefit relative to virtually *any* foreseeable harm(s)/burden(s). For the perspective of the *exclusionary* analytical method, such an assessment of benefit is illegitimate and can be used as a subterfuge to justify the rejection of a means of sustaining life based on its *claimed* inability to provide a sufficient foreseeable benefit *despite* its *actual* ability to provide a foreseeable benefit by sustaining the life of a particular patient in a particular circumstance. From this perspective, what is being illegitimately justified is the rejection of a means of sustaining the life of a person with unacceptably low functional capacity and/or quality of life. Because the assessment of insufficient benefit has nothing legitimately to do with the means, the intention of the rejection is in truth not to avoid a means incapable of providing the benefit of sustaining life, but to avoid sustaining a life that itself provides inadequate benefit to the patient, and this is held to be a form of passive euthanasia, the intentional indirect killing of an innocent person.

There is another much more potentially onerous, and, at least arguably, highly *questionable* qualification to the *inclusionary* analytical method that *may* be imposed by adherents of the *exclusionary* method who are *especially* fearful that the rejection of a means of

sustaining life can be a form of passive euthanasia. This qualification requires that *in addition to* the assessment that a means of sustaining a patient's life has foreseeable harm(s) and/or continuing burden(s) that are, on balance, disproportionate to the foreseeable benefit(s) provided to him/her, the means must *also* be considered as a method of only temporarily forestalling the effects of an *incurable* fatal pathology. This fatal pathology must, in addition, significantly reduce the patient's life expectancy to some relatively arbitrary maximum from as little as mere hours or at most days, to as much as 6 months, and give rise to the prognosis that the patient is *terminally* ill.

It seems clear that the *overall* [871] rationale for this additional requirement is based on the determination that prevention of euthanasia trumps all other concerns, the *intention* to kill is the essential element in all forms of euthanasia, whether active or passive, voluntary or involuntary, and because the intention to kill is seldom, if ever, actually expressed, [872] intention, of necessity,

[871] It should also be noted that if the exclusionary analytical method focuses exclusively on whether a means of sustaining life imposes a harm(s) and/or continuing burden(s) that are, on balance, disproportionate to the benefit(s) provided thereby, *without* the additional requirement of the existence of an incurable fatal pathology significantly limiting life expectancy, results that are, at least arguably, morally unacceptable, can result. By way of example, a narrow focus on harms(s) and continuing burden(s) *directly* imposed and benefits *directly* provided by a means of sustaining life, without regard to other considerations, can justify the rejection of a long and arduous yet *possibly* successful regimen of chemotherapy by a thirty year old single mother, the sole means of support for her three children, who is otherwise healthy and for whom successful cancer treatment might provide an excellent chance of a long cancer-free life. Based on her narrowly focused subjective assessment that the foreseeable harm(s) and continuing burdens *directly* imposed by the chemotherapy, which she considers nothing short of horrific are, on balance, disproportionate to the benefits provided thereby, she may justifiably reject the cancer treatment. Justification is, at least potentially, less likely if the inclusionary analytical method is utilized because nothing is excluded, including an arguable obligation to endure the chemotherapy because of the benefit of her continued existence for her three young children. Justification is, on the other hand, obviously completely excluded if the more exclusive analytical method requires the existence of an incurable fatal pathology because the chemotherapy *may* effectively kill all of the cancer cells and her cancer cannot, in advance of the chemotherapy, be considered an *incurabl*e fatal pathology. The requirement that a patient be diagnosed with an incurable fatal pathology that significantly reduces life expectancy clearly reduces, if not eliminates entirely, similar morally unsatisfactory results.

[872] The acknowledgment that the intention to kill is seldom, if ever, actually expressed, and intent must, therefore, be inferred, yields the resultant assessment that the *possibility* of euthanasia can best be prevented by restricting the rejection of a means of sustaining life to those circumstances that maximize the plausibility of the inference that the rejection reflects an intention to no longer prolong the dying process, and minimize or eliminate the plausibility of the inference that the rejection instead reflects an intention to kill. Specifically, although the assessment, that a means of sustaining life imposes foreseeable harm(s) and/or burden(s) that are, on balance,

must be inferred. From this perspective, the *inference* that the rejection of a means of sustaining life reflects the intention to no longer prolong the dying process rather than the intention to kill by shortening life is clearly strengthened when the means being evaluated is considered as a method of only *temporarily* forestalling the effects of an *incurable* fatal pathology that significantly reduces the patient's life expectancy, and from the effects of which an individual is apparently dying.

What is uncertain is the extent to which, if at all, that same inference is strengthened when the life-sustaining means being evaluated is considered as a method of preventing, perhaps indefinitely, death from the effects of a *second* pathology that is potentially fatal, but nonetheless treatable. In simpler terms, it seems clear that the existence of an *incurable* fatal pathology, such as stage V lung cancer, that *significantly* reduces the patient's life expectancy, and from the effects of which he/she is therefore apparently dying, clearly strengthens the inference that his/her rejection of cancer treatment considered as a method of only temporarily forestalling the effects of the cancer, such as additional chemotherapy, reflects the intention to no longer prolong the dying process rather than to kill by shortening life. Uncertain is the extent to which stage V lung cancer also strengthens the inference that an individual's rejection of a means of preventing, perhaps indefinitely, death from the effects of a second pathology that is potentially fatal, but nonetheless treatable, and is for the most part either completely unrelated to the lung cancer, such as kidney dialysis or blood pressure medication, or is a response to complications of lung

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disproportionate to foreseeable benefit(s) thereby provided, permits a plausible inference that the rejection of that means reflects an intention to no longer prolong the dying process, the inference that the intention was to kill is not excluded. When, however, *in addition to* the assessment that a means of sustaining a patient's life will impose foreseeable harm(s) and/or continuing burden(s) that are, on balance, disproportionate to the foreseeable benefit(s) provided to him/her, the patient has an incurable fatal pathology that significantly reduces his/her life expectancy, strong evidence has been provided that this individual is dying an unpreventable death, and this lends additional and critical plausibility to the inference that the rejection of this means of sustaining life reflects an intention to no longer prolong the dying process rather than an intention to kill. Although by no means totally excluded, the possibility that the rejection reflects an intention to kill seems much more unlikely.

cancer, such as artificial nitration and hydration, reflects the intention to no longer prolong the dying process rather than to kill by shortening life.

What is certain, is that if an individual is apparently dying from the effects of an incurable fatal pathology, the possibility of euthanasia, from the rejection of a means of sustaining life utilized to forestall death from *another* cause, can be almost totally excluded, *provided* it is anticipated that death from the effects of the incurable fatal pathology will occur before death from the rejection of the means being evaluated. By way of example, death from terminal dehydration usually takes ten days to three weeks. If death from an unrelated incurable fatal pathology is expected to occur in *less* than ten days the rejection of artificial nutrition and hydration cannot be logically assessed as reflecting an intention to kill through passive euthanasia, provided the patient or surrogate decision-maker is aware of the foreseeable trajectory of both the fatal pathology and terminal dehydration. This is why adherents of the exclusionary analytical method who are especially fearful of euthanasia are more comfortable with the rejection of a means of sustaining life the shorter a patient's life expectancy, and may be willing to countenance the rejection or withdrawal of virtually all life-sustaining means, even a respirator, [873] when death is considered *imminent.*

Thus far, the above described possible rationales for the imposition of this additional requirement present a case for its acceptance that is not totally unreasonable, especially because

[873] Even with death considered imminent, withdraw of the breathing assistance of a mechanical breathing machine (respirator) can cause death almost immediately. Arguments and counter-arguments that imply that cause of death is the ultimate litmus test in the determination of whether the rejection of artificial nutrition and hydration was morally appropriate seem misguided. The claim can be advanced the rejection of ANH is a form of passive euthanasia because the cause of death is terminal dehydration and not a direct result of the effects of a incurable fatal pathology, as was anticipated. In response, it can be pointed out the most death certificates list the incurable fatal pathology as the cause of death and not terminal dehydration. Unfortunately, the claim and the counter-claim both seem to erroneously assume that the technical cause of death is of overriding significance in the determination of whether the rejection of ANH can be assessed as a form of passive euthanasia. Obviously the assessment that the rejection of ANH was a form of passive euthanasia must be rejected if death was a direct result of another fatal pathology, but it is otherwise of no consequence whatsoever.

for most individuals, as long as a pathology is only *potentially* fatal and *not* considered incurable, all other considerations aside, it would be illogical to reject a means of forestalling, perhaps indefinitely, its effects. Unfortunately, other considerations can totally alter this calculus, especially the assessment that foreseeable harm(s) and continuing burdens(s) imposed are disproportionate, on balance, to the foreseeable benefit(s) provided. Regrettably this additional requirement, if strictly applied, prohibits, *absent the existence of an incurable fatal pathology*, the rejection of a means of sustaining life considered as a method of preventing, perhaps indefinitely, death from the effects of a potentially fatal, yet nonetheless treatable, pathology. This result is not only illogical but at least potentially exceedingly onerous, [874] prohibiting the rejection of such a means even when an assessment is made that the foreseeable harm(s) and/or continuing burden(s) of this means are, on balance, *overwhelmingly* disproportionate to the foreseeable benefit(s) provided thereby, ignoring, therefore, that because of the insufficiency of available resources utilization of this means may well be a physical or moral impossibility for the patient and/or his/her family/caregivers, and, at least arguably, approaches a modified vitalism.

Finally, it is at least conceivable that adherents of this exclusionary analytical method could insist that because food and water not only have enormous symbolic significance but all human life is physiologically impossible in their extended absence, there is, accordingly, a higher standard of obligation to utilize nutrition and hydration in all its forms, natural and artificial, to sustain life. Most *secular* observers, although acknowledging, when an individual is unwilling or unable to eat and drink sufficiently to sustain his/her own life, an obligation to provide sips of

[874] The cost of preventing even the possibility of passive euthanasia seems high, indeed, prohibiting the rejection of such a means even when an assessment is made that the foreseeable harm(s) and/or continuing burden(s) of this means are, on balance, disproportionate to the foreseeable benefit(s) provided thereby, and creating, therefore, the possibility of real suffering. Nevertheless, for those who consider passive euthanasia a totally abhorrent rejection of respect for the sanctity of human life, the result they seek may, at least for them, be well worth the cost.

water and to spoon feed if necessary that is significantly greater than the obligation to provide medical treatment, nevertheless reject the classification of ANH as anything other than medical treatment, rejecting as well the accompanying claim that because ANH is nothing more than simple care there is a higher obligation to utilize it than the obligation to use those means of sustaining life appropriately considered medical treatment. [875],[876]

Apparently, no secular proponent of the *exclusionary* analytical method has yet publicly insisted on an *exceptionless* obligation to use ANH. To do so would advance a claim that is essentially vitalism for ANH. This would destroy the balancing of burdens/benefits paradigm that is a core tenet of this *exclusionary* analytical method, ignoring the reality, as noted above, that the obligation to use a means of sustaining a patient's life imposed out of respect for the sanctity and enormous intrinsic value of human life is *not unlimited*, not only because there are other human goods that have legitimate and significant value, including, but not limited to,

[875] Eileen P. Flynn. *Issues in Health Care Ethics.* (Upper Saddle River, NJ: Prentice Hall, 2000), 114-115. Eileen Flynn addresses the issue at some length in her book, *Issues in Health Care Ethics*, and seems to sum up most of the arguments made that ANH is not simply another form of eating and drinking, but instead medical treatment. First, she addresses why in her assessment tube feeding is not the equivalent of eating and drinking: "Feeding tubes are not equivalent to eating or drinking by mouth, even with assistance, because the mouth and throat do not participate in the process; the person being fed is entirely passive and often unaware of what is happening, no eating and drinking utensils are used; and the color, taste, aroma, texture, and social interaction which we identify with eating food at a meal are absent." Second, she gives four reasons why tube feeding is medical treatment: "First, feeding tubes require skilled medical training or a surgeon's medical license; Second, designing a feeding formula requires the collaboration of trained professionals: dieticians, pharmacists, and physicians; Third, the experience of being tube fed is completely passive and may even be involuntary, without enjoyment of the nourishment or the sensations accompanying feeding oneself a meal; Fourth, serious medical problems can ensue if feeding tubes are improperly emplaced or if they become displaced, and irritation or abscesses can appear at the sites where tubes enter the body, adding to patient discomfort and necessitating additional treatment.

[876] What Eileen Flynn neglects to address is the inconsistency between the proposed designation of ANH as simple care and *not* medical treatment, in large part because of the enormous symbolic significance of food and water and the ability of a layman to assist in tube feeding, and the unchallenged designation of mechanical ventilation as medical treatment. Most lay persons would undoubtedly agree that breathing is every bit as fundamental as eating and drinking. Forcing oxygen, an especially efficacious form of air, into the lungs seems equivalent to forcing especially efficacious forms of nutrition and hydration into the stomach or intestines. In both instances, an absolutely essential bodily function has been compromised, and mechanical intervention is required. Perhaps there would be a greater perception of equivalency, given the claim that any layman can assist in tube feeding once the tube is in place, if the ventilator was powered by hand rather than be electricity.

human dignity, individual personal autonomy, and the well being of others, but also because a patient and/or his/her family/caregivers, community and even society as a whole have *limited* physical, financial, psychological, emotional, and spiritual resources. It seems more likely that proponents of this *exclusionary* analytical method will have to satisfy themselves with the requirement that the foreseeable harm(s) and/or burden(s) of ANH must be *significantly* greater that foreseeable benefit(s) to be assessed as disproportionate and/or require a trial period of ANH to more accurately assess harm(s) and/or burden(s).

The very heart of the *exclusionary* analytical method is the determination of whether the foreseeable harm(s) and/or continuing burden(s) of a means of sustaining life, are, on balance, disproportionate to its foreseeable benefit(s), if any. Accordingly, the remainder of this chapter examines whether there are circumstances, including the circumstances specific to this inquiry, where the foreseeable harm(s) and/or burden(s) *directly imposed* by ANH itself, without regard to the burden, if any, imposed by the patient's functional incapacity and/or quality of life, can be reasonably assessed as, on balance, disproportionate to the foreseeable benefit(s) provided thereby, with the assessment of benefit(s) restricted *only* to what ANH is *designed and capable* of providing, and *not*, in addition, its ability to restore a patient's functional capacity and/or quality of life.. Also examined is whether in the circumstances specific to this inquiry ANH can be considered as a method of only temporarily forestalling the effects of an *incurable* fatal pathology that significantly reduces the patient's life expectancy, from the effects of which an individual is apparently dying, gives rise to the prognosis that the patient is *terminally* ill, and in so doing strengthens the inference that the rejection of ANH reflects the intention to no longer prolong the dying process rather than the intention to kill by shortening life.

From the outset, it must be recognized that the accurate identification and unequivocal substantiation of foreseeable legitimate benefit(s) provided by, as well as foreseeable legitimate harm(s), and continuing burden(s) imposed by, various methods of artificial nutrition and hydration are almost entirely dependent on clinical research conducted in accordance with rigorous scientific standards. Unfortunately, patients for whom ANH is provided are in many, if not most, instances seriously ill, making unambiguously meaningful clinical research extremely difficult. There have not as yet been any *randomized* trials involving ANH where the determination of whether a patient receives or foregoes ANH is made entirely at random, based, for example, on the flip of a coin. Not only are randomized trials, what Susan L. Mitchell, et. al. [877] call the "gold standard" for scientific research, nonexistent with regard to receiving or not receiving ANH, significant ethical issues attendant to randomly assigning seriously ill patients unable or unwilling to eat and drink sufficiently to sustain their lives to either a group that receives ANH or a group from whom ANH is withheld, make such a trial highly unlikely. Accordingly, reliance is necessarily placed on non-randomized trials and simple case studies, both of which have significant methodological shortcomings relative to randomized trials. Non-randomized trials re: ANH compare patients who received ANH with patients who did not. Few of any of these trials are capable of successfully matching these two groups of patients with regard to diagnosis, in most instances mixing patients whose primary life-threatening pathologies are significantly different, and even when diagnosis is more or less equivalent, prognosis, to the extent that it can be accurately determined, creates unacceptable differences between the two groups that have the potential of significantly skewing the results. Case studies involving ANH

[877] Susan L. Mitchell, J. M Tetroe, A. M. O'Connor, and A. Rostom, et. al. "Making Choices: Long Term Feeding Tube Placement in Elderly Patients." 17. http://decisionaid.ohri.ca/docs/Tube_Feeding_DA/PDF/TubeFeeding.pdf (accessed on June 15, 2011).

simply follow patients who receive ANH and attempt to find commonalities in their respective post ANH experience and outcome. Methodologically, these studies completely lack *any* form of *control* group comprised of those patients who have not received ANH, and are accordingly unable to measure patient experience and ANH outcomes relative to patient experience and outcomes where ANH has been foregone.

Despite these methodological shortcomings, however, clinical research, although unable to provide absolutely definitive and unequivocal answers to all of the questions raised by ANH, has provided some meaningful insights into the legitimate benefit(s) provided by, as well as legitimate harm(s), and continuing burden(s) imposed by various methods of artificial nutrition and hydration. Before examining some of the published results of this clinical research it is appropriate to provide a quick review of the various methods of providing ANH, described in chapter 3.

ANH can be provided directly into the digestive tract (enteral), or bypass a blocked or malfunctioning digestive tract (parenteral), providing ANH subcutaneously (under the skin) or directly (intravenously) into the bloodstream. Parenteral methods include entry into the bloodstream through a smaller blood vessel (peripheral parenteral nutrition) through a major blood vessel in the chest (Total Parenteral Nutrition TPN), or under the skin (hypodermoclysis). Enteral methods include a tube placed into the nose (Naso Enteric Tube NET) that empties into the esophagus or beyond. An NG tube empties into the stomach; a nasoduodenal tube empties into the first section of the small intestine, the duodenum, a nasojejunal tube into the second section of the small intestine, the jejunum. Another means of enteral access bypasses the nasal passages, throat and esophagus entirely and provides direct access in to the stomach or small intestine. A gastrostomy places a tube directly into the stomach, a jejunostomy directly into the

jejunum. Surgical gastrostomies and jejunostomies, as the name implies, surgically place the respective tubes, but both can also be accomplished without general surgery through the use of an endoscope (Pecutaneous Endoscopic Gastrostomy (PEG), Percutaneous Endoscopic Jejunosotomy (PEJ) or Percutaneous Endoscopic Gastrojejunostomy PEG/J)), [878] or radiologically through the use of fluoroscope (Percutaneous Radiological Gastrostomy/Jejunostomy/Gastrojejunostomy). Proctoclysis uses the rectum as a means of placing ANH directly into the colon.

Claimed Benefits of ANH

Proponents claim that ANH provides a number of legitimate benefits to patients unwilling or incapable, even with assistance, of eating and drinking sufficiently to provide their bodies with adequate nutrition and hydration, including reducing hunger and thirst, reducing pressure sores, restoring physical strength and resistance to infection, reducing aspiration pneumonia, and extending life.

Reduction of Hunger and Thirst

There is no published clinical research confirming that ANH relieves hunger and thirst, but there is no reason to suppose that ANH does not do so, *provided* that a patient still physiologically requires nutrition and hydration and is still capable of experiencing either or both of those sensations. Not only can the human body, as a result of illness, disease, or injury, *permanently* lose the physiological capacity to successfully utilize *any* form of nutrition and hydration, the body can also lose the *need* for nutrition and hydration, as manifested in a

[878] A PEG/J tube employs two separate tubes. A larger tube that is placed directly into the stomach, and a smaller tube that passes inside the larger tube and reaches the jejunum.

patient's loss of appetite, and limited, if any, desire for water. [879] Accordingly, it cannot be automatically assumed that *every* patient, for whom ANH is considered as a *possible* response to inadequate nutrition/hydration, retains either the physiological capacity to successfully utilize nutrition and hydration or the need for nutrition and hydration, and is necessarily, therefore, hungry or thirsty.

Dr. Howard Brody, et. al. seem to capture the essence of the apparently common misperception regarding the appropriateness of ANH for dying patients whose appetite and/or thirst appears insufficient to sustain their lives: "We seem to have forgotten the difference between people who die because they stop taking in food and water, and people who stop taking in food and water because that is part of the natural dying process." [880] It seems, therefore, highly likely that patients receiving ANH will *not* give any indication of being hungry or thirsty, but not entirely for the reason some observers might suppose. Adequate ANH almost certainly relieves hunger and thirst *if it is present*, but it cannot be assumed that every patient receiving ANH was hungry and/or thirsty at the time ANH was initiated, or would be hungry and/or thirsty if ANH was withheld or withdrawn. [881] Accordingly, it must be conceded that ANH relieves a patient's hunger and thirst, but only when that patient would experience hunger and thirst in the absence of ANH.

[879] Chapter 3 examines the phenomenon of anorexia and is worth referencing.

[880] Brody, Hermer, Scott, Grumbles, Kutac and McGammon. Unpublished first draft of article that was later published as "Artificial Nutrtion and Hydration: The Evolution of Ethics, Evidence and Policy." *Journal of General Internal Medicine* 26, no. 9 (September, 2011): 1053-8.

[881] Not only can it not be automatically assumed that when nutrition and hydration appear inadequate a patient is ipso facto hungry and/or thirsty, it can neither be assumed that a patient apparently receiving inadequate nutrition/hydration who is experiencing hunger and/or thirst has not decided to endure those sensations for reasons of his/her own, including the determination not to delay the dying process.

Reduction of Pressure Sores

Another possible claim is that ANH reduces or eliminates pressure sores, also referred to as bed sores or decubitus ulcers. As the name implies, pressure sores result from prolonged pressure on the skin, especially where the skin is pressed against bone such as ankles and elbows, but also on bones of the hips, heels, and the back. Prolonged pressure on the skin in these susceptible areas results from a patient's inability to change position with sufficient frequency, and is further aggravated when the skin is wet and/or soiled. Not only can pressure sources be exceedingly painful, infection is not uncommon and can be life-threatening, especially for the older patient with a compromised immune system. Pressures sores are, as a result, a serious complication for bed ridden patients, especially the elderly, and are taken very seriously. T. S. Dharmarajan, et, al., suggests that "[l]ow body weight, hypoalbuminemia, low total lymphocyte count, and other poor nutrition parameters are strongly associated with pressure sores, [882] and David R. Thomas claims that although "[n]o study has demonstrated that improvement in nutritional status can prevent pressure ulcers. . .[t]here is at least suggestive evidence that improvement in nutritional status can improve outcome in pressure ulcer healing." [883] Thomas acknowledges, however, that although "[t]he logic behind nutritional supplementation and wound healing is almost irresistible. . . [n]utritional support can improve nutritional status [and] [t]herefore, nutritional support should be able to reduce complications," [884] "[p]roof of this reasoning. . .remains illusive in the medical literature." [885]

[882] T. S. Dharmarajan, D. Unnikrishman, and C. S. Pitchumoni. "Percutaneous Endoscopic Gastrostomy and Outcome in Dementia." *American Journal of Gastroenterology* 96, no. 9 (September 2001): 2560.

[883] David R. Thomas, "Improving Outcome of Pressure Ulcers with Nutritional Interventions: A Review of the Evidence." *Nutrition* 17, no. 2 (February 2001): 121.

[884] *Ibid*, 122.

The literature seems to support Thomas' assessment. Not only do a number of researchers report that tube feeding has no apparent effect on the healing of existing pressure sores or the prevention of new pressure sores, [886] Dharmarajan et. al. claim that "[o]n the contrary, some studies have suggested that the incidence of pressure sores is increased in tube-fed patients." [887] Dharmarajan and his associates speculate that "[t]his may be related to increased use of restraints, immobility, fecal incontinence, and diarrhea, all of which are usually seen in the ill-fed tube patient or as accompaniments of tube-feeding." [888] Counter-intuitively, and therefore surprisingly, Alan Sanders questions whether ANH has demonstrated the kind of improved nutritional status that would, at least presumably, prevent or reduce pressure ulcers: "Frequently, patients who have problems eating lose weight and develop other signs of malnutrition, such as a lower serum albumin level, lower total lymphocyte count, and impaired skin-test reactivity. Data show that the use of a PEG tube in patients at the end of life may not lead to improvement in these markers." [889]

Not only, therefore, is evidence entirely lacking of a causal relationship between ANH and the healing of existing pressure sores/prevention of new pressure sores, there is evidence that, at minimum, suggests that tube feeding and/or the accompaniments of tube feeding, can aggravate

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[885] *Ibid*.

[886] Cynthia T. Henderson, Linda S. Trumbore, Sohrab Mobarhan, Richard Benya, et. al. "Prolonged Tube Feeding in Long-Term Care: Nutritional Status and Clinical Outcomes." *Journal of the American College of Nutrition* 11, no. 3 (1992): 309. A 3-month study of chronically tube-fed long term care residents with advancing dementia who were fed enterally showed no observable effect on pressure ulcer outcome.

[887] Dharmarajan, Unnikrishman, and Pitchumoni. "Percutaneous Endoscopic Gastrostomy," 2560.

[888] *Ibid*.

[889] Alan Sanders."The Clinical Reality of Artificial Nutrition and Hydration for Patients at the End of Life." *National Catholic Bioethics Quarterly* 9, no. 2 (Summer 2009): 297.

existing pressure ulcers and contribute to the creation of entirely new pressure ulcers. Accordingly, although it is certainly possible that ANH *may*, under certain circumstances, assist in healing or preventing pressure sores, there is no credible evidence to support a claim that ANH *will* do so.

Greater Reduction to Infection

If, as Alan Sanders maintains, evidence is lacking that PEG tube feeding necessarily improves nutritional status, it should come as little surprise that there is no proven link between ANH and resistance to infection. According to Dharmarajan, et, al. "[t]here are no data to suggest that there is a decrease in the incidence of urinary, GI, viral, or other infections in *demented* (my emphasis) patients on long term enteral feeding." [890] In their view, "[t]he presence of feeding tubes may even be the reason for significant local and systemic infections such as cellulitis, diarrhea, or bacteremia." [891]

Prevention of Aspiration Pneumonia

A principal and longstanding claim of advocates of tube feeding is that it prevents aspiration pneumonia. Given, as noted in previous chapters, that aspiration pneumonia is an extremely serious, life-threatening complication not only in late stage Alzheimer's disease but with a number of other debilitating illnesses that afflict the elderly, the prevention or even the reduction of aspiration pneumonia would provide an enormous benefit to these patients. It is at the outset, important to distinguish aspiration pneumonia from aspiration pneumonitis. Paul E.

[890] Dharmarajan, Unnikrishman, and Pitchumoni. "Percutaneous Endoscopic Gastrostomy," 2560.

[891] *Ibid*.

Marik informs that "[a]spiration is defined as the inhalation of oropharyngeal or gastric contents into the larynx and lower respiratory tract, [and] [s]everal pulmonary syndromes may occur after aspiration, depending on the amount and nature of the aspirated material, the frequency of aspiration, and the host's response to the aspirated material." [892] Stephen McClave et. al. add that the host's response is determined by "age, immune status, underlying disease process, and comorbidities." [893] According to Marik, "[a]spiration pneumonitis (Mendelson's syndrome) is a chemical injury caused by the inhalation of sterile gastric contents, [894] whereas *aspiration pneumonia* (my emphasis) is an infectious process *caused by the inhalation of oropharyngeal secretions that are colonized by pathogenic bacteria* (my emphasis)." [895],[896]

Of critical importance in identifying the possible relationship between tube feeding and aspiration pneumonia, Marik identifies two ways that, before being aspirated into the lungs, material can be colonized by pathogenic bacteria: "Colonization of the gastric contents by potentially pathogenic organisms may occur when the PH in the stomach is increased. . . [including] gastric colonization by gram negative bacteria in patients *who receive enteral feedings*" (my emphasis). [897] Aspiration pneumonia can [also] develop after the inhalation of

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[892] Paul E. Marik. "Aspiration Pneumonitis and Aspiration Pneumonia." *New England Journal of Medicine* 344, no. 9 (March 1, 2001): 665.

[893]Stephen McClave, Mark T. DeMeo, Mark H. DeLegge, James A. DiSario, Daren K. Heyland, and James P. Maloney, et. al. "North American Summit on Aspiration in the Critically Ill Patient: Consensus Statement." *Journal of Parenteral and Enteral Nutrition* 26, no. 6 Supp. (November 2002): S83.

[894] For aspiration pneumonitis to occur, the gastric contents aspirated into the lungs must have a sufficiently low pH (high acidity) to damage sensitive lung tissue.

[895] Paul E. Marik, "Aspiration Pneumonitis and Aspiration Pneumonia," 665.

[896] *Ibid.* The source of these pathogenic bacteria is, somewhat surprisingly, not the gastrointestinal system. According to Marik, "[b]ecause gastric acid prevents the growth of bacteria, the contents of the stomach are sterile under normal conditions."

[897] *Ibid.*.

colonized oropharyngeal material," which in his opinion, "is the primary mechanism by which bacteria gain entrance to the lungs." [898],[899]

It is important to note that a large number of healthy individuals apparently aspirate during sleep, yet nevertheless do not develop aspiration pneumonia. [900],[901] Obviously, therefore, if aspiration alone is insufficient, in and of itself, to cause aspiration pneumonia, there are other influences at work that prevent aspiration pneumonia from being a more common occurrence. In Paul Marik's view, with regard to aspiration pneumonia "[p]resumably the low burden of virulent bacteria in normal pharyngeal secretions, together with forceful coughing, active ciliary transport, and normal humoral and cellular immune mechanisms, results in clearance of infectious materials without sequelae," [902] but he is quick to add that "if these mechanical, humoral, or cellular mechanisms are impaired or if the amount of aspirated material is sufficiently large, pneumonia may follow." [903],[904]

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[898] *Ibid.*

[899] Susan E. Langamore, Margaret S. Terpenning, Anthony Schork, and Yinmiao Chen, et. al. "Predictors of Aspiration Pneumonia: How Important is Dysphagia." *Dysphagia* 13, no. 2 (Spring1998): 75. Langamore and associates studied 189 elderly patients in an attempt to determine the greatest risk factors for aspiration pneumonia. They found that "aspiration of secretions and excess secretions in the mouth were both significantly associated with pneumonia," commenting that although "[v]ery few previous studies have considered the importance of aspirated secretions. Murray, et. al. and Harkness, et. al. independently reported this factor to be a sensitive predictor of aspiration and/or aspiration pneumonia."

[900] Paul E. Marik. "Aspiration Pneumonitis and Aspiration Pneumonia," 671. Marik claims that "[a]pproximately half of all healthy adults aspirate small amounts of oropharyngeal secretions during sleep"

[901] Eliot J. Huxley, Jose Viroslav, William R. Gray, and Alan K. Pierce. "Pharyngeal Aspiration in Normal Adults and Patients with Depressed Consciousness." *American Journal of Medicine* 64, no. 4 (April 1978): 567. Huxley and Viroslav compared 20 normal volunteers and 10 patients with altered levels of consciousness, using inert radioactive tracer which allowed detection of subtle aspiration without interfering with normal protective and clearance mechanisms. Their findings suggest that although "[a]spiration occurred more frequently and more extensively in the patients with depressed consciousness. . . all normal people frequently aspirate secretions from their pharynyx during deep sleep." In their view, "normal adults are constantly contaminating their lower respiratory tract with bacteria; however, infection only develops when normal pulmonary defense mechanisms are either impaired or overwhelmed and the aspirated bacteria can rapidly multiply."

[902] Paul E. Marik. "Aspiration Pneumonitis and Aspiration Pneumonia," 667.

[903] *Ibid.*

To summarize, in order for aspiration pneumonia to occur, an individual must aspirate into his/her lungs a sufficient quantity of material colonized with pathogenic bacteria, be incapable of mechanically clearing that material from his/her lungs, and possess a immune system that is unable to quickly destroy or, at minimum, neutralize the pathogenic bacteria. [905] It follows then, that if ANH is going to prevent aspiration pneumonia it must significantly reduce or entirely eliminate aspiration, prevent the colonization by pathogenic bacteria of material before it is aspirated in to the lungs, or provide a significant boost to an underperforming immune system. As discussed above, there is no proven link between ANH and resistance to infection, and thus no basis for concluding that ANH improves immune system function by improving nutritional status. Accordingly, to prevent aspiration pneumonia ANH must reduce or entirely eliminate aspiration, including not only the aspiration of gastric contents but oropharyngeal secretions as well, and failing that, must prevent the colonization by pathogenic bacteria of *whatever* material it is incapable of preventing from being aspirated into the lungs.

As will be discussed below, because of the very nature of intravenous access for artificial nutrition, there are limits to the length of time that an individual can receive nutrition through

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[904] William J. DePaso. "Aspiration Pneumonia." *Clinics in Chest Medicine* 12, no. 2 (June 1991): 273. DePaso adds that:"[t]he fact that occult aspiration is common and yet clinical illness is rare suggests that the development of lung injury is dependent on several factors. . .such as the ability to cough, alveolar macrophage function, nutritional status, mobility, and presence of structural lung disease."

[905] Langamore, Terpenning, Schork, and Chen, et. al. "Predictors of Aspiration Pneumonia, 76, 77. Langamore and associates reported in 1998 that that dysphagia and even aspiration are not enough to cause aspiration pneumonia: "[D]ysphagia and aspiration may not be critical risk factors in a person who is medically stable, has a clean, healthy mouth, and/or is independent for daily activities, especially feeding. If a combination of these positive conditions are not met, however, pneumonia may develop." Further, in their opinion, "aspiration will only lead to pneumonia if the material aspirated is pathogenic to the lungs and if host resistance to the inoculum is compromised." "Once aspiration has occurred," they claim,"host defenses must rally to clear the material [and c]ough and mucociliary clearance act to drive the material out of the lungs, and lymphatics and alveolar macrophages represent the cellular level of host response."

parenteral feeding. As a result, enteral feeding is the only method of ANH capable of providing adequate nutrition for an extended period of time, and it is enteral feeding that has been presumed to prevent aspiration. The logic undergirding that presumption rests, in principal part, on three apparent assumptions. The first assumption is that if an individual with dysphagia or other swallowing problems receives ANH through an enteral feeding tube, and all efforts at continuing normal eating and drinking cease, that aspiration of *orally* ingested solids and liquids into the lungs as a result of these swallowing problems will be thereby entirely prevented. The second assumption is that the direct placement of the enteral feeding tube, through which this individual receives nutrition and hydration, into the stomach or small intestine, thereby bypassing entirely the mouth, throat, and esophagus, the greater the likelihood that reflux of gastric contents up and through the esophagus and aspiration into the lungs will be prevented. [906] A third assumption is that the further this enteral feeding tube is placed down the gastrointestinal tract from the stomach, into the first or even the second section of the small intestine, the even greater likelihood that reflux up and through the esophagus and into the lungs will be prevented. [907]

There has been no shortage of research efforts undertaken to provide scientific evidence to support not only the overall presumption that ANH prevents aspiration pneumonia, but the three assumptions upon which that presumption is based. Unfortunately, research seems to have essentially rebutted the presumption that ANH prevents aspiration. In 2008, Susan Mitchell and

[906] This assumption is based in part on the assessment that whereas a nasogastric feeding tube passed down the esophagus and into the stomach keeps the sphincter separating the esophagus and stomach pried open, presumably making reflux of gastric contents from the stomach into the esophagus that much easier, an enteral feeding tube placed directly into the stomach or small intestine bypasses this sphincter altogether. In simpler terms, a PEG tube should prevent the reflux and aspiration of gastric contents that an NG tube permits.

[907] This assumption is based in part on the assessment that if the enteral feeding tube is placed in the small intestine, the problem of overfilling of the stomach with too much liquid as well as the problem of residual liquid remaining in the stomach, both of which can presumably promote reflux into the esophagus, are avoided.

her co-authors accurately summarized the roughly thirty years of scientific research into the effects of tube feeding on aspiration pneumonia:

> Non-randomized trials with and without feeding tubes show that patients with tubes are more likely to be aspirators. However, it is not clear from the studies if getting a feeding tube increases the chances of aspirating, or whether being an aspirator increases the chances of getting a tube. It is clear from several case studies that putting in a feeding tube will not necessarily stop a patient from aspirating. More than half of patients in these studies who aspirated *before* they were given a tube, still aspirated *after* they were given a tube. On average, 16 out of 100 patients with a feeding tube will aspirate. [908]

That research has rebutted the presumption that ANH prevents aspiration pneumonia seems *almost* inexplicable, at least at first blush, given that the first, [909] second, [910], [911], [912], [913], [914], [915], [916], [917]

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[908] Mitchell, Tetroe, O'Connor, and Rostom, "Making Choices," et. al., 10.

[909] There is simply no evidence from clinical research that disputes this assumption, and the weight of its logic seems overwhelming. It is impossible to aspirate food and drink ingested orally into the lungs if that ingestion never takes place.

[910] It seems likely that research conducted to verify the truth of this second assumption may have been, at least initially, undertaken because of the observed apparent poor performance, clearly contrary to expectations, of NG tube feeding in *totally* preventing aspiration. What follows in subsequent footnotes are very brief summaries of journal reported clinical research listed chronologically, that although by no means exhaustive, does include many of the principal findings that bear directly on the validity of this second assumption. Although research may ultimately prove this assumption to be correct, such a conclusion, as will be shown, is not unequivocally supported by the research findings published thus far. In simpler terms, there is no unequivocal scientific evidence that a PEG tube is superior to an NG tube in preventing aspiration and aspiration pneumonia.

[911] **1973** *Archives of Surgery*. John L. Cameron, et. al. reviewed the records of forty-seven patients with significant and well-documented aspiration to determine whether predisposing factors could be identified. Result: "Acutely ill, comatose patients with gastrointestinal or neurologic disease and an in-dwelling NG tube were at particular risk" (49).

[912] **1974** *Stroke.* Olivares, Segovia, and Revuelta.
Result: In a study of pulmonary tissue in 720 neurologic autopsy cases, it was found that the incidence of aspiration in those with gastric tubes was 24% (as opposed to 5% in those without gastric feeding tubes).

[913] **1978** *Journal of Parenteral and Enteral Nutrition.* Belcher, Seltzer, and Slocum et. al.
Result: 0.8% aspiration rate for those tube-fed.

[918] [919] [920] [921] [922] [923] [924] [925] [926] [927] [928] [929] [930] [931] [932] [933] [934] [935] [936] [937] [938] [939] [940] [941] [942] [943] [944] [945] and third [946] [947] [948] [949] [950] [951] [952] [953] [954] [955] [956] [957] [958] [959] [960] [961] [962] [963] [964] [965] [966] [967] [968] [969] assumptions

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[914] **1979** *Annals of Internal Medicine* Heymsfield, Bethel, and Ansley, et. al.
Result: aspiration pneumonia is rare (less than 1%) in patients fed via small bore NG tubes.

[915] **1981** Annals of Internal Medicine Winterbauer et. al. used glucose oxidase reagent strips to monitor for the aspiration of glucose present in the nutrition formula given 20 critically ill patients through an NG tube.
Result: 19 of the 20 showed evidence of aspiration. Of 323 patients fed with an NG tube, 38% apparently aspirated.

[916] **1982** *Journal of Parenteral and Enteral Nutrition* Bernard, Braunstein, and Stevens
Result: A 13% incidence of aspiration pneumonia was reported by a group of researchers who reviewed the charts of 99 tube-fed patients; they considered aspiration pneumonia to be present when. . .enteral fluid was identified in pulmonary secretions.

[917] **1986** *Heart and Lung* Metheny, Eisenberg, and Spies studied eight Nursing Units in two Midwestern Hospitals only requirement for inclusion in study was presence of nasogastric tubes.
Result: Of 105 patients with NG tubes, 5.75 % had documented pulmonary aspiration with traces of the feeding formula visibly present in orophayrngeal secretions.

[918] **1987** *Journal of Clinical Gastroenterology* Cole and Smith et. al.
Results: "Aspiration pneumonia, a recognized complication of enteral feeding via a nasogastric tube, is considered uncommon with percutaneously placed gastrostomy tube feeding. We report aspiration pneumonia during enteral alimentation in a neurologically compromised but conscious patient. Aspiration continued despite changing the route of enteral feeding from nasogastric to percutaneous gastrostomy. Quantitative scintigraphic studies with Tc-99m-labeled enteral infusion demonstrated frequent episodes of gastroesophageal reflux and aspiration of gastric contents, which increased when the infusion rate was speeded up for nutritional replacement." (90).

[919] **1988** *Surgery, Gynecology, and Obstetrics.* James M Hassett, et. al.
Result: 87 neurologically disabled patients with a gastrostomy. Prior to gastrostomy 29 0f the 87 aspired. Of these 29, 18 still aspirated after the gastrostomy. Of the 58 who had not aspired prior to the gastrostomy, 17 aspired after gastrostomy.

[920] **1988** *Archives of Internal Medicine* Ciicone, Silverstone, et. al.
Results: "Aspiration of oral and pharyngeal material cannot be eliminated by any method of tube feeding" (433). "Aspiration pneumonia, itself an indication for tube feeding, remains a major problem regardless of whether nasogastric or gastrostomy intubation is used" (433).

[921] **1988** *Gastroenterology* Chia-Sing Ho et. al.
Result: 100 surgical gastrostomies compared to 134 Percutaneous nonendoscopic gastrostomies
30 day Aspiration requiring trachesotomy: 2 surgical 0 percutaneous
30 day Aspiration not requiring surgery: 8 surgical 0 percutaneous

[922] **1989** *American Surgeon* Christopher Steffes et. al.
Result: 112 PEGS: Aspiration in 3 for certain suspected in 5 others

[923] **1989** *American Journal of Gastroenterology* Cogen and Weinryb.
Result: "We attempted to determine the incidence of aspiration pneumonia in gastrostomy tube-fed patients in a SNF [Skilled Nursing Facility] by retrospective chart review. . . The incidence of probable aspiration pneumonia was 19%. Addition of the possible cases increased the incidence to 23%. . . The only risk factor that was statistically significant for aspiration pneumonia was a previous history of pneumonia during the hospitalization prior to a transfer to the SNF." (1511).

[924] **1990** *Journal of Clinical Gastroenterology* Patel and Thomas
Result: Risk factors for pneumonia after PEG: esophagitis at the time of placement indicating significant gastroesophageal reflux, history of pneumonia prior to PEG, older than 70.

[925] **1990** *Gastrointestinal Endoscopy* Stiegmann, et. al.
Result: 57 surgical (48 because of neurological issues) gastrostomies compared to 64 PEG (56 because of neurological issues). Aspiration pneumonia in 5 of OG, 2 of PEGs.

[926] **1991** *American Surgeon* James Stephen Scott, et. al.
Result: 50 surgical gastrostomies compared to 50 PEGs. 61% of both groups because of neurologic disorders 6 of gastrostomies and 4 of PEGs because of aspiration. Aspiration in 2 of the gastrostomies and 2 of the PEGs.

[927] **1991** *American Journal of Gastroenterology* David Fay et. al.
Result: 80 PEG tubes compared to 29 NG tubes. Aspiration pneumonia within 14 days 24% of NG tube recipients, 6% of PEG tube recipients. No appreciable difference, however, after 14 days in aspiration rates

[928]**1991** *American Journal of Gastroenterology* William L. Horton, et. al.
Result: 224 PEGS (only 14 because of dementia). Post PEG aspiration in only 3 patients.

[929] **1992** *Scandinavian Journal of Gastroenterology* Baeten and Hoefnagels.
Result: 46 NG tubes compared with 44 PEG tubes. Equal aspiration rates in both groups (6.5%).

[930] **1992** *Journal of the American College of Nutrition* Cynthia T. Henderson, Trumbore, et. al.
Result: 40 chronically tub- fed long term care patients data collected at 3 months (3 month mortality 10%) with follow up mortality at 12 months of 30%. Of the 12 deaths at the end of 12 months, 9 of the 10 medical charts indicated pneumonia as cause of death.

[931] **1992** *Journal of Parenteral and Enteral Nutrition* Helen Mullan, et. al.
Result: 276 tube-fed patients observed over 6 month period with only 12 aspiration events (4.4%). “Pulmonary aspiration is an uncommon and generally benign event among enterally supported patients. More frequent aspiration among ward than intensive care unit patients suggests that aspiration is not an inevitable consequence of severe illness, but can be prevented with adequate nursing care and pulmonary precautions [careful nursing supervision, avoidance of bolus feedings, and good airway management]. The fear of aspiration is not a sufficient cause to withhold enteral nutrition support in acutely ill patients” (160).

[932] **1992** *Archives of Surgery* William R. Jarnagin.
Result: 64 PEGs tube placements, 24 with a history of aspiration. Of these 24, 9 developed aspiration pneumonia within 3 days of the procedure. “At present, we recommend that gastronomy be used sparingly and with utmost caution in patients with spontaneous bouts of aspiration pneumonia” (263).

[933] **1992** *Mayo Clinic Proceedings* Celeste A. Taylor and David E. Larson et. al. Result: 97 patients received a PEG tube. 54 patients (59%) had 179 episodes of pneumonia after PEG tube placement.

[934] **1994** Dysphagia John F. Croghan et. al.
Result: Of 22 patients with aspiration , 15 had feeding tubes placed This group had a higher rate of pneumonia and pneumonia death than 7 who did not have tubes. Those with NG tubes had higher death rate (7/9) than patients with gastronomy tubes (2/8) but similar rates of pneumonia.

[935] **1994** *Digestive Diseases and Sciences* Kaw and Sekas
Result: 46 nursing home residents with PEGs predominately (52%) for dementia mean age 73.6 (19-96). 20% overall aspiration rate: (14.8% aspiration rate in those with normal mental status, 18.2% of those disoriented, 30.8% of those obtunded.

[936] **1995** *Gastrointestinal Endoscopy* Victoria Light, et. al.

Result: 416 PEG tubes. Mortality risk higher in patients with urinary tract infection, previous aspiration, and over 75 years of age. 1 week mortality of patients with urinary tract infection and previous aspiration, 48%. 30 day mortality of those patients with all three risk factors, 67%.

[937] **1996** *Journal of General Internal Medicine* Linda Rabeneck, et. al.
Result: Of 7369 VA Hospital patients with PEGs (mean age 68) (28.6% with PEGs because of neurologic disease) 8% with aspiration pneumonia post PEG placement.

[938] **1996** *Journal of the American Geriatrics Society* Neora Pick, et. al.
Result: Retrospective 69 patients over18 months "Both gastric and nasogastric tubes were associated with an increased risk for aspiration." (767).

[939] **1996** *Dysphagia* Michael J. Feinberg et. al.
"Compared with the other three groups, pneumonia was significantly higher during months of artificial feeding (4.4%)" (107) "It was not a successful alternative in attempting to prevent pneumonia" (108).

[940]**1997** *Nutrition* Concetta Finocchiaro et. al.
Result: 136 patients with PEG tubes mean age 62 (range 16-89) 49% had cancer 51% non-cancer patients. Only 1 with aspiration pneumonia subsequent to tube placement.

[941]**1998** *Age and Ageing* Anthony James, et. al.
Result: 126 PEGs for dysphagia caused by acute stroke. Median age 80 (53-94), 51% male. Aspiration pneumonia was the most frequent complication post PEG insertion.

[942] **2001** *Journal of the American Geriatrics Society* Mutsuo Yamaya, et. al.
Result: "[N]asogastric tubes promote aspiration of gastric contents by impairing swallowing, causing stagnation of oropharyngeal secretions and reducing the tone of the lower esophageal sphincter"(89).

[943] **2002** *Dysphagia* Susan E. Langmore, et. al.
Result: Strongest to weakest predictors of aspiration pneumonia: suctioning use, COPD (chronic obstructive pulmonary disease), CHF(congestive heart failure), presence of tube feeding.

[944]**2003** *Journal of Gerontology* Arthur Lebowitz, et. al.
Result "The main finding in this study is the significantly higher rate of pathogenic isolations from the oropharynx of tuboenterally fed patients. GNB [gram negative bacteria] have been isolated from 81% of the 78 NGT fed patients and from 51% of the 57 PEG fed patients, as opposed to only 17.5% of the 80 orally fed group. The prevalence of *Pseudonomias* was very high and found only in those fed by NGT or PEG. Some of the highly pathogenic bacteria such as *P. aeruginosa* and *Klebsiella*, uncommon in the oral flora of normal persons (here citing Thomas, S., R. Rajagopalan, and N. Brahmadathan. "Alterations in Oropharyngeal Flora in Patients with a Nasogastric Tube: a Cohort Study" *Critical Care Medicine* 20 (1992): 82-3), have been cultured exclusively in tube fed patients" (53).

[945] **2006** *American Journal of Mental Retardation* David S. Gray and David Kimmel
Result: 93 patients, all of whom had a history of pneumonia before feeding tube insertion, 83 of whom profoundly mentally retarded. 56 PEGs, 24 surgical gastrotomies, 13 jejunostomies. 45% decrease in pneumonia in the year following tube placement.

[946] This third assumption is essentially the completely plausible contention that patients with feeding tubes placed into the duodenum will experience less aspiration that those who have feeding tubes placed into the stomach and that those with tubes placed into the jejunum will experience less aspiration than those with tubes in the duodenum. What follows in subsequent footnotes are very brief summaries of journal reported clinical research listed chronologically, that although by no means exhaustive, does include many of the principal findings that bear directly on the validity of this third assumption. Although research may ultimately prove this assumption to be correct, such a conclusion, as will be shown, is not unequivocally supported by the research findings published thus far. In simpler terms, there is no unequivocal scientific evidence that with regard to preventing aspiration a feeding

tube placed into the duodenum tube is superior to a tube placed into the stomach or a tube placed into the jejunumn is superior to a tube placed into the duodenum.

[947] **1984** *Journal of Parenteral and Enteral Feeding* Kiver et. al.
Result: 56 patients: 39 in pre pyloric group (3 NG, 11 Gastrostomy 25 nasoduodenal situated proximate to the pylorus) 17. In post pyloric group (6 jejunostomy and 11 nasoduodenal) Aspiration 46% in pre pyloric group, 6 % in post pyloric group.

[948]**1985** *American Surgeon* Burtch and Shatney
Result: 22 gastrostomies 9 jejunostomies. 8 of gastrostomies had aspiration, 0 of jejunostomies.

[949] **1986** *Archives of Surgery* Mark Adams and Gary Seabrook, et. al.
Result: 73 patients underwent jejunostomies. "Patients with a history of aspiration prior to jejunostomy continue to be at high risk for this life-threatening event. The delivery of feeding distal to the pylorus does not offer protection against duodenogastric reflux and subsequent aspiration. The risk of aspiration is not related to the type of jejunostomy performed but is strongly related to a previous history of aspiration" (238).

[950] **1987** *American Surgeon* Burtch and Shatney
Result: 26 gastrostomies 30 jejunostomies. Aspiration in 9 of gastrostomies 3 of jejunostomies.

[951] **1989** *Gastrointestinal Endoscopy* David S. Kaplan, et. al.
Results: 23 PEJ tube insertions after NG trials. 13 aspirations during NG, 5 after PEJ replacements.

[952] **1990** *Gastrointestinal Endoscopy* J. A. DiSario et. al.
20 PEJs thru PEG extensions. 10 0f 15 patients (67%) treated with PEJ to prevent aspiration continued to aspirate.

[953] **1990** *Journal of the American Geriatrics Society* Arthur Peck et. al.
Result: 104 elderly patients. 52 had feeding tubes 52 without feeding tubes served as a control group. Dementia present in 100% of tube fed 71% of controls. 17% of control group had aspiration pneumonia. Tube group had 58% aspiration pneumonia. The 39 with an NG tube 54% pneumonia, the 9 with gastrostomies had 67%, the 4 with jejunostomies 75%.

[954] **1990** *Gastrointestinal Endoscopy* H.C. Wolfsen et. al.
Result: 191 patients received either a PEG tube or a PEJ tube. Aspiration before tubes in 15 of the PEGs 14 of the PEJs. 30 days after tube placement aspiration in 5% of PEGs (6 patients), 17% of PEJs (13 patients)
"This study demonstrates that percutaneous endoscopic jejunostomies, similar to surgically placed jejunostomies, do not prevent aspiration in predisposed patients. Aspiration was significantly more common in PEJ tube patients and likely related to the underlying disease of these patients plus a significant incidence of jejunal tube migration proximally into the stomach" (263).

[955] **1990** *Journal of Parenteral and Enteral Nutrition* James V. Sitzmann
Result: 90 patients with admitting diagnosis of dysphagia. 30 of these developed aspiration pneumonia. 40% of neurologic based dysphagic patients and 20 % of mechanical dysphagic patients with NG tubes or Gastrostomy tubes had a statistically greater aspiration rate than patients receiving TPN, jejunsotomy, or oral feeding.

[956] **1991** *American Journal of Gastroenterology* Cogen et, al.
Result: 44 patients with jejunosotomes. Aspiration pneumonia 15.6 %. 31.6 % in those who had aspirated previously, 4% in those who had not.

[957] **1992** *Journal of Parenteral and Enteral Nutrition* Richard M. Strong, et. al.
Result: 33 patients fed with NG tubes 17 into stomach, 16 beyond the second portion of the duodenum. Finding: no significant difference in aspiration.

[958] **1992** *Critical Care Medicine* Marisa A. Montecalvo, et. al.
Result: 19 gastric tubes, 19 PEJ tubes. Pneumonia in 2 of gastric tubes, 0 of PEJ's.

upon which that presumption is based, although by no means unequivocally supported by

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[959] **1992** *American Journal of Surgery* Shailesh C. Kadakia et. al.
Result: Aspiration a major complication in 79 patients despite PEG or PEJ.
6 patients with various neurologic deficits and pre procedural aspiration had PEJ but continued to aspirate. 3 more patients without pre procedural aspiration also aspirated. "We conclude that aspiration is not prevented by PEG" (114). "We can speculate that our patients may be aspirating oropharyngeal secretions because they continued to aspirate after PEJ." (116)

[960] **1992** *Annals of Surgery* Christina Weltz, et. al.
Result: 100 patients had a jejunal feeding tube surgically implanted. 94 of the 100 considered to have an aspiration risk. Aspiration pneumonia in 18 preoperatively and 8 postoperatively. Of the 8, however, authors argue that only 4 can be attributed to jejunal feeding ---3 of the 4 had aspiration before tube feeding of any kind, and the fourth had aspiration while receiving patenteral nutrition.

[961] **1994** *Gastrointestinal Endoscopy* P. Frederick Duckworth, et. al.
Result: 18 PEG/J's (mean age 34) No aspiration.

[962] **1995** *Journal of Parenteral and Enteral Nutrition* Mark H. DeLegge
Result: 18 patients (mean age 56 (20-81) each given a PEG/J distal duodenal and jenunal placement –no evidence of gastroduodenal reflux.

[963] **1995** *American Journal of Surgery* Kenneth A. Fox, et. al.
Result: 69 PEGs and 86 PEJs. 4 0f 69 PEGS and 2 of 86 PEJ developed aspiration pneumonia. Not statistically significant according to the authors.

[964] **1996** *Gastrointestinal Endoscopy* Moshe Shike, et. al.
Result: 129 PEJ fed patients followed to death or resumption of oral feeding. Aspiration in only 3 patients (3%)

[965] **2001** *Intensive Care Medicine* Jan Esparza., et. al.
Result: 54 patients feeds tagged with technetium-99m radiolabeled sulfur colloid, and the pulmonary secretions or lungs of each patient were scanned daily to check for aspiration. Of 27 gastrically fed, 2 aspirated (7%). Of 24 transpylorically fed 3 aspirated (13%)

[966] **2002** *Critical Care Medicine* Juan C. Montejo, et. al.
Result: 51 NG tubes, 50 nasogastrojejunal tubes
Within 12 months pneumonia in 40% of NGs 32% of JENs

[967] **2002** *Critical Care Medicine* Daniel A. Neumann and Mark DeLegge.
Result: Sixty ICU patients: 30 tube-fed in the stomach 30 in the small bowel. Methyl blue dye added to feeds to detect aspiration. Clinically significant aspiration in 1 of small bowel group and 0 of gastric group.

[968] **2006** *American Journal of Mental Retardation* David S. Gray and David Kimmel
Result: 93 patients, all of whom had a history of pneumonia before feeding tube insertion, 83 of whom profoundly mentally retarded. 56 PEGs, 24 surgical gastrostomies, 13 jejunostomies. 45% decrease in pneumonia in the year following tube placement. Improvement only statistically significant in gastrostomies.

[969] **2008** *Nutrition in Clinical Practice* Panagiotis H. Panagiotakis et. al.
Result: 80 patients (mean age 44) received a PEG/J tube (endoscopic placement of feeding tube directly into the small intestine) 11 of the 80 received the tube for recurrent aspiration and/or aspiration pneumonia. Total number of documented aspiration pneumonia cases decreased from 29 to 3. Authors speculated that when studies report aspiration with PEG/J tubes, it is "because the jejunal extension tube often in reality lies in the duodenum and/or migrates back into the stomach, resulting in gastric feeding" (174).

available scientific evidence, may ultimately be proven correct. The problem is not the inaccuracy of the assumptions but an insufficient understanding of the physical and biological processes operative in aspiration pneumonia. Although the research has suffered from methodological problems, [970] [971] there can be little doubt that it exposed an apparent failure to fully understand those processes.

The apparent failure was the inability not only to understand and fully appreciate the significance of the role of oropharyngeal secretions in aspiration, but especially the colonization of those secretions by pathogenic bacteria present in the mouth and throat, especially on the teeth, the role of swallowing and saliva in the reduction of that bacteria, and the effect of tube feeding on swallowing and the production of saliva. [972] The mouth and throat, especially the teeth, are a source of pathogenic bacteria. So much so that David Marik informs that not only is the risk of aspiration pneumonia lower in patients totally without teeth, but "in elderly patients in institutional settings who receive aggressive oral care." [973], [974]

In addition, individuals with normal saliva production and normally functioning swallowing and mechanical clearance mechanisms apparently simply swallow, or cough up and

[970] Not only has research re: ANH's capability of preventing aspiration suffered from the overall methodological problems discussed above, differences in how aspiration has been defined and determined have seriously impaired the evidentiary value of the overall results.

[971] Mitchell, Tetroe, O'Connor, and Rostom, et. al.,"Making Choices,"10. As Mitchell and Tetroe, et. al. point out, "]t]here are no long term randomized trials comparing the chances of aspiration in patients with and without feeding tubes.

[972] It must also be noted that there has been little if any attention given in the literature as to the role pH and other chemical characteristics of the nutrition and hydration provided through ANH might have in preventing the colonization of not only gastric contents but perhaps even oropharyngeal secretions.

[973] Paul E. Marik. "Aspiration Pneumonitis and Aspiration Pneumonia," 667.

[974] Langamore, Terpenning, Schork, and Chen, et. al. "Predictors of Aspiration Pneumonia, 76. Langamore et. al. claim that oral/dental disease may be a "contributing factor to pneumonia by increasing the levels of oral bacteria in saliva, and/or by changing the composition of the salivary flora."

spit out or swallow almost all saliva and other normal oropharyngeal secretions including those secretions colonized with pathogenic bacteria. According to Lucy Palmer, et. al., "[i]n normal hosts, more than 90% of effective clearance of gram-negative bacilli (GNB) from the oropharynx appears to be due to effective *salivary flow and swallowing* (my emphasis)." [975] The very small amount that might on occasion be aspirated into the lungs during sleep is presumably effectively destroyed or otherwise neutralized by a normally functioning immune system.

On the other hand, a large number of those individuals who cannot eat and drink sufficiently to sustain their lives are incapable of doing so because they are unable to swallow normally. These individuals not only have difficulty swallowing food and drink, they also have at least some difficulty swallowing saliva and other normal oropharyngeal secretions, and some of these secretions, colonized by the pathogenic bacteria in the mouth, throat, and on the teeth, especially if these individuals' mechanical clearance mechanisms are also impaired, are aspirated permanently into the lungs. Of those individuals unable, because of dysphagia or other swallowing problems, to eat and drink sufficiently to sustain their lives, a large percentage is elderly and debilitated. Lucy Palmer, et. al. claim that "[i]n the elderly debilitated patient, both saliva flow and swallowing are frequently abnormal." [976] They further maintain that " reduction in mechanical clearance of potential pulmonary or oropharyngeal pathogens may be the first step in the path that leads sequentially from oropharyngeal colonization to pneumonia," [977] noting that "[i]mpairment in clearance has a potential twofold effect on oropharyngeal bacterial

[975] Lucy B. Palmer, Kiram Albulak, Suzanne Fields, and Marie Filkin, et. al. "Oral Clearance and Pathogenic Oropharyngeal Colonization in the Elderly." *American Journal of Respiratory and Critical Care Medicine* 164, no. 3 (August 1, 2001): 464.

[976] *Ibid.*

[977] *Ibid.*

colonization, promoting both bacterial growth and invasion," [978] They speculate that "diminished clearance would allow pathogenic organisms increased time in the mouth for proliferation and that this change in mucosal bacteria; burden promotes oropharyngeal inflammation, i. e., the influx of neutrophils and release of mediators of inflammation," [979] and that "[t]hese events could then initiate the well-described alterations in salivary enzyme concentrations and epithelial cell surface integrity that lead to bacterial adhesion, colonization, and infection." [980]

Not only, therefore, is a properly functioning swallowing mechanism and properly functioning mechanical clearance mechanisms for expelling potential aspiration from the throat and trachea, as well as aspiration that actually enters the lungs, important for the prevention of aspiration, so also is mastication and the normal production of saliva important for the prevention of the colonization of oropharyngeal secretions by pathogenic bacteria. [981] Lucy Palmer, et. al. report that "[a] marked increase in oropharyngeal gram-negative colonization is seen in patients with well-documented decreased salivary flow such as those with Sjogren syndrome or radiation-induced sialadenitis." [982],[983] What they failed to report, however, is that

[978] *Ibid.*

[979] *Ibid.*

[980] *Ibid.*

[981] Arthur Leibovitz, Galina Plotnikov, Beni Habot, Mel Rosenberg, and Rephael Segal. "Pathogenic Colonization of Oral Flora in Frail Elderly Patients Fed by Nasogastric Tube or Percutaneous Enterogastric Tube." *Journal of Gerontology* 58A, no. 1 (2003): 53. In a 2003 study published in the *Journal of Gerontology* Arthur Lebowitz, et. al. provided evidence of a definite link between tube feeding and the colonization by pathogenic bacteria of oropharyngeal secretions: "The main finding in this study is the significantly higher rate of pathogenic isolations from the oropharynx of tuboenterally fed patients. GNB [gram negative bacteria] have been isolated from 81% of the 78 NGT fed patients and from 51% of the 57 PEG fed patients, as opposed to only 17.5% of the 80 orally fed group. The prevalence of *Pseudonomias* was very high and found only in those fed by NGT or PEG. Some of the highly pathogenic bacteria such as *P. aeruginosa* and *Klebsiella*, uncommon in the oral flora of normal persons, have been cultured exclusively in tube fed patients." In addition, the authors commented that, in their view, oral pathogenic contamination was the result of tube fed patients no longer chewing and swallowing: "Our results are consistent with the view that it is the mechanical clearance associated with proper chewing and swallowing that provides the main defense against oral pathogenic contamination."

[982] Palmer, Albulak, Fields, and Filkin, et. al. "Oral Clearance and Pathogenic," 464.

tube feeding also reduces the production of saliva associated with normal eating and drinking because it eliminates the need for mastication. [984]

When one also considers, as Paul Marik contends, that "elderly persons frequently receive poor oral care, resulting in orophayngeal colonization by potential respiratory pathogens, including Enterobacteriaceae, *Pseudomonas aeruginosa*, and *Staphylococcus* aureu," [985] and that caregivers of tube fed patients may see little if any reason to provide oral care for someone no longer eating and drinking normally, it is not at all difficult to see why ANH is not only unable to prevent aspiration of oropharyngeal secretions, but may even unwittingly facilitate the colonization of those oropharyngeal secretions by pathogenic bacteria because of a reduction in the swallowing of oropharyngeal secretions colonized by pathogenic bacteria and a reduction in the dilution and inhibition, by normal saliva production, of that bacteria.

It is also of critical importance to note that regardless of whether ANH is provided enterally or parenterally, and regardless of whether *only* hydration and no nutrition is provided, ANH remains equally incapable of preventing oropharyngeal secretions, and may still unwittingly facilitate the colonization of those oropharyngeal secretions by pathogenic bacteria. This does not by any means suggest that *all* those receiving ANH will either aspirate or having aspirated acquire aspiration pneumonia, it simply means that there is no scientific evidence to suggest that enteral ANH prevents the aspiration of oropharyngeal secretions, and suspicion that enteral ANH may unwittingly facilitate the colonization of those oropharyngeal secretions by pathogenic bacteria. Enteral ANH delivered directly into the duodenum or jejunum may well

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[983] Langamore, Terpenning, Schork, and Chen, et. al. "Predictors of Aspiration Pneumonia," 76. Langamore, et. al. reported in 1998 that "[r]educed salivary flow. . increases the concentration of bacteria in the saliva."

[984] *Ibid*, 77. Langamore, et. al. also reported that "that tube feeding was likely associated with poor oral hygiene and reduced salivary flow, because the person was not eating orally."

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[985] Paul E. Marik. "Aspiration Pneumonitis and Aspiration Pneumonia," 667.

decrease the likelihood of the aspiration of gastric contents, but that would seem to be of little significance if aspiration pneumonia via the aspiration of oropharyngeal secretions is permitted and colonization of those secretions by pathogenic bacteria inadvertently facilitated.

It is certainly possible, in an attempt to offset these deleterious effects, that pharmacologic therapy might stimulate swallowing and coughing reflexes to limit permanent aspiration of oropharyngeal secretions, [986] aggressive oral care and/or frequent suctioning [987] of oropharyngeal secretions might reduce the colonization of these secretions by pathogenic bacteria, [988],[989] or that the administration of prophylactic antibiotics [990] might be effective in killing that bacteria, but

[986] Mutsuo Yamaya, Masaru Yanai, Takashi Ohrui, Hiroyuki Arai, and Hidetada Sasaki. "Interventions to Prevent Pneumonia Among Older Adults." *Journal of the American Geriatrics Society* 49, no. 1 (January 2001): 85. Mutsuo Yamaya et. al. claim that "since both swallowing and cough reflexes are mediated by endogenous substance P, pharmacologic therapy using angiotensin-converting enzyme inhibitors, which decrease substance P catabolism, may improve both reflexes and result in the lowering of the risk of pneumonia, [and] since the production of substance P is regulated by the dopaminergic neurons in the cerebral basal ganglia, treatment with dopamine analogs or potentiating drugs such as amantadine. . .should affect the incidence of pneumonia."

[987] James S. Scolapio."Methods for Decreasing Risk of Aspiration Pneumonia in Critically Ill Patients." *Journal of Parenteral and Enteral Nutrition* 26, 6 Supp. (November 2002): S58. In a 2002 article in the *Journal of Parenteral and Enteral Nutrition* James Scolapio reported that "[e]levating the head of the be (45 degrees), continuous subglottic suctioning, and oral decontamination seem to be effective in the prevention of aspiration pneumonia."

[988] Langamore, Terpenning, Schork, and Chen, et. al. "Predictors of Aspiration Pneumonia, 78. Langamore,, et. al. suggest that "[t]he best treatment strategy to prevent pneumonia in tube-fed patients might be one of aggressive oral hygiene and aggressive oral and pharyngeal suctioning of any excess secretions (and sometimes tracheal suctioning if the secretions are abundant)" They further recommend "removing the tube and re-instituting careful oral feeding as soon as possible."

[989] Takeyoshi Yoneyama, Mitsuyoshi Yoshida, Toshifumi Matsui, and Hidetada Sasaki. "Oral Care and Pneumonia." Letter to the Editor. *Lancet* 354, no. 9177 (Aug. 7, 1999): 515. Yoneyama, et. al. investigated whether oral care can lower the frequency of pneumonia in nursing home residents. Nurses or care givers cleaned patient's teeth with a toothbrush and scrubbed the pharynx with applicator containing providone iodine (1%) every day. Patients (mean age 82) were randomly assignment to oral care or no oral care. 184 received oral care and 182 did not. Pneumonia in 34 of the no oral care group (19%), and 21 of those who received oral care (11%).

[990] Yamaya, Yanai, Ohrui, Arai, and Hidetada Sasaki. "Interventions to Prevent Pneumonia Among Older Adults," 88. Yamaya, et. al. claim that prophylactic antibiotics actually promote colonization by pathogenic bacteria: "Prior use of antibiotics promotes colonization in the oropharrnyx and gastrointestinal tract by potentially resistant bacteria that can be aspirated and cause pneumonia. The normal anaerobic gastrointestinal flora create resistance to colonization by more virulent organisms; this colonization resistance is lost when antibiotics are given."

there is at present little scientific evidence to support the efficacy of any of these efforts. [991],[992] At present, therefore, the conclusion seems inescapable that not only does ANH not provide a benefit re: aspiration pneumonia, it may very well impose a burden in that regard.

Life Extension

Undoubtedly, the most important claim as to the benefits of ANH is that it extends lives, and it is important to acknowledge from the outset that *in many instances* ANH absolutely extends lives. As will be shown in the review of scientific research conducted to demonstrate the efficacy of various forms of ANH in extending lives, *many* individuals given ANH continue to live for additional weeks, months, and even years subsequent to receiving ANH. Obviously, *if* these individuals are relying *exclusively* on ANH to satisfy 100% of their body's hydration as well as nutrition needs, the extension of their lives beyond three weeks, the rough limit of their ability to survive without *any* hydration, *must* be attributed to ANH. There is no other possible

[991] American Gastroenterological Association: American Gastroenterological Association Medical Position Statement: Parenteral Nutrition." *Gastroenterology* 121, no. 4 (October 2001): 1281. In the effort to reduce aspiration pneumonia caused by the aspiration of oropharyngeal secretions, it should not be overlooked that aspiration of gastrointestinal contents can also cause pneumonia. It should be noted that a good deal of attention has been directed toward the reduction if not prevention of the reflux and aspiration of gastrointestinal contents. In 1995 American Gastroenterological Association published guidelines for the Use of Enteral Nutrition:
" 1. To limit the risk of aspiration with gastric feeding, the following precautions should be taken: raise the head of the patient's bed 30 -45 degrees during feeding and for 1 hour after, use intermittent or continuous feeding regimens rather than the rapid bolus method, gastric residuals should be checked regularly, and all patients should be watched for signs of feeding intolerance.
2. Jejunal access is helpful in patients with recurrent tube feeding aspiration (not oropharyngeal) or in critically ill patients at risk for gastric motility dysfunction (e.g. patients with head trauma)
3. To limit the risk of aspiration with small bowel feeding, the port of the nasoenteric tube or percutaneous endoscopic jejunostomy should be close to or beyond the ligament of Treitz. Severe vomiting or coughing may displace some nonsurgical tubes, and radiographs may be needed to verify the tube position."

[992] Yamaya, Yanai, Ohrui, Arai, and Hidetada Sasaki. "Interventions to Prevent Pneumonia Among Older Adults," 89. In a 2001 article published in the *Journal of the American Geriatrics Society*, Yamaya et. al. reported that there was evidence that elevating the head of the bed during tube feeding actually decreased aspiration pneumonia: "The simplest approach to all of these problems may involve elevating the head of the bed. Meguro et. al. showed that elevating the head of the bed after each meal for 2 hours may lower febrile days presumptively caused by aspiration of gastric contents. Border, et. al. also emphasized the importance of patient position in the prevention of nonsocomial pneumonia in the ICU."

conclusion. For *many* individuals unwilling or unable, even with assistance, to eat and drink sufficiently to sustain themselves, ANH extends their lives by preventing death from the complications of dehydration and/or malnutrition.

What is also obvious from a review of the relevant scientific research, is that individuals exclusively dependent on ANH for nutrition and hydration either eventually regain the ability to eat and drink sufficiently so that ANH can be discontinued, or die. That an individual would die within a matter of days or weeks after he/she begins receiving ANH is certainly no surprise. Many individuals given ANH are seriously ill and death from the effects of cancer, cardiovascular disease, or any number of other pathologies, while still being tube-fed, is not at all uncommon.

What is less obvious, however, is that some individuals receiving ANH die *not* from a pathology, such as coronary artery disease, whose pathway is unimpeded by the presence in the bloodstream and/or gastrointestinal tract of adequate nutrition and hydration to satisfy their bodies' needs, but from complications attendant to dehydration and/or malnutrition brought about as a result of a pathology or pathologies, including those associated with aging itself, that impacts the body's physiological need for and physiological capability of utilizing any form of nutrition and hydration. In simpler terms, the patient dies d*espite* ANH *because* his/her body has *permanently* lost either/or the physiological need for any form of nutrition and hydration or the physiological capacity to successfully utilize *any* form of nutrition and hydration. [993] This physiological capacity can be lost after ANH has been provided, or before ANH has begun, and

[993] In order to extend life by preventing death from complications attendant to dehydration and/or malnutrition, ANH must provide nutrition and hydration that is accessible to, usable by, and sufficient for a patient's body. That artificially provided nutrition and hydration that is accessible to, usable by, and sufficient for a patient's body would be *unable* to satisfy that patient's nutrition and hydration needs is, admittedly, at least at first blush, surprising, and, it would seem, counter intuitive, until one considers that some individuals permanently lose the physiological capacity to utilize the nutrition and hydration provided by ANH. To the extent that this capacity has been lost, ANH is going to be correspondingly unable to sustain these patients' lives.

be lost incrementally over time or much more rapidly. It is important to note, however, that if lost before ANH is begun, the loss of physiological capacity may be accompanied by a simultaneous diminution or total loss of the body's *need* for nutrition and hydration, as manifested in a patient's loss of appetite, and limited, if any, desire for water.

Any inquiry into whether ANH extends lives must, therefore, be continuously mindful of the significance of these nutrition/hydration realities. First, it cannot be automatically assumed that *every* patient, for whom ANH is considered as a *possible* response to inadequate nutrition/hydration, has the physiological capacity to successfully utilize nutrition and hydration provided by ANH. Second, it cannot be assumed that a patient's unwillingness to eat and drink sufficiently to sustain his/her life is *not* a result of the diminution or total loss of his/her body's *need* for nutrition and hydration, as manifested in that patient's loss of appetite, and limited, if any, desire for water.

The issue for this inquiry is not, therefore, whether ANH can extend lives. It can. Nor is the issue whether ANH can extend *every* life. It cannot. Instead, the primary issue for this inquiry is the extent to which it can be determined, in advance of the utilization of ANH, which lives can be extended by ANH and the foreseeable length of that extension, and which lives cannot. A second related issue is the extent to which it can be determined, also in advance of the utilization of ANH, when swallowing, although difficult and limited, is still physically possible, the life extension foreseeably provided by ANH relative to the life extension provided by careful hand feeding.

There has been no shortage of research efforts undertaken to provide scientific evidence to support the presumption that ANH extends *all* lives, a presumption that may still be considered valid by more than a few American medical professionals. Not only has this research suffered

from the same methodological problems, as discussed above, that plague other research re: the effects of ANH, four problems unique to research involving life extension are especially worrisome. First, it is difficult to know from the studies themselves whether results, that appear to show that patients receiving ANH live longer than those patients for whom ANH was foregone, are simply because those provided ANH had pathologies that were further advanced than their non-tube fed counterparts. In other words, sicker patients received tube-feeding. Second, it is also difficult to know from the studies themselves whether tube feeding was initiated at the first indication of difficulty with oral intake of food and water, or much later, only after all compensatory means of continuing oral feeding had failed. Clearly, all other things being equal, the earlier tube feeding is initiated the greater the appearance of life extension.

Third, the lack of autopsies to determine, with certainty, the cause of death, can support erroneous conclusions. Not unexpectedly, given that most patients given ANH are seriously ill, deaths subsequent to beginning tube feeding have not been infrequent, but without knowledge of the cause of death, it cannot be accurately determined whether or not a patient provided ANH died from pathologies unimpeded by the presence in the bloodstream and/or gastrointestinal tract of adequate nutrition and hydration to satisfy his/her body's needs, from aspiration pneumonia, perhaps as a result of ANH, or because his/her body no longer possessed the physiological need for, or physiological capacity to successfully utilize, the nutrition and hydration provided by ANH. Fourth, when studies compare the survival of those given ANH with those from whom it was withheld, there is usually no indication as to whether those patients from whom ANH was withheld continued some limited oral ingestion of food and especially liquids. Clearly, food and

water provided for those for whom ANH was forgone, even in limited amounts, can extend their lives and thereby skew results. [994],[995]

What follows in subsequent footnotes are very brief summaries of journal reported clinical research listed chronologically, that although by no means exhaustive, are representative of more than thirty years of research undertaken to determine whether ANH extends lives. Unfortunately, the studies are, not surprisingly, primarily directed to determining whether ANH extends lives and not the two real issues of this inquiry. The research is, nevertheless, worthy of examination, not only because *some* studies do address *which* lives can be extended by ANH, the probable length of that extension, and which lives cannot, evidentiary support for the above described nutrition and hydration realities can also be extrapolated from the results of other studies.

[996],[997],[998],[999],[1000],[1001],[1002],[1003],[1004],[1005],[1006],[1007],[1008],[1009],[1010],[1011],[1012],[1013],[1014],[1015],[1016],[1017],[1018],[1019],

[1020],[1021],[1022],[1023],[1024],[1025],[1026],[1027],[1028],[1029],[1030],[1031],[1032],[1033],[1034],[1035],[1036],[1037],[1038],[1039],[1040],[1041],[1042]

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[994] As noted in chapter 3, the nutrition and hydration requirements of the dying can be substantially smaller than that necessary to sustain the life of an otherwise healthy individual of comparable age. As also noted in chapter 3, however, absent all hydration death from terminal dehydration will probably take place in three weeks or less, regardless of the body's reduced need for fluids. We know, therefore, that anyone in the group of patients that forego ANH who lives longer than three weeks is almost certainly receiving some form of hydration.

[995] Two other problems emerge re: existing research. First, there is not enough emphasis on short term survival greater than 1 month. For many families the possibility that ANH will extend the life of their family member for 2 months or 3 months is considered an enormous benefit. Second, and conversely, there is not enough data as to the level of consciousness experienced by those given ANH prior to their deaths. This could also be of enormous significance for families considering ANH.

[996] **1954** *JAMA* Morton Pareira, et. al.
Result : 240 NG tubes. "All the patients except a few who were *in the terminal state of disease* (my emphasis) showed a significant weight increase" (813).

[997] **1981** *Archives of Surgery* James J. Matino
Result: 54 patients given jejunostomy because of neurological dysphagia.
6 month mortality 67%

[998] **1986** Archives of Surgery Mark Adams and Gary Seabrook, et. al.
Result: 73 patients jejunostomies. "Patients with severe neurologic impairment generally have a poor prognosis; ten of our fourteen patients survived less than 60 days, and none was discharged home." (238).

[999] **1988** *Gastroenterology* Chia-Sing Ho et. al.

Result: 100 surgical gastrostomies compared to 134 Percutaneous nonendoscopic gastrostomies (33 of surgical and 82 of percutaneous tubes because of neurological disorders). 30 day mortality 12 (12%) of surgical, 10 (7.5%) of percutaneous.

[1000] **1988** *American Journal of Clinical Nutrition* N. Agarwal, et. al.
Result: Tests were run on 80 consecutive patients, mean age 88, 55 females, 25 males, to predict mortality. "Serum albumin is. . the best single predictor of mortality and can provide early identification of elderly people at increased risk of death.

[1001] **1988** *Archives of Internal Medicine* Cicone, Silverstone, et. al.
Result: "Along with the underlying diseases, aspiration probably contributed to the high death rate" (433). 6 month mortality 40% for those tube fed.

[1002] **1989** *American Surgeon* Christopher Steffes et. al.
Result: 112 PEGS 30 day mortality 24%.

[1003] **1990** *Gastrointestinal Endoscopy* G. V. Stiegmann, et. al.
Result: 57 surgical gastrostomies (48 because of neurological issues) compared to 64 PEGs (56 because of neurological issues). 30 day mortality 8.8% of surgical gastrostomies, 12.5 % of PEGs.

[1004] **1990** *American Journal of Gastroenerology* Wolfsen et. al.
Result: 191 PEG/J tubes. 40 day mortality 21%, 60 day mortality 33%, 6 month mortality 50%.

[1005]**1990** *Journal of Parenteral and Enteral Nutrition* James V. Sitzmann
Result: 90 patients with admitting diagnosis of dysphagia. Of those who died 80% died from aspiration pneumonia. Mortality statistically greater with NG tubes (30%). No mortality with those fed orally or with jejunostomies.

[1006] **1991** *American Journal of Gastroenterology* William L. Horton, et. al.
Result: 224 PEGS (only 14 because of dementia) 30 day mortality 8.2 %.

[1007] **1991** *American Surgeon* James Stephen Scott, et. al.
Result: 50 surgical gastrostomies, 50 PEGs (61% of both groups because of neurologic disorders, 6 of surgical gastrostomies and 4 of PEGs because of aspiration). Mortality 4% of surgical gastrostomies, 0 of PEGs.

[1008] **1992** *Journal of the American College of Nutrition* Cynthia T. Henderson, Trumbore, et. al.
Result: 40 chronically tub- fed long term care patients data collected at 3 months (3 month mortality 10%) with follow up mortality at 12 months of 30%. "[D]espite administration of apparently adequate formula, micronutrient deficiencies and marasmic nutrition exist in chronically ill patients. Causes may include the combined effects of chronic disease, sepsis, immobility, and severe neurologic deficits. Clinical outcomes may be the result of an organism-wide diminution of protein synthesis, the cause of which is unknown" (309).

[1009] **1992** *Mayo Clinic Proceedings* Celeste A Taylor, et. al.
Result: 97 PEG tubes. 30 day mortality 22% , 18 month mortality 65%.

[1010] **1992** *Archives of Surgery* William R. Jarnagin.
Result: 64 PEGs tube placements, 24 with a history of aspiration. Of these 24, 9 developed aspiration pneumonia within 3 days of the procedure, and 4 of these died in the hospital. "It is of concern that the gastrostomy procedure and subsequent gastrostomy feedings hastened the deaths of seven of the patients. . . At present, we recommend that gastrostomy be used sparingly and with utmost caution in patients with spontaneous bouts of aspiration pneumonia" (263).

[1011] **1993** *Southern Medical Journal* Samuel Patrick Stuart, et. al.
Result: 125 feeding tubes. 30 day mortality rate: PEGs 31%, surgical gastrostomies 24%.

[1012] **1994** *Dysphagia* John F. Croghan et. al.

Of 22 patients with aspiration , 15 had feeding tubes placed This group had a higher rate of pneumonia and pneumonia death than 7 who did not have tubes. Those with NG tubes had higher death rate (7/9) than patients with gastronomy tubes (2/8).

[1013] **1994** *Digestive Diseases and Sciences* Madhukar Kaw and Gail Sekas
Result: 46 PEGs, predominately (52%) for dementia. Mean age 73.6 (19-96)
1 month mortality 20%, 12 month mortality 50%. No 12 month mortality of patients under 40. 26 % of deaths from pneumonia (26%). Survival post PEG significantly reduced in those with serum albumin < 3.5 g/dl.

[1014] **1995** *Gastrointestinal Endoscopy* Victoria Light, et. al.
Result: 416 PEG tubes. Mortality risk higher in patients with urinary tract infection, previous aspiration, and over 75 years of age. 1 week mortality of patients with urinary tract infection and previous aspiration, 48%. 30 day mortality of those patients with all three risk factors, 67%.

[1015] **1996** *Journal of General Internal Medicine* Linda Rabeneck, et. al.
Result: 7369 PEGs, mean age 68, 28.6% because of neurologic disease, 8% because of aspiration pneumonia. 23.5% died during hospitalization, 50% dead within 7.5 months, 59% at 12 months.

[1016] **1997** *Journal of Parenteral and Entertal Nutrition*. Frank Friedenburg, et, al.
Result: 64 PEGs. 30 month mortality 32.8% . 83% of those with serum albumin > 3.0g/dl survived but only 58% with serum albumin < 3.od/dl.

[1017] **1997** *Archives of Internal Medicine* Susan Mitchell, and Kiely, et. al.
Result: 1386 nursing home residents 65 years older or more with recent progression to severe cognitive impairment so that they could no longer feed themselves. 135 received feeding tubes. “This is the first investigation known to us to include a control group without feeding tubes rigorously matched for recent progression to severe cognitive impairment and where multivariate techniques were used to adjust for comorbid conditions. We did not find that feeding tubes prolonged the survival of nursing home residents with severe cognitive impairment. In fact, after adjusting for independent risk factors, feeding tube status was the least important determinant of survival in this frail population. The most significant predictors of poorer survival in our cohort included medical conditions (aspiration, chewing and swallowing problems, and pressure ulcers), advanced age and DNR status (331).

[1018] **1997** *Nutrition* Concetta Finocchiaro et. al.
Result: 136 PEGs: Mean age 62 (16-89), 49% with cancer, only 1 with aspiration pneumonia. 30 day mortality (9.5%), 6 month 48%), 12 month 58%.

[1019] **1998** *Digestive Diseases and Sciences* C. Loser, et. al.
Result: 210 PEGs: 30 day mortality, 26.9%, 12 month mortality, 65.7%.

[1020] **1998** *Journal of Gerontology* Susan L. Mitchell and Kiely, et. al.
Result: 5266 nursing home residents with chewing and swallowing problems.10.5 % received feeding tubes. 12 month mortality significantly greater of those patients tube-fed, although authors acknowledge that tube fed patients may have simply been sicker.

[1021] **1998** *JAMA* Mark D. Grant, et. al.
Result: 81,105 tube-fed Medicare beneficiaries 65 years and older. 30 day mortality 23.9%, 12 month mortality 63%. “The substantial mortality rates may be reason to consider that some enterally fed patients who do not have swallowing disorders are not dying because of lack of nutrition, but rather, lack the need to eat because they are dying” (1976).

[1022] **1999** *Journal of Parenteral and Enteral Nutrition* Mark A. Rudberg et. al.
Result: Nursing home residents totally dependent on assistance in eating with swallowing disorder. No statistically significant difference in mortality with or without PEGS. 12 month mortality 39% without PEGs, 50% with PEGs. Authors are aware that this study contradicts the findings published by Susan Mitchell et. al. and speculate that in Mitchell’s study those without feeding tubes had milder eating disorders and better health.

[1023] **1999** *Journal of the American Geriatrics Society* David N. Fisman "Survival"
Result: 173 PEGs: 30 day mortality 18.3%, 12 month mortality 1 year 38.9%.

[1024] **2000** *American Journal of Gastroenterology* G. A. Buskis, et. al.
Results: 114 PEGs: 47 in Group 1 were residents of nursing homes. (87% with PEGs because of dementia) 67 in Group 2 hospitalized patients. (46% with PEGs because of dementia) Group 3 were hospitalized patients matched to Group 2 for diseases, except mental disorders and not given PEGs. Group 4 the general hospital population matched for age. Mortality rate 5 times higher in Group 2 than in Group 3, 30 day mortality 7 times higher in Group 2 than in Group 3, twice that in Group 3 and 5 times higher than Group 4.

[1025] **2000** *American Journal of Gastroenterology* D. S. Sanders, et. al.
Result: 361 PEGs insertions. Of those with dementia, 30 day mortality 54%, 3 month mortality 78%.

[1026] **2000** *Journal of the American Geriatrics Society* Christopher M. Callahan, et. al.
Result: 150 PEGs all 60 years of age and older. 30 day mortality 22%, 12 month mortality 60 "We were unable to document clinically meaningful benefits from PEG tube feeding in the majority of these patients. Whether the PEG tube feeding slowed the rate of their decline or prolonged an imminent demise is unclear from these data" (1526).

[1027] **2000** *American Journal of Gastroenterology* Satheesh Nair, et. al.
Result: 6 month mortality of patients with PEGs 44%, no PEGs 26%.
Hypoalbuminemia at the time of PEG predicted a higher mortality rate for patients started on gastrostomy feeding. Those with an albumin level of < 2.8 g% had 6 month mortality level of 58%. When those with a low albumin level were excluded. 6 month mortality for those with PEGs and without PEGs not significantly different statistically.

[1028]**2001** *Journal of the American Geriatrics Society* B. Lindemann and T. Nikolaus
Result: 36 PEGs, all patients with severe dementia and 65 years of age or older. 30 day mortality 25%.

[1029] **2001** *Archives of Internal Medicine* Diane E. Meier and Judith C. Ahronheim, et. al.
Result: 99 hospitalized patients with advanced dementia. 51 received feeding tube and 17 were admitted with a feeding tube. No impact on survival with or without feeding tube. 6month mortality 50%.

[1030] **2001** *Journal of Clinical Gastroenterology* Marja J. Verhoef and Guido Van Rosendaal.
Result: 71 PEGs, mean age 66. 30 day mortality, 27% 12 month mortality 39%.

[1031] **2002** *Critical Care Medicine* Juan C. Montejo, et. al.
Result: 51 NG tubes and 50 nasogastrojejunal tubes: 12 month mortality NG 43% JEN 38%.

[1032] **2002** *Clinical Nutrition* R.H. Skelly et. al.
Result : Authors previously reported a 30 day mortality after PEG insertion of 8 % (1988-92). In this study the 30 day mortality increased to 19% (1998-99), the 90 day mortality increased from 20% to 35%. They speculate that in 1998-99 a larger proportion of PEGs were because of for cerebrovascular disease, and a smaller proportion for motor nerone disease.

[1033] **2003** *Archives of Internal Medicine* Lynne Murphy and Timothy Lipman
Result: 41 patients met criteria for PEG placement 23 patients had PEG placement accepted by surrogates while 18 patients had PEG placement refused by surrogates. Median survival for the PEGs was 59 days for those without PEGs 60 days.

[1034] **2004** *American Surgeon* Timothy Bullock, et. al.
Result: Retrospective Review of 1969 patients who underwent general elective surgery 77 developed pneumonia. At diagnosis of pneumonia 31 given NG tubes, 1 PEG, 1 PEJ, 41 no tubes. Mortality rate from all causes 33% for tube fed 17% for non tube fed.

[1035] **2005** *International Journal of Geriatric Psychiatry* Baldomero Alvarez-Fernandez

There is no shortage of observers claiming that scientific research has *failed* to demonstrate that ANH extends the life of *every* recipient. Muriel Gillick emphasizes that "survival time is the same for those with a gastrostomy tube and those who do not have a feeding tube" [1043]Alan Sanders implies that those who claim that ANH extends the life of *every* recipient, even the terminally ill, are simply mistaken: "Perhaps the most prevalent misperception with regard to nutritional status and feeding tubes is that feeding tubes will prolong life.

Result: 67 patients mean age 82.2, 92.5% were women.
In patients with advanced dementia mortality greater if pneumonia during previous year, or presence of a permanent NG tube and serum albumin levels < 3.5 g/dl.

[1036] **2005** *Journal of Nutrition Health and Aging* P. M. Shah, et. al.
Result: 71 PEGs, 40% with dementia. 3 month mortality 25% 12 month mortality 46%. Post PEG survival decreased with greater age, lower serum albumin, and increased number of commorbidities. When patient has dementia, however, none of these 3 factors predicted survival.

[1037] **2005** *Age and Ageing* Ephraim Rimon et. al.
Result: Nursing home residents 674 PEGs, mean age 80. Median survival in days:
128 days for diabetics, 161 days for patients referred from hospital, 171 days for those patients with dementia 80 years of age and older.

[1038] **2008** *American Journal of Gastroenterology* Fumiyo Higaki et. al.
Result: 311 PEGs: 12 month mortality of patients with dementia 49%, without dementia 51%.

[1039]**2008** Surgical Endoscopy Brian M. Smith et. al.
Result: 714 PEGs. 7 day mortality 5%, 30 day mortality 22%, 60 day mortality 31%.

[1040] **2009** *Journal of the American Medical Director's Association* Sylvia Kuo, et. al.
Result: 5000 nursing home residents with advanced dementia 66 and older who had a tube inserted. 64% 1 year mortality median survival 56 days.

[1041] **2009** *Journal of Parenteral and Enteral Nutrition* David Isaac Gaines et. al
Result: 190 PEGs 45 of whom diagnosed with dementia and /or SCI (significant cognitive impairment). Median survival of dementia patients 53 days, those patients without dementia, 78 days. Age and serum albumin are risk factors for 30 day mortality after PEG placement. 30 day mortality for patients with dementia/SCI not significantly different between those patients receiving PEGs and those not tube fed.

[1042] **2009** *Nutrition* L. Donini, et. al.
Result : 312 patients analyzed to identify risk factors for mortality. "The present study shows that a patient's general status (i. e. comorbidity, social quality of life, frailty) and nutritional and inflammatory status (i.e. lymphocyte count, albumin, prealbumin, C-reactive protein) have good predictive value on the effectiveness of [ariticial nutrition]" 11).

[1043] Gillick, Muriel**,** "Artificial Nutrition, 13.

Notwithstanding ethical debates, evidence suggests that tube feeding does not prolong the lives of most *terminal* (my emphasis) patients." [1044]

With regard to patients with dementia, Elizabeth Menkin writes [1045] that "studies do not demonstrate a decrease in mortality after PEG tube placement compared to similar patients with chewing and swallowing disorders who do not receive a PEG tube." [1046] Elaine Amella opines that "[*o]verwhelmingly* (my emphasis), research shows that tube feeding does not lengthen life, reduce morbidity or even increase weight in persons with advanced Alzheimer's disease and other cognitive impairments." [1047] The California Workshop *Guideline for Alzheimer's Disease Management* finds no evidentiary support for tube feeding for patients with dementia: "Current evidence argues against the use of feeding tubes in patients with severe dementia due to uncertainty about whether nutritional intake has any clinically meaningful outcomes in advanced dementia … as well as evidence that tube feeding does not necessarily prolong life or decrease suffering in severely demented patients." [1048] [1049] Given, however, that the *overall* research results can, not inaccurately, be described as equivocal, it comes as no surprise that Daniel Buff, John Howland and Eric Palecek have the opposite view.

[1044] Alan Sanders, "The Clinical Reality," 294

[1045] Elizabeth Menkin. "Artificial Nutrition and Hydration." *Journal of Palliative Medicine* 7, no. 5 (October 2004): 726. Dr. Menkin's statement is actually taken from the test of a letter she suggests might be in an appropriate form for asking a court to permit the withholding of tube feeding from a demented patient represented by a public guardian.

[1046] *Ibid*, 725.

[1047] Elaine J. Amella. "Decision Making for Tube Feeding In Dementia: When Evidence Becomes Paramount." *Journal of Clinical Nursing* 12, no. 6 (November 2003): 793.

[1048] California Workshop on Guidelines for Alzheimer's Disease Management. *Guidelines for Alzheimer's Disease Management: Final Report* (April 2008) http://www.caalz.org/PDF_files/Guideline-FullReport-CA.pdf (accessed on December 10, 2011)

[1049] *Ibid.*

Daniel Buff claims that it is impossible to *rationally* claim that ANH has *no* survival benefit: [1050] "Given that patients who do not drink would be expected to die from dehydration in 7 to 10 days and that the median survival of tube fed dementia patients is more than 6 months, can one rationally conclude that tube feeding does not provide a survival benefit." [1051] Howland claims that the benefit of ANH for patients with *dementia* (my emphasis) is far from clear:

> Although dozens of articles have been published on the subject of PEG tubes in advance dementia, there has never been a randomized, controlled clinical trial to evaluate the issue empirically. Studies have been observational, retrospective, or cohort-based research. Such studies are not sufficient to answer the key question: *Does PEG feeding benefit patients with advanced dementia?*" [1052] [1053]

He notes that in 1997 Mitchell and Kiely et. al. conceded that patients with feeding tubes may had a poorer survival record than anticipated because they were simply sicker, [1054] and that eleven years later Mark DeLegge suggested that "[i]n reality, we do not know if PEG placement for nutrition is or is not beneficial in *dementia* (my emphasis) patients who cannot eat as compared with similar patients receiving standard nutrition care." [1055] Howland painstakingly critiques and thereby discounts a number of studies seen as providing evidentiary support for the contention that ANH is unable to extend the lives of patients with dementia,[1056]and then points to

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[1050] Buff may appear to be talking past Howland, but his comment is a direct contradiction of Gillick.

[1051] Daniel Buff. "Against the Flow: Tube Feeding and Survival in Patients with Dementia." *Quarterly Newsletter of the American Academy of Hospice and Palliative Medicine* 7, no.1 (Spring 2006): 1.

[1052] John Howland, "A Defense of Assisted Nutrition," 703.

[1053] *Ibid.* Howland further claims that "[o]bservational studies are notoriously flawed because of selection bias."

[1054] *Ibid*.

[1055] *Ibid.*

[1056] Howland, John. "A Defense of Assisted Nutrition," 704-705. Howland critiques the following studies; his comments are summarized:

three other studies whose results, in his opinion, support the opposite conclusion. [1057] His point is that with so much uncertainty and with lives conceivably at risk, "[w]hile contemplating denial of food and water to a patient, surely the burden of proof should rest on those who would deny that there is a benefit to such care." [1058]

Eric Palecek affirms Howland's assessment, suggesting that three recent studies, Sampson, et. al., 2009, Gaines et. al., 2009, as well as the 2008 Higaki study referenced by Howland, "suggest that further research may be necessary before the conclusion is reached that PEG tubes

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Mitchell and Kiely, et. al., 1997

"The authors never provide information to indicate why the patients were given ANH. . . yet this is critical to a rigorous analysis of survival benefit. A patient who has completely stopped eating and drinking has a much different prognosis from a patient who has merely lost ten pounds over the course of six months. Furthermore, the study does not define the cause of cognitive decline among the study population or controls. . . Despite attempts to control for these and other variables, the Mitchell study is hopelessly muddled by its broad inclusion criteria" (704).

Meier and Ahronheim, et. al., 2001

"[D]oes not address the broader issue" (704)

Murphy and Lipman, 2003.

"[L]imited by very small sample" (704)

Sanders, et. al., 2000.

"This study may tell us something about guidelines, but very little about the effectiveness of ANH" (705).

Abuksis, et. al. 2004

"[S]howed only that there is a high mortality among patients with dementia who have ANH started at the time of an acute hospitalization" (705)

[1057] Howland, John. Howland points to the following studies as providing evidentiary support for the contention that ANH extends the lives of patients with dementia; his comments are summarized: 705-706.

Higacki et. al., 2008

"Higaki's findings clearly suggest that dementia is not a risk factor for survival in patients who receive PEG tube feeding. This is significant because it is often claimed that patients with dementia cannot benefit nutritionally from ANH; if that were the case one would expect them to have significantly worse survival" (705)

Rudberg, et. al. 1999

"Rudberg and colleagues used roughly the same observational, cohort study and inclusion criteria as Mitchell and colleagues, yet came to the opposite conclusion: patients with severe cognitive impairment live longer with ANH than without" (705)

Rimon, et. al., 2005

"It appears that some patients—those who are younger and healthier despite their dementia—will have a better survival after beginning ANH" (706)

[1058] *Ibid*, 703.

are never life-sustaining in patients with *advanced dementia* (my emphasis)." [1059] Buff, on the other hand, claims that a careful review of the available research data suggests that the tube feeding actually *reduces* mortality:

> [I]n most cases, the studies cited included a control group that was not adequately matched to the tube-fed group for many important prognostic factors. Usually the control patients were healthier from a neurologic, nutritional, and functional standpoint. If one chooses to look positively at the data, it would appear that the tube-fed patients should have had a higher mortality than controls, yet mortality in most studies was the same. This may indicate a survival advantage for tube feeding. Such a conclusion is bolstered by the fact that in the only study in which tube-fed *dementia* (my emphasis) patients and controls were similar for important prognostic data, a statistically significant survival advantage for PEG tube-feeding was demonstrated. [1060]

In fairness to both sides, if the conclusion is based entirely on the *overall* results of reported research, it seems no less unreasonable to hold that ANH extends the lives of *all* recipients than that ANH does *not* extend the lives of *all* recipients, for there are individual studies that appear to provide evidentiary support for both positions. In addition, it must be acknowledged that there are other possible explanations for what would appear to be conflicting results. For example, studies that show longer survival associated with tube feeding can certainly be attributed to the prevention of death from complications attendant to dehydration and/or malnutrition, but it is also possible that those from whom tube feeding was withheld appeared to be so near death that tube feeding was seen as futile for someone with such a poor prognosis while conversely those for whom tube feeding was provided appeared to have a more favorable

[1059] Palecek, Eric J. Palecek, Joan M. Teno, David J. Casarett, Laura C. Hanson, Ramona Rhodes, and Susan L. Mitchell. "Comfort Feeding Only: A Proposal to Bring Clarity to Decision-Making Regarding Difficulty with Eating for Persons with Advanced Dementia." *Journal of American Geriatrics Society* 58, no. 3 (March 2010): 581.

[1060] Daniel Buff, "Against the Flow," 3.

prognosis and were accordingly deemed to be better candidates for ANH. In such a scenario, those given tube feeding were relatively healthier than those from whom tube feeding was withheld, and as a consequence, lived longer. Studies with a contrary result, showing a shorter survival associated with tube feeding can likewise certainly be attributed to ANH facilitating aspiration pneumonia or those patients given tube feeding being physiologically incapable of utilizing the nutrition and hydration provided, but it is also possible that those from whom ANH was withheld continued to receive nutrition and hydration from careful hand feeding and hydration, while those given tube feeding were simply sicker, as suggested by Palecek and acknowledged by Mitchell and Kiely, et. al.

Nevertheless, as discussed above, the real issues for this inquiry are, to the extent to which it can be determined *in advance of the utilization of ANH,* which lives can be extended by ANH and the foreseeable length of that extension, and which lives cannot, and, when swallowing, although difficult and limited, is still physically possible, the life extension foreseeably provided by ANH relative to the life extension provided by careful hand feeding. Research, therefore, is of most value when it addresses those two issues. As to the extent to which it can be determined *in advance of the utilization of ANH,* which lives can be extended by ANH, the foreseeable length of that extension, and which lives cannot, results seem to indicate that certain patients unwilling or unable to eat and drink sufficiently to sustain their lives *might be* especially poor candidates for tube feeding and cannot accordingly *be certain* of significant, if any, life extension once ANH is initiated. These could include patients already severely undernourished, those with low serum albumin, those who tend to aspirate their food, those with non-aspiration pneumonia or influenza, and older patients, especially those with reduced consciousness and/or dementia.

Unfortunately, there is no research that provides a meaningful comparison of the life extension provided by ANH and the life extension provided by careful hand feeding.

Clearly, much more definitive research is needed, but at minimum, existing research along with a basic understanding of human physiology informs that although ANH *can* extend human life by preventing death from dehydration and/or malnutrition, ANH *cannot* extend the lives of those patients who have permanently lost the physiological need for, or physiological capability of utilizing, nutrition and hydration, or *meaningfully* extend the life of other patients who at least initially retained but subsequently lost their physiological need for, or physiological capability of utilizing, the nutrition and hydration provided. For those patients who initially retained but subsequently lost the physiological need for, or physiological capability of utilizing, the nutrition and hydration provided by ANH, life extension is *limited* by that loss, as well as the advance of pathologies whose pathway is unimpeded by the presence in the bloodstream and/or gastrointestinal tract of adequate nutrition and hydration to satisfy his/her body's needs. Whether the length of time between the institution of ANH and subsequent death is meaningful, is entirely a subjective assessment by a patient and his/her family.

In summary, proponents of ANH claim that ANH provides a number of legitimate benefits to patients unwilling or incapable of eating and drinking sufficiently to provide their bodies with adequate nutrition and hydration, including reducing hunger and thirst, reducing pressure sores, restoring physical strength and resistance to infection, reducing aspiration pneumonia, and extending life. Although there is no published clinical research confirming that ANH relieves hunger and thirst, there is no reason to suppose that ANH does not do so, *provided* that a patient still physiologically requires nutrition and hydration and is still capable of experiencing either or both of those sensations. On the other hand, there is no evidence from scientific research that

ANH reduces pressure sores or restores physical strength or resistance to infection. In addition, not only is there is no evidence demonstrating that ANH eliminates or even reduces aspiration or aspiration pneumonia, there is a suspicion that enteral ANH may unwittingly facilitate aspiration pneumonia by promoting the colonization of oropharyngeal secretions by pathogenic bacteria.

Finally, it is evident that ANH can and does extend lives by preventing death from the complications of dehydration and/or malnutrition, but it is also quite clear that ANH *cannot* extend the lives of those patients whose bodies no longer physiologically need nutrition and hydration or have permanently lost the physiological capability to utilize nutrition and hydration, or *meaningfully* extend the life of other patients, who initially retained but subsequently that need for, or physiological capacity of utilizing, nutrition and hydration. Accordingly, there is little question that ANH can be beneficial to many, although clearly not all, individuals unwilling or unable, even with assistance, to eat and drink sufficiently to sustain their lives. The remaining issues for this chapter are first, whether in relieving hunger and thirst and extending life ANH *also* imposes a harm(s) or continuing burden(s), and second, whether that harm(s) or continuing burden(s) can under certain circumstances, including the circumstances specific to this inquiry, be reasonably assessed as disproportionate to the foreseeable relief of hunger and thirst and/or the extension of life.

Harms(s) and/or Continuing Burdens of ANH

It must be conceded from the very outset that although various forms of ANH can impose serious harm, including death, significant harm from ANH is apparently relatively rare, and at least arguably, surprisingly low given the age and health of many recipients of ANH. In addition, although various forms of ANH can also impose an ongoing burden(s), in most, although clearly

not all, instances that burden(s) can be significantly reduced once it is identified. The issue thus becomes what harm(s) and/or continuing burden(s) are foreseeable, their respective probability and what can be done in response should they occur as anticipated. Recall that the exclusionary analytical method affirms the moral authority to reject a means of sustaining life *if and only if* it can be reasonably assessed that the foreseeable harm(s)/continuing burden(s) of that means is disproportionate to its foreseeable benefit(s). Recall further that the exclusionary analytical method insists that only that foreseeable harm(s) and continuing burden(s) *directly imposed* by the means itself and *not* by the patient's functional incapacity or poor quality of life, can be included in the balancing of harm(s)/burden(s) against benefit(s). The following examination of foreseeable harm(s) and continuing burden(s) imposed by various forms of ANH is accordingly confined to those harms(s)/burdens(s) *directly* imposed by ANH itself.

As noted earlier in this chapter, ANH can be provided directly into the digestive tract (enteral), or bypass the digestive tract (parenteral) entirely, providing ANH under the skin or into the bloodstream. Enteral methods include a tube placing a tube into the nose (Naso Enteric Tube (NET) that empties into the stomach (NG tube), the duodenum (Nasoduodenal tube) or into the jejunum (Nasojejunal tube). A gastrostomy places a tube directly into the stomach, a jejunostomy directly into the jejunum, either surgically, using an endoscope (PEG or PEG/J tube), or using a fluoroscope (Percutaneous Radiological Gastrostomy/Jejunostomy/Gastrojejunostomy). Proctoclysis uses the rectum as an avenue for placing means of placing nutrition and hydration directly into the colon.

Parenteral methods of providing nutrition and hydration include entry into the bloodstream through a smaller blood vessel (peripheral parenteral nutrition) through a major blood vessel in the chest (Total Parenteral Nutrition (TPN), or under the skin (hypodermoclysis). Parenteral

methods are usually assessed as riskier and costlier than enteral feeding, and as a result are considered more as emergency bridges to either more permanent methods of enteral feeding or the resumption of oral intake, not usually for the debilitated elderly but for patients recovering from surgery or serious injury. A principal risk of all forms of parenteral nutrition and hydration is infection, which should not be surprising given that hypodermoclysis creates one or more openings in the skin for possible access of harmful bacteria and especially in the case of peripheral and total parenteral nutrition because potential access is given directly into the blood stream. [1061]

In addition, however, because parenteral methods of providing nutrition and hydration to the human body bypass the digestive tract, another serious risk of *prolonged* parenteral feeding is that the digestive tract will effectively shut down from lack of use and permit bacteria normally kept in check to invade the rest of the body. The American Gastronterological Association's Technical Review on Tube Feeding for Enteral Nutrition claims that "[i]t is now considered important to provide fuel to the intestine not only for growth and maintenance of the body but also to keep the local defense barrier of the intestine intact . . . [for] [w]ithout intraluminal fuels, even while receiving total parenteral nutrition, intestinal integrity may deteriorate and, under stress, allow gut bacteria to colonize and systematically invade the body." [1062],[1063]

According to Erik Meidl, "[r]isks in peripheral IV placement and use include infection, bleeding complications, thrombosis (blood clot formation), and sclerosis (destructive scarring) of

[1061] When the digestive tract is bypassed, nutrition must of necessity be in ready to use form for organs and tissues served by the bloodstream. The glucose used to provide ready to use nutrition also unfortunately promotes the growth of bacteria.

[1062] American Gastroenterological Association: "American Gastroenterological Association Technical Review on Tube Feeding for Enteral Nutrition." *Gastroenterology* 108, no. 4 (April 1995): 1282.

[1063] Intravenous ANH can apparently also cause liver dysfunction.

the vein." [1064] There is, in addition, a small risk that in inserting the needle, the wall of the vein could be inadvertently punctured permitting infiltration of nutritional formula into surrounding tissues. Even if the needle catheter is placed correctly, Meidl claims that "[a]ccess to a particular peripheral vein can be maintained only for a few days at most before the vein becomes nonfunctional due to infiltration, infection, or thrombosis." [1065] If so, another suitable vein must immediately be found. Total parenteral nutrition involves access through a central vein in the chest or abdomen. Meidl makes the claim:

> Placing a catheter into the larger, central veins is technically more difficult," [and although] "potential complications include pneumothorax (collapse of the lung), arterial and venous bleeding, thrombosis, and infection, [1066] [a] central venous catheter. . .allows for more calories to be provided to the patient, is more comfortable for the patient after it has been placed. . is less likely to cause vein sclerosis from the nutrition or medications [and can] be maintained for a longer period. [1067]

Although hypodermoclysis has very limited, if any, potential for nutritional supplementation, it is suitable for infusing fluids under the skin for absorption into surrounding tissues. Unfortunately, it involves a needle and a tube protruding from the skin, and although hypodermoclysis can certainly be tolerated by a patient who is either aware of the benefit being providing, or totally unaware of its presence, it is problematic for a cognitively impaired patient who cannot understand why a tube is protruding from his/her body.

[1064] Eric J. Meidl, "A Case Studies Approach to Assited Nutrition and Hydration," *National* Catholic Bioethics Quarterly 6, no. 2 (Summer 2006), 320.

[1065] *Ibid.*

[1066] Complications of TPN can also apparently include a pulmonary embolism from deep vein thrombosis, as well as constipation, and nausea.

[1067] Eric J. Meidl, "A Case Studies Approach," 320.

All methods of enteral ANH pass nutrition and hydration through a tube into some portion of the gastrointestinal tract. Obviously, this tube can not only leak, but can cause immediate injury to delicate tissues as it enters the body through the nose, stomach wall, abdominal wall, and rectum, respectively. In addition, a tube can over time, irritate and ulcerate delicate tissue in the nasal passages, esophagus, stomach and intestines. Nutrition provided by enteral tubes is almost always in the form of specially designed nutritional formulas which can cause nausea, intestinal cramping, vomiting, and diarrhea. The need to flush tubes with water to prevent blockage and overall difficulty in ascertaining the correct amount of fluids to provide can create fluid and electrolyte imbalances and fluid retention leading to a number of respiratory [1068] and even cardiac problems [1069]As noted above, because all forms of enteral feeding [1070] eliminate the need for chewing and swallowing, aspiration pneumonia may be facilitated through the bacterial colonization of oropharyngeal secretions. Finally, enteral feeding can cause serious infection other than aspiration pneumonia, especially in older patients and others with compromised immune systems. [1071] Not to be overlooked, is the burden all forms of both enteral and parenteral feeding impose on a conscious patient from the loss of the taste of both food and drink.

In addition to the above, nasal tubes can contribute to the reflux of gastro-intestinal contents into the esophagus, upper airways, and even the lungs, because the tube itself prohibits complete closure of the lower esophageal sphincter separating the esophagus from the stomach. Perhaps a more immediate and painful burden to patients fully conscious of the tube in their nose is the discomfort not only in their in their nose and throat, but in their possibly blocked and

[1068] Apparently including pneumothorax, hydrothorax, emphysema, and mediastinitis.

[1069] Including, apparently, serious hypertension.

[1070] and parenteral as well.

[1071] Apparently including cellulitis, peritonitis, and necrotizing fasciitis

infected sinus passages, and from periodic gagging. [1072] In addition to the complications attendant to all forms of enteral feeding, PEG and PEG/J tubes require that the patient be sedated, and although sedation for PEG and PEG/J tubes is not as risky as the sedation necessary for surgical placement of feeding tubes, there is an undeniable risk, especially for elderly patients. Susan Mitchell et. al. in an article entitled "Making Choices: Tube Feeding Placement in Elderly Patients,"provide an easy to decipher chart reproduced here that graphically demonstrates the probability of the most common, yet obviously reasonably rare, complications of PEG tubes for elderly patients:

Table 2. Comparison of Complications of PEG Tubes for Elderly Patients

Type of Complication	How many of 100 patient might get it
Infections:	
Minor skin:	4 out of 100
Major (life threatening)	1 out of 100
Bleeding:	
Minor (no transfusion)	Less than 1 out of 100
Major (need transfusion)	Nearly 0 out of 100
Temporary diarrhea, cramping	12 out of 100
Temporary vomiting, nausea	9 out of 100
Tube Problems:	
Minor (dislodgment, blockage, leaking	4 out of 100
Major (Perforation of the bowel)	Less than 1 out of 100
Death from putting the tube in	Less than 1 out of 100

Source: Susan L. Mitchell, J. M Tetroe, A. M. O'Connor, and A. Rostom, et. al. "Making Choices: Long Term Feeding Tube Placement in Elderly Patients." http://decisionaid.ohri.ca/docs/Tube_Feeding_DA/PDF/TubeFeeding.pdf (accessed on June 15, 2011).

[1072] For an exhaustive list of possible complications from NG tubes, consult the American Gastroenterological Association Medical Position Statement: Guidelines for the Use of Enteral Nutrition

Surgical placement of feeding tubes, both gastrostomies and jejunostomies, require general surgery and general anesthesia with their respective attendant risks. Proctoclysis apparently does not have any additional significant risks other than those possible with all other forms of enteral feeding.

It seems reasonably clear that although serious harm, including death, from enteral feeding *is possible*, significant harm is relatively rare. In addition, although enteral feeding can also impose ongoing burden(s), *many* of these can be significantly reduced once identified. Although there are certainly particular patients for whom enteral feeding represents a much more formidable foreseeable risk, it is not difficult to envision a circumstance, when the foreseeable benefit of enteral feeding is assessed to be of real significance, that it might not be at all unreasonable for a patient or surrogate decision maker to dismiss its foreseeable harm(s) and/or burdens as unlikely or otherwise insignificant relative to its probable benefit(s), *provided* the patient is capable of understanding the reason for the presence of the tube, and is willing to accept whatever ongoing burden(s) imposed thereby in exchange for the benefit(s) provided.

On the other hand,, the foreseeable harm(s) and ongoing burden(s) of tube feeding for a conscious but cognitively impaired patient, aware of the presence of the tube but unable to understand why the tube has been inserted into his/her body, cannot be underestimated, as evidenced by the number of such patients that must have their hands restrained, [1073],[1074] given

[1073] Stanley A. Terman. *The Best Way to Say Goodbye: A Legal Peaceful Choice at the End of Life.* (Carlsbad, CA: Life Transitions Publications, 2007), 87.In his book, *The Best Way to Say Goodbye,* Stanley Terman claims that"as many as 7 out of 10 tube-fed dementia patients require physical restraints."

[1074] Arthur Peck, Camille E. Cohen, and Michael N. Mulvihil. Long-term Enteral Feeding of Aged Demented Nursing Home Patients." *Journal of the American Geriatrics Society* 38, 11 (November 1990):1195. In a 1990 article in the *Journal of the American Geriatrics Society,* Arthur Peck, et. al. reported that in a study of the effects of various forms of tube feeding on aspiration pneumonia, 90% of tube fed patients with dementia had mittens to prevent them from dislodging their feeding tubes.

special mittens, or otherwise prevented from dislodging the tube. There can be little doubt that feeding tubes are at minimum a source of annoyance to many patients with dementia, but Joanne Lynn and James Childress claim that tube feeding for these patients is a "constant source of fear, discomfort and struggle." [1075], [1076] In addition, according to Lois K. Evans et. al., in a 1989 article in the *Journal of the American Geriatrics Society* entitled "Tying Down the Elderly," [1077] there are serious medical consequences for restraining the cognitively impaired patient:

> Immobilization of the elderly patient by prolonged use of restraints can lead to many serious biochemical and physiologic effects. Abnormal changes in body chemistry, basal metabolic rate and blood volume, orthostatic hypotension, contractures, lower extremity edema and decubitus ulcers, decreased muscle mass and tone/strength, bone demineralization, overgrowth of opportunistic organisms, and EEG changes have been well-documented.

Evans et. al. further claim that "animal studies indicate that physical restraint causes a stress response resulting in increased corticosterones and decreased function of the blood brain barrier in the autonomic centers. [1078] Finally, the authors suggest that "[p]erceptual and behavioral responses that have been noted with immobilization lend support to these physiologic effects in humans and may account for the disorganized behavior noted among elderly restrained patients. [1079]

[1075] Joanne Lynn, and James F. Childress. "Must Patients Always Be Given Food and Water?" *Hastings Center Report* 13, no. 5 (October 1983):18.

[1076] Timothy E. Quill. "Utilization of Nasogastric Feeding Tubes in a Group of Chronically Ill, Elderly Patients in a Community Hospital. *Archives of Internal Medicine 149. no. 9* (September 1989): 1938. Timothy Quill suggests that, in such a circumstance, tube feeding "violate[s] the basic tenets of humane care."

[1077] Lois K. Evans, and Neville E. Strumpf. "Tying Down the Elderly: A Review of the Literature on Physical Restraint" *Journal of the American Geriatrics Society* 37, no. 1 (January 1989): 65-74.

[1078] *Ibid*, 69.

[1079] *Ibid*.

Balancing Harm(s) and/or Burden(s) Against Benefit(s)

Given the above examination of both foreseeable benefit(s) provided by the various forms of ANH and foreseeable harm(s) and continuing burden(s) imposed thereby, even when restricted, as required by the exclusionary analytical method, to foreseeable harm(s) and/or burden(s) *directly imposed* by ANH itself, and without regard to the burden, if any, imposed by the patient's functional incapacity and/or quality of life, it is not difficult to envision circumstances where the not at all unreasonable assessment can be made that although the patient is unwilling or unable, even with assistance to eat and drink sufficiently to sustain his/her life, that the foreseeable harm(s) and/or burden(s) of ANH are disproportionate to its foreseeable benefit(s). [1080]

Clearly, the smaller and/or less certain the foreseeable benefit(s) of ANH the more reasonable the assessment that the foreseeable accompanying harm(s) and/or continuing burden(s) are disproportionate. Given that virtually any foreseeable harm/burden is disproportionate to benefit when that benefit is highly improbable, such an assessment seems *almost* inescapable when, to the extent that it can be determined, it appears that the patient, for whose *benefit* ANH is being considered, either no longer has the physiological need for nutrition and hydration or has permanently lost the physiological capability of utilizing the nutrition and

[1080] John S Howland., "A Defense," 706-7. As pointed out in some detail in Chapter 3, there are reversible causes of an unwillingness or inability to eat and drink sufficiently to sustain one's life, and it is clearly important that efforts at reversing those causes be exhausted before a decision to accept or reject ANH is made. In John Howland's view, however, the evaluation of patients with dementia necessitates a broader search for a reversible cause of their overall clinical deterioration: "As George Isajiw has pointed out, some elderly patients with dementia have a treatable, reversible cause for their clinical deterioration. . . Numerous other potential causes for misdiagnosis [of irreversible decline] could be mentioned, including dental disease, chronic infections, depression, polymyalgia rheumatica, thyroid disease, and unrecognized spinal compression fractures. Iatrogenic causes of decline and inability to eat in dementia should also be considered. . . In treating patients with advanced dementia the only options may not be 'to PEG or not to PEG;' sometime a third option is available—to treat and cure the underlying cause of the patient's decline."

hydration thereby provided. [1081] Such an assessment also seems *almost* inescapable when, to the extent that it can be determined, it appears that the patient is so near death, from a pathology unimpeded by the presence in the bloodstream and/or gastrointestinal tract of adequate nutrition and hydration to satisfy his/her body's needs, that it is highly probable that death from this pathology will likely occur before death would occur from complications of dehydration and/or malnutrition should ANH be foregone. [1082]

In addition, it also seems clear that the greater and/or more certain the foreseeable harm(s) and/or continuing burden(s) imposed by ANH the more reasonable the assessment that this harm(s) and/or continuing burden(s) is disproportionate to its foreseeable benefit(s). Such an assessment seems *almost* inescapable, when a patient, including the Alzheimer's patient in the circumstances specific to this inquiry, lacks the cognitive capacity to grasp the reason for a feeding tube, given the likelihood, as discussed above, that he/she will have to be restrained in order to prevent the tube from being dislodged.

The careful reader is likely to have noticed that the above commentary qualified the use of the word inescapable with the word *almost*. It seems clear that there is apparently general agreement that the identification, assignment of a relative weight, and balancing of foreseeable benefit(s) provided by a means of sustaining life against foreseeable harm(s) and/or continuing burden(s) imposed thereby is inherently a subjective assessment and that some measure of discretion in doing so is entirely appropriate. Accordingly, a particular circumstance that this

[1081] Without a physiological need for nutrition and hydration or the physiological capability of utilizing nutrition and hydration, ANH is incapable of providing a benefit.

[1082]There is obviously no survival benefit provided by ANH if death is expected to occur with ANH in less time than if ANH is foregone It must also be noted that given the nearness of death such an assessment becomes *more* reasonable, even for those embracing the exclusionary analytical method, the *shorter* the patient's anticipated survival, despite the expectation that because of ANH his/her life will be extended *beyond* that anticipated if ANH had been foregone. Unless one is a vitalist, totally committed to life extension regardless of attendant harm(s)/burden(s), it is totally legitimate and appropriate to evaluate the foreseeable survival *benefit* provided by ANH based on the *length* of that survival.

observer characterizes as requiring an assessment that the foreseeable harm(s) and/or burden(s) provided by ANH are disproportionate to its foreseeable benefit(s) that is *almost* inescapable, reflects the reality that in a virtually identical circumstance, a patient or his/her surrogate would be not be unreasonable and entirely within the range of permissible discretion in assessing that the foreseeable harm(s) and/or burden(s) of ANH are *not* disproportionate to its foreseeable benefit(s).

Obviously, the accuracy of the above described balancing of foreseeable harm(s)/burden(s) against foreseeable benefit(s) is significantly weakened by an obvious inability to *inerrantly* foresee the future, and whereas other means of sustaining life, such as surgery, do not permit a temporary trial, other means, including ANH, clearly do. Why not then, it can easily be supposed, if there is any possibility whatsoever that a patient's body still needs nutrition and hydration and retains the physiological capability of successfully utilizing that nutrition and hydration, institute a brief trial period of ANH to determine with certainty whether ANH is capable of providing a legitimate benefit or imposing a significant burden, if for no other reason than out of respect for the sanctity and intrinsic worth of human life. The advisability of such a trial is dependent on four considerations. First, what is the level of certainty re: the foreseeable harms(s)/burdens and benefit(s). Second, how serious is the foreseeable ongoing burden(s), and more importantly, how serious is the foreseeable *immediate* harm. Third, how comfortable, if at all, is the patient or his/her surrogate with that level of certainty, especially considering the harm(s)/burdens a trial could impose. Fourth, what difficulty, if any, does the patient or his/her surrogate anticipate with withdrawing ANH should the harm(s)/burden(s) prove equal to or greater than anticipated or the benefit(s) prove unsatisfactory. Clearly, a trial itself has both foreseeable benefits and foreseeable risks, and a patient or his/her surrogate is entirely within

his/her discretion in requesting a trial if comfortable that the foreseeable benefit(s) of the trial itself are sufficiently greater than its foreseeable harm(s)/burden(s).

Options Other Than ANH

In making an informed choice to accept or reject ANH, it is of critical importance that a patient or his/her surrogate be aware that the choice to reject ANH does not necessarily foreclose the option of either continuing to aggressively hand feed, and as discussed in Chapter 3, utilizing the numerous methods of not only increasing a patient's appetite for food and drink but increasing his/her ability to swallow without aspiration, or beginning what has been termed *comfort feeding*. Eric J. Palecek, et. al. suggest that the *comfort* in comfort feeding has two meanings: "First, comfort refers to the stopping point in feeding, emphasizing that the patient will be fed so long as it is not distressing. Second, comfort refers to the goals of the feedings. The feedings are comfort oriented in that they are the least invasive way of attempting to maintain nutrition through careful hand feeding." [1083] With particular significance for the circumstances specific to this inquiry, the Alzheimer's Association of Greater Illinois, in a booklet entitled "Encouraging Comfort Care," advises caregivers that comfort feeding, for Alzheimer's patients unwilling or unable to eat and drink what is perceived to be insufficient to sustain their lives, is not about calories but about comfort:

> The goal is to offer pleasure through taste and smell, rather than a sufficient number of calories. For example, you can offer a teaspoon of chocolate pudding or vanilla pudding every few hours. Just a taste can be pleasurable . . . Comfort can be maintained by frequently swabbing the mouth with water and lubricating the lips. . . Alternatively, swab the mouth with

[1083] Palecek, Teno, Casarett, Hanson, Rhodes, and Mitchell. "Comfort Feeding Only," 581.

> pineapple juice or place drops of honey or chocolate on the tongue for a more pleasurable taste. [1084] [1085]

The Alzheimer's Association is quick to address caregiver's fears about starvation: "Your loved one will not 'starve to death,' without artificial nutrition and hydration. As a result of dementia, body functions are slowing down and no longer require additional calories or liquids." [1086] John Hoffer affirms the Association's assessment:

> People who reach the advanced stage of dementia have a low metabolic rate. Their resting metabolic rate is low because muscle wasting has shrunk their lean body mass and their brains are atrophic: their metabolic rate above basal is low because they are physically inactive. Finally, they have a history of weight loss which their body adapts to by reducing its metabolic rate and retaining dietary protein more efficiently. This adapted state can persist indefinitely. They are in a state of physiological homeostasis. [1087], [1088]

There is a third option for patients in the late stages of Alzheimer's disease which arguably combines the best elements of aggressive hand feeding and comfort feeding, which might be called *nutrition/aspiration sensitive comfort feeding*. It would differ from comfort feeding in the

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[1084] Alzheimer's Association of Greater Illinois, "Encouraging Comfort Care," 11-12.

[1085] *Ibid*, 12. The Association also suggests that '[p]ain medications may continue by mouth or may be changed to other forms such as small drops of liquid under the tongue, patches on the skin or rectal suppositories"

[1086] Alzheimer's Association, "Treatments for Behavior," 12.

[1087] John L. Hoffer. "Tube Feeding in Advanced Dementia: The Metabolic Perspective." *British Medical Journal* 333, no. 7580 (December 9, 2006): 1214.

[1088] John L. Hoffer, "Tube Feeding." 1214-1215. Hoffer also insists that if fear of starvation is an issue, constant monitoring of body weight can provide reassurance: "Doctors can readily determine which of their patients are progressively starving by weighing them. In advanced dementia, a constant body weight, even if subnormal, rules out progressive starvation and eliminates any medical indication for tube feeding. There is no physiological reason nor any medical evidence to presume that a medically stable, severely demented person whose body mass index exceeds 18.5 is at a high enough risk of the complications of malnutrition." In addition, he avers, "It is also possible for weight loss to occur but be physiologically inconsequential."

utilization of the numerous methods of increasing the Alzheimer's patient's appetite for food and drink, increasing his/her ability to swallow without aspiration, and preventing his/her mouth and/or teeth from providing a source of bacterial infection for the aspirant, if any, inhaled into his/her lungs.

As Alzheimer's disease continues its trajectory toward death, hand feeding and hydration by mouth of an Alzheimer's patient may not be possible at some point, and it is important to note that even absent *all* oral ingestion of food and liquids, it is unlikely that a late stage Alzheimer's patient will suffer as a result. Obviously, death may occur at any time from a pathology unrelated to nutrition and hydration levels, but even if dehydration is the ultimate cause of death, [1089] evidence examined in Chapter 3 not only suggests that terminal dehydration is far less painful than one might imagine, preemptive palliative sedation is available should a decision be made to eliminate *even the possibility* of any form of suffering once oral ingestion of food and drink are completely precluded. Stephen G. Post implies that comfort feeding not only provides comfort for the patient but comfort for family and caregivers, because it feels right: "The laudable tendency to provide food and drink to any human being has deep roots in evolutionary psychology; it should be honored by families, society, and professionals through an emphasis on assuring assisted oral feeding as needed for the person in advanced dementia before a natural death." [1090]

Additional Requirement of an Incurable Fatal Pathology

[1089] It must be admitted that although death from dehydration in such a circumstance will, in all probability, occur long before death from malnutrition, there is at least a possibility that even with careful hand feeding a patient may be incapable of ingesting sufficient nutrition to prevent malnutrition while simultaneously capable of ingesting enough liquids to prevent death from dehydration. Iin such a circumstance, eventually the patient's condition is going to deteriorate to the point that even with careful hand feeding he/she will be unable to ingest enough liquids to forestall terminal dehydration. If this state of affairs is unacceptable, the option of tube feeding is still available.

[1090] Stephen Post, "The Moral Challenge," 17.

Finally, as noted above, is it not difficult to envision circumstances where it might be not at all unreasonable for a patient or his/her surrogate to assess that the foreseeable harm(s) and/or burden(s) of ANH are disproportionate to its foreseeable benefit(s), even when the assessment of foreseeable harm(s) and/or burden(s) is restricted to harm(s)/burden(s) *directly imposed* by ANH, as required by the exclusionary analytical method. There is, however, as discussed earlier in this chapter, another much more potentially onerous, and, at least arguably, highly *questionable* additional requirement that *may* be imposed by adherents of the *exclusionary analytical* method who are especially fearful that the rejection of a means of sustaining life can be a form of passive euthanasia. This qualification requires that *in addition to* the assessment that a means of sustaining a patient's life has foreseeable harm(s) and/or continuing burden(s) *directly imposed by he means itself* that are, on balance, disproportionate to the foreseeable benefit(s) provided to him/her, the means must *also* be considered as a method of only temporarily forestalling the effects of an *incurable* fatal pathology that significantly reduce the patient's life expectancy to 6 months or less, and give rise to the prognosis that the patient is *terminally* ill.

Onerous as this additional requirement might be, it is clear that a late stage Alzheimer's patient, unwilling or unable, even with assistance, to eat and drink sufficiently to sustain his/her life, has an incurable fatal pathology, ANH is only capable, *at best*, of *temporarily* forestalling the effects of that pathology, and subject to a prognosis that he/she is terminally ill, fully satisfies this requirement. Unfortunately, as noted in previous chapters, physicians have, at least historically, had difficulty in accurately predicting when death from Alzheimer's disease can be expected to occur, and have been accordingly been reluctant to classify an Alzheimer's patient as terminally ill. John Shuster claims that "[d]espite substantial effort to develop models to predict

death within 6 months in dementia, accurate prediction remains difficult." [1091] In his view, "[t]he 6-month prognosis criterion is clearly a poor fit for terminal dementia. The NHO guidelines themselves acknowledge that 'even severely demented patients have a prognosis of up to two years." [1092] Ladislav Volicer suggests that "it seems that it is impossible to develop a reliable instrument to predict 6-month survival, because the death of Alzheimer's patients is caused by events, such as the development of infections and other complications that are unpredictable." [1093] Even Muriel Gillick, in claiming that "[s]tudies that have followed individuals with dementia over time have found that eating problems are the very last capacity to be lost in the course of the diseas. . . [and [t]herefore, at the point these problems arise, the typical person with dementia is extremely cognitively impaired and in the final stage of dementia, [acknowledge that] [t]his final stage may be as short as a few months or as long as 3 years." [1094]

The issue, therefore, is even in the absence of the classification of being terminally ill with 6 months or less to live, does a late stage Alzheimer's patient, unwilling or unable, even with assistance, to eat and drink sufficiently to sustain his/her life, satisfy this additional requirement. Recall that the *overall* rationale for this additional requirement is that prevention of euthanasia trumps all other concerns, the *intention* to kill is the essential element in all forms of euthanasia, and because the intention to kill is seldom, if ever, actually expressed, intention, of necessity, must be inferred. From this perspective, the *inference* that the rejection of a means of sustaining life reflects the intention to no longer prolong the dying process rather than the intention to kill

[1091] John L. Shuster, "Palliative Care for Advanced Dementia," 375.

[1092] *Ibid.*

[1093] Ladislav Volicer, "Palliative Medicine in Dementia," 1376.

[1094] Muriel R. Gillick. "Facing Eating Difficulties in End-Stage Dementia." *Alzheimer's Care Quarterly* 3, no. 3 (Summer 2002): 228.

by shortening life is clearly strengthened when the means being evaluated is considered as a method of only *temporarily* forestalling the effects of an *incurable* fatal pathology that significantly reduces the patient's life expectancy, and from the effects of which an individual is apparently dying. It would seem, therefore, that the essence of the additional requirement, as it applies in the circumstances specific to this inquiry, is whether in rejecting ANH, the more *plausible* inference is an intention to kill *or* to no longer prolong the dying process.

On the other hand, once the assessment is made that ANH must be rejected because its foreseeable harm(s) and/or continuing burden(s) are disproportionate to its foreseeable benefit(s), if the option of *nutrition/aspiration sensitive comfort feeding* is chosen, *any* inference of an intention to kill is completely *implausible* not only because the patient is being provided nutrition and hydration orally, but because a strong effort is being made to increase his/her appetite and prevent aspiration, subject only to the limitations imposed by his/her comfort, which, given his/her condition and prognosis, trumps all else. As long as all reasonable efforts, even though short of ANH, are being made to provide nutrition and hydration it is extremely difficult to draw a *plausible* inference that ANH was rejected, even though its harm(s)/burden(s) exceed its benefit(s), because of an intention to kill through passive euthanasia.

Why, Despite the Evidence, ANH Continues to be Used

It can certainly be asked, with no little justification, why so many elderly debilitated patients have continued to be tube-fed, given what is currently known to professional medicine, and arguably has been known to professional medicine for the last two decades, specifically that there is no evidence from scientific research that ANH reduces pressure sores, restores physical strength or resistance to infection, reduces aspiration or aspiration pneumonia or extends the

lives of those patients whose bodies no longer need nutrition and hydration or have permanently lost the physiological capability to utilize nutrition and hydration. Families and other surrogate decision makers, physicians, and long term care facilities, such as nursing homes, have all had a role in maintaining a very high level of tube feeding.

There are a number of reasons why a family might acquiesce to a physician's recommendation of a PEG tube or other form of ANH. Some families are guilt ridden at their inability to prevent the death of a loved one, or are simply unable to "let go," and are determined, by whatever means is available, to extend his/her life. Other families see feeding as an expression of love. Joanne Lynn suggests that there is "a link made in the mind between feeding and loving that is difficult to dismiss in the practice of making decisions for those who can no longer make decisions for themselves." [1095],[1096]

Families can and do make erroneous assumptions regarding the consequences of malnutrition and dehydration, assuming that an individual unwilling or unable, even with assistance, to eat and drink sufficiently to sustain his/her life will starve unless ANH is provided, and not only suffer grievously, as a result, but be visibly disfigured. They may, in addition, be totally unaware that various forms of ANH can not only impose both harm(s) and continuing burden(s) on a patient, such as the facilitation of aspiration pneumonia, but cannot extend the lives of those patients whose bodies no longer need nutrition and hydration or have permanently

[1095] Joanne Lynn, ed. *By No Extraordinary Means: The Choice to Forgo Life-Sustaining Food and Water.* (Bloomington, IN: Indiana University Press, 1986), 47.

[1096] Muriel R. Gillick, and Angelo E. Volandes. "The Standard of Caring: Why Do We Still Use Feeding Tubes in Patients with Advanced Dementia." *Journal of the American Medical Directors Association* 9, no. 5 (June 2008): 365. Muriel Gillick and Angelo Volandes suggest that in asking for additional information families may be asking for a way to reconcile caring with foregoing ANH. "[P]erhaps one overlooked reason that many loving families and caring physicians continue to opt for artificial nutrition is that the case for feeding tubes is a moral one and scientific one. Clinical experience suggests that family members who express concerns about 'starving' their relatives to death may not be asking for more data. . . What may be at issue for families is how best to demonstrate caring, and caring is not readily susceptible to empirical study."

lost the physiological capability to utilize nutrition and hydration. [1097] Attending physicians [1098] and other medical professionals [1099] may be reluctant or unable to provide *accurate* information to families, in some instances because they are themselves misinformed. Caroline A. Vitale, et. al. make the case for physicians themselves being misinformed based in part on a survey mailed to 7500 American primary care physicians, of which 490 were returned:

> Despite the small sample, among those who responded, physician misconceptions about tube feeding predominated. This finding is important in that it probably reveals the poor quality of information given to families and caregiver of those with feeding problems in the terminal stages of dementia. This may explain, in part, the reports of many surrogate decision makers that they are not informed by physicians about the long-term risks of PEG placement or viable alternatives. [1100]

[1097] Brody, Hermer, Scott, Grumbles, Kutac and McGammon. Unpublished first draft of article that was later published as "Artificial Nutrtion and Hydration: The Evolution of Ethics, Evidence and Policy." *Journal of General Internal Medicine* 26, no. 9 (September, 2011): 1053-8. Howard Brody et. al. claim that patients, families, and even medical staff are misinformed re: ANH:"Palliative practitioners discussing ANH with patients, families, and other medical staff commonly encounter significant knowledge deficits. It is often wrongly believed that malnutrition and dehydration are not a part of the underlying disease but are independent comorbidities. It is often wrongly believed that tube placement and enteral feeding are totally benign procedures. There is a general failure to understand that for many patients with terminal disease, the loss of appetite and true thirst parallels that of the body's inability to utilize nutrients even if provided"

[1098] Joseph W. Shega, Gavin W. Hougham, Carol B. Stocking, Deon Cox-Hayley, and Greg A. Sachs. "Barriers to Limiting the Practice of Feeding Tube Placement in Advanced Dementia." *Journal of Palliative Medicine* 6, no. 4 (2003):885. In a 2003 random sample of 500 AMA doctors (of 416 eligible 195 completed surveys), 46.9% believed that a PEG tube has advantages: reduces aspiration pneumonia (76.4%), improves pressure ulcer healing (74.6%), increases survival (61.4%), improves nutritional status (93.7%), and functional status (27.1%).

[1099] Helen M. Sharp, Joseph W. Shega. "Feeding Tube Placement in Patients With Advanced Dementia: The Beliefs and Practice Patterns of Speech-Language Pathologists." *American Journal of Speech Language Pathology* 18, no. 3 (August 2009): 224. In a 2009 survey of Speech-Language pathologists, using data from 362 out of 1050 random mailings,78% believed PEGS improve nutritional status of those with advanced dementia, and nearly 50% believed that PEGs reduce risk of aspiration pneumonia.

[1100] Caroline A.Vitale, Tad Hiner, Wayne A. Ury, Cathy S. Berkman, and Judith C. Ahronheim. "Tube Feeding in Advanced Dementia: An Exploratory Survey of Physician Knowledge." *Care Management Journals* 7, no. 2 (Summer 2006):82.

Given their enormous influence on decision making, it is likely, however, that for patients *not* in long term care facilities, doctors are much more responsible for the large number of elderly patients given some form of ANH. In their defense, there is no shortage of legitimate justification for why doctors have so frequently recommended feeding tubes. Although some doctors may have simply been remiss in not informing themselves as to the results of scientific research on the benefit(s) and harm(s)/burden(s) of ANH, others are simply not persuaded by the available evidence. As pointed out by John Berkman, until very recently, the presumption that ANH extends lives has been widespread and largely unchallenged:

> One of the shared assumptions about MANH [mechanically assisted nutrition and hydration] is that it increases longevity for almost all classes of patients. This assumption has been held for the last forty years with little empirical verification. Until recently, it was assumed that tube feeding was almost always a relatively safe, effective and valuable therapy. This assumption has always been particularly strong in the United States where the use of tube feeding is four to eleven times more common than in other industrialized nations. [1101]

Muriel Gillick and Angelo Volandes persuasively claim that because ineffectiveness of ANH is, in addition, counter-intuitive, research evidence alone may simply not be enough:

> Another possible explanation for the continued use of PEGs is that the data that from the case against feeding tubes are not sufficiently compelling. . . If our intuition tells us that feeding tubes ought to prolong life, even in individuals who are in the final stage of dementia, then surely we should demand rigorous proof, not merely a statistical analysis of government-mandated nursing home data. [1102]

[1101] John Berkman, "Medically Assisted Nutrition and Hydration," 162.

[1102] Muriel R.Gillick and Angelo E. Volandes, "The Standard of Caring," 365.

Even, however, if a doctor is persuaded by the available scientific evidence re: ANH, and concludes that given his/her patient's diagnosis/prognosis [1103] that the foreseeable harm(s) and/or continuing burden(s) of all forms of ANH are disproportionate to its benefit(s), he/she may opt for the path of least resistance and reduced risk and recommend ANH, reasoning that persuading a particular patient's family to forego ANH will be simply too long and too difficult a process, [1104] and may ultimately even precipitate a law suit for malpractice when the patient ultimately dies and his/her family seeks to assign blame. As James Hoefler points out, there are a number of other possible influences on doctors, some of which may be almost irresistible:

> There are also religious admonitions that pervade our culture regarding the duty to feed the hungry and provide drink to the thirsty, [1105] [and] [p]hysicians also get caught up in the cross-cutting currents about whether to feed the hopelessly ill and demented patients in their care or not, especially when family members (and, perhaps, nurses) are clamoring for the physician to 'Do something! [1106]

Hoeffler also reminds his readers that what he terms"[t]he *technological imperative*, the sense that one needs to employ every means of technology available, regardless of the costs or benefits

[1103] As noted above, not only is an accurate prognosis for Alzheimer's patients, especially as to life expectancy, often problematic, this inability to accurately predict mortality makes a hospice referral difficult, making a recommendation for some form of ANH even more attractive.

[1104] Brody, Hermer, Scott, Grumbles, Kutac and McGammon. Unpublished first draft of article that was later published as "Artificial Nutrtion and Hydration: The Evolution of Ethics, Evidence and Policy." *Journal of General Internal Medicine* 26, no. 9 (September, 2011): 1053-8. For Howard Body et. al., a doctor's unwillingness to take the time to carefully and painstakingly discuss the benefits and burdens of ANH with family and surrogate decision makers is no surprise: "In short, the results are those we would expect from a health system that generously reimburses for procedures and reimburses very poorly for taking the time to explain complex concepts to families. And even the most dedicated physician and well-educated family members may make no headway against administrative policies based primarily on fear and staffing limitations."

[1105]James M Hoefler, "Making Decisions out Tube Feeding," 247.

[1106] *Ibid.*

of treatment, may drive physicians to recommend tube feeding when it is not otherwise indicated." [1107]

Finally, as noted in previous chapters, it is clear that the utilization of feeding tubes in long term care facilities, such as nursing homes, is particularly high, [1108] and may, it is claimed, be more dependent on the influence of financial and regulatory considerations than that of doctors or families. Stanley Terman suggests that tube-feeding offers a financial incentive for long term care facilities in two different ways: First, it takes far less staff time than the frustrating job of assisted feeding. Second, the reimbursement rate from Medicare is greater." [1109] Specifically, according to Stephen Post, "[m]edicare reimburses nursing homes for 'skilled care,' which includes tube feeding, but not for 'custodial care,' which includes 'help in walking, getting in and out of bed, bathing, dressing, eating, and taking medicine." As a result," opines Post, "nursing homes have a financial incentive to use tube feeding," and '[i]n fact, some nursing homes require tube feeding because of current reimbursement policies." State and federal regulations, as well as the public perception of negligence, may also influence nursing homes. Susan L. Mitchell informs that "nursing home quality indicators are now publicly available that include 'weight loss." [1110] Thus," in her view, "facilities may feel compelled to offer tube

[1107] *Ibid*.

[1108] Susan L. Mitchell, Joan M. Teno, Jason Roy, Glen Kabumoto, and Vincent Mor. "Clinical and Organizational Factors Associated With Feeding Tube Use Among Nursing Home ResidentsWith Advanced Cognitive Impairment." *JAMA* 290. no. 1 (July 2, 2003): 73. Susan Mitchell, et. al. claim that "[m]ore than one-third of cognitively impaired residents in US Nursing homes have feeding tubes."

[1109] Stanley Terman, "The Best Wat to Say Goodbye," 87.

[1110] Susan L. Mitchell, "A 93 Year-Old," 2533.

feeding to avoid penalization, even when weight loss occurs as part of the dying process."[1111], [1112]

Despite all of the above, however, according to John Howland, the use of feeding tubes has begun to decline: "Use of PEG tubes in the elderly grew rapidly, from 15 thousand in 1989 to 121 thousand in 1995 and 216 thousand in 2000, according to Medicare data. The majority of these were for elderly patients with dementia. Since about the year 2000, the use of feeding tubes has begun to decline. By one estimate in 2005, the use of PEG tubes had dropped to 75 thousand per year." [1113] Howland seems to believe that research evidence led the way, and that now the tide has turned:

> Opposition to the use of ANH in advanced dementia began among research specialists and has now spread to include community-based physicians, gastroenterologists, internists, geriatricians, and family physicians. Evidence -based medicine practice guidelines for the treatment of Alzheimer's have begun to appear and now strongly discourage the use of feeding tubes. . . Another development has been the move to steer patients with advanced dementia into hospice and palliative care programs. [1114]

In conclusion, the question posed at the outset of this chapter was whether, from a strictly secular perspective, an adult with decisional capacity has the *moral* authority to reject a means of sustaining his/her life, including, but not limited to, ANH. As previously pointed out, although the determination of whether one possesses legal authority for a particular course of action can

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[1111] *Ibid*

[1112] Mitchell, Teno, Roy, Kabumoto, and Mor. "Clinical and Organizational Factors,"73, 80. With regard specifically to cognitively impaired residents in US Nursing homes, Susan Mitchell et. al. claim that "[f]eeding tube use is independently associated with both the resident's clinical characteristics and the nursing home's fiscal, organizational, and demographic features. In their opinion, "[t]his study confirms that severely cognitively impaired residents living in nursing homes that are larger, and lack dementia special care units, have a greater likelihood of using tube feeding."

[1113] John S. Howland, "A Defense of Assisted Nutrition and Hydration," 698-9.

[1114] *Ibid*, 700.

be made with a degree of assurance that approaches certainty, the determination of whether or not one possesses moral authority for that course of action cannot be made with that same level of confidence. Reasonable minds can and do disagree on moral authority, including the circumstances under which an adult with decisional capacity possesses the moral authority to reject a means of sustaining his/her life. Although some may find this result completely unsatisfactory, it reflects the very nature of moral inquiry and especially moral judgments. Nevertheless, in the final analysis, there is ample justification for the conclusion that, from an exclusively secular perspective, [1115] an adult with decisional capacity possesses the moral authority to reject a means of sustaining his/her life, *provided that the foreseeable harm(s) and continuing burden(s) of that means can be reasonably assessed as, on balance, disproportionate to its foreseeable benefit(s), if any*. Whether harm(s) and burden(s) are broadly assessed or restricted to only that harm(s) and benefit(s) directly imposed by the means itself, is entirely dependent on the extent to which the decision maker wants reassurance that the rejection of the means is not a form of passive euthanasia. If an adult with decisional capacity finds passive euthanasia completely abhorrent and has genuine concerns that the rejection of a means of sustaining his/her life might possibly be a form of passive euthanasia, [1116] the exclusive method of analysis appropriately addresses those concerns. [1117]

[1115] The reader is reminded that an entirely secular perspective is based, in part, on the premise that each individual possesses full and complete ownership rights to his/her own body. Although such a premise may be totally contrary to the opposite premise embraced by most organized religions that because God created humans He retains ownership rights in all human bodies, *obviously* neither premise is subjective to objective verification.

[1116] It seems from a distance, at least somewhat surprising that an individual would be unable to determine, with introspection, whether in rejecting ANH his/her intention was to avoid the disproportionate burdens of ANH or to avoid the underlying burdens of his/her life by ending his life through passive euthanasia. The reality for many, however, may be quite different, and fearing euthanasia they may be looking for reassurance that their decision to reject ANH is not euthanasia.

[1117] The reader is again reminded that this is an entirely secular perspective and although passive euthanasia is, at least in the abstract, abhorrent to most persons, there is no absolute secular consensus as to how it can or should be defined, much less an absolute secular consensus as to under what circumstances, if any, it can be excused or

Specific to this inquiry, given the doubts raised about foreseeable benefit(s) provided by the various forms of ANH and the awareness of foreseeable harm(s) and continuing burden(s) imposed thereby, even when restricted, as required by the exclusionary analytical method, to foreseeable harm(s) and/or burden(s) *directly imposed* by ANH itself, and without regard to the burden, if any, imposed by the patient's functional incapacity and/or quality of life, it is not difficult to envision circumstances where the not at all unreasonable assessment can be made that although a late stage Alzheimer's patient is unwilling or unable, even with assistance to eat and drink sufficiently to sustain his/her life, that the foreseeable harm(s) and/or burden(s) of ANH are disproportionate to its foreseeable benefit(s).

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justified. On simply cannot say with total certainty, at least from an entirely secular perspective, that when a competent adult makes the assessment that the foreseeable harm(s) and/or burden(s) of a means of sustaining his/her life is, on balance, disproportionate to its foreseeable benefit(s), *despite a very broad definition of burden(s)*, that he/she does not possess the requisite moral authority for the rejection of that means.

Chapter Six: Moral Authority of Advance Directives

The previous chapter confirmed that under certain circumstances an adult with decisional capacity possesses the moral authority to reject a means of sustaining his/her life. This chapter examines whether when such a rejection is made in advance through an advance directive(s), the requisite moral authority to do so is still present. The chapter on legal authority confirmed that an advance directive is a legally enforceable method of expressing, in advance of the loss of decisional capacity or consciousness, an adult's medical treatment preferences. That an advance directive has legal authority does not, however, mean that it also has moral authority and the assessment that an advance directive has moral authority, especially in a circumstance where decisional capacity but not consciousness is lost, can be of considerable significance. Legal authority alone, without corresponding moral authority, may not be sufficient to insure that one's preferences regarding medical treatment expressed in an advance directive are honored as written. Those asked to assist in carrying out another's

preferences regarding medical treatment expressed in an advance directive, whether they be legally designated surrogate decision makers, care givers, attending medical personnel or even family members, are much more likely to do so faithfully when persuaded that an advance directive has both legal *and* moral authority, *especially* when they *disagree* with the medical preferences expressed therein.

It is not difficult to understand why when decisional capacity but not consciousness is lost the reaction to the medical preferences expressed in an advance directive can sometimes be so contentious, emotional, and emphatic. Concern that an advance directive(s) can, in this instance, lack sufficient moral authority to be determinative of medical treatment is fueled in part by the vision of a vivacious although demented octogenarian, living a life that from all appearances is full of satisfaction and seemingly stress free, who, while still in possession of the requisite decisional capacity to do so, executed a living will that mandates the refusal of all general surgeries, including a relatively safe and inexpensive life saving procedure that she now needs to remove a life-threatening bowel obstruction. Those who find the prospect of her easily preventable death morally unacceptable, claim that despite her advance directive's indisputable legal authority it nonetheless lacks the requisite *moral* authority to be determinative of her medical treatment.

Describing a vastly different circumstance is the competing vision of another octogenarian with dementia. Unlike his female counterpart, this man's twisted and mobility impaired body clearly evidences a long life. Although not in apparent physical pain, his general countenance and body language are reflective of someone who is frightened, bewildered, and for whom life is apparently short on satisfaction and long on stress. He shuns all interaction with fellow patients and staff, spending hour after hour, day after day, when not sleeping, staring at the wall. The living will he executed, while still possessed of the decisional capacity to do so, mandates the acceptance of all available means of sustaining his life. In accordance with the provisions of his living will, his life will be prolonged by surgery for liver cancer followed by several long and extremely arduous and debilitating rounds of chemotherapy that may or may not

significantly extend his life. Although both visions represent two very extreme ends of a long continuum of possible circumstances that can confront the designated surrogates, families, caregivers, and attending medical professionals of a demented patient who previously executed a valid advance directive, fears arising from these and similar worst-case scenarios exacerbate concern over the moral authority of advance directives. Without a doubt, there are those that would find equally troubling the circumstances specific to this inquiry in which a previously executed advance directive(s) of a now late-stage Alzheimer's patient, expressly rejects artificial nutrition and hydration (ANH) if and when he/she is no longer willing or able, even with assistance, to eat and drink sufficiently to sustain life, and insists upon preemptive palliative sedation once terminal dehydration has begun.

As morally unacceptable, at least to some observers, as the consequence of strict adherence to the provisions of an advance directive might seem in the above described circumstances, there is another aspect to an assessment of the moral authority of an advance directive that is especially worth noting and is of particular relevance to this inquiry. Given an accurate diagnosis of a disease such as Alzheimer's, an individual's fear of the likely unavoidable consequences of the disease and his/her resultant determination to minimize its impact not only on him/her but especially on his/her family and caregivers can hardly be considered irrational. In addition, it is not difficult to see why individuals so diagnosed would look to a disease specific advance directive(s) as a means of insuring, within moral limits, that in the late stages of the disease, should they lose decisional capacity or consciousness, a particular means of sustaining their lives not be *inappropriately* utilized to provide *unwarranted* life extension. An accurate and thorough assessment of the legitimate moral authority of advance

directives in general and the advance directive specific to this inquiry in particular requires, therefore, that all moral considerations be examined.

As discussed in previous chapters, advance directive is a general term employed to describe those legal documents that permit individuals to provide written instructions regarding their future medical treatment preferences (living will), and/or to appoint some other person to make medical treatment decisions on their behalf ("durable power of attorney for health care"), should illness, disease, or injury render them unconscious and unable to communicate or conscious yet lacking decisional capacity and thus legally incapable of making critically important decisions involving medical treatment.

It must be acknowledged that advance directives are a relatively recent phenomenon, created to address a particular public perception, and although eventually acknowledged as appropriate and worthwhile, have nevertheless also been widely criticized as ineffective. The concept of a living will, as noted in the chapter on legal authority, originated in the late sixties, and was crafted as a response to the apparently widespread and growing public perception that patients with minimal functional capacity unable to speak for themselves were inappropriately being kept alive by extraordinary medical treatment. As a result, according to the President's Council on Bioethics, Americans began to worry "about burdening loved ones, existing as mere shells of their former selves, or bankrupting their family with the costs of long-term care." [1118] The Council claims that in response, Americnas "sought means to restrict the kinds of medical interventions they would accept should they become incapacitated, or to appoint trusted

[1118] President's Council on Bioethics. *Taking Care: Ethical Care Giving in Our Aging Society,* 59. http://bioethics.gov/Reports/taking_care/index.html (accessed on May 10, 2009).

surrogates to make decisions armed with the necessary legal authority to forego or stop unwarranted interventions." [1119]

Susan Hickman, et. al., suggest that it was "*indiscriminate* (my emphasis) use of aggressive, life-prolonging treatments . . . [and] publicized cases such as those of Karen Ann Quinlan and Nancy Cruzan [that] drew attention to the importance of end of life planning for healthy adults." [1120] The President's Council also noted an evolution of the form of the living wills that apparently evidenced a none too surprising change in intention:

> The earliest living wills typically expressed the person's wish not to receive 'heroic' or 'extraordinary' measures if death was 'imminent.' Later versions moved away from these vague terms and gave people the opportunity to refuse specific medical interventions, such as resuscitation, respirator care, antibiotics, or medical nutrition and hydration. Later versions were also designed to allow individuals to *request* as well as *refuse* particular types of treatment. [1121]

The initial professional enthusiasm for advance directives began to fade in the late eighties with the realization that although advance directives were being executed in unprecedented fashion, they were being ignored when the time came to make medical treatment decisions. [1122] From Robert Burt's viewpoint, the explanation for the failure of the advance directive movement emerged with considerable clarity in the early 1990's, with the empirical findings of the Study to

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[1119] *Ibid*.

[1120] Susan E. Hickman, Bernard J. Hammes, Alvin H. Moss, and Susan W. Tolle. "Hope for the Future: Achieving the Original Intent of Advance Directives." *Hastings Center Report* 35, no. 6 (November/December 2005): S26.

[1121] President's Council On Bioethics, "Taking Care, 57.

[1122] Rebecca Dresser. "Advance Directives." *Hastings Center Report* 24, no. 6 (November/December 1994): S5. Rebecca Dresser claimed that "three empirical studies have found that the presence of a formal advance directive had no significant effect on the end-of-life care subjects received."

Understand Prognosis and Preferences for Outcomes and Risks of Treatment (SUPPORT).

According to Burt:

> [T]he SUPPORT data . . . revealed-in findings that have been subsequently confirmed in other settings-that most patients and their families did not want to make decisions about end of life care. Though most patients in the study were persuaded to fill out advance directives, a substantial portion of these patients and their families ignored their prior directives as death drew near. They simply did not want to talk about the reality that they were facing death, and most medical professionals retuned the favor with equal reluctance to talk about dying. [1123], [1124]

Precedent Patient Autonomy

The bedrock bioethical principle that gives advance directives legitimate moral authority is *patient autonomy*. James Nelson and Joel Frader accurately restate the widely accepted affirmation of the exclusive right afforded an adult patient to determine for himself/herself whether to accept or reject medical treatment: "Patient's values are the 'gold standard' for making medical decisions. . .patient's decisions are accordingly dispositive, at least when it comes to refusing treatment. . . [and] the standing presumption is that nothing is to be done to patients who are able to understand their situation and express their preference without [their

[1123] Robert A. Burt "The End of Autonomy, Improving End-of-Life Care: Why Has It Been So Difficult?" *Hastings Center Report* 35, no. 6 (November/December 2005): S10-11.

[1124] Rebecca Dresser, and John A. Robertson. "Quality-of-Life and Non-Treatment Decisions for Incompetent Patients: A Critique of the Orthodox Approach." *Law, Medicine and Health Care* 17, no. 3 (September 1989): Footnote 243. Rebecca Dresser and John Robertson make the additional claim that the legal climate in the United States has changed such that there is a significantly reduced risk of over treatment and that consequently advance directives are no longer needed to prevent over treatment. "The need for advance certainty about future medical procedures through the device of an enforceable prior directive is important in an environment of overzealous treatment that cannot otherwise be avoided. But the great progress that has been made in recognizing the right to have treatment withheld, especially in situations of terminal illness, lessens the need for the living will, since treatment may often be withheld regardless of such directives. In a legal climate evolving even further toward acceptance of nontreatment, there is even less need to run the risk of conflict between prior directive and current interests, since the goal of avoiding excessive treatment may be achieved anyway."

express] authorization." [1125] That *patient autonomy* has almost universal acceptance in the United States is hardly surprising, given the prevailing *zeitgeist*. In a culture that views unbridled individual personal autonomy as virtually an inalienable right it is easy to grasp the implicit claim being made by every individual executing an advance directive: "My life, my body, my right to choose."

Obviously, however, an individual who has lost decisional capacity or consciousness can no longer give his/her express authorization for the acceptance or refusal of medical treatment and advance directives were created to permit individuals, in *advance* of the loss of decisional capacity or consciousness, to make autonomous decisions regarding *future* medical treatment. One can express certain preferences for future medical treatment in a *living will*, from which authorization can at the appropriate time be inferred, and/or designate a trusted friend or family member to make medical treatment decisions on one's behalf by giving that person a *power of attorney for health care*. Advance medical treatment decisions made in the form of either a living will or durable power of attorney for health care are distinctive but nonetheless, at least arguably, authentic expressions of patient autonomy, what Nelson and Frader refer to as *precedent* patient autonomy: "W]hen patients are unable to make choices on their own behalf, we invoke *precedent autonomy.* If a patient has left tolerably clear and focused instructions, or has explicitly chosen someone to act in his or her stead, the authorization or refusal of various treatments should follow the written directives or the decision of the elected surrogate." [1126]

It must be noted, however, that any assessment that contemporaneous patient autonomy and *precedent* patient autonomy are *equivalent* expressions of patient autonomy must

[1125] James Lindemann Nelson and Joel Frader, "Brain Trauma and Surrogate Decision Making: Dogmas, Challenges, and Response." *Journal of Clinical Ethics* 15, no. 4 (Winter 2004): 265.

[1126] *Ibid.*

acknowledge, as does H. M Chan, that there are conditions attendant to a legitimate and authoritative exercise of patient autonomy in choosing or refusing medical treatment, absent which the exercise of individual will lacks moral authority: "Autonomy does not just mean being free from external interference in exercising one's choice. Choices are deemed morally binding only if they are made under the rational condition that the patient is mentally sound, not under emotional distress, and properly informed of her health condition and treatment alternatives." [1127] Because it represents the voice of the patient, if the exercise of *precedent* patient autonomy in the form of an advance directive meets the three criteria identified by Chan, it has, at minimum, at least arguably, a presumption of moral authority, and to the extent that it does not, its moral authority is correspondingly weakened if not eliminated altogether. Despite this presumption, there is no shortage of claims that advance directives lack moral authority. Some of these claims, however, can, at least arguably, be effectively addressed by the manner in which advance directives and appropriate accompanying documents are designed and, as needed, revised. Other claims, however, are directed against the principle of precedent patient autonomy itself and are not necessarily effectively addressed by document design and revision. Much of the balance of this chapter accordingly examines whether the presumptive moral authority of an advance directive can be rebutted.

General Claims that Advance Directives Lack Moral Authority

A frequently heard claim is that advance directives are, by their very nature, too vague and too ambiguous to be of any real usefulness in end of life decision making. Rebecca Dresser insists that "most of the directives that are completed fail to convey meaningful information,"

[1127] H. M. Chan and Ho Mun. "Sharing Death and Dying: Advance Directives, Autonomy and the Family." *Bioethics* 18, no. 2 (April 2004): 91.

[1128] and joins John Robertson in suggesting that this failure stems from an overall lack of specificity: "Living wills and other non-treatment directives tend to consist of broad statements that may supply little guidance on specific treatment questions." [1129] Vagueness and ambiguity need not, however, be fatal to the moral authority of an advance directive. Both of these flaws are by products of poorly drawn documents and can be successfully minimized if not eliminated, especially in the case of Alzheimer's disease, with the utilization of an Alzheimer's disease specific living will, prepared with professional medical assistance as well as professional legal assistance, accompanied by a durable power of attorney and personal statement that describes the rationale for one's goals, awareness of foreseeable moral issues, and personal values. Specificity requires professional medical knowledge of the medical treatment issues that will likely arise as Alzheimer's disease progresses as well as an understanding of the treatment options that will probably be available. Coupling a durable power of attorney with a living will provides the flexibility needed when otherwise unforeseeable developments arise in the patient's condition, prognosis, or available treatment options. A personal statement provides evidence that the individual utilizing the living will and durable power of attorney was aware of the foreseeable moral issues and based on that awareness as well as his/her personal values formed specific goals re: medical treatment based on a particular rationale. Such a personal statement provides invaluable information for whomever is given the durable power of attorney because it permits a necessary alteration of the planned course of action that is truly responsive to the patient's expressed goals and personal values should unforeseen developments occur, especially re: the patient's condition, prognosis, and available medical treatment.

[1128] Rebecca Dresser. "Pre-commitment: A Misguided Strategy for Securing Death with Dignity." *Texas Law Review* 81, no. 7 (June 2003): 1829.

[1129] Dresser and Robertson. "Quality-of-Life and Non-Treatment Decisions," 237.

A second claim is that advance directives lack moral authority because they rob us of the safeguard of family and friends persuading us that we are making the wrong decision, especially with regard to the rejection of a means of sustaining life. Robert Burt argues that "there are other importantly affected participants who should have some voice in the patient's ultimate decision-not a veto, but a voice." [1130] In his view, "their stake may ultimately deserve less weight than the competent patient's choice; but some weight nonetheless is appropriate and can be respected by rules providing for some consultative process." [1131] Ron Berghmans maintains that in drafting an advance directive "important informal safeguards that tend to restrain imprudent or unreasonable contemporaneous choices by a competent patient are not likely to be present." [1132] According to Berghmans, "[i]f a competent patient refuses life-sustaining care, those around the person who are responsible for care can and often do urge the patient to reconsider his or her choice." [1133] In response to the suggestion that appropriate consultation with family and friends can take place during the process of drafting an appropriate advance directive(s), A. Buchanan claims that such an occurrence is unlikely at best:

> This safeguard, if it occurs at all, is unlikely to come into play as forcefully during the process of drawing up an advance directive. For when the decision to forego life-sustaining treatment is a remote and abstract possibility it is less likely to elicit the same protective responses that are provoked in family members and health care professionals when they are actually confronted with a human being who they believe can lead a meaningful life but has chosen to

[1130] Robert A. Burt "The End of Autonomy," S12.

[1131] *Ibid*.

[1132] Ron Berghmans. "Advance Directives and Dementia." In *Medical Ethics at the Dawn of the 21st Century*, edited by Raphael Cohen-Almagor, 105-110. (New York, NY: New York Academy of Sciences, 2000), 106.

[1133] *Ibid*.

die. [1134]

Although Buchanan seems quite correct in asserting that the urgency of such a discussion is lacking when undertaken years in advance, such a discussion can, nonetheless, successfully address the fear that prompts this claim. Anyone whose opinion one respects and/or might be significantly impacted by one's refusal of a means of sustaining life can and should be apprised of the choices one intends to include in an advance directive. One can, if one chooses, give this discussion an increased sense of urgency by informing friends and loved ones that this is likely their final chance of dissuasion, and once the advance directive is signed and notarized that one expects friends and family to honor one's wishes.

A third claim is that advance directives that reject a means of sustaining life lack moral authority because they inappropriately compromise the values and violate the integrity of not only surrogate decision makers, caregivers, and family members but also attending medical staff who, it is assumed, are committed to saving lives. The President's Council advanced this claim, at least arguably declaring that advance directives lack the moral authority to direct others to violate their own particular moral precepts or to transgress the moral boundaries of the society as a whole:

> Even a competent person's wishes should be limited by . . . moral boundaries and considerations, because sometimes one's own wishes do an injustice to the value of one's own life, or to the concerns of one's loved ones, or to the norms of the broader society. Our lives are intertwined with others, who are affected powerfully by our choices, and who are themselves conscience bound moral agents. Our caregivers are not obligated to execute our wishes if those wishes seem morally misguided, nor obligated to enter into contracts that require them to violate important moral precepts that are binding on everyone. [1135]

[1134] A. Buchanan. "Advance Directives and the Personal Identity Problem." *Philosophy and Public Affairs* 17, no. 4 (Fall 1988): 279.

Thomas Murray and Bruce Jennings add their concurrence: "We sometimes seem to act as though dying were solely the concern of the dying person. The fact is we die, as we live, in a web of vital and complex relationships. What happened in life, and what happens in dying, is shaped by and shapes those relationships." [1136]

This is clearly not a frivolous claim, especially in the circumstances specific to this inquiry. When a previously executed advance directive(s) of a now late-stage Alzheimer's patient, expressly rejects artificial nutrition and hydration (ANH) if and when he/she is no longer willing or able, even with assistance, to eat and drink sufficiently to sustain life, he/she may still ask for food and water if, although probably unlikely, he/she is hungry and thirsty. Obviously, it is admittedly exceedingly difficult at best to withhold ANH in such a circumstance.

Nevertheless, careful and prudent planning can mitigate if not entirely prevent such a moral crisis. As was discussed in the previous chapter, and will be discussed in greater detail in the final chapter, there are a number of methods of addressing this particular possibility as well as similar possibilities and choices must not only be identified and made with professional medical and legal assistance in an Alzheimer's disease specific living will, a durable power of attorney is essential to provide flexibility when otherwise unforeseeable developments arise in the patient's condition, prognosis, or available treatment options. It is also critically important that all those who are being asked to assist in carrying out one's medical treatment preferences as expressed in an advance directive(s) know well in advance what moral issues are likely to

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[1135] President's Council On Bioethics, "Taking Care, 122.

[1136] Thomas H. Murray, And Bruce Jennings. "The Quest to Reform End of Life Care: Rethinking Assumptions and Setting New Directions." *Hastings Center Report* 35, no. 6 (November/December 2005): S54.

present themselves. Equally important, however, these individuals deserve to know why in view of the moral issues that may arise these particular medical preferences were chosen. A statement of personal values accompanying the living will and durable power of attorney must clearly convey to family, caregivers, attending medical professionals and whomever is given the durable power of attorney, one's goals, an awareness of the moral issues that are likely to arise from the medical treatment preferences and with these moral issues firmly in mind the personal values upon which one's goals and preferences are based. With these documents in hand, it should be relatively easy to "shop" for a physician, medical facility, medical staff, and a friend of family member to whom one can give a durable power of attorney that can and will follow one's instructions *without* compromising their values or destroying their integrity. Obviously, however, one cannot "shop" for one's family and given one's particular financial resources, perhaps not one's caregivers, either. For family and perhaps also caregivers, it is necessary that one make a concerted effort to discuss in detail not only the medical treatment preferences that are being contemplated and the probable moral issues that arise there from, but with the moral issues firmly in mind one's goals and the personal values upon which these goals and these preferences are based. One may not be able to persuade one's family and caregivers that one's medical treatment preferences are morally acceptable for them, but one should be able to make perfectly clear why these medical preferences are morally acceptable for oneself.

A fourth claim, advanced by Rebecca Dresser, is that advance directives that reject a means of sustaining life lack moral authority because they could require physically coercive conduct by clinicians: "In my view, giving effect to a harmful directive would be inconsistent with the moral judgments underlying the *parens patria* doctrine. Following such a directive could require insensitive and even physically coercive conduct by clinicians, which the law

condemns in other contexts." [1137] This particular claim is not persuasive because it is based on a most unlikely scenario especially regarding the specifics of this inquiry. A fifth claim, also advanced by Rebecca Dresser, is that advance directives that reject a means of sustaining life lack moral authority because our interests may change in radical and unforeseen ways. In her view, a person's preferences regarding future life-sustaining treatment may change over time," [1138] and presumably it is then an outdated, erroneous, and thus invalid expression of patient autonomy. This is a legitimate claim but can be successfully addressed by periodic reviews and, if necessary, revision of the medical preferences expressed in one's directives. A sixth claim advanced by Rebecca Dresser is based on a study that in her view "suggests that many people are making directives on the assumption that others will *not* adhere to their instructions if there appears to be good reason not to." [1139] This claim, assuming that the referenced study is correct, can be appropriately addressed by coupling a living will with a durable power of attorney. Power of attorney can bestow whatever level of flexibility that the one considers appropriate, including the power to override choices made in the living will.

These first six claims can, at least arguably, be effectively addressed by the manner in which advance directives and appropriate accompanying documents are designed and revised and the prudence with which one chooses a physician, medical facility, medical staff, and a friend of family member to whom one gives a durable power of attorney. Two other claims, however, are directed against the principle of precedent patient autonomy itself, and are not necessarily effectively addressed by document design and revision. The first claim is based on the contention that precedent patient autonomy is, by its very nature, an invalid exercise of

[1137] Rebecca Dresser, "Pre-commitment: A Misguided Strategy for Securing Death with Dignity," 1840.

[1138] Ibid, 1829.

[1139] Rebecca Dresser, "Advance Directives," S5.

patient autonomy. The second claim is that even if precedent patient autonomy is a valid exercise of patient autonomy and the medical treatment preferences expressed in an advance directive therefore authoritative, these preferences must nevertheless be subordinated to an assessment of the best interests of the patient.

Specific Claims that Precedent Autonomy is an Invalid Exercise of Patient Autonomy

Claims that patient *precedent* autonomy is, by its very nature, an invalid exercise of patient autonomy also take two very different forms. The first is based on three premises. The initial premise is that because patient decisions to forego life-saving medical treatment have such grave consequences, such decisions must undergo much greater scrutiny than decisions to forego other less critical medical treatments. The second premise is that authentic, legitimate, and thus authoritative patient autonomy requires not only competency and freedom (absence of coercion), but also the possession of whatever information is necessary to make a truly informed decision about consenting to or refusing medical treatment. The third premise is that the information necessary to make a truly informed judgment about consenting to or refusing medical treatment is not available to an individual making an advance directive because the future is much too uncertain.

Carol Gill contends that patient decisions to forego life-saving medical treatment require greater scrutiny: “In general, we must acknowledge others’ expertise regarding their own lives and, therefore, support their decisions regarding treatment of their bodies. But when the possible risks include wrongful death, we have a social obligation to check the decision making process

and to question its outcome." [1140] She continues: "I do not oppose the right of competent, informed people, who have access to all reasonable options and adequate support to pursue them, to make uncoerced decisions to refuse medical treatment. However, when stakes are life and death, my standards for 'competent,' informed,' 'reasonable options,' 'support,' and 'uncoerced' are high." [1141] Gill's contention has not gone unchallenged. Nelson and Frader question the need for the additional scrutiny:

> *How* strict should this scrutiny be? Should we be so skeptical about the authority of explicit declarations or their long-term patterns of valuation that we should override decisions against, for example, indefinitely maintaining a patient in a persistent vegetative or minimally conscious state? As fraught with difficulty as such choices are, their difficulty cannot successfully support a general refusal to take `individual's explicit declarations or long term patterns of valuation seriously. [1142]

The second premise is that authentic, legitimate, and thus authoritative patient autonomy requires *informed* consent/refusal. Obviously, an uncompromising advocate of totally unfettered patient autonomy will be completely unmoved by this argument, insisting that with correct information, incorrect information, insufficient information, or no information, one has a completely unrestricted right to choose or refuse any and all forms of medical treatment, including all means of sustaining life. Nelson and Frader suggest that emphasis on the *accuracy* of the attempt to foresee the future made in preparation for drafting an advance directive misses the point. In their apparent view, factual uncertainty and the presumably resultant inaccuracy is

[1140] Carol Gill. "Depolarizing and Complicating the Ethics of Treatment Decision Making in Brain Injury: A Disability Rights Response to Nelson and Frader." *Journal of Clinical Ethics* 15, no. 4 (Winter 2004): 282.

[1141] *Ibid*, 286.

[1142] Nelson and Frader, "Brain Trauma and Surrogate Decision Making," 290.

not lethal to the exercise of precedent patient autonomy for, in simplest terms, it is less about the what and the why of future medical treatment and more about it being exclusively one's own choice and no one else's:

> For many of us, it isn't enough that what we chose to happen should actually happen; its important that what happens does so *as a result* (at least in part) of our choice. Accordingly, interference in the expression of self-directed agency is widely seen as an offense against human dignity, as it frustrates something central to and distinctive of us as persons. This is true even if the interference is well-meant, indeed even if it proceeds on the basis of a better grasp of the resultant situations than the agent may have. . . These questions are morally troubling if the moral authority of advance decision making rests on the reliability of predictions that people make about how satisfied they might find themselves in 'various possible futures.' But the reason to respect a person's previously expressed choice is not that person's are infallible about what choices will turn out to be the best for them. Advance decision-making involves an act of will, not a forecast. It is an expression of us as agents, not as prophets. [1143]

The contention that authentic, legitimate, and thus authoritative patient autonomy requires *informed* consent/refusal is not, however, without its supporters, among them, Carol Gill: "In the absence of a best answer, I would err on the side of life-not because I privilege life over the freedom of choice, but because I believe dying without informed consent eradicates self-determination." [1144] Rebecca Dresser affirms this view: "We do not advance people's autonomy by giving effect to choices that originate in insufficient or mistaken information. Indeed, interference in such choices is often considered a form of justified paternalism." [1145] Justified or soft paternalism in such a circumstance finds support from J. K. Davis: "Soft

[1143] *Ibid*, 266.

[1144] Carol Gill, "Depolarizing and Complicating the Ethics," 286.

[1145] Rebecca Dresser. "Dworkin on Dementia." *Hastings Center Report* 25, no. 6 (November/December 1995): 38.

paternalism consists of preventing someone from having what he thinks he wants on grounds that he truly wants something else and does not realize it." [1146]

The third premise is that the uncertainty of the future makes informed consent/refusal of medical treatment made in advance exceedingly difficult if not impossible. Although the uncertainty of the future is incontrovertible, it should be noted that, at least arguably, the significant issue is not whether *complete* information about the future is available at the time an advance directive is written, but rather whether *sufficient* information is available. To insist that anything less than complete information is fatal to the informed consent/refusal of medical treatment imposes a totally unrealistic standard. Seldom, if ever, does anyone ever possess complete information before making a decision. The issue is whether despite the absence of complete information there is nonetheless *sufficient* information for a legitimate and thus authoritative exercise of informed consent or refusal of life sustaining medical treatment made prospectively in the form of an advance directive. Clearly, sufficiency of information upon which to base an informed consent/refusal of medical treatment will depend in significant part on one's rationale for that acceptance/refusal. If, for example in the circumstances specific to this inquiry, in which a previously executed advance directive(s) of a now late-stage Alzheimer's patient, expressly rejects artificial nutrition and hydration (ANH) if and when he/she is no longer willing or able, even with assistance, to eat and drink sufficiently to sustain life, and insists upon preemptive palliative sedation once terminal dehydration had begun, if the principal rationale for the rejection of ANH is the burden that Alzheimer's disease imposes on one's family, whether or not one may or may not be more or less content with one's life lived with dementia is not of great importance.

[1146] J. K. Davis. "The Concept of Precedent Autonomy." *Bioethics* 16, no. 2 (April 2002): 129.

Factual Uncertainty Inherent in Advance Directives is Fatal to Informed Consent

Nevertheless, those who claim that patient *precedent* autonomy is, by its very nature, an invalid exercise of patient autonomy point to five separate ways in which the factual uncertainty resulting from the inability to accurately foresee the future is fatal to informed consent/refusal of medical treatment, rendering patient precedent autonomy an invalid exercise of patient autonomy and destroying an advance directive's moral authority. First, when an advance directive(s) is ultimately used to authorize the acceptance or rejection of medical treatment, one's condition may be significantly better than was anticipated when the directive(s) was written. Second, prognosis and treatment options for a particular illness/disease/injury may have also dramatically improved. Third, one's fears about the impact of an illness/disease/injury and resulting debilitation on family and caregivers may prove to be exaggerated, overblown, and thus unfounded. Fourth, one's desire to live with an illness/disease/injury and resulting discomfort and debilitation may prove to be much greater than one was able to foresee. Fifth, and specific to this inquiry, one's desire to live with dementia may prove to be much greater than one was able to foresee. In all five instances, it is argued, the choice made in one's advance directive(s) to reject a means of sustaining life is, as a result of the inability to accurately foresee the future, far different from the choice one would make had he/she been still conscious and possessed of decisional capacity when the directive(s) is ultimately used to authorize the rejection of a means of sustaining life. Such a result, critics presumably claim, is unconscionable, and destroys an advance directive's moral authority.

Advance directives are formed with certain implicit *assumptions* about one's medical condition, prognosis, and available medical treatment, at some generally indeterminate time in

the future when a decision regarding the acceptance or rejection of medical treatment must be made. Obviously these assumptions can be mistaken, and the claim is made, not at all surprisingly, that informed consent/refusal cannot possibly *rest on mere assumptions* regarding such critical information as patient condition, prognosis, and available treatment. Rebecca Dresser maintains that are in most instances there are far too many unknowns when an advance directive is written: "Unless the person making a directive has a relatively clear prognosis and limited treatment options, there are too many potential situations to address. Most people simply cannot predict all the medical conditions that the future might bring, much less understand what would be the possible harms and benefits of interventions targeting those conditions." [1147] Sanford Kadish also seems quite correct in asserting that "unforeseen changes, such as new medical treatments may substantially alter the person's interests." [1148] It is, by way of example, not difficult to imagine how a cure for Alzheimer's disease would dramatically alter the attitude of someone diagnosed with the disease re: the acceptance of life-sustaining medical treatment.

There is obviously inherent factual uncertainty in an advance directive. The issue, however, is whether the particular factual uncertainty re: the patient's condition, prognosis, and available medical treatment destroys or seriously diminishes an advance directive's moral authority. As discussed above, the impact of factual uncertainty can be minimized, although clearly not eliminated completely, especially in the case of a diagnosis of Alzheimer's disease, with the utilization of an Alzheimer's disease specific living will, prepared with professional medical assistance as well as professional legal assistance, and accompanied by a durable power of attorney and personal statement. The greater the effort made by an individual diagnosed with

[1147] Rebecca Dresser, "Pre-commitment: A Misguided Strategy for Securing Death with Dignity," 1829.

[1148] Sanford H. Kadish "Letting Patients Die: Legal and Moral Implications." *California Law Review* 80, no. 4 (July 1992): 873.

Alzheimer's disease to immediately apprise himself/herself of the probabilities regarding his/her conceivable condition, prognosis, and available medical treatment as Alzheimer's disease advances the greater the chance that specific to this inquiry, the rejection of ANH and insistence on PPS will be a truly informed refusal and consent, respectively. It must also be noted, however, as pointed out above, that the sufficiency of information upon which is based an informed consent/refusal of medical treatment will depend in significant part on the rationale for that acceptance/refusal. Accordingly, and specific to this inquiry, one's rationale for refusing ANH and insisting on PPS, as described in one's personal statement, will reveal how much or how little those decisions are dependent on one's condition, prognosis, and available medical treatment if and when one is no longer willing or able, even with assistance, to eat and drink sufficiently to sustain one's life. To the extent these decisions are dependent on condition, prognosis, and treatment, the factual uncertainty re: the accuracy of that prospective assessment of those three variables can be reduced if not eliminated by conditioning the rejection of ANH and acceptance of PPS on the accuracy of the previously made assumptions re: one's condition, prognosis, and available treatment at the time one is no longer willing or able, even with assistance, to eat and drink sufficiently to sustain one's life.

Those who insist that patient *precedent* autonomy is, by its very nature, an invalid exercise of patient autonomy also claim that one's fears about the impact of an illness/disease/ injury and resulting debilitation on family and caregivers may prove to be overblown, and thus unfounded. There is no doubt that such an exaggeration is possible, and that information concerning the probability and severity of burdens imposed on one's family and/or caregivers by one's illness/disease/injury and resulting debilitation can never be anything more than a projection. Obviously, expectations regarding the burdens related to the cost of medical treatment and

extended care can prove to be in error, and against all reasonable expectations, a family may ultimately embrace the burdens and draw strength and satisfaction from bearing them.

Nevertheless, it must be noted, that for at least some individuals, especially, at least arguably, fathers, *any* burden placed on his family as a result of his long-term inability to care for himself may be unacceptable to him, regardless of whether or not it is embraced by his family. In the circumstances specific to this inquiry, the risk of overstating the probable burdens of Alzheimer's disease on family and caregivers can be significantly minimized when appropriately experienced professional medical assistance is called upon to provide information about the probable progression of the disease and the usual range of responses from families. Of even greater importance, when a living will is coupled with a durable power of attorney and personal statement, as outlined above, whoever possesses the durable power of attorney can alter the planned course of action to the extent to which expectations regarding burdens on family and caregivers fail to materialize and were identified in the personal statement as a significant part of the rationale for the rejection of ANH and insistence on PPPS.

Those who insist that patient *precedent* autonomy is, by its very nature, an invalid exercise of patient autonomy also claim that one's desire to live with an illness/disease/injury and resulting discomfort and debilitation may prove to be much greater than one was able to foresee. In essence, this claim rests on two premises. First, one has no real frame of reference to accurately assess in advance what one's response will be to serious illness/disease/injury and resulting discomfort and debilitation. Rebecca Dresser makes such a claim in asserting that "healthy people generally lack experience of serious illness. . . [and] they often do not know what it is like, or what they want done about it, until they are in that state." [1149] Second, such

[1149] Rebecca Dresser, "Dementia and Advance," 276.

advance assessments regarding illness/disease/injury and resulting discomfort and debilitation generally underestimate one's desire to live in those circumstances.

Dresser and Alan Astrow opine that "[f]aced with the alternative of death, people may adapt to new life circumstances in ways they could not previously have imagined." [1150] Sanford Kadish adds that "life-imperiling illness may well produce a marked revision in . . . attitudes and values." [1151] Christopher Ryan's claims that the experience of palliative care specialists points to an apparently widespread tendency to underestimate one's desire to live when faced with terminal illness:

> Human beings are, I suggest, very poor at determining their attitudes to treatment for some hypothetical future terminal illness and very frequently grossly under-estimate their future desire to go on living. . . Most palliative care specialists will readily recall one or two patients who persistently requested that they be allowed to die. Some will recall several. However, palliative care physicians do not report that this sustained desire is very common and certainly do not report that it is the norm. This strongly suggests that many people, who, when healthy, predict that they would refuse treatment in the future, will *change their mind* (my emphasis) [1152] when they develop a

[1150] Rebecca Dresser and Alan B. Astrow. "An Alert and Incompetent Self." *Hastings Center Report* 28, no. 1 (January/February 1998): 28.

[1151] Sanford H. Kadish, "Letting Patients Die," 873.

[1152] Rebecca Dresser, "Dworkin on Dementia," 34; Dresser, and Robertson, "Quality-of-Life and Non-Treatment Decisions," Footnote 243. Rebecca Dresser claims that advanced directives lack moral authority because they deny individuals the right to change their minds with regard to accepting of rejecting medical treatment, a right that all competent persons possess: "A policy of absolute adherence to advance directives means that we deny people . . . the freedom we enjoy as competent people to change our decisions that conflict with our subsequent experiential interests." John Robertson joins her in further explicating that claim: "Competent individuals generally retain the opportunity to alter their choices to accommodate their altered interests to the extent a person's prior choices concerning career, health, residence, and promises to others permit them to do so. Incompetent persons should also be able to free themselves from prior choices when their current interests require it, and others have not changed their position in reliance on their past directives." Dresser and Robertson's claim seems well founded and is a consequence of the desire to make one's own decisions re: medical treatment while still competent to do so. Protection against changing one's mind regarding medical treatment can, however, be provided, as discussed above, by coupling a living will with a durable power of attorney and personal statement. If one determines that the "right" choice reflects the inference that one has changed his/her mind, one's personal statement should so indicate, and the individual to whom was given power of attorney should have the discretion to act accordingly. If on the other hand, the "right" choice is one's own choice, regardless of whether or not an inference can be made that one has changed his/her mind, one's personal statement should also so indicate.

> terminal illness. This anecdotal evidence is supported by a number of studies in the psychiatric literature. [1153]

One cannot, it is therefore concluded, rationally reject a means of sustaining life in advance based on a likely inaccurate prospective assessment of one's desire to live with illness/disease/injury and resulting discomfort and debilitation. Daniel Callahan seems to sum up this contention quite nicely when he comments: "How can someone in any rational way determine well in advance what they will want in a situation they have never experienced before." [1154],[1155] This is a serious claim but is best examined, given the circumstances specific to this inquiry, with specific reference to dementia.

Those who insist that patient *precedent* autonomy is, by its very nature, an invalid exercise of patient autonomy also claim that one's desire to live with *dementia* may prove to be much greater than one was able to foresee. For Rebecca Dresser, the subjective experience of dementia is widely underestimated: "I make no claim to expertise in this area, but my reading and discussions with clinicians, caregivers, and patients suggests that the subjective experience of dementia is more positive than most of us would expect." [1156] Much of this claim is based on the contention that one makes the erroneous assessment that those afflicted with dementia have little or no quality of life because the quality of life of the disabled is frequently underestimated. Disability activists have long maintained that the non-disabled have a prejudicial view of the

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[1153] Christopher James Ryan. "Betting Your Life." *Journal of Medical Ethics* 22, no. 2 (April 1996): 96.

[1154] Daniel Callahan. "The Sanctity of Life Seduced: A Symposium on Medical Ethics." *First Things* 42 (April 1994): 26.

[1155] Nelson and Frader, "Brain Trauma and Surrogate Decision Making," 267. Nelson and Frader seem to take issue with Callahan's claim: "There is nothing necessarily irrational in the judgment that a shorter life is preferable to a longer life, even if that longer life would include many more experiences of a kind that the decision maker would regard as pleasant."

[1156] Rebecca Dresser, "Dworkin on Dementia," 37.

disabled. According to Nelson and Frader, [s]ome scholars in the field of disabilities reject [Bioethics'] orthodox model [regarding advance directives] . . . stress[ing] the ubiquity of ignorance about the character and potential richness of life with disabilities, as well as the prevalence of deeply prejudicial attitudes about the worth of disabled lives." [1157] Carol Gill is in full agreement: "[M]ost American citizens have access to very little accurate information about the viability of life with a disability, and are inundated with distorted stereotypes about what that life is like. These conditions promote a form of coercive social conditioning about what constitutes valid and invalid humanity that signals the untenability of being disabled." [1158] In Gill's view, this inability to accurately assess quality of life also extends to those with neurological impairments:

> Empirical evidence exists, then, for a treatment team to suspect that the values of new patients with a traumatic brain injury in their care will end up to be significantly different from the patient's pre-injury values regarding life as a disabled person. There is also evidence to suggest that, with time, and adequate environmental supports, survivors of TBI are likely to appreciate their lives. [1159]

Gill concludes by charging that advocates of precedent personal autonomy are "more protective of the authority and voice of the pre-injury individual than that of the post-injury individual who may have changing views of life and disability." [1160] Pithily, she claims that whereas advance directive proponents "seem to lean toward defending the agency of the pre-injured person not to

[1157] Nelson and Frader,"Brain Trauma and Surrogate Decision Making," 265.

[1158] Carol Gill,"Depolarizing and Complicating the Ethics," 281.

[1159] *Ibid*, 279.

[1160] *Ibid*, 283.

be disabled, [she seems] to lean toward defending the agency of the post-injury person, the *right of the disabled person not to be dead* (my emphasis)." [1161]

Sunil Kothari argues that "like most of the able-bodied, healthcare professionals significantly underestimate the quality of life of people with disabilities." [1162] She reports that when health care professionals were asked to predict the responses of individuals, who had suffered spinal cord injuries and were diagnosed as chromic quadriplegic, to two questions: "Are you glad to be alive?" and "Is your quality of life average or above average," the individuals with chronic quadriplegia gave responses that were not only 500% higher than were anticipated by the health care professionals, "there was no statistically significant difference between the life satisfaction scores of the healthcare professionals and the people with spinal cord injury." [1163]According to Kothari "[o]ur beliefs about quality of life with a disability are so distorted because our underlying premise is false: quality of life has very little to do with the more medically oriented categories of impairment and disability, and almost everything to do with the more socially determined category of handicap." [1164](305). Arienne Asch seems to confirm Kothari's assessment that the true significance of disability is much less the physical incapacity itself and more the consequences of that incapacity: "When people with illness and disability report dissatisfaction and unhappiness, they link their distress not to physical pain or reliance on medications, dialysis, or ventilators, but to those factors that also trouble non-disabled people-

[1161] *Ibid*, 286.

[1162] Sunil Kothari. "Clincal (Mis)Judgments of Quality of Life after Disability."*Journal of Clinical Ethics* 15, no. 4 (Winter 2004): 300.

[1163] *Ibid*, 303.

[1164] *Ibid*, 305.

problematic relationships, fears about financial security, or difficulties in playing a valued work or other social role." [1165]

Nevertheless, the question arises as to whether an accurate assessment of the quality of life of those suffering from *severe* cognitive impairments can be determined from interviews of the *physically* disabled. Nelson and Frader have their doubts:

> The findings reflect expressions of satisfaction and changed attitudes toward disability among those able to provide intelligible answers to research inquiries. Those with severe and profound cognitive impairments cannot articulate their feelings and views. We cannot know what these individuals experience. It seems the case that the story has several sides, only one of which we can know and understand well. This limits the value of empirical contributions. [1166]

In addition, one wonders whether, in arguing that the true burdens of disability are less related to the impairment itself than the resulting social issues that arise, Kothari and Asch are not unwittingly making the case for a poorer quality of life for those living with dementia. It can argued that dementia robs individuals of the social relationships that count the most, family and friends of long standing. True social integration may be difficult if not impossible if one can't remember from one day to the next the identities of other people, especially one's own family. In any case, there is sufficient *contradictory* anecdotal evidence regarding the apparent desire to go on living of those afflicted with dementia to conclude that it is impossible to know when

[1165] Arienne Asch." Recognizing Death while Affirming Life: Can End-of-Life Reform Uphold a Disabled Person's Interest in Continued Life?" *Hastings Center Report* 35, no. 6 (November/December, 2005): S32.

[1166] James Lindemann Nelson and Joel Frader. "A Response to Gill" *The Journal of Clinical Ethics* 15, no. 4 (Winter 2004): 291.

diagnosed with Alzheimer's disease or other dementia inducing illness or disease how one will respond to this form of cognitive impairment. Those afflicted with dementia exhibit a wide range of behavior. Some demented individuals seem to be, day in and day out, simply "happy as a clam," from which can be inferred an unmistakable desire to go on living, while the general countenance and body language of others is more indicative of fear and bewilderment, which clearly supports the inference that for them life has lost much if not all of its value.

To make any advance assessment of how one will respond to dementia even more problematic, there is a wide range of behavior in between these two extremes, sometimes even exhibited by the same individual in a relatively short span of time. The issue is thus not whether factual uncertainty exists regarding how one will ultimately respond to dementia, but whether this particular form of factual uncertainty is fatal to informed consent/rejection of medical treatment. As outlined above, the sufficiency of information upon which is based an informed consent/refusal of medical treatment will depend in significant part on the rationale for that acceptance/refusal. Accordingly, and specific to this inquiry, one's rationale for refusing ANH and insisting on PPS, as described in one's personal statement, will reveal how much or how little those decisions are dependent on how one responds to living with dementia. Not only might this response have no significance whatsoever in one's rationale, it is also possible that one might consider the possibility that one would be demented yet "happy as a clam" every bit as repulsive as the thought that dementia would cause one to be fearful, bewildered, and withdrawn.

If, however, specific to this inquiry, one's rationale for the rejection of ANH and insistence on PPS is the fear that dementia will cause one to be fearful, bewildered, and withdrawn, the factual uncertainty re: the accuracy of that prospective assessment can nevertheless be reduced if not eliminated. Rebecca Dresser seems to suggest that that an

antecedent informed refusal of life sustaining treatment in the case of dementia is at least possible if one acknowledges that one's response to dementia is unknowable in advance and conditions one's medical preferences on that response. In her view, "[b]efore implementing directives to hasten death in the event of dementia, we should have some confidence [that the patient, when [he]/she executed the advance directive], exhibit[ed] a reasonable understanding of the choices [he/she was] making." [1167] "At minimum, according to Dresser, "we would want [him]/her to understand that the experience of dementia differs among individuals, that for some it appears to be a persistently frightening and unhappy existence, but that most people with dementia do not experience the distress and misery we competent people tend to associate with the condition." [1168]

According to M. Harvey:

> Dresser argues that [he/she] should also have been knowledgeable of the general course [his/her] dementia was likely to follow in order to have been more precise about which 'behavioral indications' should be taken as signals to activate their [advance directive]. Lastly, he or she should have thought about what his or her life might be like at various stages of their illnesses and indicated the degree to which he or she favored an aggressive approach to care relative to the stage thereof. [1169]

Dresser seems to be suggesting that with regard to an advance directive of a now demented individual the rejection of a means of sustaining life must be conditioned on the existence of specifically described behavioral symptoms, and not otherwise. As discussed above, there is another method of achieving this result by coupling a living will with a durable power of

[1167] Rebecca Dresser, "Dworkin on Dementia," 37.

[1168] *Ibid,* 36.

[1169] M. Harvey. "Advance Directives and the Severely Demented." *Journal of Medicine and Philosophy* 31, no.1 (February 2006): 61.

attorney and personal statement so that medical treatment preferences expressed in the living will can be appropriately adjusted by whoever holds the durable power of attorney based on his/her understanding of the rationale for the preferences as expressed in the personal statement and his/her observation of how the patient responds to dementia.

Adopting a much more extreme perspective, John K. Davis argues that *only* the hypothetical choices one would make *after* losing competency have moral authority: "The key practical question is ascertaining the moral authority of an advance directive is whether the agent anticipated and understood the preferences she would later have in dementia. If that understanding was not sufficient, then arguably, she cannot have autonomously rejected the future preferences, for she did not know what she was rejecting." [1170] In his view, an individual executing an advance directive is required to think *hypothetically*, and this goes to the heart of his understanding of precedent autonomy:

> [W]e must inquire] whether the patient would reaffirm her preference, for the same reasons, in hypothetical circumstances as close as possible to her current circumstances except for having the mental capacity to affirm or reject the earlier preference. This requires us to distinguish between an agent's mental capacity and her reasons. In other words, we ask her to assess her earlier preference, using the mental capacity she has in her hypothetical state to think about the reasons she has now, in her incapacitated state – not about the reasons she had when she had full mental capacity. [1171]

Davis is essentially claiming that the real issue is what, if any, of her current values she believes she will be capable of embracing once demented:

[1170] J. K. Davis, "The Concept," 132-133.

[1171] *Ibid*, 125-126.

> [S]he must ask herself how much she values the depth and maturity of her relationships and her professional and intellectual pursuits from her incapacitated perspective, in circumstances where her psychological and other properties have changed, such that she can no longer have such relationships and pursuits. She must use full mental capacity to determine how important those things are to her in her current circumstances, where she is mentally incapacitated, not how important they are to her in a state of full mental incapacity (even though she must have full mental capacity to answer such a question. [1172]

Davis fails to offer any justification for subordinating the medical treatment preferences of an individual with decisional capacity as expressed in his/her advance directive, based presumably on his/her wants and values at the time that advance directive(s) was written, to the medical treatment preferences he/she speculates she would have once demented based presumably on whatever values he/she is capable of embracing from his/her demented perspective. This is an extraordinary demand, for it requires one to abandon his/her value system in anticipation of the consequences of dementia. Dementia inexorably steals from its suffers so much already, Davis' demand to think hypothetically arguably surrenders to dementia what it is other wise incapable of stealing without assistance, the role one's life-long pre-dementia value system plays in determining one's autonomous preferences for medical treatment.

Advance Directives Represent the Autonomous Preferences of the Wrong Person

Taking a very different form, the highly controversial claim is also advanced that patient *precedent* autonomy is, by its very nature, an invalid exercise of patient autonomy when an individual loses decisional capacity but not consciousness, because an advance directive represents the autonomous medical treatment preferences of the wrong person. Brain damage from injury or disease, including Alzheimer's disease and other dementia producing pathologies, it is suggested, so changes an individual's wants and values that a *second* self has effectively

[1172] *Ibid,* 125-126.

been created, and since wants and values appropriately determine one's preferences for medical treatment, the medical treatment preferences of the second self, especially as to the acceptance of a means of sustaining life, will almost certainly be different than those of the first self. This second self, it is argued, has the right to his/her own preferences for medical treatment which are inferable from his/her demeanor and behavior, and these inferable preferences can and must be honored if true patient autonomy is to be respected. To otherwise permit the medical preferences expressed in an advance directive to be determinative, it is argued, unconscionably permits the first self to usurp the rightful and legitimate autonomy of the second self. If one accepts this line of reasoning, two potentially competing medical treatment preferences, one expressed by the first self, and the other inferred from the demeanor and behavior of the second self, have been created, but only the latter is a legitimate expression of authentic and thus authoritative patient autonomy. An advance directive of a now demented patient, representing as it does the medical preferences of the first self based on wants and values not shared by the second self, accordingly has no moral authority.

Not surprisingly, the concept of the autonomy of a second self has not gained widespread acceptance, although at least some stalwart adherents. The notion of an individual having successive selves arose in the writing of British philosopher, Derek Parfit. Parfit's principal contention is that when those elements of personal identify that make us who we are: short and long term memory, moods, demeanor, personality, ability to focus and concentrate, experiences, attitudes, beliefs, desires, and values sufficiently change, we can effectively be considered a different person, another *self*. According to Parfit this change can come about over a lifetime, and in this sense a person can have a number of successive selves. [1173] In addition, such a

[1173] D. Parfit. *Reasons and Persons.* (New York, NY: Oxford University Press, 1986), 302.

change can take place in an instant with serious brain trauma. Those who argue that advance directives are not morally authoritative for making medical treatment decisions for those suffering from dementia also claim that such a change can also take place because of dementia, and that at some point in the progression of Alzheimer's disease or another dementia producing pathology the now demented person effectively possesses a new and different identify, so different they insist, that the connection between the competent and demented selves, could, in Rebecca Dresser's words, "be no stronger than that between you and me." [1174] Given the absence of connection between the first and second selves, Dresser and John Robertson insist that "the former self's preferences would have no particular authority to govern the [now] incompetent patient's [medical] treatment." [1175]

Nelson and Frader, while admitting that " what might be called the Parfit-Dresser position rests on highly controversial views in the philosophy of mind and metaphysics," [1176] nevertheless refuse to summarily reject the argument "that the survivor of a severe brain trauma literally may not be the same person as the individual who wrote his or her advance directive or who articulated the patterns of value or best interests that are to be applied by appointed or natural proxies to the various decisions that will need to be made." [1177] In their view, the concept of a second self, at the very minimum, raises serious issues about whose values should ultimately control medical treatment decisions: "Do survivors of serious brain trauma continue to endorse the same values they cherished, or even expressly stated, prior to injury? If their expressed pretrauma values lead a treatment team to forego a possibly lifesaving intervention, has the

[1174] Rebecca Dresser, "Dworkin on Dementia," 33.

[1175] Dresser and Robertson, "Quality-of-Life and Non-Treatment Decisions," 236.

[1176] Nelson and Frader,"Brain Trauma and Surrogate Decision Making," 266.

[1177] *Ibid*, 266.

patient been robbed of a chance to come to appreciate a richly valuable-albeit different-way of living a human life?" [1178]

For proponents of the concept of a second self, what must occupy our complete attention is the demented person sitting before us, and it is our perception of that person's expression of wants, and desires, what Rebecca Dresser terms *experiential interests*, that should solely guide medical treatment decisions. They insist that it is patently absurd to be bound by a former expression of this now demented person's former preferences for medical treatment that was based on entirely different wants and most importantly different values. Even if one agrees with Michael Quante that ontology cannot be used to determine whether the demented individual's present or past interests should prevail, [1179] or simply finds the concept of a second self balderdash, the contention that because of dementia a demented individual has different wants and values than he/she did before dementia, is not at all unreasonable, and requires a determination as to which of these competing sets of wants and values has greater moral authority. This is probably not a difficult determination for most people, even when a diagnosis of Alzheimer's disease and awareness on the part of the person so diagnosed that his/her medical preferences as expressed in his/her advance directive(s) could possibly conflict with his/her inferred preferences once dementia has destroyed his/her competency.

On the other hand, this determination seems to be much more difficult if one accepts the contention that dementia creates a second self. The concept of a second self gives a demented individual a new identify, separate from his/her previous identity, and a greater moral status is thereby conferred on that new identity's inferable set of wants and values. Instead of competing

[1178] *Ibid*.

[1179] Michael Quante. "Precedent Autonomy and Personal Identity." *Kennedy Institute of Ethics Journal* 9, no. 4 (December 1999):374.

sets of wants and values belonging to the same person, one expressed while possessing decisional capacity the other inferred after dementia has stolen that capacity, we have competing sets of wants and values belonging to different persons. A case can now be made to give this second self what presumably every self is entitled to, a right to choose or refuse medical treatment based on his/her own set of wants and values. Obviously, if one is willing to recognize the existence of a second self, a previously drawn advance directive of a now demented individual has no moral authority and must be ignored.

Criticism of the Second Self Concept

Not at all surprisingly, there has been no shortage of criticism directed against the concept of a second self. A fundamental claim advanced by critics is that the medical treatment preferences inferred from the apparent experiential interests of the demented individual must be disregarded in favor of the medical treatment preferences expressed when that individual still possessed decisional capacity because these expressed preferences reflect critical judgments based on the enduring values acquired over a lifetime and from a perspective that sees an entire life and not just a moment in time. Even, in the critic's estimation, if proponents of the concept of a second self are quite correct in characterizing the issue as a contest of whose values will be imposed on the other, the value undergirding and guiding the medical treatment preferences expressed in the advance directive must nevertheless prevail.

Ronald Dworkin is the primary proponent of the critical interests theory:

> Most people think they . . . have . . . critical interests: interests that it does make their life genuinely better to satisfy, interests they would be mistaken, and genuinely worse off, if they did not recognize. Convictions about what helps to make a life good on the whole are convictions about those more

> important interests. They represent critical judgments rather than just experiential interests. [1180] . . . By the time the dementia has become advanced, Alzheimer's victims have lost the capacity to think about how to make their lives more successful on the whole. They are ignorant of self-not as an amnesiac is, not simply because they cannot identify their pasts-but more fundamentally, because they have no sense of a whole life, a past joined to a future, that could be the object of any evaluation or concern as a whole. They cannot have projects or plans of the kind that leading a critical life requires. [1181]

To a large extent, Dwokin's distinction between experiential and critical interests frames the debate over which interests have greater moral authority, and there is no shortage of observers that find agreement with him.

According to James L. Nelson, Dworkin is arguing that "the authority to make decisions for demented people rests most of its weight on the human ability to make choices that reflect, reinforce, or constitute a certain conception of their lives as a whole," [1182] and not solely on the perspective of the demented individual. At issue it seems is an individual's right, prior to dementia, to prospectively and critically determine that life with dementia is totally repugnant and should not be inappropriately extended, not only despite the knowledge, but because of the knowledge that once he/she has completely lost her memory and sense of self outside of the moment, he/she might, on at least some minimal level, find life pleasurable and worth living. In Nelson's view: his/her principle fear could be that *she might lose that very repugnance* and end her life in a state where she was not merely demented but content to be so." [1183] For Nelson,

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[1180] Ronald Dworkin. *Life's Dominion: An Argument about Abortion, Euthanasia, and Individual Freedom.* (New York, NY: Random House, 1993), 210-202.

[1181] Ibid, 230.

[1182] James Lindemann Nelson. "Critical Interests and Sources of Familial Decision-Making Authority for Incapacitated Patients." *Journal of Law, Medicine, & Ethics.* 23, no. 2 (June 1995): 143.

[1183] *Ibid*, 140.

"[a]lthough [he/]she is not now in a position to ratify [his/]her past decision, no one is in an authoritative position to annul it either; thus respect for autonomy requires that her past conviction guide practice" [1184] even though he/she appears happy and content. According to him, "Dworkin's view of the self is . . . [that]the self is more than simply what is going on at the present moment: its character, its fate, is caught up with things that happened in the past-despite its having no memory of them-and with things that will happen in the future, of which they may have no experience." [1185]

According to Nelson, our legitimate interests, what Dworkin calls our critical interests, extend beyond our ability to actually experience the consequence of our choices:

> We have good reason to believe that persons do in fact have morally significant interests that go beyond what they are currently capable of experiencing. . . [W[e generally allow that we can be harmed or at least wronged by the calumny of others, even if we never find out about it. . . Many of us are not at all indifferent to the fate of future generations, even though what happens long after we are dead will have no impact on our experiences. My interest in enjoying the good opinion of others does not end with my death; indeed, it might be more important that people think well of me after I am dead than before, since I shall have no opportunity to change people's minds. [1186]

For Ben Rich, the subordination of experiential interests to critical interests is not uncommon. Parents, for example, sometime make financial sacrifices subordinating their own experiential interests to the critical interest of giving their children advantages in life the parents

[1184] *Ibid*, 144.

[1185] *Ibid*, 145.

[1186] *Ibid*

never enjoyed. [1187] What Rich calls the nonreductionist view "insists that the lives of persons, particularly the profoundly demented, become unintelligible unless we look back over the life narrative, and in particular to those occasions when the person engaged in self-defining and self-actualizing expressions and behaviors, such as the execution of an advance directive." [1188] "Dresser," Rich charges, "would have us jettison the life history of the demented [individual] as irrelevant to how [he]/she should be treated now," [1189] Rich's salient point is that "[t]he now demented individual] must be viewed as a unique individual person who has *become* demented." [1190] Nancy Rhoden concurs: "Considering the patient only in the immediate present divides the patient from her past, her history, her values, and her relationships-from all those things that make her human." [1191]

Dworkin's subordination of experiential interests to critical interests has by no means been universally affirmed. For Soren Holm, not all critical interests trump experiential interests because not all critical interests survive into dementia. If, in his opinion, a person claims in his/her advance directive that a life only a life with the ability to appreciate great literature is acceptable, yet in his/her demented state is happily occupied watching television, "it becomes very difficult to explain why the previous interest, despite its critical nature at the time it was formed, should now guide the decisions of the carers." [1192] For Rebecca Dresser:

[1187] (Ben Rich,"Prospective Autonomy and Critical Interests: A Narrative Defense of the Moral Authority of Advance Directives." *Cambridge Quarterly of Health Ethics* 6, no. 2 (Spring 1997): 144.

[1188] *Ibid*, 142.

[1189] *Ibid*.

[1190] *Ibid*.

[1191] Nancy K. Rhoden. "Litigating Life and Death." *Harvard Law Review* 102, no. 2 (December 1988): 375.

[1192] Seren Holm. "Autonomy, Authenticity, or Best Interest: Everyday Decision-making and Persons with Dementia." *Medicine Health Care and Philosophy* 4, no. 2. (2001): 157.

> When the capacity to appreciate critical interests is lost, experiential interests should take priority. Competent patients are free to elevate their critical interests above experiential interests. But after they lose decisional capacity, they have a different set of concerns. Experiential interests become central to their lives. Experiential interests should also be central to decisions about life-sustaining treatment. [1193]

Aginieszka Jaworska. however, dismisses the claim that demented persons are no longer capable of generating critical interests. Contrary to Dworkin, Jaworska maintains that critical interests do not require a grasp of one's past, present, and future, but only the ability to value rather than merely desire. For her, to value is not only to pursue one's desires, but also to intentionally eschew satisfying a desire such as compulsive gambling. In her view, Alzheimer's patients may be unable to grasp their life history or to understand their options for medical treatment but they can still value, and are "in the most basic sense, capable of self governance," [1194] although only with the assistance of family and caregivers who take the time to determine "how [their] values would best be upheld in a reality [they] no longer fully understands, as well as helping [them] implement these solutions in practice." [1195] Jaworska is careful to point out that in the *latter* stages of the disease, Alzheimer's robs patients even of the ability to value, and she accepts Dworkin's contention that they are incapable of generating critical interests.

Critics have also identified a number of what they consider additional problematic elements of the second self concept, including the possibility that the first self is able to survive all but the final stages of dementia, the uncertainty as to *when* the psychological continuity necessary for the preservation of personal identity is insufficient and whether sufficiency is a yes

[1193] Rebecca Dresser, "Pre-commitment: A Misguided Strategy for Securing Death with Dignity," 1823.

[1194] A. Jaworska, "Respecting the Margins of Agency," 109-34.

[1195] *Ibid.*

or no determination or that greater degrees of insufficiency further diminish the moral authority of an advance directive(s), the possibility that at some point in the progression of dementia a second self is created only to itself lose the selfhood necessary for personal autonomy, and the inconsistency in insisting that the demented are second selves for the purpose of invalidating their advance directive(s) but whose other legal rights and obligations, including contractual relationships and testamentary powers are unaffected.

Those who insist that it is possible that the first self is able to survive all but the final stages of dementia make two separate claims. One is that if, according to second self theory, the existence of a second self depends on the loss of psychological continuity between an individual as he was when he had decisional capacity and as he is now that he is demented, it is possible that an individual through his own efforts and those of family and caregivers can prevent the loss of psychological continuity and thus retain his pre-dementia identity. Ron Berghmans maintains "that to some degree, a person can-him-or herself, affect [psychological continuity] by trying to preserve particular memories or to erase others." [1196] Jeffrey Bluestein suggests that the severely demented lack the capacity to give narrative sense to their lives, and have lost their identities. Nevertheless, in his view, they can have their identities figuratively maintained by those who act on their behalf if the decisions are "faithful to *who* the patient was, as expressed in the organizing principles of her life through which she understood herself and her world." [1197]

The second claim is that personal identity is a product of both external and internal elements, especially family, peer group, and culture, and that our identity is thus not only how

[1196] Ron Berghmans, "Advance Directives and Dementia," 108.

[1197] Jeffey Bluestein. "Choosing for Others." *Journal of Law, Medicine, and Ethics* 27, no. 1 (Spring 1999), 21-23.

we view, relate to, and are influenced by others, especially how we perceive others view us, but also how others actually view us, relate to us, and influence us. Thus, it is further claimed, change from within an individual may sometimes be insufficient to change that individual's personal identity. In the opinion of J. Moody, the concept of a situated self emphasizes context and the external factors that contribute to personal identity. As he sees it, "according to the situated-embodied-agent view, the person is most adequately perceived as a human agent-that is, a being that acts and interacts in the cultural and historical context in which it is embedded, [and this human agent could possibly] survive even into severe dementia." [1198] [1199]

According to Berghmans, if one applies what he terms Sabat and Harre's social constructionist perspective, "[t]he self that is projected in the public domain, which depends on its existence on the cooperation of others, can get lost, but only indirectly as a result of the disease." [1200] In his view, [a]t least as important, is the way in which others perceive and communicate with the patient." [1201] For Soren Holm:

[1198] Janis Moody. "Dementia and Personhood: Implications for Advance Directives." *Nursing Older People* 15, no. 4 (June 2003): 20-1.

[1199] *Ibid.* For Moody, the issue is whether individuals with dementia are incapable of maintaining psychological continuity and thus become a separate second self, or as a situated-embodied-agent the first self is able to survive even into severe dementia: " [In] advanced dementia it would seem that there can be no psychological continuity, regardless of how low the threshold is set, as ultimately, extensive and permanent neurological damage will occur, with result that the functions necessary to maintain psychological continuity are effectively destroyed with basic perpetual awareness being all that remains. . . According to the psychological continuity [perspective], the process that results in the individual becoming incompetent and brings the advanced directive into play destroys the conditions necessary for awareness and maintenance of personal identity, and thereby undercuts the moral authority of the advance directive. . . [On the other hand] the concept of a situated self emphasizes context and the external factors that go to make up a person. In this view, humans are situated among other things, in a familial, cultural and historical context. This concept of the person necessarily involves the body as it is the body that places us in a historical context of time and place. . .Therefore, if being a person is integral to the individual's life history and narrative, as well as to their bodily form, then it seems reasonable to view the individual with dementia as a person even in the advance stages of the disease. Further, the situated-embodied-agent view of the person allows that the person today is continuous with and connected to the person who signed the advance directive"

[1200] Ron Berghmans, "Advance Directives and Dementia," 107-108.

[1201] *Ibid*.

> Real persons are embedded in social networks and occupy social roles. My maternal grandfather kept on being my maternal grandfather, even at a time when, even at a time when his dementia had developed so far that he could no longer recognize me as his grandson. It is through these social structures that normal contracts and promises are mediated, reconfirmed, and reinforced, including normal Ulysses-contracts like "I will not smoke anymore. [1202]

Also problematic for critics of the second self concept is the uncertainty as to *when* the psychological continuity necessary for the preservation of personal identity is insufficient and whether sufficiency is a yes or no determination or that greater degrees of insufficiency further diminishes the moral authority of an advance directive. Ron Berghmans suggests that not only is the "first problem with the personal identity view that the criteria of psychological connectedness and continuity are inherently vague," [1203] but that "connectedness and continuity are not a matter of all-or-nothing, but more-or-less," [1204] For Allan Buchanan, "[s]o long as the degree of psychological continuity which we take to be necessary for the preservation of personal identity [between A, the competent patient who issued the advance directive, and B, the (incompetent) individual whose body (and brain) are spatiotemporally continuous with A's is present, the advance directive has full moral authority." [1205] In his view, "[a]s we move 'downward' from this threshold, through lessening degrees of psychological continuity, the moral authority or

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[1202] Seren Holm,"Autonomy, Authenticity, or Best Interest," 157.

[1203] Ron Berghmans, "Advance Directives and Dementia," 107.

[1204] Ibid, 108.

[1205] A. Buchanan, "Advace Directives and the Personal Identity Problem," 298.

force of the advance directive diminishes correspondingly." [1206] Buchanan acknowledges that there can be no definitive answer to where this threshold should be situated.

Another criticism points to the possibility that at some point in the progression of dementia a second self is created only to itself lose, as the dementia deepens, the selfhood necessary for personal autonomy. For Allen Buchanan, if the threshold of psychological continuity necessary for the preservation of personal identity is set too low, "the cases in which we are confident the loss of personal identity has occurred will be those in which what remains is not a person, and *a fortiori*, not a different person." [1207] H. Kuhse seems to suggest that the selfhood necessary for personal autonomy may be lost much earlier in the progression of dementia, when the capacity to situate oneself in time and space is lost: "Only a being capable of understanding that it has a prospect of future existence can have a desire to go on living, and only a continuing self-or 'person'-can have an interest in continued life." [1208] In his apparent view, one could therefore argue that the advance refusal of life-sustaining treatment must be honored if the second self is incapable of having an interest in its own continued existence. [1209]

A final, and perhaps the most damaging criticism draws attention to the inconsistency in insisting that the demented are second selves for the purpose of invalidating their advance directives but whose other legal rights and obligations, including contractual relationships and testamentary powers are unaffected. Ron Berghman's sees the inconsistency: "We will want to hold people accountable, both legally and morally, to commitments and responsibilities over time. If the demented person is really a different person metaphysically, morally, and legally,

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[1206] *Ibid*.

[1207] Allen Buchanan, *Deciding for Others: The Ethics*, 30.

[1208] H. Kuhse. "Some Reflections on the Problem of Advance Directives, Personhood, and Personal Identity." *Kennedy Institute of Ethics Journal* 9, no. 4 (December 1999): 354.

[1209] *Ibid*.

then the former competent person has ceased to exist and the demented person has no property, no insurance, and no relatives." [1210] Ben Rich is of like mind:

> I simply do no think it is a defensible position to (on the one hand) pull out all of the metaphysical stops to declare the demented [individual] a new and different person with no connections of any consequence to the former, competent [individual] who executed the clear and definitive advance directive, but then (on the other hand) to suggest for every other practical purpose the demented [individual] must be treated as though she were integrally connected to the prior competent [individual]. [1211]. . . If her advance directive has no authority over the new demented [individual], then the new demented [individual] has no claim to the estate of the former competent [individual]. The incompetent [individual] has no property, no insurance, no relatives. If the incompetent [individual] had been married, her husband, by the logic of Dresser's account, would be a widower. [1212]

To accept the invalidation of a validly executed advance directive(s) because of the theoretical creation of a second self brought on by dementia whose inferred preferences for medical treatment care are at variance with the preferences recorded in the advance directive(s) is to establish a very strange continuum regarding an individual's legal rights. Based strictly on an application of the second self concept, precedent autonomy as expressed in both a last will and testament and an advance directive(s) is legitimate when the individual has decisional capacity but temporarily loses consciousness, legitimate for the will but illegitimate for the advance directive(s) if he/she regains consciousness but later becomes demented and a second self is created, again legitimate, conceivably this time for all eternity, for both the will and the advance directive(s) if the now demented person permanently loses consciousness or sinks so deeply into dementia that it is concluded that this second self is itself now lost as the first self

[1210] Ron Berghmans, "Advance Directives and Dementia," 107-108.

[1211] Ben Rich,"Personhood, Patienthood, and Clinical Practice: Reassessing Advance Directives." *Psychology Public Policy and Law* 4, no. 3 (September 1998):617.

[1212] Ben Rich, "Prospective Autonomy," 139.

was lost. Most tellingly, during that period of time when the well established legal right of an individual who executed an advance directive(s) is being trumped by the supposed right of the theoretical second self, those individuals and entities with whom this now demented individual has a contractual relationship honor his expressed wishes that were made part of the terms of the contract between them. One wonders whether a health insurance carrier contractually obligated to reimburse providers for health care, whose now demented policy holder requires life sustaining medical treatment but whose validly executed advance directive(s) mandates the refusal of that treatment has legal standing to enforce the advance directive(s) as a third party beneficiary.

Arguably mistaken assumptions undergirding the second self concept, although apparently not yet publicly critiqued, are nevertheless also worth examining. An unspoken but nonetheless critical assumption in the contention that the medical treatment preferences that can be inferred from the demeanor and behavior of a demented patient are authentic and thus authoritative expressions of that patient's autonomy is that if this demented individual could somehow be made aware of the necessity of the acceptance of life-saving medical treatment, he/she would consent to that treatment because of his/her apparent desire to continue living in spite of dementia. A second unspoken but critical assumption is that his/her consent is a truly informed consent because were he somehow to be made aware of the necessity of the acceptance of life-sustaining medical treatment he would be presumably also be aware of his/her satisfaction with living with dementia and resultant desire to continue living. In terms consistent with the second self concept, the second self's consent to a means of sustaining his/her life, although inferred rather than expressed, is thus legitimately informed consent, while in contrast, the first self's expressed rejection of this means of sustaining his/her life, *viewed retrospectively*, fails the

informed consent/rejection litmus test, because it was based on the first self's now clearly erroneous expectations regarding his/her willingness to live with dementia.

The seemingly omnipresent in the literature example of a demented individual who at least by all appearances is perfectly happy with dementia and has therefore an inferred desire to go on living is Margo, first identified by medical student Andew Firlik in a 1991 article in the *Journal of the American Medical Association* (*JAMA*) column entitled "Margo's Logo." According to Firlik, Margo was a 54 year old Alzheimer's victim who read the same pages in a mystery novel over and over again, painted pretty much the same picture over and over again, who particularly enjoyed eating peanut butter sandwiches, and was, according to Firlik, undeniably one of the happiest people he had ever met. [1213] To his credit, Dworkin intentionally chose Margo as an example of the possible moral dilemma presented when a blissfully happy but nonetheless demented individual has an advance directive proscribing certain life sustaining medical treatment:

> Suppose, for example, that years ago, when fully competent, Margo had executed a formal document directing that if she should develop Alzheimer's disease . . . she should not receive treatment for any other serious, life-threatening disease she might contract. . . If we accept the integrity view [of autonomy], we will be drawn to the view that Margo's past wishes must be respected. [1214]

It is certainly reasonable to infer that like Margo, a demented individual exhibiting similar demeanor and behavior is blissfully happy, but the further inference that he/she desires to go on living is problematic because it does not take into account the limited information available to him/her. It is certainly possible that if a now demented individual was capable of processing the

[1213] Ronald Dworkin, *Life's Dominion*," 224-5.

[1214] *Ibid*, 116.

same information that he/she possessed the day she executed his/her advance directive(s), especially information regarding his/her critical interests, which might well have included an interest in not compelling her children to bear the emotional and financial cost of her continued care, he/she would affirm her earlier choice to reject life-sustaining medical treatment. He/she is blissfully ignorant of the life and death consequences of a refusal of life saving medical treatment but equally ignorant of her critical interests. It cannot and should not be *assumed* that if the ignorance was somehow lifted regarding the life and death consequences of the rejection of life saving medical treatment that he/she would repudiate her advance directive(s), and not assume that if it could also be lifted regarding her critical interests she would not reaffirm her advance directive(s). The further assumption that his/her inferred consent to life-sustaining medical treatment is truly informed consent is also clearly mistaken because his/her consent is informed only by information re: his/her satisfaction with living with dementia and the necessity of accepting life-sustaining medical treatment if she desires to continue living, and *not* information as to his/her critical interests.

What is additionally troubling in the construction of the second self concept is that inference as to the wants and values of the second self are apparently employed only when it is convenient to do so. Proponents of the concept of a second self seem strangely silent when the medical treatment preferences expressed in an advance directive(s) that *accept* life-sustaining medical treatment seemingly conflict with the medical treatment preferences that can be inferred from the countenance and behavior of a demented second self. By way of example, when an advanced directive(s) directs that all life saving measures, including a feeding tube be employed, yet a demented second self continually pulls out the feeding tube or otherwise physically resists tube feeding and has to be restrained, where is the hue and cry that in this instance the second

self's preferences for medical treatment inferable from his/her behavior are clearly being ignored? Why is it not inferred that this individual is unmistakably rejecting a life saving intervention? If the response given is that if this demented second self somehow could be made aware that the tube feedings were sustaining his/her life he/she would not object, then how does one explain why inference is eschewed when in addition to physically resisting tube feeding this demented second self has a general countenance and body language reflective of someone who is frightened, bewildered, and for whom life is apparently short on satisfaction and long on stress. Is it not abundantly clear that he/she gives every indication of having absolutely no satisfaction with his/her life and thus by inference is indifferent to whether it continues.

Medical Treatment Preferences in an Advance Directive Must be Subordinated to the Best Interests of the Patient

Finally, the claim is made that even if precedent patient autonomy is a valid exercise of patient autonomy and the medical treatment preferences expressed in an advance directive therefore authoritative, these preferences must nevertheless be subordinated to an assessment of the best interests of the patient. The essence of this claim is that regardless, of how competent, free, and informed an individual was when he/she executed an advanced directive(s), how skillfully crafted that directive(s) and supplementary documents, and accordingly authentic and legitimate his/her exercise of precedent patient autonomy, his/her preferences for medical treatment must be subordinated to the medical treatment choices made on his/her behalf and in his/her best interests by someone deemed qualified to do so. One of the strengths of this claim is that it is totally straightforward. It is not about a second self, nor inference about wants, values, choices, or the requirements for informed consent/refusal of medical treatment. It focuses strictly on the patient's needs and best interests, and contends that what is in the best interests of the

patient must always determine medical care, even to the extent of invalidating that patient's admittedly valid autonomous medical care choices. It is nothing less than unabashed paternalism, but it does not lack for advocates, including the President's Council on Bioethics. The Council maintains that too often those empowered to make medical treatment decisions on behalf of a patient unable to speak for himself/herself mistakenly emphasize what is wanted rather than what is needed:

> Ethics committees. . .should do everything possible to ensure that surrogate decision-making focuses as much as possible on the best care for the incapacitated patient in his or her current condition. . . They should be concerned less with trying to figure out *what the incapacitated patient would want done* (my emphasis), were he now to be consulted in his own case, and concerned more with discerning what the incapacitated patient now needs in order to serve best the ongoing, if dwindling, life he now has. Judges. . .would also do well to make sure that the course of action recommended *does not overvalue "precedent autonomy"*(my emphasis) or past wishes and pay proper regard to *what best care owes this human being in his current situation* (my emphasis). [1215]

Carol Levine seems quite correct when she remarks that: "the Council's report is at heart a sustained critique of individual autonomy as a guiding principle and its expression through advance directives when a person has Alzheimer's disease or dementia." [1216] Levine points to a particular phrase in the Council's report as especially telling: "[T]rying to dictate the precise terms of one's future care is often misguided or ineffective." [1217] "Here," in Levine's view, "the President's Council has two targets: the individual who prepares the advance directive and the

[1215] President's Council On Bioethics, "Taking Care," 216-217

[1216] Carol Levine. "The President's Council on Autonomy: Never Mind!" *Hastings Center Report* 36, no. 3 (May/June, 2006): 46.

[1217] *Ibid.*

surrogate who interprets it." [1218] For Levine, in effect the report is saying: "Even if you think you don't want to be treated, you may change your mind; and even if you don't change your mind, it diminishes society for you to knowingly act in a way that would knowingly lead to your death." [1219] According to the Council, "[c]aregivers need to consider the incapacitated person's present needs and satisfactions, not only the once-competent person's past wishes; and they are summoned to make decisions not only for the self that exists in memory, but also (and especially) for the self that exists now in embodied reality." [1220]

As discussed above, critics of advanced directives focus special attention on patient decisions to forego life-saving medical treatment, insisting, not without some justification, that because such decisions have such grave consequences, they should undergo much greater scrutiny than decisions to forego other less critical medical treatments. Some advocates of the best interest standard further insist that under particular circumstances even the most zealous proponents of unrestricted patient autonomy are forced to acknowledge that the best interests of the patient with dementia must prevail over precedent patient autonomy even when following the dictates of the advance directive(s) does *not* have deadly consequences. Dresser suggests that even Dworkin might make such an exception if the advance directive mandated the absolute refusal of all pain relief and the patient was suffering unconscionably. [1221] The President's Council reaches the same conclusion, suggesting that those who "oppose overriding the living

[1218] *Ibid*, 47.

[1219] *Ibid.*

[1220] President's Council On Bioethics, "Taking Care," 122.

[1221] Rebecca Dresser, "Dworkin on Dementia," 34.

will should ask themselves whether they would also object to surgical pinning of a fractured hip, should the patient fall and break it, leaving him in pain and unlikely to walk again." [1222]

Since the President's Council is by far the most prestigious advocate of the necessity of subordinating precedent autonomy to the best interests standard it is worth examining their report, "Taking Care: Ethical Care Giving in Our Aging Society," in greater detail. At first glance, the Council seems totally unyielding in its contention that the best interests of the patient with dementia must *always* guide medical care decisions. Certain comments in the report seem to indicate a matter of fact rejection of the authority of a living will if its provisions conflict with what is perceived as the best interests of the patient:

> [P]ast wishes, as we have explored, are not always morally decisive. . . They are a crucial point of consideration, but not the only or even the most important one. No individual can foresee every future circumstance in his or her life; an individual's best interests and true needs can change over time; and medical situations are so complex that we can only judge wisely what to do case-by-case and in the moment. [1223]. . . The primary moral obligation of caregivers is to serve the well-being of the patient now here, and to ask not only what the patient would have wanted but what we owe the person who lies before us. This means paying attention to an advance instruction directive if one exists, but not following its orders *regardless of all other circumstances*. [1224]

Based exclusively on these comments, the Council's position seems clear and unambiguous, yet the Council seems to equivocate somewhat when discussing a hypothetical case study of particular significance for the circumstances relevant to this inquiry, making the

[1222] President's Council On Bioethics, "Taking Care," 195.

[1223] President's Council On Bioethics, "Taking Care," 194.

[1224] *Ibid*, 194-195.

reader wonder whether the Report had more than one author, at least two of whom view this issue very differently. In the case study described in the Council's Report, an Alzheimer's patient needs surgery for an operable tumor in his sigmoid colon, which if not removed could lead to a complete obstruction of the bowel. The Report further discloses that "[w]hile making plans for the recommended surgery, the doctors discover in [the patient's] file that [the patient] has written a living will stating very clearly that he wants no invasive treatments of any kind once his dementia has progressed to the point where he is no longer self-sufficient and can no longer recognize family members." [1225] Two comments in the Report, although admittedly taken somewhat out of context, seem to indicate an inflexible attitude in favor of overriding this particular advanced directive: "In this case, there seem to be clear and compelling reasons for caregivers to override the terms of the advance instruction directive and proceed with treatment, understood by both the daughter and the doctors as the best way possible to benefit the life the patient still has." [1226] "In cases such as the one presented here – involving a not excessively burdensome treatment, a cheerful and physically strong patient, and the fact that forgoing treatment will lead to a painful and imminent death – prudent judgment points toward overriding the living will, even when caregivers disagree." [1227]

On the other hand, other comments in the Report seem to imply first, that the manner in which an advance directive(s) is crafted, especially the inclusion of the rationale for the choices made, can give its instructions greater, and perhaps even sufficient moral weight to avoid being over ridden by the patient's best interests: "In caring for the person that patient now is,

[1225] *Ibid*, 193.

[1226] *Ibid*, 195.

[1227] *Ibid*, 194.

caregivers should never ignore the wishes and values of the person the patient once was. This requires more than their written instructions, it obliges caregivers to consider the reasons that animated the person who wrote them." [1228] Second, still another comment seems to suggest that disagreement among caregivers and ambiguity about best interests can provide additional, and perhaps even sufficient justification for honoring an advance directive as written: "But in many cases, where the best interests of the patient are not so clear and where caregivers disagree, there is solid moral ground to defer to the living will." [1229]

Finally, and especially indicative of the apparent ambivalence the Council had re: overriding an advance directive(s), and once again perhaps revealing multiple authors not of like mind, a comment suggests the necessity of an advance directive speaking unequivocally only to further state that such an instruction discriminates against a second self:

> Only by making an all-encompassing determination that his life with (more than minimal) dementia would never be worth sustaining might the competent individual rule out in advance *all* future treatments should he become demented. But such a blanket assertion about the worth of a future self denies the intrinsic dignity of embodied life even when one's cognition is impaired; it discriminates against an imaginary future self long before the true well-being of that future self is really imaginable. [1230]

Criticism of the Best Interests Standard

The best interests standard does not lack for opponents. Advocates of precedent patient autonomy respond with three different counter arguments. First, that the best interests of the patient is the authoritative guide for medical treatment decisions is an egregious hijacking of a patient's right to decide for himself/herself what medical care should be accepted or rejected,

[1228] *Ibid*, 193-194.
[1229] *Ibid*, 194-196.

[1230] *Ibid*, 194.

specifically his/her right to act *contrary* to what *from a medical standpoint someone else* determines to be in his/her best interests. Ronald Dworkin seems to suggest that those who embrace the best interests standard miss the point: "The *point* or *value* of autonomy [is] . . . respect[ing] the decisions people make when *we* believe these are *not in their best interests* (my emphasis)." [1231] Dworkin claims that autonomy extends to more than rejecting what others say is in one's best interests from a medical standpoint, but also to what one *acknowledges* as being in one's best interest from a medical standpoint: "[A]utonomy requires us not only to allow someone to act in what he takes to be his best interest but to allow him to act in a way he accepts is not in his interests at all." [1232] For Dworkin: "[A]utonomy emphasizes . . . not the welfare of the choosing agent, but his *intergrity*. The value of autonomy, on this view, lies in the scheme of responsibility it creates: autonomy makes each of us responsible for shaping his own life according to some coherent and distinctive sense of character, conviction, and interest." [1233] In sum, we should honor the patient's autonomous choice *not because of our belief that he has chosen wisely but in spite of it.*

Second, even if one accepts the best interests of the patient as the gold standard in determining medical treatment, what is in an individual's best interests from a medical standpoint may, it can be claimed, be very different from what is in an individual's *overall* best interests, and who, it can be further claimed, knows a patient's *overall* best interests more completely and definitively than the patient himself/herself. A patient's overall best interests, it can be argued, can legitimately be determined only by a patient's *own* assessment of his/her

[1231] Ronald Dworkin. "Autonomy and the Demented Self." *Milbank Quarterly* 64, Supp. 2 (1986): 7.

[1232] *Ibid*, 8.

[1233] *Ibid*, 9.

needs, wants, values, and world view, and not what someone else assumes these to be, or even more egregiously, insists that they should be. By way of example, otherwise controllable pain, as generally seen from a medical perspective, is not in a patient's best interests, and should be minimized or eliminated if at all possible. On the other hand, pain can be viewed entirely differently from a patient's own religious perspective, and in certain circumstances very much in what he/she believes to be in his/her overall best interests. Likewise, sustaining life is one of the principle purposes of medicine and clearly, therefore, in a patient's medical best interests, but does not take into consideration a patient's willingness to die if other more important values are mutually exclusive with continued existence.

Third, in a sense, the contention that the best interests of the patient with dementia *always* guides medical care decisions arises from a third party observer's compassionate response to the prospect of a demented patient's otherwise preventable suffering and/or death. Viscerally one recoils at human suffering and death, but care must be exercised that compassion does not cloud judgment. Employment of a best interests standards may arise from the very best of motives but feeling good about preventing suffering and death must not blind one to the untoward consequences of exclusive reliance on the best interests standard. If the best interests standard can be used to override an advance directive that rejects ANH when in the late stages of Alzheimer's disease one is unwilling or unable, even with assistance, to eat and drink sufficiently to sustain life, it can also be used to override an advance directive that rejects ANH should one be diagnosed as being in a permanent vegetative state. All that is necessary is that one conclude that biological life alone is in a patient's best interests. Those who applaud the utilization of a best interests standard to invalidate an advance directive in order to prevent what they view from a third party perspective as the unconscionable suffering and/or death of a demented patient, may

later recoil in horror that the same standard is being used to invalidate an advance directive in order to prevent the unconscionable death of a patient diagnosed as being in a permanent vegetative state.

In fairness to advocates of the best interest standard, there is no one that publically claims that the best interests of the patient should *always* override a patient's advance directive. Rebecca Dresser, the best known critic of advanced directives, suggests that the grounds for overriding an advance directive(s) should be narrow and limited and that the best interests standard justifiably overrides a patient's advance directive only to prevent a particularly egregious result:

> I am not arguing that all directives regarding dementia care should be overridden, nor that family choices should always be disregarded. I think directives and family choices should control in the vast majority of cases, for such cases are rarely in clear conflict with the patient's contemporaneous interests. But I believe that state restriction is justified when a systematic evaluation by clinicians and others involved in patient care produces agreement that a minimally intrusive life-sustaining intervention is likely to preserve the life of someone [that is] contented and active. [1234]

Also counseling a balanced approach is M. Harvey. For him, this is a conflict between two prima facie duties, and our task is to choose which duty to honor and observe: [1235]

> For [Dworkin], the duty to follow the AD presupposes a categorical principle requiring us to respect the critical interests of others as constitutive of their precedent autonomy, full stop. Thus, critical interests should trump . . . professional interests hands down. Dresser, on the contrary, heavily discounts critical interests in favor of experiential interests. For her, the duty to follow the Best Interests Standard presupposes a calculative principle requiring us to

[1234] Rebecca Dresser, "Dworkin on Dementia," 33.

[1235] M. Harvey, "Advance Directives and the Severely Demented," 58.

> maximize benefits and minimize harms solely in terms of . . . prospective experiential interests (58). Justice, however, requires that a balance be struck. I have argued that at times we should respect the AD's of the severely demented while at other times we should suspend them. The cost of seeking to strike such balances entails forgoing the easy security afforded by more dogmatic approaches.[1236]

Affirmative Arguments for the Moral Authority of Advance Directives

Stating the case for the moral authority of advance directives to be determinative of medical treatment, especially when decisional capacity but not consciousness is lost, is more than simply refuting claims to the contrary. There are affirmative arguments for the moral authority of advance directives in determining medical treatment for the demented that are worthy of examination. The first is that an advance directive provides a morally legitimate opportunity for a parent and spouse, especially in light of a diagnosis such as Alzheimer's disease, to subordinate his/her interests to those of his/her spouse, children, and grandchildren. What critics of the moral authority of advanced derivatives to determine medical treatment for the demented have overlooked is the extent to which some individuals executing advanced directives rejecting under certain circumstances life sustaining medical treatment might choose to do so less from concerns about their own prospective well-being but primarily from their perception of the physical, emotional and financial burden that is imposed on their families by illness, especially dementia. This oversight contributes to the absence of an analysis of these motives, and produces three significant consequences.

The first consequence is a failure to acknowledge the moral legitimacy of the patient's concerns about the burdens his/her illness imposes on her family,[1237] and the moral sufficiency

[1236] *Ibid*, 62.

of those concerns as a justification for foregoing medical treatment despite the deadly consequences. For Allen Buchanan, utilizing an advance directive to reject under certain circumstances life sustaining medical treatment based on one's desire to spare one's spouse and children the emotional and financial burden imposed by illness makes advance directive(s) "vehicles for new forms of altruism, new ways of exercising the virtue of charity." [1238] It is hard to argue against the morality of such a decision when one hears a parent and spouse's justification. Inez deBeaufort does so rather eloquently:

> [Y]our view on the interests and feelings of others has everything to do with how you see yourself and the meaning of your life. For me, the thought of my children spending their precious time visiting me when I do not recognize them is very painful, as is the idea that I know they would suffer from that situation. Their suffering would, in my view, not be compensated by any interest I have in continuing my life. They will be sad because they knew me as the person I was, and feel powerless in not being able to save me from my fate. The fact that I consider this, and take their future feelings at heart in viewing my possible future is an essential part of me, of who I am and what I value. When I am demented, I may enjoy the visit of my 'mother' or whomever I think is visiting me, and I may be genuinely pleased about that. But the purpose and point of my AED is precisely that I do not want to end up in the situation of someone who cannot be there for her loved ones anymore. . .The argument that you will be another you and will experience things differently when you are demented, does not convince me. To the contrary, because what I want to prevent is precisely this fact that I will experience things differently. I do not want to become someone who does not recognize her children anymore even if the demented-me would not suffer from not recognizing them anymore. [1239]

[1237] Nelson and Frader,"Brain Trauma and Surrogate Decision Making," 272. An argument can be made that society has an obligation to provide support for the families and caregivers of those individuals suffering from dementia, but that society's failure to do so does not provide individuals executing advance directives with the moral justification to choose to forego life-saving medical treatment in order to spare their families and caregivers the burdens associated with their care. Nelson and Frader argue that we must deal with reality: "In the absence of social support that is adequate to preserve practical identities, it seems unfair to require families alone to accept whatever sacrifices medical care and rehabilitation might require. Some of those sacrifices can require heroism, which we may warmly applaud, but which can hardly demand."

[1238] Allen Buchanan, *Deciding for Others: The Ethics*, 278

[1239]Inez deBeaufort, Inez. "The View from Before." *American Journal of Bioethics* 7, no. 4 (April 2007): 58.

The second consequence is the failure to recognize that an advance directive rejecting under certain circumstances life sustaining medical treatment because of concerns about the physical, emotional and financial burden that is imposed on one's family by dementia can contribute to one's peace of mind from the minute the ink is dry until dementia finally robs one of the ability to understand anything at all about a previously written advance directive. In Allen Buchanan's view: "the issuance of an advance directive can contribute to its author's well-being *while she remains competent* by reducing her anxiety about the stress her loved ones would experience in making difficult decisions without her guidance, and by assuring her that they will not be subjected to crushing and wasted financial costs." [1240]

The third consequence is the failure to recognize the extent to which the author of an advance directive's concerns about the physical, emotional and financial burden imposed by dementia on his/her family weaken if not invalidate those arguments voiced against strict adherence to the provisions of advanced directives that are based on the inability of the author of an advance directive to accurately foresee how he/she will be impacted by and react to dementia. If one's primary concern is the impact of dementia on one's family, it may be totally inconsequential that one becomes a "Margo," by all appearances perfectly content with living with dementia.

A second argument for the moral authority of an advance directive questions how far society is willing to go to coerce the conduct of others with regard to their own lives. According to Ronald Dworkin: "the critical question is whether a decent society will choose coercion or responsibility, whether it will choose to impose a collective judgment on matters of the most

[1240] Allen Buchanan, *Deciding for Others: The Ethics*, 278 Footnote 1.

profound spiritual character on everyone, or whether it will allow and ask its citizens to make the most central, personality-defining judgment about their own lives for themselves." [1241] A third and final argument for the moral authority of an advance directive is that invalidating an advance directive exacerbates the destructive power of dementia by destroying one's opportunity through an advance directive to prevent dementia from stealing one's right to subordinate experiential interests to critical interests, and in so doing subordinating one's own interests to those of others, especially one's spouse and children, one's short term interests to long term interests, one's personal comfort to self sacrifice, and one's immediate self gratification to long term goals. Doesn't dementia punish an individual enough already without taking away the right to subordinate experiential interests to critical interests? With a validly executed advance directive, one retains the ability to give through self sacrifice even though demented. Isn't dementia devastating enough without permitting it to rob one of his/her autonomy? Isn't the invalidation of a validly executed advance directive a preventable and thus needless further injury to someone suffering from a pitiless disease?

[1241] Ronald Dworkin, *Life's Dominion*, 216.

Conclusion

There is no legitimate reason why an individual diagnosed with Alzheimer's disease cannot make his/her own medical treatment and care decisions, including decisions made in advance, in anticipation of the eventual loss of his/her decisional capacity, as long as those decisions are made *before* decisional capacity is lost. Although there will very likely be some measure of uncertainty regarding an Alzheimer patient's prognosis, especially the probable length of time from diagnosis to loss of decisional capacity, as well as ultimate life expectancy, there is also no reason why his/her medical treatment and care choices cannot be informed decisions, as long as he/she is willing to take the time to do the necessary "homework" of gathering and digesting relevant information. In addition, although there is not as yet any cure for Alzheimer's, and only limited means of mitigating symptoms and slowing the progress of the disease, there is no reason why the quality of life of both the Alzheimer's patient and his/her family/caregivers cannot be maximized with honest and realistic advance planning, and flexibility in making appropriate adjustments to both anticipated and unanticipated problems, as they emerge.

Absent some intervening fatal injury or pathology, an individual diagnosed with Alzheimer's disease will ultimately be unwilling or unable, even with assistance, to eat and drink sufficiently to sustain his/her own life. As is certainly common knowledge, there are fatal

consequences for failure to eat and drink sufficiently to sustain one's life, absent the satisfactory utilization of one or more of a number of methods of providing artificial nutrition and hydration (ANH.) What is less commonly understood, however, is that if in such a circumstance ANH is rejected, death ultimately results not from starvation, but from terminal dehydration. What is even less commonly understood is that death from terminal dehydration can be virtually painless, especially when certain symptoms, occurring almost exclusively in the mouth, are appropriately managed. Reassurance that the experience of terminal hydration will be *entirely* free of *any* form of pain or suffering, physically, psychologically, emotionally, or existentially, can be provided to a patient, and/or his family through the prudent application of preemptive palliative sedation.

In the United States, an adult with decisional capacity possesses the legal authority to reject a means of sustaining his/her life, including, but not limited to, artificial nutrition and hydration (ANH), subject only to constitutionally valid procedural or substantive limitations on that authority imposed by state legislation, currently in force in only a handful of states. In addition, subject to these and other constitutionally valid procedural or substantive limitations and/or evidentiary standards re: the determination of his/her previously expressed or implied intention, all imposed by particular state legislation, an adult with decisional capacity can, in anticipation of the possible loss of that capacity, make such a rejection in advance, through the use of an advance directive(s), such as a living will or durable power of attorney. In the absence of an advance directive(s), a surrogate may be given the legal authority to make medical treatment decisions, but his/her decisions may not necessarily correspond to the decisions the now decisionally incapacitated patient would have made for himself/herself if he/she still had the decisional capacity to do so.

Reflecting the very nature of moral inquiry and especially moral judgments, reasonable minds can and do disagree on moral authority, including whether an individual possesses the moral authority to reject a means of sustaining his/her life. Nevertheless, there is ample justification for the assessment that, from an exclusively secular moral perspective, an adult with decisional capacity, including an Alzheimer's patient, possesses the moral authority to reject a means of sustaining his/her life, including but not limited to ANH, *provided that the foreseeable harm(s) and continuing burden(s) of that means can be reasonably assessed as, on balance, disproportionate to its foreseeable benefit(s), if any*. Whether harm(s) and burden(s) are broadly assessed or restricted to only that harm(s) and benefit(s) directly imposed by the means itself, is entirely dependent on the extent to which reassurance is needed that the rejection of a means does not reflect an intention to kill through passive euthanasia.

Concern that the rejection of a means of sustaining life might possibly be a form of passive euthanasia can be appropriately addressed by the requirement that foreseeable harm(s)/burden(s) assessed in the process of balancing foreseeable harm(s)/burden(s) against foreseeable benefit(s) must be restricted to *only* that harm(s) and/or continuing burden(s) *directly imposed, as strictly interpreted, by the means* of sustaining life being evaluated, and nothing else. All other foreseeable burdens, especially the burdens imposed by the *continued existence of the patient*, on the patient, his/her family/caregivers, and society as a whole, including the burden(s) imposed by the patient's underlying illness/disease/injury and/or resultant functional incapacity and/or poor quality of life, are *absolutely* excluded. The rationale for the requirement is perfectly clear. When this requirement is observed, moral justification for the rejection of a means of sustaining life, even though death follows, is based on the assessment that foreseeable harm(s) and continuing burdens(s) *imposed by the means itself* are disproportionate, on balance, to the foreseeable

benefit(s) provided and the critically important *inferred* intent in rejecting this means is to avoid the foreseeable harm(s) and/or continuing burden(s) with the regrettable but completely unintended consequence that death *may* also foreseeably result. If on the other hand, foreseeable harm(s) and/or burden(s) that are assessed as disproportionate, on balance, to the benefit(s) are *also* those harm(s) and/or continuing burden(s) *imposed by the continued existence of the patient*, the inferable intent is that the rejection of this means is *not* only to avoid the harm(s) and/or burden(s) imposed by the means *itself*, if any, but to avoid the burden(s) imposed by the continued existence of the patient by ending his/her life. Avoidance of the burden(s) imposed by the continued existence of the patient is held to be a form of passive euthanasia, the intentional indirect killing of an innocent person.

Claims that advance directives lack moral authority rely for much of their persuasiveness on especially egregious examples of what is characterized as an unconscionable rejection of medical treatment, especially life-sustaining medical treatment, made in advance by someone who it is insisted would invalidate this rejection were they somehow apprised of the information available at the time an advance directive is called upon to be determinative, and still had decisional capacity to make such an invalidation. There is, however, no apparent "red flag" moral insufficiency inherent in an advance directive that cannot be overcome with personal determination, professional consultation, and the appropriate choice of documents, documentary language, surrogate decision makers, caregivers and medical professionals. Accordingly, it is by no means unreasonable to conclude that with care and prudence, one can construct an advance directive(s) for health care that has the requisite moral authority to be ultimately determinative of one's medical treatment, including an Alzheimer's disease specific living will coupled with a durable power of attorney and personal statement that rejects ANH and requests PPS when and if

one is no longer willing or able, even with assistance, to eat and drink sufficiently to sustain one's life.

For many Americans, exclusively secular moral authority and even legal authority to reject a means of sustaining their lives may not provide sufficient license to make such a choice. These individuals may require some degree of religious approbation. It is perfectly reasonable for an American Jew, regardless of his/her particular religious orientation, to conclude that there is general approbation within Judaism for the utilization of an advance directive, subject to the limitations found in the model documents published by each of the three principal movements, Reform, Conservative, and Orthodox. It is also reasonable to conclude, subject to the necessity of observing certain specific conditions outlined in the model documents, that there is Reform and Conservative approbation for the utilization of an advance directive(s) by an individual diagnosed with Alzheimer's disease, in advance of the loss of decisional capacity, to authorize the rejection of ANH if and when in the late stages of the disease that patient is unwilling or unable, even with assistance, to eat and drink sufficiently to sustain his/her life. American Orthodox approbation of such a rejection can be reasonably assessed to be somewhat problematic, although ultimately dependent on one's choice of rabbi to interpret and apply relevant *halacha*, and the possibility cannot be absolutely excluded, although probably unlikely, that an American Orthodox rabbi would give his approval.

It is also reasonable to conclude that for the moment there is, in principle, no apparent legitimate theological objection within Judaism to the utilization of preemptive palliative sedation provided that PPS does not compromise respiratory or cardiac function or otherwise contribute to death. Presumably, therefore, there is Reform and, depending on how one chooses to define pain, Conservative approbation for the utilization of an advance directive(s) to

authorize, if and when a late stage Alzheimer's patient is unwilling or unable, even with assistance, to eat and drink sufficiently to sustain life, not only the rejection of ANH but the utilization of PPS once terminal dehydration begins. Orthodox approval of PPS will be entirely dependent on one's choice of an Orthodox rabbi, but there appears to be no legitimate justification for withholding approval if it can be clearly demonstrated to his satisfaction that PPS does not compromise respiratory or cardiac function or otherwise contribute to death.

The Roman Catholic Church holds that there is a divinely imposed obligation to preserve human life and that obligation not only includes the use of available and appropriate medical treatment, but in addition, the normal care due to the sick, including, but not limited to, *all* forms of nutrition and hydration. One exception to the obligation to use ANH is provided when a individual's body is physiologically incapable of utilizing the nutrition and hydration thereby provided or death is imminent. Another exception is when, presumably in the underdeveloped world, the availability of ANH creates a genuine physical impossibility. A final exception is permitted when a determination is made that ANH imposes a significant physical discomfort on the patient because of the means of delivery, or is otherwise significantly burdensome for the patient such that the burden(s) of ANH can be correctly determined to be disproportionate to its benefit. Uncertainty arises as to what the Church considers to be an excessive burden, but apparently *excluded* are expense, the patient's psychological repugnance to ANH, or any burdens that fall on the patient's family or community rather than on the patient himself/herself. Given that an individual in a PVS is presumably incapable of physical discomfort from any method of ANH or vulnerable to being otherwise excessively burdened by ANH, there is, therefore effectively an exception-less obligation to provide ANH for an individual in a PVS as long as his/her body retains the physiological capability of utilizing the nutrition and hydration provided.

In addition, it also seems highly doubtful that the Church would countenance an apriori determination, possibly through the use of an advance directive, *before ANH is actually utilized*, that an individual's body is physiologically incapable of utilizing ANH, or that ANH imposes a significant physical discomfort on or is otherwise excessively burdensome for him/her.

Of particular significance for this inquiry, it is also abundantly clear that the Church categorically rejects the contention that Alzheimer's disease so reduces the functional capacity of an individual that ANH provides no benefit. As to whether the Church holds that ANH can be legitimately assessed as creating significant physical discomfort or being excessively burdensome for an Alzheimer's patient, there is, not surprisingly, some uncertainty. It seems clear that, unlike an individual in a PVS, an Alzheimer's patient is not only capable of experiencing physical stimulus, but that it is highly likely that he/she can experience physical discomfort. In addition, it seems equally clear that emotional and psychological problems resulting from the inability of a late stage Alzheimer's patient to understand the justification for presence of a tube, IV line or needle also have the potential of creating an excessive burden, especially if physical restraints are needed to prevent intentional or even unintentional dislodging, and that the possibility that such a burden could be excessive cannot easily be dismissed. Of particular importance, because the Church views the burden of patient care imposed on the family of an individual in the late stages of Alzheimer's disease as morally comparable to the burden imposed on the family of an individual in a PVS, burdens imposed by ANH *on family members* of an Alzheimer's patient cannot be used to provide a legitimate exception to the obligation to utilize ANH based on the assessment that this burden(s) *on the family* is disproportionate to the benefit that ANH provides to their family member patient.

The Roman Catholic Church also holds that palliative sedation is acceptable only as a means of last resort for addressing otherwise uncontrollable pain and suffering, because loss of consciousness can deprive a dying patient of the opportunity to spiritually prepare for his/her death. On the other hand, if the Church's justification for its prohibition of using unconsciousness to eliminate suffering arises out of a concern that the unconscious patient is incapable of addressing appropriate moral, spiritual, and familial obligations as death approaches, it must be recognized that the late stage Alzheimer's patient, even when completely conscious, is quite likely totally incapable of addressing any of these obligations. Nevertheless, the Church is at least so far unwilling to make such an assessment, perhaps only because it has not been formally asked to do so.

There is strong American Protestant approbation for the utilization of an advance directive(s) to reject a means of sustaining-life, including ANH, *provided that rejection is in accord with Christian biblical principles.* The apparent overriding concern from an overall American Protestant *perspective* is whether, in such a circumstance, a theologically acceptable justification exists that distinguishes the withholding of ANH from voluntary passive euthanasia. Although no Protestant theologian or scholar has publicly claimed that late stage dementia alone provides a legitimate theologically acceptable justification for the withholding of ANH, there are other acceptable theological justifications, from an overall American Protestant *perspective*, for the rejection of a means of sustaining life that apply with equal force to ANH, and effectively distinguish the withholding of ANH from passive euthanasia. An expressed preference for preemptive palliative sedation does not appear to be categorically excluded by those few Protestant voices that have addressed the issue, and the assessment that PPS is in general accord

with Christian principles seems particularly reasonable when it can be demonstrated that PPS does not accelerate the trajectory toward death.

It is inevitable that Islamic voices, including Islamic religious scholars, will, with much greater specificity, address all of the issues raised by this inquiry. Until then, the question remains as to whether there is sufficient Islamic religious approbation or insufficient condemnation for the rejection of ANH, the utilization of PPS and the utilization of advance directive(s) for a Muslim to conclude that he/she can execute an Alzheimer specific advance directive(s) rejecting ANH when he/she is no longer willing or able, even with assistance, to eat and drink sufficiently to sustain life and insisting on PPS and still consider himself/herself a legitimate Muslim faithful to the *Qu'ran* and Islamic legal principles. Such a conclusion is clearly a subjective assessment for each individual conscience but does not appear to be *completely* unreasonable. Those Muslims unfamiliar with the plurality of opinion historically permitted within Islam are likely to be disconcerted by the simultaneous Islamic religious approbation and condemnation for the rejection of ANH, but this will not be an insurmountable obstacle for those willing to embrace diversity of opinion as an opportunity for individual choice. Conservatives may well require more specific approbation and the total absence of any form of condemnation, but others may not be so insistent.

There is virtual unanimity within American professional medicine regarding the right of a patient with decisional capacity to reject ANH, and to do so through the use of an advance directive(s). According, on the other hand, to the apparent consensus view of its appropriateness, PPS fails to meet all three of professional medicine's principal criteria for its protocol re: the utilization of palliative sedation. PPS is not only preemptive, given in anticipation of suffering that has not even been experienced much less proved to be refractory, but is used to prevent *all*

forms of suffering, including psychological, emotional, or existential distress, and not just physical pain, and is intended to *permanently* preclude the possibility of suffering. Although there is ample historic justification for this protocol, it can no longer be legitimately and appropriately used to deny a request for PPS in the circumstances specific to his inquiry: subsequent to the rejection of ANH and as terminal dehydration is beginning but before any symptoms of suffering are apparent.

Unless we choose to avert our glance, we can clearly see the handwriting on the wall. As modern medicine extends lives, more and more Americans are going to be afflicted with Alzheimer's disease. At present not only is there no cure, efforts at mitigation of symptoms have produced only limited success. A tidal wave is forming and it is unconscionable that we not make every effort to prepare ourselves for its impact. Without question, Alzheimer's has enormous implications as we move further into the second decade of the twenty-first century. The long-term care demands of the Alzheimer's patient are alone capable not only of financially devastating virtually every family who has the misfortune of having one or more of its members afflicted, but of putting enormous strain on the family structure itself. If and when long-term care for the Alzheimer's sufferer is unequivocally included under the Medicare umbrella, this single disease has the potential to bankrupt the system. It is simply not sufficient for modern professional medicine, the legal community, and society as a whole to remain impotent in the face of this impending crisis.

First, responsible voices both within and without the medical community need to be raised to alert our nation of the impending crisis, and argue for a greater allocation of resources to address its foreseeable implications. It is insufficient, however, to focus this much needed "call to arms" only on raising public awareness and making the case for increased federal funding for

research directed at delaying onset, mitigating symptoms, and perhaps even finding a cure. Given the unrelenting and crushing burden that the long term care requirements of this disease place on care giving families, it is nothing short of a moral imperative that society as a whole somehow find a way to assume at least some of the financial responsibility of bearing that burden. As critically important, however, as are research and at least a partial underwriting of long-term care, we cannot permit ourselves to ignore the discrimination that, not infrequently, strips the Alzheimer sufferer of personal autonomy in making personal health care decisions.

Unfortunately, at least some Alzheimer's patients fail to pass the "eye" test. They are not only fully conscious but don't appear to be suffering either physically or emotionally, and are not dependent on "machines" to sustain bodily functions. At first blush, therefore, a decision to withhold or withdraw life-sustaining medical treatment from such a patient seems unreasonable, unjustified, and has a euthanasia like feel to it. Viscerally and intuitively, when evaluating circumstances appropriate for withholding or withdrawing life-sustaining medical treatment, Americans seem to privilege physical impairment, and especially physical pain, over mental impairment and psychic pain. Mental impairment, regardless of its cause or its severity, as long as consciousness is preserved and there is no dependence on machines to sustain life, may be viewed by many Americans as an insufficient justification for permitting the withdrawing or withholding of life-sustaining medical treatment.

Particularly egregious discrimination occurs when an individual, diagnosed with Alzheimer's disease but with decisional capacity, executes an advanced directive(s) that unambiguously sets out his/her very specific intentions for medical treatment and care once decisional capacity is lost, including his/her intention to withdraw or withhold antibiotics, artificial nutrition and hydration, and/or other means of sustaining his/her life when certain

thresholds of physical and mental incapacity are reached, such as the inability to recognize family members, and/or the unwillingness or inability, even with assistance, to eat and drink sufficiently to sustain his/her own life. Unlike other circumstances where trauma or disease renders an individual with an advanced directive unconscious or otherwise incapable of expressed or even inferred communication, the usual trajectory of Alzheimer's disease can result in a circumstance where family, caregivers, legally designated surrogates, and/or attending medical professionals conclude that the Alzheimer's patient's previously expressed rejection, under certain very specific circumstances, of life sustaining medical treatment, should be overridden or ignored. This conclusion to override or ignore can be based on the assessment that the rejection of life-sustaining medical treatment is contrary to the patient's best interest, the assessment that his/her present interests, as inferred from his/her behavior, trump his/her prior interests expressed in his/her advance directive(s), or are simply contrary to the interests of someone else of influence in making this decision. In such a scenario, it is quite possible that the voice of the advanced directive, the voice of the Alzheimer's patient himself/herself, expressed while possessed of decisional capacity, may be the only voice advocating the rejection of life-sustaining medical treatment. Unlike those who will die of cancer or heart disease, the will of the Alzheimer's patient is being ignored, at least arguably, because of the nature of the disease itself. This is completely unacceptable, and should not be permitted to continue unchallenged.

First, professional medicine should publicly and privately encourage everyone fifty years and older to execute an advanced directive and durable power of attorney for health care. Thanks to the publicity surrounding the death of Teri Schiavo, we experienced an unprecedented but apparently short-lived increase in the number of Americans executing advance directives for their health care. It may be necessary, therefore, for professional medicine to urge the Congress

to mandate that in exchange for benefits, Medicare recipients are required by law to execute and update annually a detailed and, once diagnosed with a life-threatening pathology, disease specific advanced directive for health care.

Second, the American Bar Association should develop a set of Alzheimer's disease medical treatment and care options to be included in an Alzheimer's disease specific medical care directive. Consultation should be sought with representatives of the principle religious denominations in the United States to provide input as to the acceptability, from each denomination's perspective, of each of these options. This consultation should not be undertaken with the illusion that unanimity is possible or even desirable but in the interest of providing the comprehensive information upon which truly informed consent is based. An addendum should be provided to the Alzheimer specific medical care directive and guide that provides a commentary from each of the principle religious denominations as to the doctrinal acceptability of each of the Alzheimer medical treatment and care options.

Finally, advocates of individual personal autonomy, specifically the right of an adult with decisional capacity to make his/he own medical treatment choices, including the decision to reject life-sustaining medical treatment, should begin a nation-wide public relations campaign designed to promote public awareness re: the legal and medical authority of an individual with decisional capacity, including those diagnosed with Alzheimer's disease, to accept or reject, in advance, all forms of life-sustaining medical treatment.

The bottom line is that the family of an individual diagnosed with Alzheimer's disease who has chosen, for whatever reason, moral, religious, or otherwise, to live with the disease as long as it is medically possible to do, should be given the maximum possible emotional and financial support necessary not only to carry out their loved one's wishes, but to maximize, to the

extent possible to do so, his/her functional and cognitive capacity and overall quality of life. Fear of the physical, emotional, and financial consequences of a choice to live with Alzheimer's disease must not be allowed to unduly influence an individual diagnosed with Alzheimer's decision to reject life-sustaining medical treatment. Just as importantly, however, the family/care givers/medical care providers of an individual diagnosed with Alzheimer's disease who has chosen to execute an advance directive(s) that unambiguously sets out his/her intention that antibiotics, artificial nutrition and hydration, and/or other means of sustaining his/her life be withdrawn or withheld when certain thresholds of physical and/or mental incapacity are reached, should not be permitted to intentionally or unintentionally frustrate this patient's wishes. This inquiry is, in part, an effort to demonstrate how, regardless of the medical treatment decisions contained therein, an individual can maximize the legal and especially the moral authority of his/her advance directives. Without, however, significant attitudinal change among Americans re: the right of an Alzheimer's patient to reject, under certain circumstances, life-sustaining medical treatment, his/her right to do so will continue to be denied in far too many instances.

Appendix

1. John Davis, B. C. Bountra, and J. Richardson. “Perspectives of Alzheimer’s Disease Treatments.” In *Handbook of Clinical Neurology*, edited by Michael J. Aminoff, Francois Boller, and Dick F. Swaab, 273-90. (Edinburgh, Scotland: Elsevier, 2008), 274. “Glutamate is a main excitatory neurotransmitter in the CNS [central nervous system]. . . In neurodegenerative conditions increased levels of extracellular glutamate result in increased levels of intracellular calcium. The latter is believed to initiate a cascade of events resulting in cell death. Memantine is a noncompetitive, moderate-affinity, phencyclidine-site-NMDA antagonist that may prevent neurons from glutamate-mediated excitotoxicity without preventing activation of the NMDA receptor.”

2. American Association for Geriatric Psychiatry, “Consensus Statement,” 8. “Tacrine is a centrally active aminoacridine with reversible nonspecific cholinesterase inhibitor activity and a duration of action of less than 7 hours. In clinical trials involving approximately 2000 patients with mild to moderate AD, between 20% and 30% of tacrine patients showed clinically observable improvement compared with placebo, representing on average about 6 months of deterioration. However, approximately one fifth experienced cholinergic adverse effects, most

frequently gastrointestinal distress. . . Donepezil is a second-generation cholinesterase inhibitor that, like tacrine, shows dose-dependent activity but has a longer duration of inhibitory action and greater specificity for brain tissue. In 3 double-blind, placebo controlled trials including more than 1000 patients, donepezil produced significantly greater cognitive effects (e.g. enhanced memory, orientation, language, an reasoning) than placebo over periods of 12 and 24 weeks but did not cause hepatoxicity. The drug has a recommended starting dose of 5mg/d, which may be increased to 10mg/d after 1 month. The higher dose, while more efficacious, has a greater tendency to cause cholinergic adverse effects (e.g. nausea, diarrhea, and insomnia) if increased too rapidly, and such effects may worsen behavior."

3. Davis, Bountra, and Richardson, "Perspectives," 274. Davis, Bountra, and Richardson claim that "AD patients have a marked reduction in cortical nicotine cholinergic receptor binding relative to age-matched control subjects. They report research has shown that "[t]here is little doubt about the therapeutic potential of nicotine, but the therapeutic index for nicotine is small. . . [and] [t]his has led to the search for many selective nicotine agonists. . . now a major focus for the industry."

4. Khachaturian and Radebaugh, "Alzheimer's," 7; Joan Glickstein, "Therapeutic," 14; Gomez-Isla, Spies, de Calignon and Hyman, "Neuropathology," 240; Douglas Galasgo, "New Approaches," 6; and Dennis Selko, "Biochemistry," 255. Khachaturian and Radebaugh claim that "[i]n the early 1980's the 'cholinergic hypothesis' of AD engendered great optimism that the cholinergic deficits could be corrected—and the disease cured-- through pharmacological manipulation." In their opinion, "[t]he confidence that many scientists placed in this approach

was based on the apparent similarity between AD and another neurogenerative disorder, Parkinson's disease, in which neurotransmitter deficits can be ameliorated by an increase in the supply of the deficient chemical. " The problem, according to Glickstein, is "in Parkinson's dopamine appears to be the major neurotransmitter that is affected. . .[but] occurs primarily in a small, focused region of the brain." In Alzheimer's disease, by contrast, she claims, "widespread degeneration of nerve cells takes place throughout the cerebral cortex involving a large array of neurotransmitters." Khachaturian and Radebaugh add that although "a number of strategies were tried for correcting the cholinergic deficits in AD. . .[g]enerally, these approaches have not fulfilled their initial promise in spite of modest successes in some patients for short periods." They conclude that "it is highly likely that an effective treatment for AD would need to select multiple targets since it is known that the disease affects many biochemical systems, all of which influence the neuronal signal transduction pathway." Gomez-Isla, Spies, de Calignon and Hyman, on the other hand, insist that "understanding how and in what ways plaques and tangles relate to one another may prove central to ultimately preventing or curing this illness. . . [and that] future therapies [need to be] able to tackle both amyloid production/deposition and tau pathology, in order to successfully halt and/or reverse the pathology and cognitive decline in AD." In their view, the question of whether plaques or tangles] are the culprit in AD is probably no longer a relevant question," concluding that "Rather than EITHER/OR, it is most likely AND." How to prevent, reduce, or eliminate amyloid plaques continues, however, to prove illusive. Douglas Galasko claims that "[t]here are several enzymes within and outside cells that are capable of breaking down [Alpha-Beta amyloid] and cells, such as microglia, can clear extracellular [Alpha-Beta amyloid]." Selkoe adds that"[i]nhibitors of alpha-beta production, that is, small compounds that can cross the blood-brain barrier and decrease (but do not eliminate)

either beta or y-secretase activity, could be therapeutic in the early clinical phases of the disease, particularly in patients with minimum cognitive impairment, amnestic type, as well as in non-demented (presymtomatic) subjects." He claims that "[o]ne particularly promising approach in this regard emerges from the discovery that certain non-steroidal and anti-inflammatory drugs (NSAIDS) e.g. ibuprofen and indomethacin. . . [can] reduce selectively the amount of Alpha betas 42 generated, but also notes that "[t]he problem with such [an] approach may turn out to be that there are multiple ways in which neurons respond to alpha beta and the associated inflammatory process, and blocking one or two of these response pathways might not significantly decrease overall neuronal dysfunction and loss." Finally, Galasko notes that "[t]he long-held idea that neurons in the adult human brain do not divide has now been overthrown. . . [and] [i]n some brain areas, neuronal precursor cells have been discovered." These neuronal precursor cells are, in his opinion,. . . capable of division and being grown in culture, and have the potential of being grafted into the damaged brain, where they may be induced to mature and extend connections to adjacent neurons."

5. Alzheimer's Association, "Treatments," 3.

Antidepressants: Citalopram (Celexa), Fluoxetine (Prozac), Paroxeine (Paxil), Sertraline (Zoloft), Trazadone

(Desyrel)

Anxiolytics: Lorazepam (Ativan), Oxazepam (Serax)

Antipsychotic medications: Ariprazole (Abilify), Clozapine (Clozaril), Haloperidol (Haldol), Olanzapine (Zyprexa),

Quetiapine (Seroquel), Risperidone (Risperdal), Ziprasidone (Geodon).

6. Peter Whitehouse, “Fairhill Guidelines,” 44-65.

Physicians should sensitively inform affected individuals and their families about the diagnosis of probable Alzheimer’s disease (AD).

With diagnostic disclosure comes the responsibility to direct the affected individual and family to available resources.

Diagnosis of AD is never itself sufficient reason for loss of driving privileges.

The person with dementia, if competent, should participate in decision making regarding driving privileges.

Whether the physician or other health professional should have a role in the restriction of driving privileges remains unclear, such a role is paternalistic and is probably better left to family members and community. But the physician may take a role in some cases as needed.

People with dementia should be allowed to exercise whatever competencies (capacities) for specific tasks and choices they retain, for denying this challenges their independence and dignity.

In almost all cases, judgments of competency in health care settings for medical decision making cane be made without the need for legal proceedings.

It is important to plan for the global incompetency of advanced dementia through the use of advanced directives, especially the durable power of attorney for health care.

The best approach to problem behaviors relies on social and environmental modifications and creative activities, thereby preserving independence and self-esteem.

Physical and chemical restraints should not be substituted for social, environmental, and activity modifications.

Behavior controlling drugs should be used cautiously and only for specified purposes.

An activity profile of the person with dementia should be available to facility-based caregivers (nursing home, assisted living, or other care settings), highlighting an interactive and activity-based care plan know to be most effective for the individual.

AD should be acknowledged as a terminal illness, thereby removing doubt about the right of affected people to refuse treatment by advance directive should they become incompetent to make medical decisions.

Family members, AD-affected people, and health care professionals should sensitively discuss and plan for a good death, supported by appropriate documentation.

Many people with families want to entrust treatment decisions to loved ones who will act in their best interests; this should be supported.

Patient refusals of life-support and its withdrawal are distinguishable from voluntary euthanasia and suicide.

"Quality of Life" for people with dementia is difficult to assess because it includes a subjective element; therefore, those who are cognitively intact must avoid simplistic assertions.

While we must be cautious about assessing quality of life, there may come a point in the progression of dementia where quality of life is so severely compromised that many would justifiably wish to limit life-extending treatment.

Quality of life in nursing homes requires commitment to resident autonomy and respect for treatment refusals; government regulation should strongly uphold both of these goals.

In 1998 the Fairfield Dialogue was reconvened and Whitehouse added the following:

"Temporary and modest improvement in cognition within the context of an irreversible progressive dementing condition can create ethical issues. Patients and caregivers who have already navigated certain crises of cognitive decline may have to repeat the process. The individual who has lost insight into his or her losses may regain insight, along with renewed anxiety. Thus, for AD patients who have already navigated significant decline, the sudden intrusion of a modest and fleeting cognitive improvement may not necessarily enhance quality of life; for caregivers, some of the most taxing phases of care may need to be repeated, resulting in renewed stress."

7. Alzheimer's Association, "Treatments," 3.

Monitor Personal Comfort. Check for pain, hunger, thirst, constipation, full bladder, fatigue, infections, and skin irritation. Maintain a comfortable room temperature.

Avoid Being Confrontational or arguing about facts. For example, if a person expresses a wish to go visit a parent that died years ago, don't point out that the parent is dead. Instead, say 'Your mother is a wonderful, person, I would like to see her too."

Redirect the Person's Attention. Try to remain flexible, patient and supportive by responding to the emotion, not the behavior

Create a Calm Environment. Avoid noise, glare, insecure space and too much background distraction, including television.

Allow Adequate Rest between stimulating events.

Provide a Security Object

Acknowledge Requests, and respond to them

Look for Reasons behind Each Behavior. Consult a physician to identify any causes related to medications or illness

Don't Take the Behavior Personally, and share your experiences with others

8. Susan Mitchell, "A 93-Year-Old," 2530.

Medicare Hospice Benefit Guidelines for Determining Prognosis in Dementia

To be eligible for hospice, patients must meet both of the following criteria:

Functional Assessment Staging (FAST) Patient must be at or beyond stage 7c and show all the features of stages 6a-7c.

Medical Conditions: Patients must have at least 1 of the medical conditions over the prior year

Functional Assessment Staging (FAST)

Stage 1: No objective or subjective difficulties

Stage 2: Subjective reports of forgetting

Stage 3: Decreased job functioning evident to coworkers. Difficulty travelling to new locations.

Stage 4: Decreased ability performing complex tasks (e. g. planning dinner for guest, handling finances).

Stage 5: Requires assistance to choose proper clothes for day, season, or occasion.

Stage 6a: Cannot dress without assistance occasionally or more frequently.

Stage 6b: Cannot bathe without assistance occasionally or more frequently

Stage 6c: Cannot toilet without assistance occasionally or more frequently

Stage 6d: Incontinent of urine occasionally or frequently

Stage 7a: Speech limited to fewer than 6 intelligible words during an average day

Stage 7b: Speech limited to a single intelligible word during an average day

Stage 7c: Unable to ambulate independently

Stage 7d: Cannot sit up independently

Stage 7e: Cannot smile:

Stage 7f: Cannot hold head up independently

Medical conditions:

Aspiration pneumonia

Pyelonephritis or other upper urinary tract infection

Septicemia

Decubitus ulcer, multiple, stage 3-4

Recurrent fever after treatment with antibiotics

Eating problems such that fluid or food intake is insufficient to sustain life (or, if tube fed, weight loss greater > 10% over prior 6 months or serum albumin < 2.5 g/dl).

8. Alzheimer's Association Greater Illinois Chapter, "Encouraging Comfort Care," 15.

Staff members anticipate the needs of people with dementia

Staff members know each person so well that basic needs never become major problems

Staff members embrace the philosophy of 'person-directed care'

Staff members use a 'soft approach'

Staff members recognize and treat pain aggressively

Staff members recognize you as a true partner in care (8-9).

9. **BOOKS:**

Ann Davidson. A *Curious Kind of Widow: Loving a Man with Advanced Alzheimer's Disease*. McKinleyville, CA: Fithian Press, 2006.

Sam. Fazio *The Enduring Self in Alzheimer's Disease: Getting to the Heart of Individualized Care*. Baltimore, MD: Health Professions Press 2008.

Ladislav Volicer. *End-of-Life Care for People with Dementia in Residential Care Settings* L. (2005) available at www.alz.org/national/documents/endoflifelitreview.pdf

Nancy L. Mace and Peter V. Rabins. *The 36 Hour Day: A Family Guide to Caring for Persons with Alzheimer's Disease, Related Dementing Illnesses, and Memory Loss in Later Life*. Baltimore, MD: Johns Hopkins, 2011.

Richard Schultz, edit. *Handbook on Dementia Caregiving: Evidence-Based Interventions for Family Caregivers.* New York, NY: Springer Publishing, 2000.

OTHER RESOURCES:

Alzheimer Research Forum http://www.alzforum.org/

Alzheimer's Solutions http://www.caregiving-solutions.com/

Alzheimer's Disease Education and Referral Center http://www.alzheimers.org

Alzheimer's Association Hotline 24/7 800-272-3900 www.alz.org

Caring Connections www.Caringinfo.org

National Hospice and Palliative Care Organization www.nhpco.org

National Long Term Care Ombudsman Resource Center www.ltcombudsman.org

The Alzheimer's Store www.alzstore.com

National Institute on Aging http://www.alzheimers.org

American Hospice Foundation http://www.amerianhospice.org

Medicare http://www.medicare.gov

Alzheimer's Disease Education and Referral (ADEAR) Center

http:www.nia.nih.gov/alzheimers

10. Meals on Wheels

Local chapter of the Alzheimer's Association.

Geriatric Psychiatry Association

American Geriatrics Society

Alzheimer's Disease Education and Referral center

Caring Connections http://www.caringinfo.org/

11. Webster's Third New International Dictionary. Phillip Patrick Grove, edit. (Springfield, MA: Miriam-Webster, 2002), 459, 2256. The Webster's Dictionary definition of common law provides a long but accurate explanation of the term common law: "[T]he system of unwritten law governing the rights and duties of persons that was developed in England in courts of superior jurisdiction having general application throughout the kingdom, that was declared in written opinions by the judges and based either on the general customs or on reason and fixed principles of justice but even in the absence of a precedent capable of being adapted to a new situation or being changed or modified in light of different circumstances or needs, and that is distinguished both from the written statute laws enacted by the parliament and from other systems of law." There is little doubt that there were apparently time-honored traditions and customary ways of dealing with disputes among persons and between individual persons and those charged with keeping the peace that had achieved over time widespread acceptance and were well known to all. That these traditions and customs were accepted and applied by local magistrates is not really surprising. Not only was there widespread acceptance of the reasoning

behind these principles, jurists apparently embraced the logic that the interests of justice are best served when the law is applied uniformly and consistently. From this desire for uniformity and consistency likely sprung the doctrine of *stare decicis* which literally translates from Latin as "to stand by decided matters," and which Webster's Third Dictionary defines as "to stand by decided matters: the doctrine or policy of following rules or principles laid down in previous judicial decisions unless they contravene the ordinary principles of justice."

12. Peter Filene, *Into the Arms of Others*, 98. Although the legislation actually passed both houses in 1976, Filene revealed that the initiative for the law actually predated Quinlan: "In the early 1970's Barry Keene, a thirty-three-year-old state assemblyman from Eureka, was called upon by his neighbor for help. The neighbor's wife had terminal cancer and had vowed not to be hooked up to machines that would prolong her suffering. On his latest visit to the hospital, however, her husband found her tied by the wrists so that she wouldn't pull out the nasogastric and ventilator tubes. Didn't they have some legal power, the husband asked Keene, to prohibit such treatment? The assemblyman promised to find a remedy, but after searching the statute books he came up empty handed. Soon Keene went through the same experience again, this time closer to home and more galling to his professional principles. His mother-in-law developed cancer and signed a statement directing her physicians not to use certain aggressive treatments. But after she entered the hospital the doctors disregarded her wishes, and she had no legal power to override them. " According to Filene, Keene drafted his first bill in 1974 and was greeted with substantial and, given what Keene thought to be the prevailing opinion in California, unexpected opposition.

13. *In re: Conroy* 486 A. 2nd 1209 (N. J. 1985) "Whether based on common-law doctrines or on constitutional theory, the right to decline life-sustaining medical treatment is not absolute. In some cases, it may yield to countervailing societal interests in sustaining the patient's life. Courts and commentators have commonly identified four state interests that may limit a patient's right to refuse medical treatment: preserving life, preventing suicide, safeguarding the integrity of the medical profession, and protecting innocent third parties. The state's interest in preserving life is commonly considered the most significant of the fours state interests. It may seen as embracing two separate but related concerns: an interest in preserving the life of a particular patient, and an interest in preserving the sanctity of all life. While both of these state interests in life are certainly strong, in themselves they will usually not foreclose a competent person from declining life-sustaining medical treatment for himself. This is because the life that the state is seeking to protect in such a situation is the life of the same person who has competently decided to forego the medical intervention; it is not some other actual or potential life that cannot adequately protect itself. In cases that do not involve the protection of the actual or potential life of someone other than the decision maker, the state's indirect and abstract interest in preserving the life of the competent patient generally gives way to the patient's much stronger personal interest in directing the course of his own life. . . [D]eclining life-sustaining medical treatment may not properly be viewed as an attempt to commit suicide. Refusing medical intervention merely allows the disease to take its natural course; if death were eventually to occur, it would be the result, primarily, of the underlying disease, and not the result of a self-inflicted injury. In addition, people who refuse life-sustaining medical treatment may not harbor a specific intent to die; rather, they may fervently wish to live, but to do so free of unwanted medical technology, surgery, or drugs, and without protracted suffering. . . Medical ethics do not require medical

intervention in disease at all costs. . . Indeed, recent surveys have suggested that a majority of practicing doctors approve of passive euthanasia."

14. *Cruzan v. Director, Missouri Department of Health* 497 U. S. 261 (1990). Chief Justice Rehnquist authored the majority opinion in Cruzan, significant parts of which is worth quoting at some length "At common law, even the touching of one person by another without consent and without legal justification was considered a battery. Before the turn of the century, this court observed that '[n]o right is held more sacred, or is more carefully guarded, by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference from others, unless by clear and unquestionable authority of law.' *Union Pacific v. Botsford*, 141 U.S. 250, 251 (1891). This notion of bodily integrity has been embodied in the requirement that informed consent is generally required for medical treatment. Justice Cardozo, while on the Court of Appeals of New York, aptly described this doctrine: 'Every human being of adult years and sound mind has a right to determine what shall be done with his body; and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages.' *Schloendorff v. New York Hospital*, 105 N.E. 92, 93 (N.Y. 1914). . . The legal corollary of the doctrine of informed consent is that the patient generally possesses the right not to consent, that is, to refuse treatment. . . This is the first case in which we have been squarely presented with the issue whether the United States Constitution grants what is in common parlance referred to as a 'right to die.' The Fourteenth Amendment provides that no state shall 'deprive any person of life, liberty, or property, without due process of law.' The principle that a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions. In *Jacobson v.*

Massachusetts, 197 U. S. 11, 24-30 (1905), for instance, the Court balanced an individual's liberty interest in declining an unwanted smallpox vaccine against the state's interest in preventing disease. Decisions prior to the incorporation of the Fourth Amendment into the Fourteenth Amendment analyzed searches and seizures involving the body under the due process clause and were thought to implicate substantial liberty interests." Just this Term, in the course of holding that a state's procedures for administering antipsychotic medication to prisoners were sufficient to satisfy due process concerns, we recognized that prisoners possess 'a significant liberty interest in avoiding the unwanted administration of antipsychotic drugs under the due process clause of the Fourteenth Amendment.' *Washington v. Harper*, 494 U. S. 210, 221-222 (1990). Still other cases support the recognition of a general liberty interest in refusing medical treatment. *Vitek v. Jones*, 445 U. S. 480, 494 (1980) (transfer to mental hospital coupled with mandatory behavior modification treatment implicated liberty interests); *Parham v. J. R.*, 445 U. S. 584, 600 (1979) ('[A] child, in common with adults, has a substantial liberty interest in not being confined unnecessarily for medical treatment.').

15. U. S. Consitution, amend. 14, sec. 2. Section 1 of the Fourteenth Amendment of the Constitution declares: "All persons born or naturalized in the United States, and subject to the jurisdiction thereof, are citizens of the United States and of the State wherein they reside. No State shall make or enforce any law which shall abridge the privileges or immunities of citizens of the United States; nor shall any State deprive any person of life, liberty, or property, without due process of law; nor deny to any person within its jurisdiction the equal protection of the laws." A straightforward and literal reading of Section 1 speaks only to what has been termed *procedural due process*. Procedural due process oblige states to cross all the t's and dot all the i's

in a careful, deliberate, and fair application of the law before an individual is legally deprived of "life, liberty, or property." Summary justice in the form of lynch mobs, vigilantes, or even seated jurists who do not observe settled procedural rules simply do not pass constitutional muster. Unfortunately, it eventually became all too evident that even when procedural due process is provided, individuals can still be unjustly deprived of life, liberty, and property. In response, a legal theory that ultimately found acceptance with both the U. S Supreme Court and legal scholars, claims that the Fourteenth as well as the Fifth amendment of the Constitution provide individuals with a right to substantive due process. What this means, is that even when the government provides procedural due process, it may nevertheless not deprive an individual of life, liberty, or property without sufficient justification.

16. *Cruzan v. Director, Missouri Department of Health* 497 U. S. 261 (1990). Chief Justice Rehnquist, again for the majority: "Missouri has in effect recognized that under certain circumstances a surrogate may act for the patient in electing to have hydration and nutrition withdrawn in such a way as to cause death, but it has established a procedural safeguard to assure that the action of the surrogate conforms as best it may to the wishes expressed by the patient while competent. Missouri requires that evidence of the incompetent's wishes as to the withdrawal of treatment be provided by clear and convincing evidence. The question, then, is whether the United States Constitution forbids the establishment of this procedural requirement. We hold that it does not. . . The choice between life and death is a deeply personal decision of obvious and overwhelming finality. We believe Missouri may legitimately seek to safeguard the personal element of this choice through the imposition of heightened evidentiary requirements. It cannot be disputed that the due process clause protects an interest in life as well as an interest in

refusing life-sustaining treatment. Not all incompetent patients will have loved ones available to serve as surrogate decision-makers. And even where family members are present, '[t]here will, of course, be some unfortunate situations will not act to protect a patient.' *In re: Jobes,* 529 A.2nd 434, 437 (N.J. 1987). A state is entitled to guard against potential abuses in such situations."

17. Washington v. Glucksberg, 521 U. S. 702 (1997). Chief Justice Rehnquist, for the majority: "Prohibitions against assisting suicide [from colonial and early state legislatures] never contained exceptions for those near death. . . By the time the Fourteenth Amendment was ratified, it was a crime in most states to assist suicide. . . Attitudes toward suicide have changed since [the thirteenth century], but our laws have consistently condemned, and continue to condemn assisting suicide. . . The decision to commit suicide with the assistance of another may be just as personal and profound as the decision to refuse unwanted medical treatment, but it has never enjoyed similar legal protection. Indeed, the two acts are widely and reasonably regarded as quite distinct. . . The history of the law's treatment of assisted suicide in this country has been and continues to be one of the rejection of nearly all efforts to permit it."

18. Washington v. Glucksberg, 521 U. S. 702 (1997). Chief Justice Rehnquist, for the majority: "Our established method of substantive-due-process analysis has two primary features: First we have regularly observed that that the due process clause specifically protects those fundamental rights and liberties which are objectively, 'deeply rooted in this nations' history and tradition,' *Moore, 431* U.S. at 503(plurality opinion), and 'implicit in the concept of ordered liberty,' such that 'neither liberty nor justice would exist if they were sacrificed' *Palko v. Connecticut,* 302 U.S. 319, 325, 326 (1997). Second, we have required in substantive-due-process cases a 'careful

description' of the asserted fundamental liberty interest. *Flores*, 507 U. S. at 302." "Given the common-law rule that forced medication was a battery, and the long tradition of protecting the decision to refuse unwanted medical treatment, our assumption [in *Cruzan*] was entirely consistent with the nation's history and constitutional traditions. . . That being said, our decisions lead us to conclude that the asserted 'right' to assistance in committing suicide is not a fundamental liberty interest protected by the due process clause."

19. *Vacco v. Quill* 521 U.S. 793 (1997). "[W]e think the distinction between assisting suicide and withdrawing life-sustaining treatment, a distinction widely recognized and endorsed in the medical profession, and in our legal tradition, is both important and logical: it is certainly rational. The distinction comports with fundamental legal principles of causation and intent. First, when a patient refuses life-sustaining medical treatment, he dies from an underlying fatal disease or pathology; but if a patient ingests lethal medication prescribed by a physician, he is killed by that medication. . . Similarly, a patient who commits suicide with a doctor's aid necessarily has the specific intent to end his or her own life, while a patient who refuses or discontinues treatment might not. The law has long used actors' intent or purpose to distinguish between two acts that might have the same result. Put differently, the law distinguishes actions taken 'because of' a given end from actions taken 'in spite of' their unintended but foreseen consequences."

20. *Vacco v. Quill* 521 U.S. 793 (1997). Two footnotes to Chief Justice Rehnquist's majority opinion, both on page 808, lend additional judicial support, although admittedly only in footnotes, for the legal authority to utilize methods of pain control, including palliative sedation,

to alleviate a patient’s suffering even though it might unintentionally cause unconsciousness and even death:

[11] “Just as a State may prohibit assisting suicide while permitting patients to refuse unwanted lifesaving treatment, it may permit palliative care related to that refusal, which may have the foreseen but unintended "double effect" of hastening the patient's death. See New York Task Force, When Death is Sought, *supra* n. 6, at 163 ("It is widely recognized that the provision of pain medication is ethically and professionally acceptable even when the treatment may hasten the patient's death, if the medication is intended to alleviate pain and severe discomfort, not to cause death").

[12] We do not insist, as Justice Stevens suggests, *ante*, at 750 (opinion concurring in judgments), that "in all cases there will in fact be a significant difference between the intent of the physicians, the patients, or the families [in withdrawal-of-treatment and physician-assisted-suicide cases]." See *supra*, at 801-802 ("[A] physician who withdraws, or honors a patient's refusal to begin, life-sustaining medical treatment purposefully intends, *or may so intend*, only to respect his patient's wishes . . . . The same is true when a doctor provides aggressive palliative care; . . . the physician's purpose and intent is, *or may be*, only to ease his patient's pain" (emphasis added)). In the absence of omniscience, however, the State is entitled to act on the reasonableness of the

21. Arizona Living Will Legislation

http://www.azag.gov/lifecare/LivingWill.pdf

(Some general statements concerning your health care options are outlined below. If you agree with one of the statements, you should initial that statement. Read all of these statements carefully before you initial your selection. You can also write your own statement concerning life-sustaining treatment and other matters relating to your health care. You may initial any combination of paragraphs 1, 2, 3 and 4 but if you initial paragraph 5 the others should not be initialed.)

_____ 1. If I have a terminal condition I do not want my life to be prolonged and I do not want life-sustaining treatment, beyond comfort care, that would serve only to artificially delay the moment of my death.

_____ 2. If I am in a terminal condition or an irreversible coma or a persistent vegetative state that my doctors reasonably feel to be irreversible or incurable, I do want the medical treatment necessary to provide care that would keep me comfortable, but I do not want the following:

_____ (a) Cardiopulmonary resuscitation, for example, the use of drugs, electric shock and artificial breathing.

_____ (b) Artificially administered food and fluids.

_____ (c) To be taken to a hospital if at all avoidable.

_____ 4. Notwithstanding my other directions I do want the use of all medical care necessary to treat my condition until my doctors reasonably conclude that my condition is terminal or is reversible and incurable or I am in a persistent vegetative state.

22. Kentucky Living Will Directives Act

Living Will Directives Act. Ky. Rev. Stat Ann. 311.623 effective July 15, 2010:

(1) An adult with decisional capacity can make a living will directive that does any or all of the following:

(a). Directs the withholding or withdrawal of life-prolonging treatment; or

(b) Directs the withholding or withdrawal of artificially provided nutrition or hydration.

23. Illinois Living Will Act and Power of Attorney Act

Http:www.ilga.gov/legislation/ilcs/ilcs3asp?ActID=2110&Chapter

ILLINOIS LIVING WILL ACT (755 ILCS 35/3)

"If at any time I should have an incurable and irreversible injury, disease, or illness judged to be a terminal condition by my attending physician who has permanently examined me and has determined that my death is imminent except for the death delaying procedure."

http:www.ilga.gov/legislation/ilcs5.asp?ActID=2113&Chapter

IILINOIS POWER OF ATTORNEY ACT (755 ILCS 45

"Nothing in this Article shall impair or supersede any legal right or legal responsibility which a person may have to effect the withholding or withdrawal of life-sustaining or death-delaying procedures in any lawful manner, and the provisions of this article are cumulative in this respect."

24. Ohio Living Will Declaation and Durable Power of Attorney for Health Care.

http://co.lucas.oh.us/documents/Recorder/Living%20Will.pdf

"Under Ohio law, a Living Will Declaration is applicable only to individuals in a terminal condition or a permanently unconscious state."

http://www.co.lucas.oh.us/documents/Recorder/Health%20Care%20POA.pdf

Ohio Durable Power of Attorney for Health Care

"1. My agent cannot order the withdrawal of life-sustaining treatment unless I am in a terminal condition or a permanently unconscious state, and two physicians have confirmed the diagnosis and have determined that I have no reasonable possibility of regaining the ability to make decisions."

"2. My agent cannot order the withdrawal of any treatment given to provide comfort care or to relieve pain."

"4. My agent cannot order the withdrawal of artificially or technologically supplied nutrition and hydration unless I am terminally ill or permanently unconscious and two physicians agree that nutrition and hydration will no longer provide comfort or relieve pain and, in the event that I am permanently unconscious, I have given a specific direction to withdraw nutrition or hydration elsewhere in this document."

"5. If I previously consented to any health care, my agent cannot withdraw that treatment unless my condition has significantly changed so that the health care is significantly less beneficial to me, or unless the health care is no longer significantly effective to achieve the purpose for which I choose the health care."

25. Shuck, Peter H. "Rethinking Informed Consent." *Yale Law Journal* 103, no. 899. (1994): 902. Peter Shuck suggests that there is much uncertainty regarding informed consent that three different conceptions of informed consent are identifiable: "The first is the letter and spirit of the

doctrine as developed primarily by courts—the law 'in books.' The second is the doctrine as imagined, feared, and often caricatured by some physicians—the law 'in the mind.' The third version, a consequence both of the gap between the first two and other situational constraints, is the doctrine as actually practiced by clinicians—the law 'in action." He sees the second conception of informed consent as embraced primarily by individuals he characterizes as idealists: "Informed consent idealists—primarily some judges and medical ethicists—advocate a relatively expansive conception of the physician's obligation to disclose information about risks and alternatives. Mores specifically, the idealists tend to define informed consent law's pivotal concepts—materiality of risk, disclosure, alternatives, and causation—broadly and subjectively from the perspective of the individual patient rather than the professional, while defining the law's exceptions narrowly." Conversely, in his view, the third conception of informed consent is favored by individuals he identifies as realists: "The realists—primarily practicing physicians—harbor a different vision of informed consent. Although they emphatically do not contest the principle and goals of informed consent, they do question whether most patients really desire the kind of dialogue that the idealists propose. They also question whether, whatever patients desire, the gains in patient autonomy and improved outcomes produced by the dialogue are worth the additional time, money, and needles patient anxiety and confusion that informed consent may entail."

26. Hall, Bobinski, and Orentlicher, *Bioethics and Public Health Law,* 155, 171. Not surprisingly, the uncertainty as to what constitutes informed consent suggested by Peter Shenk is manifested in the different standards that courts and legislatures have used in applying the principle to the practice of medicine in the United States: Hall, Bobinski, and Orentlicher

identify four different ways that courts and legislatures have applied the informed consent principle: “Some jurisdictions, a majority in fact, use some version of a ‘professional malpractice’ standard, under which physicians are required to disclose to patients that information which would have been disclosed by the reasonable, minimally competent physician. A growing number of states use the ‘material risk’ or ‘reasonable patient’ standard, which require disclosure of risks that a reasonable patient would consider to be material in making a medical treatment decision. A small number of jurisdictions take an even more protective approach, requiring disclosure of information that a particular patient (as contrasted with a ‘rational’ patient) would have wanted to make a decision. Finally, courts seeking tools to regulate the nature of the physician-patient relationship have recently turned to fiduciary law as a source of additional disclosure obligations for physicians.” Nevertheless, and perhaps in response to the claim by physicians that the lived reality of informed consent is vastly different than its “ivory tower” conceptualization, Hall, Bobinski, and Orentilicher claim that there are five limitations to a doctor’s duty to provide information to his/her patients that at least in some instances have been applied by American courts. These include “Common knowledge, Patient knowledge, Emergencies (There is no duty to disclose information in an emergency situation where the patient is not competent, immediate treatment is required to prevent more serious harm, and no substitute decision maker is available), Therapeutic privilege (There is no duty to disclose information where the disclosure process would ‘foreclose rational decision’ or ‘pose psychological damage’ to the patient), and Waiver.” To these five limitations, Hall, Bobinski, and Orentilicher arguably add a sixth, claiming that a“physician discharges the duty [to disclose information to a pateint] when he makes a reasonable effort to convey sufficient information although the patient, without fault of the physician, may not fully grasp it.”

27. Marson, Schmitt, Ingram, and Harrell, “Determining the Competency,” 6. Marson, Schmitt, Ingram, and Harrell suggest that there are a number of legal standards for assessing decisional capacity to give informed consent, including: “(1) [t]he capacity to ‘evidence a treatment choice (this standard focuses on the presence or absence of a decision, and not on the quality of the decision; (2) [t]he capacity to make the ‘reasonable’ choice (this standard emphasizes outcome rather than the mere fact of a decision or how it has been reached. The patient who fails to make a decision that is roughly congruent with the decision that a ‘reasonable’ person in like circumstance would make is viewed as incompetent; (3) [t]he capacity to ‘appreciate’ emotionally and cognitively the consequences of a treatment choice (this standard emphasizes the patient’s awareness of the consequences of a treatment decision: its emotional impact, rational requirements, and future consequences; (4) [t]he capacity to make a treatment choice based on ‘rational’ reasons (this standard tests the capacity to use logical processes to compare the benefits and risks of various treatment options and weigh this information to reach a decision; and (5) [t]he capacity to make a choice based on an ‘understanding’ of the treatment situation and alternatives (this standard requires memory for words, phrases, ideas, and sequences of information, and also comprehension of the fundamental meaning of information about treatment.”

28. Arthur Derse, “Limitation of Treatment,” 225. Arthur. Arthur Derse proposes a slightly different standard for determining decisional capacity to give informed consent: “(1) The patient must possess the ability to comprehend the information about the medical problem and appreciate the impact of the disease and the consequences of various options for treatment,

including forgoing treatment (2) the patient must possess the ability to evaluate the options by comparing the risks and benefits of each option, to deliberate in accordance with the patient's own values, and to make choices that are not irrational. The patient should be able to maintain a consistent choice over time; and (3) the patient should be able to communicate his or her own choice."

29. Hastings Center, *Hastings Center Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying*. 130, 132, 133.

The Hastings Center Guidelines define decision-making capacity as " (a) the ability to comprehend information relevant to the decision; (b) the ability to deliberate about the choices in accordance with personal values and goals; and (c) the ability to communicate (verbally or non verbally) with caregivers." The Hastings Center notes, however, the differences in applicable standards and chooses to group them under three different classifications: "A number of different and competing standards [to use in determining capacity] have been proposed. The key alternatives are: (1) the *outcome standard* in which capacity is judged solely by the content and consequences of the patient's treatment choice; (2) a *status or category standard* in which all patients with certain characteristics (retarded people and minors, for example) are automatically judged to lack decision-making capacity; and (3) a *process standard* in which capacity is determined by assessing the patient's exercise of particular abilities in the decision-making process. We believe the process standard should be used in determining capacity. This standard is the most flexible and sensitive to each patient's circumstances, and strikes the most reasonable balance between the patient's autonomy and well being." "The more harmful to the patient his or her choice seems to be, the higher level of capacity required and the greater the level of certainty

the professional should have about the assessment of capacity."

30. Norman Cantor, *Advance Directives and the Pursuit,* 76. Norman Cantor points out the possibility, however remote, that a written statement expressing an individual's medical treatment preferences can be deemed to have been revoked if sufficiently persuasive evidence is adduced that he/she had changed his/her mind before decisional capacity was lost and the statement became presumably effective: "Consideration of a declarant's post-directive statements may even, in rare instances, curtail reliance on the advance directive document. A person's values or perspectives may change over time, and the declarant may have altered or contradicted the original directive, even without formally revoking it. Statutes relating both to living wills and durable power of attorney commonly recognize this possibility by providing for revocation of the relevant directive by any expression 'evidencing an intent to revoke the document. . . In other words, revocation of an advance directive can occur without the formality usually demanded for the original creation of the document. This liberal approach to revocation is grounded on the common policy favoring preservation of life. Legislators apparently anticipated a situation where a declarant would repudiate his or her original life-relinquishing inclinations upon being confronted with some real life-threatening prospects. Though allowance of informal revocation might tempt some of the declarant's family to invent conversations, the strong public policy favoring preservation of life warrants the risk involved."

References

Alzheimer's Association of Greater Illinois. "Encouraging Comfort Care: A Guide for Families of People with Dementia Living in Care Facilities." 2010.

Alzheimer's Association. "Treatments for Behavior." http://www.alz.org/alzheimers_disease_treatments_for_behavior.asp (accessed on December 8, 2011).

Amella, Elaine J. "Decision Making for Tube Feeding In Dementia: When Evidence Becomes Paramount." *Journal of Clinical Nursing* 12, no. 6 (November 2003): 793-795.

American Gastroenterological Association: "American Gastroenterological Association Technical Review on Tube Feeding for Enteral Nutrition." *Gastroenterology* 108, no. 4 (April 1995): 1282-1301.

American Association for Geriatric Psychiatry, American Alzheimer's Association. and the American Geriatrics Society. "Consensus Statement: Diagnosis and Treatment of Alzheimer's Disease and Related Disorders." *JAMA* 278, no. 16 (October 22, 1997): 1363-71.

Annas, George J., and Leonard H. Glantz. "The Right of Elderly People to Refuse Life-sustaining Treatment." *Milbank Quarterly* 64, Supp. 2 (1986): 95-162.

Asch, Arienne." Recognizing Death while Affirming Life: Can End-of-Life Reform Uphold a Disabled Person's Interest in Continued Life?" *Hastings Center Report* 35, no. 6 (November/December, 2005): S31-S36.

Berghmans, Ron. "Advance Directives and Dementia." In *Medical Ethics at the Dawn of the 21st Century*, edited by Raphael Cohen-Almagor, 105-110. New York, NY: New York Academy of Sciences, 2000.

Berkman, John. “Medically Assisted Nutrition and Hydration in Medicine and Moral Theology.” In *Medicine, Health Care and Ethics: Catholic Voices, edited by* John F. Morris, 143-72. Washington, DC: Catholic University of America, 2007.

Bernat, James. L. “Ethical Issues in the Care of the Patient with Dementia.” In *Handbook of Clinical Neurology*, edited by Michael J. Aminoff, Francois Boller, and Dick F. Swaab, 121-36. Edinburgh, Scotland: Elsevier, 2008.

-------. *Ethical Issues in Neurology.* Philadelphia, PA: Wolters Kluwer, 1994.

Billings, J. Andrew. “Comfort Measures for the Terminally Ill: Is Dehydration Painful?” *Journal of the American Geriatrics Society* 33, no. 11 (November 1985): 808-810.

Blass, John P. “Metabolism and Alzheimer’s Disease.” In *Alzheimer’s Disease: A Physician’s Guide to Practical Management,* edited by Ralph W. and Brigitte Zoeller Richter, 39-47. Totowa, NJ: Humana Press, 2004.

Bluestein, Jeffrey “Choosing for Others.” *Journal of Law, Medicine, and Ethics* 27, no. 1 (Spring 1999).

Boettger, Soenke, Steven Passik, and William Breitbart. “Delirium Superimposed on Dementia Versus Delirium in the Absence of Dementia: Phenomenological Differences.” *Palliative and Supportive Care* 7, no. 4 (December 2009): 495-500.

Brody, Howard, Laura D. Hermer, Larrry D. Scott, L. Lee Grumbles, Julie Kutac and Susan D. McGammon. Unpublished first rough draft of article that was later published as “Artificial Nutrtion and Hydration: The Evolution of Ethics, Evidence and Policy.” *Journal of General Internal Medicine* 26, no. 9 (September 2011): 1053-8.

Brooker, Stephen. “Dehydration Before Death.” *Nursing Times* 88, no. 2 (January 8, 1992): 59-62.

Buchanan A. ”Advance Directives and the Personal Identity Problem.” *Philosophy and Public Affairs* 17, no. 4 (Fall 1988): 277-302.

Buchanan, Allen, and Dan W. Brock. “Deciding For Others.” *Milbank Quarterly* 64, Supp. 2 (1986): 17-94.

------. *Deciding For Others: The Ethics of Surrogate Decision Making.* New York, NY: Cambridge University Press, 1989.

------. “Deciding For Others: Competency” In *Ethical Issues in Modern Medicine,* edited by Bonnie Steinbock, John D. Arras, and Alex John London, 290-301. New York, NY: McGraw Hill, 2003.

Buff, Daniel. “Against the Flow: Tube Feeding and Survival in Patients with Dementia.”

Quarterly Newsletter of the American Academy of Hospice and Palliative Medicine 7, no. 1 (Spring 2006): 1-4.

Burt, Robert A. "The End of Autonomy, Improving End-of-Life Care: Why Has It Been So Difficult?" *Hastings Center Report* 35, no. 6 (November/December 2005): S9.

California Workshop on Guidelines for Alzheimer's Disease Management. *Guidelines for Alzheimer's Disease Management: Final Report* (April 2008) http://www.caalz.org/PDF_files/Guideline-FullReport-CA.pdf (accessed on December 10, 2011)

Callahan, Daniel. "The Sanctity of Life Seduced: A Symposium on Medical Ethics." *First Things* 42 (April 1994): 13-27.

Cantor, Norman. "*Advance Directives and the Pursuit of Death with Dignity.* Bloomington, IN: Indiana University Press, 1993.

Caselli, Richard J., Thomas G. Beach, Roy Yaari, and Eric M. Reiman. "Alzheimer's Disease a Century Later." *Journal of Clinical Psychiatry* 67, no. 11 (November 2006):1784-2000.

Chan, Ho Mun. "Sharing Death and Dying: Advance Directives, Autonomy and the Family." *Bioethics* 18, no. 2 (April 2004): 87-103.

Chen, Jen-Hau, Jennifer L. Lamberg, Yen-Ching Chen, Dan K. Kiely, and John K. Paige, et. al. "Occurrence and Treatment of Suspected Pneumonia in Long-Term Care Residents Dying With Advanced Dementia." *Journal of the American Geriatrics Society* 54, no. 2 (February 2006): 290-295.

Chouinard, Jean. "Dysphasia in Alzheimer's Disease." *Journal of Nutrition, Health, and Aging.* 4, no. 4 (2000): 214-217.

Chui, T.Y., W.Y. Hu, B.H. Lue, S.Y. Cheng, and C.Y, Chen. "Sedation for Refractory Symptoms of Terminal Cancer Patients in Taiwan." *Journal of Pain and Symptom Management* 21, no. 6 (June 2001): 467-472.

Cowan, J.D., and T.W. Palmer. "Practical Guide to Palliative Sedation." *Current Oncology Reports* 4, no. 3 (May 2002): 242-249.

Cranford, Ronald E., and Raymond Gensinger. "Hospital Policy on Terminal Sedation and Euthanasia." *HEC Forum* 14, no. 3 (September 2002): 259-264.

Dash, Paul, and Nicole Villermarette-Pittman, *Alzheimer's Disease*. New York, NY: Demos Medical Publishing, 2005.

Davis J. K. "The Concept of Precedent Autonomy." *Bioethics* 16, no. 2 (April 2002): 114-133.

Davis, John B., C. Bountra and J. Richardson. “Perspectives of Alzheimer’s Disease Treatments.” In *Handbook of Clinical Neurology*, edited by Michael J. Aminoff, Francois Boller, and Dick F. Swaab, 273-290. Edinburgh, Scotland: Elsevier, 2008.

deBeaufort, Inez. “The View from Before.” *American Journal of Bioethics* 7, no. 4 (April 2007): 58-60.

DeLegge, Mark H. “Percutaneous Endoscopic Gastronomy in the Dementia Patient: Helpful or Hindering?” *American Journal of Gastroenterology* (April 2008): 1018-1020.

Demaret, Kent. “For Patients Who Can’t Eat, Dr. Stanley Dudrick’s Intravenous Feeding System.” http:www.people.com/people/archive/article/0,,20071854,00.html (accessed on April 1, 2011).

DePaso, William J. “Aspiration Pneumonia.” *Clinics in Chest Medicine* 12, no. 2 (June 1991): 269-281.

Derse, Arthur. “Limitation of Treatment at the End-of-Life: Withholding and Withdrawal.” *Clinics in Geriatric Medicine* 21, no. 1 (February 2005): 223-228.

Desai, Abhilash, and George T. Grossberg. “Diagnosis and Treatment of Alzheimer’s Disease.” *Neurology* 64, no. 12 (Supp. 3 (June 28, 2005): S34-S39.

Detweiler, Mark B., Kye Y. Kim, and Jim Bass. “Percutaneous Endoscopic Gastronomy in Cognitively Impaired Older Adults: A Geropsychiatric Perspective.” *American Journal of Alzheimer’s Disease and Other Dementias* 19, no. 1 (January/February 2004): 24-30.

Dharmarajan, T.S., D. Unnikrishman, and C. S. Pitchumoni. “Percutaneous Endoscopic Gastrostomy and Outcome in Dementia.” *American Journal of Gastroenterology* 96, no. 9 (September 2001): 2557-2563.

Drachman, David A., Robert P. Friedland, Eric P. Larson, and Mark E. Williams. “Making Sure It’s Really Alzheimer’s.” *Patient Care* 25, no. 18 (November 15, 1991): 13-30.

Dresser, Rebecca. “Advance Directives.” *Hastings Center Report* 24, no. 6 (November/December 1994): S2-S6.

-------. “Dworkin on Dementia.” *Hastings Center Report* 25, no. 6 (November/December 1995): 32-39.

-------. “Life, Death, and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law.” *Arizona Law Review* 28, no. 3 (1986): *373*-405.

-------. "Pre-commitment: A Misguided Strategy for Securing Death with Dignity." *Texas Law Review* 81, no. 7 (June 2003): 1823-1847.

Dresser, Rebecca, and Alan B. Astrow. "An Alert and Incompetent Self." *Hastings Center Report* 28, no. 1 (January/February 1998): 28-31.

Dresser, Rebecca, and John A. Robertson. "Quality-of-Life and Non-Treatment Decisions for Incompetent Patients: A Critique of the Orthodox Approach." *Law, Medicine and Health Care* 17, no. 3 (September 1989): 234-244.

Dworkin, Ronald.. "Autonomy and the Demented Self." *Milbank Quarterly* 64, Supp. 2 (1986): 4-16.

-------. *Life's Dominion: An Argument about Abortion, Euthanasia, and Individual Freedom.* New York, NY: Random House, 1993.

Ellershaw, John E., Jane M. Sutcliffe, and Cicely M. Saunders. "Dehydration and the Dying Patient." Journal of Pain and Symptom Management 10, no. 3 (April 1995): 192-197.

Evans, Lois K., and Neville E. Strumpf. "Tying Down the Elderly: A Review of the Literature on Physical Restraint" *Journal of the American Geriatrics Society* 37, no. 1 (January 1989): 65-74.

Fainsinger, Robin L., and Eduardo Bruera. "When to Treat Dehydration in a Terminally Ill Patient." *Support Care Cancer* 5, no. 3 (May 1977): 205-211.

Feinberg, Michael J., Janice Knebl, and Joann Tully. "Prandial Aspiration and Pneumonia in an Elderly Population Followed Over 3 Years." *Dysphagia* 11, no. 2 (March 1996): 104-109.

Filene, Peter G. *Into the Arms of Others: A Cultural History of the Right-to-Die in America.* Chicago, IL: Ivan R. Dee, 1998.

Flynn, Eileen P. *Hard Decisions: Foregoing and Withdrawing Artificial Nutrition and Hydration.* Kansas City, KS: Sheet and Ward, 1996.

-------. *Issues in Health Care Ethics*. Upper Saddle River, NJ: Prentice Hall, 2000.

Foley, Joseph M. "The Experience of Being Demented." In *Dementia and Aging: Ethics, Values, and Policy Choices,* edited by Robert H. Binstock, Stephen G. Post, and Peter J. Whitehouse, 30-43. Baltimore, MD: John Hopkins Press, 1992.

Frierson, Richard L., and Katherine A. Jacoby. "Legal Aspects of Dementia." In *Handbook of Clinical Neurology*, edited by Michael J. Aminoff, Francois Boller, and Dick F. Swaab, 113-119. Edinburgh, Scotland: Elsevier, 2008.

Article IV. Galasko, Douglas. “New Approaches to Diagnose and Treat Alzheimer’s Disease: A Glimpse of
Article V. the Future.” *Clinics in Geriatric Medicine* 17, no. 2 (May 2001): 393-410.

Article VI. Ganzini, Linda, Elizabeth R. Goy, Lois I. Miller, Theresa A. Harvath, and Ann Jackson, et. al. “Nurses’ Experiences with Hospice Patients Who Refuse Food and Fluids to Hasten Death.” *New England Journal of Medicine* 349, no. 4 (July 24, 2003): 359-366.

Gill, Carol J. “Depolarizing and Complicating the Ethics of Treatment Decision Making in Brain Injury: A Disability Rights Response to Nelson and Frader.” *Journal of Clinical Ethics* 15, no. 4 (Winter 2004): 277-288.

Gillick, Muriel R.. “Artificial Nutrition and Hydration in the Patient with Advanced Dementia: Is Withholding Treatment Compatible with Traditional Judaism.” *Journal of Medical Ethics* 27, no. 1 (February 2001): 12-15.

-------. “Facing Eating Difficulties in End-Stage Dementia.” *Alzheimer’s Care Quarterly* 3, no. 3 (Summer 2002): 227-232.

-------. “Rethinking the Role of Tube Feeding in Patients with Advanced Dementia.” *New England Journal of Medicine* 342, no. 3 (January 20, 2000): 206-210.

Gillick, Muriel R., and Angelo E. Volandes. “The Standard of Caring: Why Do We Still Use Feeding Tubes in Patients with Advanced Dementia.” *Journal of the American Medical Directors Association* 9, no. 5 (June 2008): 364-367.

Glickstein, Joan K. *Therapeutic Interventions in Alzheimer’s Disease*. Gaithersburg, MD: Aspen Publishers, 1997.

Gomez-Isla, Teresa, Tara Spies, Alix De Calignon and Bradley T. Hyman. “Neuropathology of Alzheimer’s Disease.” In *Handbook of Clinical Neurology*, edited by Michael J. Aminoff, Francois Boller, and Dick F. Swaab, 233-43. Edinburgh, Scotland: Elsevier, 2008.

Hall, Mark A., Mary Anne Bobinski, and David Orentlicher. *Bioethics and Public Health Law.* New York, NY: Aspen Publishers, 2005.

Harding, Anne, “Diabetes Doubles Alzheimer’s Risk.” http://health.yahoo.net/articles/alzheimers/diabetes-doubles-alzheimers (accessed on October, 30, 2011).

Harkness, Laura. “The History of Enteral Nutrition Therapy: From Raw Eggs and Nasal Tubes to Purified Amino Acids and Early Postoperative Jejunal Delivery.” *Journal of the American Dietetic Association* 102, no. 3 (March 2002):399-404.

Harvey M. “Advance Directives and the Severely Demented.” *Journal of Medicine and Philosophy* 31, no.1 (February 2006): 47-64

Hastings Center. *Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying.* Briarcliff Manor, NY: Hastings Center, 1987.

-------. “Quality of Life.” in *Quality of Life: The New Medical Dilemma*, edited by James J. Walter and Thomas A. Shannon, 325-6. New York, NY: Paulist Press, 1990.

Henderson, Cynthia T, Linda S. Trumbore, Sohrab Mobarhan, Richard Benya, et. al. “Prolonged Tube Feeding in Long-Term Care: Nutritional Status and Clinical Outcomes.” *Journal of the American College of Nutrition* 11, no. 3 (1992): 309-25.

Hickman, Susan E., Bernard J. Hammes, Susan W. Tolle, Alvin H. Moss, Fagerlin and Schneider.” A Viable Alternative to Traditional Living Wills.” *The Hastings Center Report* 34, no. 5 (September/October 2004): 4-7.

Hickman, Susan E., Bernard J. Hammes, Alvin H. Moss, and Susan W. Tolle. ”Hope for the Future: Achieving the Original Intent of Advance Directives.” *Hastings Center Report* 35, no. 6 (November/December 2005): S26-S31.

Hoefler, James M. “Making Decisions about Tube Feeding For Severely Demented Patients at the End of Life: Clinical, Legal, and Ethical Considerations.” *Death Studies* 24, no. 3 (April/May 2000): 233-254.

Holm S. ”Autonomy, Authenticity, or Best Interest: Everyday Decision-making and Persons with Dementia.” *Medicine Health Care and Philosophy* 4, no. 2. (2001): 153-159.

Horner, Jennifer, Mark J. Alberts, Deborah V. Dawson, and Gail M. Cook. “Swallowing in Alzheimer’s Disease.” *Alzheimer’s Disease and Associated Disorders* 8, no. 3 (Fall 1994): 177-189.

Howland, John S. “A Defense of Assisted Nutrition and Hydration in Patients with Dementia.” *National Catholic Bioethics Quarterly* 9, no. 4 (Winter 2009): 697-710.

Humbert, Ianessa A., Donald G. McLaren, Kris Kosmatka, and Michelle Fitzgerald, et. al. “Early Deficits in Cortical Control of Swallowing in Alzheimer’s Disease.” *Journal of Alzheimer’s Disease* 19, no. 4 (January 2010): 1185-1197.

Hurley, Ann C., and Ladislav Volicer. “Alzheimer’s Disease: It’s Okay, Mama, If You Want to Go, It’s Okay.” *JAMA* 288, no. 18 (November 2002): 2324-2331.

Huxley, Eliot J., Jose Viroslav, William R. Gray, and Alan K. Pierce. “Pharyngeal Aspiration in Normal Adults and Patients with Depressed Consciousness.” *American Journal of Medicine* 64, no. 4 (April 1978): 564-8.

Jaworska A. “Respecting the Margins of Agency: Alzheimer’s Patients and the Capacity to Value.” *Philosophy and Public Affairs*. 28, no. 2 (Spring 1999):105-138.

Jennings, Bruce. “Autonomy” In *The Oxford Handbook of Bioethics.* Edited byBonnie Steinbock 72-89. Oxford, UK: Oxford University Press, 2007.

Jequier, E., and F. Constant. “Water as an Essential Nutrient: The Physiological Basis of Hydration.” *European Journal of Clinical Nutrition* 64, no. 2 (February 2010): 115-123.

Kadish, Sanford H. “Letting Patients Die: Legal and Moral Implications.” *California Law Review* 80, no. 4 (July 1992): 857-888.

Katzman, Robert. “Current Research on Alzheimer’s Disease in a Historical Perspective.” In. *Alzheimer’s Disease:Cause(s), Diagnosis, Treatment, and Care.* edited by Zaven S Khachaturian and Teresa S. Radebaugh, 15-30. Boca Raton, Fl: CRC Press, 1996.

Kelly, David F. *Contemporary Catholic Health Care Ethics.* Washington, DC: Georgetown University Press, 2004.

------. *Medical Care at the End of Life: A Catholic Perspective.* Washington, DC: Georgetown University Press, 2006.

Khachaturian, Zaven S. and Teresa S. Radebaugh, eds. *Alzheimer’s Disease: Cause(s), Diagnosis, Treatment, and Care.* Boca Raton, FL: CRC Press, 1996.

Kiely, Dan K., Jane L. Givens, Michelle L. Shaffer, Joan M. Teno, and Susan L. Mitchell. “Hospice Use and Outcomes in Nursing Home Residents with Advanced Dementia.” *Journal of the American Geriatrics Society* 58, no. 10 (December 2010): 2284-2291.

King, Nancy M. P. *Making Sense of Advance Directives*. Boston, MA: Kluwer Academic Publishers, 1991.

-------. *Making Sense of Advance Directives*. Washington, DC: Georgetown University Press, 2007.

Knopman, David S., Bradley F. Boeva, and Ronald C. Petersen. “Essentials of the Proper Diagnoses of Mild Cognitive Impairment, Dementia, and Major Subtypes of Dementia.” *Mayo Clinic Proceedings* 78, no. 10 (October 2003): 1290-1307.

Kolata, Gina. “Alzheimer’s Test Gains Approval of Expert Panel,” *Houston Chronicle*, January 21, 2011.

Kothari, Sunil.”Clincal (Mis)Judgments of Quality of Life after Disability.”*Journal of Clinical Ethics* 15, no. 4 (Winter 2004): 300-307.

Kuhse H. “Some Reflections on the Problem of Advance Directives, Personhood, and Personal Identity.” *Kennedy Institute of Ethics Journal* 9, no. 4 (December 1999): 347-364.

Laino, Charlene “Lifestyle Changes May Prevent Alzheimer’s Disease” http:www.webmd.com/alzheimers/news/20110719/lifestyle-change… (accessed on October 30, 2011).

-------.“New Alzheimer’s Gene Found.” http:www.webmd.com/alzheimers/news/20100414/bew-alzheimes… (accessed on October 30, 2011).

Langamore, Susan E., Margaret S. Terpenning, Anthony Schork, Yinmiao Chen, et. al. “Predictors of Aspiration Pneumonia: How Important is Dysphagia.” *Dysphagia* 13, no. 2 (Spring1998): 69-81.

Levine, Carol. ”The President’s Council on Autonomy: Never Mind!” *Hastings Center Report* 36, no. 3 (May/June, 2006): 46-48.

Luchins, Daniel J. and Patricia Hanrahan. “What is Appropriate Health Care for End-Stage Dementia.” *Journal of the American Geriatrics Society* 41, no. 1 (January 1993): 25-30.

Lynn, Joanne, and James F. Childress. “Must Patients Always Be Given Food and Water?” *Hastings Center Report* 13, no. 5 (October 1983): 17-21.

Lynn, Joanne ed. *By No Extraordinary Means: The Choice to Forgo Life-Sustaining Food and Water*. Bloomington, IN: Indiana University Press, 1986.

Lynch, Maureen. “Palliative Sedation.” *Clinical Journal of Oncology Nursing* 7, no. 6 (May 22, 2003): 653-667.

Major, David. “The Medical Procedures for Providing Food and Water: Indications and Effects.” In *By No Extraordinary Means: The Choice to Forgo Life-Sustaining Food*, edited by Joanne Lynn, *21-8.* Bloomington, IN: Indiana University Press, 1986.

Marik, Paul E. “Aspiration Pneumonitis and Aspiration Pneumonia.” *New England Journal of Medicine* 344, no. 9 (March 1, 2001): 665-671.

-------. “Aspiration Pneumonia and Dysphasia in the Elderly.” *CHEST* 124, no. 1 (July 2003): 328-336.

Marchione, Marilyn.“Falls, Eye Tests May Give Clues to Alzheimer’s” *YAHOO News* http://news.yahoo.com/falls-eye-test-may-clues-alzheimers-0739042 (accessed on October, 10, 2011).

Marson, Daniel C., Frederick A. Schmitt, Kellie K. Ingram, and Lindy E. Harrell. “Determining the Competency of Alzheimer Patients to Consent to Treatment

and Research." *Alzheimer Disease and Associated Disorders* 8, Supp. 4 (Winter 1994): 5-18.

Mayeux, Richard. "Alzheimer's Disease Epidemiology." In *Handbook of Clinical Neurology*, edited by Michael J. Aminoff, Francois Boller, and Dick F. Swaab, 195-202. Edinburgh, Scotland: Elsevier, 2008.

Mayo Clinic Staff. "Alzheimer's Disease." MayoClinic,com http:www.mayoclinic.com/health/alzheimers-genes/AZ00047 (accessed on October, 30, 2011).

McCann, Robert M., William J. Hall, and Annmarie Groth-Juncker. "Comfort Care for Terminally Ill Patients: The Appropriate Use of Nutrition and Hydration." *JAMA* 272, no. 16 (Oct. 26, 1994): 1263-1266.

McClave, Stephen A., Mark T. DeMeo, Mark H. DeLegge, James A. DiSario, Daren K. Heyland, and James P. Maloney, et. al. "North American Summit on Aspiration in the Critically Ill Patient: Consensus Statement." *Journal of Parenteral and Enteral Nutrition* 26, no. 6 Supp. (November 2002): S80-S85.

Medicare. "Long Term Care." http://www.medicare.gov/LongTermCare/Static/ (accessed on December 11, 2011).

-------. "Medicare Hospice Benefits." http://www.medicare.gov/Publications/Pubs/pdf/02154.pdf (accessed on December 11, 2011).

-------. "Paying for Long Term Care." http://www.medicare.gov/LongTermCare/Static/Medicare.asp?dest... (accessed on December 11, 2011).

Meisel, Alan. "Barriers to Forgoing Nutrition and Hydration in Nursing Homes." *American Journal of Law and Medicine* 21, no. 4 (1995): 335-382.

-------. "The Legal Consensus About Forgoing Life-Sustaining Treatment: Its Status and Prospects." *Kennedy Institute of Ethics Journal* 2, no. 4 (March 1992): 309-345.

Menkin, Elizabeth. "Artificial Nutrition and Hydration." *Journal of Palliative Medicine* 7, no. 5 (October 2004): 723-726.

Miller, Ronald D., ed. *Miller's Anesthesia*. Philadelphia, PA: Elsevier/Churchill/Livingstone, 2005.

Mitchell, Susan L. "Extrapyramidal Features in Alzheimer's Disease." *Age and Ageing* 28, no. 4 (July 1999): 401-409.

-------. “A 93-Year-Old Man With Advanced Dementia and Eating Problems.” JAMA 298, no. 21. (Dec. 5, 2007): 2527-2536.

Mitchell, Susan L., Joan M. Teno, Dan K. Kiely, Michelle L. Shaffer, and Richard N. Jones, et. al. “The Clinical Course of Advanced Dementia.” *New England Journal of Medicine* 361, no. 16 (Oct. 15, 2009): 1529-38.

Mitchell, Susan L., J. M Tetroe, A. M. O’Connor, and A. Rostom, et. al. “Making Choices: Long Term Feeding Tube Placement in Elderly Patients.” http://decisionaid.ohri.ca/docs/Tube_Feeding_DA/PDF/TubeFeeding.pdf (accessed on June 15, 2011).

Monias, Anne, and Diane Meier. “Palliative Care in Early, Moderate, and Advanced Dementia.” In *Geriatric Medicine: An Evidence Based Approach*, edited by Christine Cassel, 343-50. New York, NY: Springer, 2003.

Moody, Janis. “Dementia and Personhood: Implications for Advance Directives.” *Nursing Older People* 15, no. 4 (June 2003): 18-22.

Morita, Tatsuya, Junichi Tsunoda, Satoshi Inoue, and Satoshi Chihara.“Effects of High Dose Opiods and Sedatives on Survival in Terminally Ill Cancer Patients.” *Journal of Pain and Symptom Management* 21, no. 4 (April 2001):282-289.

-------. “Perceptions and Decision-Making on Rehydration of Terminally Ill Cancer Patients and Family Members.” *American Journal of Hospice and Palliative Care* 16, no. 3 (May/June 1999): 509-516.

-------“Terminal Sedation for Existential Distress.” *American Journal of Hospice and Palliative Care* 17, no. 3 (May/June 2000):189-195.

Morris, John C. Foreword to *Early Diagnosis of Alzheimer’s Disease*, by Leonard F. M. Scinto, and Kirk R. Daffner. Totowa, NJ: Humana Press, 200.

Morrison, R. Sean, and Albert L. Siu. “Survival in End-Stage Dementia Following Acute Illness.” *JAMA* 284, no. 1 (July 5, 2000): 47-52.

Morita, Tatsuya, Yoshikazu Chinone, Masayuki Ikenaga, Makoto Miyochi, and Toshimichi Nakaho, et. al. “Ethical Validity of Palliative Sedation Therapy: A Multicenter, Prospective,Observational StudyConducted on Specialized Palliative Care Units in Japan.” *Journal of Pain andSymptom Management* 30, no. 4 (October 2005): 308-319.

------- “Sedation in Palliative Care-A Critical Analysis of 7 Years Experience. *BMC Palliative Care* 2, no. 2 (May 13 2003): 1-9.

Murphy, Claire. “Loss of Olfactory Function in Patients with Alzheimer’s Disease.” In

Alzheimer's Disease: A Physician's Guide to Practical Management,. edited by Ralph W. and Brigitte Zoeller Richter, 165-73. Totowa, NJ: Humana Press, 2004.

Murray, Thomas H., And Bruce Jennings. "The Quest to Reform End of Life Care: Rethinking Assumptions and Setting New Directions." *Hastings Center Report* 35, no. 6 (November/December 2005): S52-S57.

National Center for Biotechnology Information. "Gene Tests" http://www.ncbi.nlm.gov/projects/GeneTests/static/about/aboutin... (accessed on December 1, 2011).

National Hospice and Palliative Care Organization. "Caring for Persons With Alzheimer's and Other Dementias." http:www.nhpco.org/files/public/Dementia-Caring Guide-Final.pdf

Nelson, James Lindemann and Joel Frader."Brain Trauma and Surrogate Decision Making: Dogmas, Challenges, and Response." *Journal of Clinical Ethics* 15, no. 4 (Winter 2004): 264-76.

Nelson James Lindemann And Joel Frader. "A Response to Gill" *The Journal of Clinical Ethics* 15, no. 4 (Winter 2004): 289-91.

Nelson, James Lindemann. " Critical Interests and Sources of Familial Decision-Making Authority for Incapacitated Patients." *Journal of Law, Medicine & Ethics*. 23, no. 2 (June 1995): 143-148.

-------"Dementia and Advance Decision Making: Who's Choosing for Whom?" *Alzheimer Disease Associated Disorder* 8, no. 1 (Spring 1994): 3-7.

Oak Ridge National Laboratory. "Human Genome Project Information." http://www.ornl.gov/sci/techresources/Human_Genome/medicine /gen.... (accessed on December 1,2011).

Orr, Robert D. "Just Put Me to Sleep….PLEASE! Ethical Issues in Palliative and 'Terminal' Sedation. *Loma Linda University Center for Christian Bioethics* 18, no. 2 (September 2002): 1-12.

Palecek, Eric J., Joan M. Teno, David J. Casarett, Laura C. Hanson, Ramona Rhodes, and Susan L. Mitchell. "Comfort Feeding Only: A Proposal to Bring Clarity to Decision-Making Regarding Difficulty with Eating for Persons with Advanced Dementia." *Journal of American Geriatrics Society* 58, no. 3 (March 2010): 580-584.

Palmer, Jeffrey B., Jennifer C. Drennan, and Mikoto Bara. "Evaluation and Treatment of Swallowing Impairments." *American Family Physician* 61, no. 8 (April 15, 2000): 2453-2462.

Palmer, Lucy B., Kiram Albulak, Suzanne Fields, and Marie Filkin, et. al. "Oral Clearance

and Pathogenic Oropharyngeal Colonization in the Elderly." *American Journal of Respiratory and Critical Care Medicine* 164, no. 3 (Aug. 1, 2001): 464-468.

Parfit, D. "Personal Identity." *Philosophical Review* 80, no. 1 (January1971): 3-27.

-------. *Reasons and Persons*. New York, NY: Oxford University Press, 1986.

Patient Self-Determination Act of 1990, 42 U.S.C. 1395 cc (a) (1) (Q). (Suppl. 1991).

Pautex, Sophie, Dina Zekry, Gilbert Zulian, Gabriel Gold, and Jean-Pierre Michel. "Pain and Palliative Care in Late Stage Dementia Patients." In *Alzheimer's Disease: A Physician's Guide to Practical Management,* edited by Ralph W. and Brigitte Zoeller Richter, 217-223. Totowa, NJ: Humana Press, 2004.

Pence, Gregory E. *Classic Cases in Medical Ethics*. New York, NY: McGraw Hill Higher Education, 2007.

Percy, Maire. E. "Risk Factors and Biological Consequences." In *Dementia, Aging, and Intellectual Disabilities: A Handbook*, edited by Matthew P. Janicki and Arthur J. Dalton 55-83. Philadelphia, PA: Brunner/Mazel, 1998.

Phillips, Nicole M. Nasogastric Tubes: An Historical Context." *Medsburg Nursing* 15, no. 2 (April 2006): 84-88.

Phillips, Thomas E., Carol J. Cornejo, Eric. K. Hoffer, and Wayne C. McCormick. "Gastronomy and Jejunostomy Placement: The Urban Hospital Perspective Pertinent to Nursing Home Care." *Journal of the American Medical Director's Association* 6, no. 6 (November/December 2005): 390-395.

Post, Stephen G. "Ethics and Dementia: Current Issues. Alzheimer Disease and Physician-Assisted Suicide." *Alzheimer's Disease and Associated Disorders* 7, no. 2 (Summer 1993): 65-68.

-------. "Alzheimer's Disease: Ethics and the Progression of Dementia." *Clinics in Geriatric Medicine* 10. no. 2 (May 1994): 379-94

-------. "The Fear of Forgetfulness: A Grassroots Approach to the Ethics of Alzheimer's Disease." *Journal of Clinical Ethics* 9, no. 1 (Spring 1998): 71-80.

-------. "Key Issues in the Ethics of Dementia Care." *Neurologic Clinics*. 18, no. 4 (November 2000):1011-1022.

-------. *The Moral Challenge of Alzheimer's Disease*. Baltimore, MD: John Hopkins University Press, 2000.

-------. “Tube Feeding and Advanced Progressive Dementia.” *Hastings Center Report* 31, no. 1 (January/February 2001): 36-42.

-------. “Nutrition, Hydration, and the Demented Elderly.” *Journal of Medical Humanities* 11 (1990): 185.

Pratico, Domenico. “Oxidative Stress in the Development of Alzheimer’s Disease and other Dementias.” In *Alzheimer’s Disease: A Physician’s Guide to Practical Management,* edited by Ralph W. and Brigitte Zoeller Richter, 33-38. Totowa, NJ: Humana Press, 2004.

President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. *Deciding to Forego Life-Sustaining Treatment*: *Ethical, Medical, and Legal Issues in Treatment Decisions.* Washington, DC: U. S. Government Printing Office, 1983.

President’s Council on Bioethics. *Taking Care: Ethical Care Giving in Our Aging Society.* http://bioethics.gov/Reports/taking_care/index.html (accessed on May 10, 2009

Printz, Louise A. “Withholding Hydration in the Terminally Ill: Is it Valid?” *Geriatric Medicine* 337, no. 24 (November1989): 1768-1771.

--------. “Terminal Dehydration, a Compassionate Treatment.” *Archives of Internal Medicine* 152, (1999): 697-700.

-------. “Is Withholding Hydration a Valid Comfort Measure in the Terminally Ill.?” *Geriatrics* 43, no. 11 (November 1988): 84-88.

Quante, Michael. ”Precedent Autonomy and Personal Identity.” *Kennedy Institute of Ethics Journal* 9, no. 4 (December 1999):365-381.

Quill. Timothy E., and Ira R. Brock for the ACP-ASIM End of Life Care Consensus Panel. “Responding to Intractable Suffering: The Role of Terminal Sedation and Voluntary Refusal of Food and Fluids.” *Annals of Internal Medicine* 132, no. 5 (March 7, 2000): 408-414.

Rabins, Peter V. “Dementia and Alzheimer’s Disease: An Overview.” *Georgia Law Review* 35 No. 1 (Winter 2001): 451-464.

Rhoden, Nancy. K. “Litigating Life and Death.” *Harvard Law Review* 102, no. 2 (December 1988): 375-406.

Rich, Ben A. “Advance Directives: The Next Generation.” In *Contemporary Issues in Bioethics*, edited by Tom L. Beauchamp and LeRoy Walters, 171-8. Belmont, CA: Wordsworth-Thompson Learning, 2003.

------- ”Personhood, Patienthood, and Clinical Practice: Reassessing Advance Directives.“ *Psychology Public Policy and Law* 4, no. 3 (September 1998):61.

-------. ”Prospective Autonomy and Critical interests: a Narrative Defense of the Moral Authority of Advance Directives.” *Cambridge Quarterly of Health Ethics* 6, no. 2 (Spring1997): 138-147.

Richter, Ralph W., and Brigitte Zoeller Richter, eds. *Alzheimer's Disease: A Physician's Guide to Practical Management.* Totowa, NJ: Humana Press, 2004.

-------. “Alzheimer Disease: Epidemiological and Statistical Data.” In *Alzheimer's Disease: A Physician's Guide to Practical Management,* edited by Ralph W. and Brigitte Zoeller Richter, 51-56. Totowa, NJ: Humana Press, 2004.

--------. “Treatment of Alzheimer's Disease: Basic Considerations.” In *Alzheimer's Disease: A Physician's Guide to Practical Management,* edited by Ralph W. and Brigitte Zoeller Richter, 177-8. Totowa, NJ: Humana Press, 2004.

Richter, Ralph W. “Medical Diagnosis and Workup of Alzheimer's Disease.” In *Alzheimer's Disease: A Physician's Guide to Practical Management,* edited by Ralph W. and Brigitte Zoeller Richter, 75-87. Totowa, NJ: Humana Press, 2004.

Ripich, D and M. Wykle “Developing Health Care Professionals' Communication Skills with Alzheimer's Disease Patients. Paper presented at the annual meeting of the American Society on Aging, San Francisco.

Rolls, B. J. and T. M. McDermott. “Effects of Age on Sensory-Specific Satiety.” *American Journal of Clinical Nutrition* 54, no. 6 (1991): 988-96.

Rousseau, Paul C. “Existential Distress and Palliative Sedation.” *Anesthesia and Analgesia* 101, no. 2 (August 2005): 611-612.

-------“Terminal Sedation in the Care of Dying Patients.” *Archives of Internal Medicine* 156, no. 16 (September 9, 1996): 1785-1786.

Ryan, Christopher James “Betting Your Life.” *Journal of Medical Ethics* 22, no. 2 (April 1996): 95-99.

Sachs, Greg A., Joseph W. Shega, and Deon Cox-Hayley. “Barriers to Excellent End-of-life Care for Patients with Dementia.” *Journal of General Internal Medicine* 19, no. 10 (October 2004): 1057-63.

Sachs, Greg A., and Christine K. Cassell. “Ethical Aspects of Dementia.” *Ethical Issues in Neurological Practice. Neurologic Clinics* 7, no. 4 (1989): 845-858.

Sanders, Alan. “The Clinical Reality of Artificial Nutrition and Hydration for Patients at the

End of Life." *National Catholic Bioethics Quarterly* 9, no. 2 (Summer 2009): 293-304.

Schmitz, Phyllis and Merry O'Brien. "Observation on Nutrition and Hydration in Dying Cancer Patients." In *By No Extraordinary Means: the Choice to Forego Life-Sustaining Food and Water*, edited by Joanne Lynn, 29-38. Bloomington, IN: Indiana University Press, 1989.

Schultz, Christian, Kelly Del Tredici, and Heiko Braak. "Neuropathology of Alzheimer's Disease." In *Alzheimer's Disease: A Physician's Guide to Practical Management*, edited by Ralph W. and Brigitte Zoeller Richter, 21-32. Totowa, NJ: Humana Press, 2004.

Schuster, John L. "Palliative Care for Advanced Dementia." *Clinics in Geriatric Medicine* 16, no. 2 (May 2000): 373-386.

Schwarz, Judith. "Exploring the Option of Voluntarily Stopping Eating and Drinking Within the Context of a Suffering Patient's Request for a Hastened Death." *Journal of Palliative Medicine* 10, no. 6 (2007): 1288-97.

Scinto, Leonard F. M., and Kirk R. Daffner. *Early Diagnosis of Alzheimer's Disease.* Totowa, NJ: Humana Press, 2000.

Selkoe. Dennis J. "Biochemistry and Molecular Biology of Amyloid Beta-protein and the Mechanism of Alzheimer's Disease." In *Handbook of ClinicalNeurology*, edited by Michael J. Aminoff, Francois Boller, and Dick F. Swaab, 245-60. Edinburgh, Scotland: Elsevier, 2008.

Sieger, Carol E., Jason F. Arnold, and Judith C. Ahronheim. "Refusing Artificial Nutrition and Hydration: Does Statutory Law Send the Wrong Message" *Journal of the American Geriatrics Society* 50, no. 3 (April 2002): 544-550.

Simard, Joyce, and Ladislav Volicer. "Barriers to Providing Hospice Care for People with Dementia/" 231-46. In *Hospice Care for Patients with Advanced Progressive Dementia*, edited by Ladislav Volicer and Ann Hurley, 231-46. New York, NY: Springer, 1998.

Smith, Karen L., and Carol E. Greenwood. "Weight Loss and Nutritional Considerations in Alzheimer Disease." *Journal of Nutrition for the Elderly* 27, no. 3-4 (2008): 381-403.

Steiger, Ezra. "Tools for Living Better on Home IV and Tube Feedings." http: www.oley.org/lifetime/95-052.html (accessed December, 10, 2010).

Sullivan, Robert J. "Accepting Death Without Artificial Nutrition and Hydration." *Journal of General Internal Medicine* 8, no. 4 (April 1993):220-224.

Sutcliffe, Jayne. "Terminal Dehydration." *Nursing Times* 90, no. 6 (February 1994):

61-3.

Sykes, Nigel, and Andrew Thorns. “Sedative Use in the Last Week of Life and the Implications for End of Life Decision Making.: *Archive of Internal Medicine* 163, no. 3 (February 10, 2003): 341-344.

-------. “The Use of Opiods and Sedatives at the End of Life.” *Lancet Oncology* 4, no. 5 (May 2003): 312-318.

ten Have, Henk A. M. J., and Ruth B. Purtilo. “Historical Overview of a Current Global Challenge.” in Purtilo, Ruth B. and Henk A.M.J. ten Have, editors. In *Ethical Foundations of Palliative Care for Alzheimer’s Disease*, edited by Ruth B. Purtilo and Henk A.M.J. ten Have. Baltimore, MD: Johns Hopkins University Press, 2004.

Terman, Stanley A. *The Best Way to Say Goodbye: A Legal Peaceful Choice at the End of Life.* Carlsbad, CA: Life Transitions Publications, 2007.

-------.“Determining the Decision-Making Capacity of a Patient Who Refused Food and Water.” *Palliative Medicine* 15, no. 1 (January 2001): 55-60.

Thomas, David R. “Improving Outcome of Pressure Ulcers with Nutritional Interventions: A Review of the Evidence.” *Nutrition* 17, no. 2 (February 2001): 121-5.

Torack, Richard M. “The Early History of Senile Dementia.” In *Alzheimer’s Disease*, edited by Barry Reisberg, 23-8. New York, NY: Free Press, 1983.

Vaux, Kenneth L. *Death Ethics: Religious and Cultural Values in Prolonging and Ending Life.* Philadelphia, PA: Trinity Press International, 1992.

Ventafridda, V., C. Ripamonti, F. DeConno, M. Tamburini and B.R. Cassileth. “Symptom Prevalence and Control During Cancer Patient’s Last Days of Life.’ *Journal of Palliative Care* 6, no. 3 (Autumn 1990): 7-11.

Vitale, Caroline, Tad Hiner, Wayne A. Ury, Cathy S. Berkman, and Judith C. Ahronheim. “Tube Feeding in Advanced Dementia: An Exploratory Survey of Physician Knowledge.” *Care Management Journals* 7, no. 2 (Summer 2006):79-85.

Vitetta, Luis, David Kenner, and Avni Sali. “Sedation and Analgesia-Prescribing Patterns in Terminally Ill Patients at the End of Life.” *American Journal of Hospice and Palliative Care* 22, no. 6 (November /December 2005): 465-473.

Volicer, Ladislav. “Alzheimer’s Disease and Dementia: Management of Severe Alzheimer’s Disease and End-Of-Life Issues.” *Clinics in Geriatric Medicine* 17, no. 2 (May 2001): 377-91.

-------. “Palliative Medicine in Dementia.” In *Oxford Textbook of Palliative Medicine*, edited

by Geoffrey Hanks, Nathan I. Cherney, Nicholas A. Christakis, and Marie Falton, et. al, 1375- 85. Oxford, England: Oxford University Press, 2010.

-------. "Impact of Special Care Unit for Patients With Advanced Alzheimer's Disease on Patient's Discomfort and Costs." *American Geriatric Society* 2 (1994): 597-603).

Volicer, Ladislav, Bemjamin Seltzer, Yvette Rheaume, Kathy Fabiszewski, and Lawrence Herz, et, al. "Progression of Alzheimer-Type Dementia in Institutionalized Patients: A Cross-Sectional Study." *Journal of Applied Gerontology* 6, no. 1 (March 1987): 83-94.

Volicer, Ladislav, Yvette Rheaume, June Brown, Kathy Fabiszewski, and Roger Brady. "Hospice Approach to the Treatment of Patients with Advanced Dementia of the Alzheimer's Type." *JAMA* 256, no. 16 (October 24/31 1986):2210-2213.

Volicer, Ladislav, and Ann Hurley. *Hospice Care for Patients with Advanced Progressive Dementia.* New York, NY: Springer, 1998.

Waller, A., M. Bercovitch, and R. Fainsinger et. al. "Symptom Control and the Need for Sedation during Treatment." In *Patient Hospice. Book of Abstracts. 6th Congress of the European Association for Palliative Care*, edited by Tel Hashomer, 21-29. Geneva, Switzerland: Springer, 2000.

Wasson, Katherine, Helen Tate, and Carmel Hayes. "Food Refusal and Dysphagia in Older People With Dementia: Ethical and Practical Issues." *International Journal of Palliative Nursing* 7, no. 10 (October 2001): 465-471.

Webster, Patrick. "Enforcement Problems Arising From Conflicting Views of Living Wills in the Legal, Medical, and Patient Communities." *University of Pittsburg Law Review* 62, no. 4 (Summer 2001): 793-813.

Welie, Joe V.M., and Sander P.K. Welie. "Patient Decision Making Competence: Outlines of a Conceptual Analysis." *Medicine, Healthcare, and Philosophy 4, no. 2* (May 2001): 125-126.

-------. "Is Incompetence the Exception or the Rule." *Medicine, Healthcare and Philosophy 4, no. 2* (May 2001): 127-138.

White, Gregory N., Finian O'Rourke, Bin S. Ong, Dennis Cordato, and Daniel K.Y. Chan. "Dysphagia: Causes, Assessment, Treatment, and Management." *Geriatrics* 63, no. 5 (May 2008): 15-20.

Whitehouse, Peter J. "Conclusion Quality of Life: Future Directions." In *Assessing Quality of Life in Alzheimer's Disease*, edited by Steven M. Albert and Rebecca G. Logsdon, 179-183. New York, NY: Springer Publishing, 2000.

-------. "Dementia: The Medical Perspective." In *Dementia and Aging: Ethics, Values, and*

Policy Choices, edited by Robert H. Binstock, Stephen G. Post, and Peter J. Whitehouse, 21-29. Baltimore, MD: John Hopkins Press, 1992.

-------. "Fairhill Guidelines on Ethics and the Care of People with Alzheimer's Disease." In *The Moral Challenge of Alzheimer's Disease*, edited by Stephen G. Post, 44-65. Baltimore, MD: John Hopkins University Press, 2000.

Whitehouse, Peter J., Konrad Maurer, and Jesse F. Ballenger, eds. *Concepts of Alzheimer's Disease, Biological, Clinical, and Cultural Perspectives.* Baltimore, MD: John Hopkins University Press, 2000.

Williams, Elizabeth A. "Gags, Funnels, and Tubes: Forced Feeding of the Insane and Suffragettes." *Endeavour* 32, no. 4 (December 2008): 134-40.

Winakur, Jerald. "What Are We Going to Do With Dad." *Health Affairs* 24 no. 4 (July/August 2005): 1064-72

Yahoo News, "New Alzheimer's Gene." http://news.yahoo.com/s/nm/20070114/hl_nm/alzheimers_gene_dc (accessed on January 14, 2007).

Yap, L.K.P., S. H. Tan, and W. H. Koo. "Hypodermoclysis or Subcutaneous Infusion Revisited." *Singapore Medical Journal* 42, no. 11 (November 2001): 526-529.

.

Zarit, Steven A. "Diagnosis and Management of Caregiver Burden in Dementia." In *Handbook of Clinical Neurology*, edited by Michael J. Aminoff, Francois Boller, and Dick F. Swaab, 100-106. Edinburgh, Scotland: Elsevier, 2008.

Zerwekh, Joyce V. "The Dehydration Question." *Nursing* 13, no. 1 (January 1983): 47-51.

Vita

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