

9-14-2017

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Recommended Citation

Schwarz, Judith K. (2017) "Alzheimer's Disease and Written Directives to Withhold Oral Feedings: Clinical Challenges in New York State," *Seattle Journal for Social Justice*: Vol. 15 : Iss. 3 , Article 15.

Available at: <http://digitalcommons.law.seattleu.edu/sjsj/vol15/iss3/15>

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Alzheimer's Disease and Written Directives to Withhold Oral Feedings: Clinical Challenges in New York State

Judith K. Schwarz

New York State does not recognize a legal right to a physician's assistance in dying for any of its citizens, including those who are decisionally capable and suffering from a terminal illness. The only legal option for patient-controlled dying in New York is a decision to forgo life sustaining treatments. Increasingly, New Yorkers suffering from incurable and progressive or terminal diseases are choosing to voluntarily stop eating and drinking (VSED) as an effective way to hasten death, and die on their own terms.

As the Clinical Director of End of Life Choices New York (EOLCNY), an end of life advocacy and support organization in New York State, I have provided information and guidance to hundreds of individuals and their family members who contact our consultation program. Their reasons for contacting EOLCNY are varied. Some seek information about advance medical directives, others have questions about hospice or palliative care, and some seek information about how to control the circumstances and timing of death. Some of those who seek counseling are already dying and receiving hospice care; they want to know how they can hasten their dying process.

Others who contact our program are not yet in the *terminal* stage of their disease—understood as a physician's expectation that death will occur within six months. These individuals call because they are made miserable by their current symptoms and fear the certainty of further decline will compromise their future independence and quality of life. Increasingly,

individuals in this group have been diagnosed with an early stage of Alzheimer's disease (AD).

This article will focus on the challenges that exist when New York patients with an early stage of AD seek counseling about how best to achieve their goal of avoiding the advanced or final stages of this disease. Several approaches to achieving that goal will be described, including completing a comprehensive advance directive that instructs caregivers to withhold oral or assisted feedings once an advanced stage of dementia occurs and the person loses the ability to self-feed and the capacity to make informed decisions. Providing information about forgoing life-prolonging measures occurs within the context of New York State health care law. As the question of the decisional capacity of patients with AD is an important consideration, I will provide a summary of the recognized stages of cognitive disability in AD, and discuss the issue of how decisional capacity can impact choices made to avoid the final stages of this disease.

I. INCIDENCE AND STAGES OF AD

The number of Americans diagnosed and living with AD is increasing and is expected to dramatically escalate in coming years as the baby boomer generation reaches age 65 and beyond.¹ Currently, an estimated 5.4 million Americans of all ages have the disease, and by the year 2050, as many as 16 million Americans may be diagnosed with AD.²

In 2016, the number of New Yorkers age 65-74 with AD was 51,000, age 75-84 had 160,000, and the number in 85 and older age group was the highest of all—180,000.³ Due to the increasing accuracy of the diagnostic tests for AD in the preclinical stage of the disease, a growing number of

¹ *2017 Alzheimer's Disease Facts and Figures*, ALZHEIMER'S ASSOCIATION, www.alz.org/facts (last visited Feb. 2, 2017).

² *Id.*

³ *Alzheimer's Statistics: New York*, ALZHEIMER'S ASSOCIATION, www.alz.org (last visited Feb. 2, 2017)

New Yorkers and other Americans are learning that they have the disease long before they experience significant symptoms of cognitive disability.

II. ASSESSING THE STAGE OF DISEASE

By the time an individual makes an appointment with a physician to explore whether the memory problems they are experiencing are caused by AD, he or she often has been worrying about that possibility for a long time. The patient's primary care physician frequently recommends an evaluation by a neurologist or a neuropsychologist who will examine the patient in order to rule out other causes of the changes in behavior and personality.⁴ These physicians interview both the patient and others who know the patient well.⁵ Included in the examination are tests of memory, problem solving and organizational skills, attention, counting, and language skills.⁶ These tests can subsequently be repeated to provide information that documents changes in the person's memory and cognitive function over time.⁷

III. THE STAGES OF DECLINE

There are three general stages of AD, mild, moderate, and severe, that are further sub-divided into seven stages.⁸ In the earliest and mildest stages of the disease, the person demonstrates normal outward behavior and experiences no memory problems or other symptoms of impairments.⁹ This "pre-clinical" stage of the disease can last for many years. Stage two is Very

⁴ *About Alzheimer's Disease: Diagnosis*, NATIONAL INSTITUTE ON AGING, <https://www.nia.nih.gov/alzheimers/topics/diagnosis> (last visited Mar. 3, 2017).

⁵ *Id.*

⁶ *Id.*

⁷ *Id.*

⁸ *What are the 7 Stages of Alzheimer's Disease?*, ALZHEIMER'S.NET, <http://www.alzheimers.net/stages-of-alzheimers-disease/> (last visited Jun. 24, 2017).

⁹ *Id.*

Mild Decline.¹⁰ While the individual notices some minor memory problems, this memory loss is very difficult to distinguish from normal age-related memory loss, and the person will do well on memory tests.¹¹ The final early stage of AD is stage three, Mild Decline or Mild Cognitive Impairment.¹² At this point, memory loss and cognitive decline will be apparent to family members and close friends, and will be measurable on memory and cognitive tests.¹³ Patients in this stage will experience difficulties in planning and organization, and in remembering the names of new acquaintances. They are still able to make informed decisions.¹⁴

Stage four is the first of the two moderate stages.¹⁵ In stage four, Moderate Decline, patients will have clearly apparent memory and cognitive difficulties, and will begin to forget parts of their life histories.¹⁶ Short term memory deficits begin to create significant challenges, and as a rule, patients will no longer be able to successfully manage their financial affairs.¹⁷ Patients in Stage five, Moderately Severe Decline, will need help with some activities of daily living.¹⁸ They may evidence significant confusion and an inability to remember simple details of their lives including current phone numbers and their home address.¹⁹ Generally, they can still function with some independence with regards to bathing and toileting.²⁰ Whether a person with moderately severe dementia will be able

¹⁰ *Id.*

¹¹ *Id.*

¹² *Id.*

¹³ *Id.*

¹⁴ *Id.*

¹⁵ *Id.*

¹⁶ *Id.*

¹⁷ *Id.*

¹⁸ *Id.*

¹⁹ *Id.*

²⁰ *Id.*

to make an informed choice becomes difficult to determine and will require a careful assessment.²¹

Patients in the sixth stage of AD are in Severe Decline, and will require constant supervision. They may need placement in an institutional setting as their care needs are often beyond what most family members can safely provide in the home.²² Symptoms often include: confusion, significant personality changes, and disruptive behavior.²³ They frequently are unaware of their surroundings and wander.²⁴ They are unable to recognize most caregivers, have forgotten the names of family members and most details of personal history, are incontinent, and will need assistance with all activities of daily living including eating and drinking.²⁵

Stage seven is Very Severe Decline and will become, finally, the terminal stage of the disease. In this stage, all speech is lost, along with urinary and bowel control.²⁶ Ultimately, patients will lose their ability to swallow.²⁷ They become completely bedridden, and usually die of infection.²⁸ In general, people with Alzheimer's live about eight years after diagnosis, but survival can range from 3 to 20 years.²⁹ Once this terminal stage is entered, patients can live another one to two years.³⁰

IV. DECISIONAL CAPACITY

It was well recognized that individuals have the right to make decisions about their own health care, including decisions to forgo life prolonging

²¹ *Id.*

²² *Id.*

²³ *Id.*

²⁴ *Id.*

²⁵ *Id.*

²⁶ *Id.*

²⁷ *Id.*

²⁸ *Id.*

²⁹ *Id.*

³⁰ *Id.*

measures. It is also well established that a person's right to control medical interventions extends to a post-competent stage so long as clear prior instructions exist that can be applied once decisional capacity is gone.³¹ What is less clear is how best to determine whether the person retains sufficient decisional capacity to make such decisions.

Generally, capacity determinations are made by clinicians who know the patient well, or by other professionals who examine the patient carefully. The goal is to determine whether the patient is able to express a consistent treatment choice that appears based on an understanding of information about risks and benefits associated with the proposed intervention. Additionally, the patient should be able to appreciate how the information and treatment decision applies to their personal situation and life goals, and demonstrate reasoning in their evaluation and choice.³² Ethel Milly, a nurse scholar in the Hartford Institute for Geriatric Nursing notes that, "Patients whose cognitive status is unclear or fluctuates need protection from two kinds of mistakes: first mistakenly preventing capacitated patients from directing the course of their healthcare; second failing to protect incapacitated patients from the harmful effects of their decisions."³³ It is also generally accepted that as the consequences of a decision increase, the extent of capacity should similarly increase.³⁴ For example, a patient with moderately severe dementia might still be able to make some decisions about dressing, choosing meals or deciding when to sleep.³⁵ Other decisions

³¹ NL Cantor, *Can the right to stop eating and drinking be exercised via a surrogate acting pursuant to an advance instruction?*, BILL OF HEALTH (June 20th, 2017), <http://blogs.harvard.edu/billofhealth/2017/01/23>

³² J. Moye & D.C. Marson. *Assessment of Decision-Making Capacity in Older Adults: An Emerging Area of Practice and Research*, 62 J. GERONTOL. B. SCI. SOC. SCI. 1, 3-11 (2007).

³³ EL Mitty. *Decision-Making and Dementia*, ALZHEIMER'S ASSOC. (June 27th, 2017), https://www.alz.org/stl/documents/decision_making_capacity.pdf

³⁴ *Id.*

³⁵ *Id.*

with grave or life-threatening consequences would require demonstration of a more robust capacity for decision making.³⁶

Determining the patient's decisional capacity is a significant part of my responsibility when meeting with a patient with an Alzheimer's diagnosis because of the potential consequences of decisions about future treatment. I need significant input from family members or others who know the patient well, to help me accurately make that determination.

As previously noted, the consultation service of EOLCNY responds to all requests for information and support made by New Yorkers or their significant others who contact our organization. We frequently enter into long-term relationships with patients and their family members or close friends, and subsequently stay in contact by phone or email as their disease progresses and their suffering increases. When patients first contact our service seeking information about patient-controlled dying, an initial phone interview/assessment occurs and is followed by an in-home interview of patient and family (when geographically possible).

V. INITIAL ASSESSMENT

Often, the first contact is made by a family member of the person diagnosed with AD. I collect as detailed a medical and social history as possible during that first contact. I am particularly interested in knowing the caller's understanding of what the patient is hoping to achieve by contacting EOLCNY. This is frequently a difficult call for patients or family members to make. Most people who are diagnosed with a terminal or incurable/progressive disease do not seek information about patient-controlled dying—but some do. The individuals that contact EOLCNY tend to want as much information as possible about various end of life (EOL) options, including those that permit a hastened death.

³⁶ *Id.*

Persons diagnosed with AD have particular fears about living with and dying from this disease. Davis, a philosopher, notes that people who are interested in taking pre-emptive steps to escape the final stages of dementia often have several motivations: autonomy (distaste for a life of dependence), non-maleficence, (a desire to avoid burdening others) and beneficence (a wish to preserve assets to pass on to others).³⁷ The people I meet who have been diagnosed with AD often have witnessed the prolonged and undignified dying of a close family member; those memories continue to haunt them. They want to know how they can escape or avoid such an ending for themselves and protect their loved ones from witnessing their own dying in a similar fashion. Simply knowing that legal EOL choices exist and understanding they have the right to make such a choice can provide comfort to the patient, regardless of whether those choices are ever taken. Having a ‘choice’ can relieve their feeling of being victimized by the disease, and the sense of isolation that often accompanies being told that you have AD.

VI. INITIAL PATIENT/FAMILY MEETING

During the initial interview with a person newly diagnosed with AD and their family, I explore the person’s understanding of their current illness and its likely progression. I also want to understand their personal values and their EOL goals or wishes. I explore what they most fear as they imagine the progression of their disease. Desperate people sometimes seek desperate solutions; one patient with a diagnosis of early Alzheimers asked my thoughts about suicide by gunshot. I worked hard to discourage that possibility.

In addition to the above topics, I want to know whether the individual has completed any advance medical directives, and who they have appointed as

³⁷ D. Davis, *Alzheimer Disease and Pre-emptive Suicide*, J. MED. ETHICS. (Jul 10, 2013) jme.bmj.com/content/early/2013/07/09/medethics-2012-101022

their health care agent. I also explore the nature and strength of their relationship with a medical provider, and ask whether they have discussed their fears and hopes about their EOL with that clinician. If they have not yet done so, I encourage them to begin that conversation. I also talk extensively with their family members or friends, exploring their understanding of the patient's wishes and their potential willingness to support him or her if a decision is made to hasten dying. Throughout this interview and during all subsequent interactions with the patient, I continue to explore whether the patient has decision making capacity.

VII. NEW YORK STATE HEALTH CARE LAW

I explain New York State health care law with regard to the legally available EOL options that permit a patient to hasten dying. It is not uncommon for New Yorkers to be unaware that physician assisted dying (PAD) is not legally available in NYS. Patients who have lost decision making capacity are never eligible for PAD in any of the current states where that option is legally available. Applicants in the states that have legalized access to PAD must be both terminally and decisionally capable in order to meet state guidelines and requirements.

In New York State, the Health Care Proxy Law requires that the appointed health care agent have prior knowledge of an incapacitated patient's wishes about the use of medically provided or 'artificial' nutrition and hydration before being permitted to make a decision about this intervention.³⁸ Medically provided nutrition and hydration is most often administered by a feeding tube that has been surgically implanted into the patient's digestive system.³⁹ A health care agent or other surrogate must give prior permission before this medical intervention is initiated.

³⁸ *Health Care Proxy: Appointing Your Health Care Agent in New York*, New York Department of Health (June 27th, 2017), www.health.ny.gov/publications/1430

³⁹ *Id.*

The NYS Department of Health provides an informational booklet about appointing a health care agent under the Health Care Proxy Law.⁴⁰ It suggests that persons appointing an agent might want to add “special” instructions about specific interventions they wish their agent to authorize or forgo under medical circumstances such as: terminal illness, permanent coma, brain damage, or diseases that prevents the person from recognizing or speaking to others.⁴¹ The NYS Department of Health provides a list of medical treatments for consideration that include familiar life-prolonging interventions such as: artificial ‘respiration’, artificial nutrition and hydrations, cardiopulmonary resuscitation, surgical procedures, antibiotics and dialysis. There is no mention of “hand feeding” or natural feeding as an intervention the health care agent should consider.⁴² This may become significant in the future as more New Yorkers learn about the option of including instructions about hand feeding in their advance directives.

The most recently passed NYS health care legislation, the Family Health Care Decisions Act, does address the issue of oral feeding. This legislation recognizes the right of family members or other surrogates to make end of life decisions for an incapacitated adult who had not completed an advance directive, but limits decisions about ‘health care’ to decisions that do not include providing nutrition or hydration orally.⁴³ In order to avoid this restriction on decisions about oral feeding, a health care agent must have been appointed and given clear instructions before decisional capacity is lost.⁴⁴

While New York does not have a statute governing living wills, the Court of Appeals, New York’s highest court, has stated that living wills are

⁴⁰ *Id.*

⁴¹ *Id.*

⁴² *Id.*

⁴³ The Family Law Health Care Decisions Act, N.Y. Public Health Law section 2994-c (2010)

⁴⁴ *Id.*

legally valid as long as they provide “clear and convincing” evidence of a citizen’s wishes.⁴⁵ That evidentiary standard is understood as, “proof that the patient made a firm and settled commitment to the termination of life support under clinical circumstances like those presented.”⁴⁶

When patients with early Alzheimer’s ask how they can control the circumstances and timing of their death, we explore whether they have any life-prolonging measures that can be discontinued—such as a surgically implanted cardiac defibrillator or an insulin pump. If they have implanted life-prolonging devices, they can be discontinued with assistance from a physician or other medical clinician. In the absence of life prolonging treatments or medications that can be discontinued, the patient with an early dementia has two options to facilitate a hastened death.

The first option involves a pre-emptive decision to voluntarily stop eating and drinking (VSED) while the person retains decisional capacity. This option allows the him or her to make a contemporaneous decision to fast unto death. The second option involves completing a written directive which explicitly states that he or she does not want to be hand fed in the event that both decision making capacity and the ability to self-feed are lost. Before discussing these options, a brief over-view of the concept and the process of VSED will be provided.

VSED refers to an intentional decision made by a decisionally capable patient who is physically capable of eating and drinking but deliberately refuses further oral intake with the intention of hastening his or her death.⁴⁷ The goal of this refusal is to avoid further suffering that cannot otherwise be

⁴⁵ In re Westchester County Medical Center (O’Connor), 72 N.Y. 2d 527, 531, 534 N.Y.S. 2d 886, 892 (1988)

⁴⁶ Swidler, Robert 2010. New York’s Family Health Care Decisions Act. NYS Bar Journal, 82;5 p. 19

⁴⁷ See Generally, Judith Schwarz, *Exploring the option of voluntarily stopping food and fluid within the context of a suffering patient’s request for a hastened death*. 10 J. of Palliative Med. 1288 (2007)

relieved in a manner acceptable to the patient.⁴⁸ The cause of death is dehydration.⁴⁹ Depending upon the patient's pre-existing physical condition and the extent and nature of the underlying disease, death occurs within days to weeks after the start of the fast.⁵⁰ Terminally ill patients who choose to hasten death by VSED usually die peacefully within 10 days to 2 weeks. Absent terminal or other advanced disease, the process can be much more arduous, and the length of the fast can be several weeks.

To achieve a VSED death, several factors must be present. The person making the choice must be decisionally capable, well informed about the process, and very determined to control the timing of death in order to escape suffering that is currently or will soon become intolerable. In addition, the following must be available for a 'successful' outcome: family or other psycho-social supporters, care-giving assistance that may ultimately increase to 24 hours a day, access to hospice or other palliative medical over-sight, and patience.

Care giving support is necessary because the patient will become bed-bound and eventually slip into a coma, thus constant care-giving attention will be necessary. Access to palliative or hospice care can address any physical symptoms associated with the underlying disease or the process of fasting.⁵¹ Forgoing all fluids can be very challenging and requires good nursing care to palliative distressing symptoms.⁵² As death nears, some patients experience agitation or delirium, and those symptoms require aggressive and immediate palliation.⁵³

⁴⁸ Quill, TE & Byock, IR "Responding to intractable terminal suffering: the role of terminal sedation and voluntary refusal of food and fluids. *Ann Internal Med* 2000;132:408-414

⁴⁹ *Id.*

⁵⁰ Based on my clinical experience

⁵¹ *Id.*

⁵² *Id.*

⁵³ *Id.*

VIII. A PREEMPTIVE VSED DECISION

A person with an early diagnosis of AD who considers making a preemptive decision to forgo all food and fluid must understand how difficult it will likely be too fast “unto death” in the absence of a terminal or other advanced disease. The person must be extremely determined to control the timing of death and have access to the support noted above. Those who consider this option tend to be certain that living with an advanced stage of dementia is truly a fate that is worse than death.

The clearest advantage to such a choice is that it is the individual him or herself who makes the decision to initiate the fast, and, throughout the fast, while still conscious, that person decides whether to continue. By assuming the responsibility for implementing this choice, the person removes the moral and emotional burden from family or other care-givers of having to determine that the person’s quality of life has so deteriorated, that death would be preferable. As noted by Davis, “people have a strong interest in ending their lives with a final chapter that is consonant with the narrative as a whole.”⁵⁴ It can be very empowering to make an autonomous choice, as the disease progresses but before the window for self-determination closes, for those who wish to die as they have lived—in charge and making important decisions.

The challenges to a preemptive VSED choice to hasten death are significant. Perhaps the most difficult is the necessity to take steps to hasten death while life may still be enjoyable and worth living because of the fear that the ‘window of opportunity’ is closing. Because these individuals fear getting trapped in the fog of dementia, some may feel the need to act sooner than they or their loved ones wish, in order to avoid what they consider a worse fate.

⁵⁴ Davis, DS. D. Davis, *Alzheimer Disease and Pre-emptive Suicide*, J. MED. ETHICS 2. (Jul 10, 2013) jme.bmj.com/content/early/2013/07/09/medethics-2012-101022

Additional challenges based upon my clinical experience include difficulty obtaining access to palliative or hospice oversight. In order to receive government reimbursement, hospices need a physician's judgment that a patient is in the terminal stage of disease. Unless a patient has other chronic and progressive diseases, or are very elderly, many hospices would be reluctant to enroll a patient whose only diagnosis is an *early* stage of Alzheimer's disease. Sometimes, the patient's long-term physician will provide palliative symptom management, provided they support their patient's decision to hasten death.

A related challenge is the difficulty in predicting the duration of the fast in the absence of an underlying terminal illness. Previous studies of terminally ill cancer patients who chose to VSED suggest that the average duration of the fast until death is approximately 10 to 14 days.⁵⁵ However, patients whose only diagnosis is a dementing disease must anticipate a longer fast before death. Individuals and families who are considering this option want and need to know what to expect. This uncertainty adds to the difficulty for those who are exploring this option.

The final challenge to this choice is the very nature of fasting—unto death—while eating and drinking may still be a source of pleasure. Feelings of hunger and thirst would likely be more significant and challenging to palliate in the absence of an underlying terminal illness.

IX. WRITTEN ADVANCE DIRECTIVE STIPULATING WHEN ORAL FEEDINGS SHOULD BE WITHHELD

Patients with an early stage of AD have an alternative to a preemptive choice to VSED before they lose decisional capacity. The alternative is for the patient to complete a comprehensive written document that stipulates

⁵⁵ Judith Schwarz, *Hospice care for patients who choose to hasten death by voluntarily stopping eating and drinking.*, 16 J HOSPICE & PALLIATIVE CARE NURSING 126-131 (2014)

the clinical circumstances under which oral feedings are to be stopped. The instructions in this document would direct the appointed health care agent to request that oral feeding be withheld from the now incompetent patient, when the 'triggering' clinical circumstances or stage of dementia described in the written directive are present (see the attached living will document that describes these clinical circumstances).⁵⁶

There are a number of significant legal, ethical and clinical challenges to this approach that will be addressed in the next section.

A. Challenges to Honoring Advance Directives to Withhold Oral Feeding

One significant challenge results from the fact that even patients with a very advanced stage of Alzheimer's disease may still *appear* willing to eat and to *cooperate* in being hand fed, long after decisional capacity has disappeared along with their ability to feed themselves. The following is one of my cases that illustrates such a situation.

Adelle was 97 years old when I first met her; she had been diagnosed with AD more than 15 years previously. She has been bed-bound and in diapers for the past 7 years and is now mute, motionless, and apparently unable to recognize her only child, Ann. She is very thin and severely cognitively impaired; she would be considered in the final, 'terminal' stage of the disease.

When Adelle's husband died, more than 20 years ago, she and her daughter met with the family attorney to draft a new advance directive and Ann became her health care agent. After a careful discussion of her mother's treatment wishes and personal goals, Ann knew her mother would never want life-prolonging measures like tube feedings or cardiac resuscitation. But nobody advised them to consider whether she would want to be hand fed if she became incapacitated by advanced dementia. Ann said

⁵⁶ The attached Living Will was created by myself and Dr. Peter Rogatz, MD.

her mother would be horrified if she could see herself, lying in a hospital bed in diapers, in the living room of her lovely New York City apartment. She added that her mother would say, “Just shoot me now!”

Adelle is lovingly cared for by a group of round-the-clock aides who have been caring for her for many years; paid for, “out of pocket”, by Ann. I observed one of those aides feeding Adelle her lunch. The aide stood patiently at her bedside and verbally coaxed her to open her mouth with soothing terms of endearment. She gently brought the spoon to the corner of Adelle’s mouth, in conjunction with verbal encouragement, and Adelle would open her mouth so the pureed ‘glop’ could be spooned into her mouth. She swallowed the food with apparent relish and without evidence of physical difficulty—there was no coughing or choking. Similarly, when the thickened liquids were carefully spooned into her mouth, she readily swallowed those also without difficulty. The aide told me that it takes at least an hour to feed Adelle each meal. Adelle’s care is over-seen by a home hospice program; she has been enrolled and receiving that support for over a year now.

Ann first contacted me in hopes that I could help her to *legally* help her mother to die. I confess that I initially thought that Ann could simply decide, as her mother’s health care agent, to forgo further life-prolonging measures (food and fluid) because this is the choice her mother would make if she were able to speak and could appreciate her current condition. But then I observed Adelle willingly opening her mouth and swallowing whatever was put into it, and the problem came into sharper focus.

Absent a written advance directive stipulating that assisted feeding be stopped when advanced dementia occurred, Adelle will continue to be fed indefinitely, regardless of the pleas to the contrary by her daughter. The fact that these feedings must continue was confirmed by the hospice clinicians. In time, Adelle will forget how to swallow, and then she will begin to cough and choke when she is fed. *Then* the burdens of continued feeding will outweigh the presumed benefit of continued life—even though Ann and her

mother would have chosen a much earlier time to make that determination. Only then will the feedings be discontinued.

Even *if* Adelle had previously completed a written directive stipulating the withholding of food and fluid in her current stage of dementia, the fact that she now “willingly” eats and *appears* to derive pleasure from doing so would create a significant challenge for many caregivers. This is the case for any severely demented patient who still seem to willingly cooperate in being fed. The memory of previously completing such an advance directive would have long since disappeared. Adelle does not currently remember her only child! The “then” Adelle, who once cared passionately about such values as personal dignity, independence, and frugality, as described by her daughter, has long since stopped caring about or remembering such things. But the “now” Adelle really does seem to like her pureed “glop.”

Continuing with the above hypothetical situation of Adelle having a previously completed directive directing that assisted feeding be withheld even as she cooperates in being fed, those who observed such behavior might wonder whether she had ‘changed her mind’ about eating. While clinically it is unlikely that anyone with severe dementia would possess the cognitive ability to reconsider any previously made decision, many caregivers would attach such meaning to the behavior they observe—the “willingness” to be fed.

It is well recognized that previously completed medical directives can be revised or revoked at any time by the person who completed them. Thus, when a now incompetent patient appears to behave in a manner that is inconsistent with what they previously said they would want, caregivers might understandably wonder *who* to believe – the ‘then’ person who wrote the document, or the ‘now’ person who seems blissfully unaware of the document and its instructions – the ‘now’ person who *might* have changed her mind. Although there is agreement among those who care for frail, elderly patients with advanced dementia that when the side of the mouth is gently touched, a reflex ‘causes’ the mouth to open. That this reaction is a

reflex rather than an actual decision or choice may be hard for many other caregivers to accept.

Once decisional capacity is gone, no *voluntary* (V) choice can be made, thus the term SED is used instead for VSED. Another significant challenge to a prospective decision to SED once advance dementia occurs is the question of whether hand feeding is medical care that can be refused or whether it is basic or ordinary care that is obligatory. The right to refuse any and all medical treatment, including those treatments necessary to sustain life, is well established in the American legal system.⁵⁷ In addressing the question of whether providing oral nutrition and hydration constitutes *medical* treatment, Pope and West state the following: “It could be argued that any intervention performed upon an individual in a healthcare setting by healthcare employees for the purpose of sustaining life can be considered “treatment,” at least for the purposes of determining whether a patient has the right to refuse it. Moreover, spoon feeding requires inserting a foreign object into the mouth of a patient.”⁵⁸

Norman Cantor, a retired law professor, adds caution and nuance to the question of whether assisted feeding is medical or ordinary care. He acknowledges that the eating deficits associated with progressive dementia result in reduced nutritional intake and require assisted feeding as the remedy.⁵⁹ He speculates that “from one perspective,” assisted feeding could be viewed as “a therapeutic ‘medical’ response to pathology associated with the degenerative affliction.”⁶⁰ But he adds, if the demented patient still

⁵⁷ Thaddeus M. Pope & Amanda West, *Legal Briefing: Voluntarily Stopping Eating and Drinking*, 25 J. Clinical Ethics 68, 70 (2014), https://www.researchgate.net/profile/Thaddeus_Pope/publication/261996427_Legal_briefing_Voluntarily_stopping_eating_and_drinking/links/561ae42108ae78721f9f8e48.pdf.

⁵⁸ *Id.* at 70

⁵⁹ Norman Cantor, *Can the Right to Stop Eating and Drinking be Exercised via a Surrogate Acting Pursuant to an Advance Instruction?*, HARV. L.: BILL OF HEALTH BLOG (Jan. 23, 2017), <http://blogs.harvard.edu/billofhealth/2017/01/23>

⁶⁰ *Id.*

seems willing to cooperate in hand feeding, and the eating assistance can be provided by non-medical personnel (such as nursing aides), then he concludes that such feeding might be classified as basic personal care.⁶¹ There can be no doubt that as AD advances to even a moderately severe stage, the incompetent patient will require assistance in eating. In time, as the disability increases, the feeding assistance may necessitate artful if not clinically sophisticated techniques to provide sufficient nutritional intake to sustain life.

When patients with AD and their families first contact EOLCNY, they still reside in their own homes. Many refuse to even consider transferring to a long-term care facility, yet the majority of individuals with an advanced stage of AD will ultimately require such placement. The question of whether nursing home clinicians would honor an advance directive to forgo assisted feeding will be addressed in the next section.

B. Challenges to Written Directives Forgoing Feeding in Long Term Care Settings

Long-term care residents with advanced AD often lose interest in eating and drinking along with the cognitive and physical ability to feed themselves. As noted, providing these residents with adequate nutritional intake becomes a significant daily challenge, and requires skilled persistence on the part of aides who must patiently stand at the bedside, carefully spoon-feeding the individuals in their charge.

Medicare and Medicaid guidelines address the facility's responsibility to provide adequate nutrition and hydration, and facility administrators may fear loss of eligibility for Federal reimbursements if they are found to have failed to provide enough nutrition and hydration to support and maintain

⁶¹ *Id.*

health.⁶² Thus, nursing home residents are weighed on a regular basis to document the status of their weight gain or loss.

Menzel and Chandler-Cramer note that those who would conclude that such a Medicare/Medicaid ruling would preclude honoring a previously made directive to withhold oral feeding do not fully understand this regulation.⁶³ They state that "...the very regulation at issue explicitly says that advance directives constitute an exception: it is withholding nutrition and hydration without advance directive that triggers review of a facility's certification."⁶⁴

Nonetheless, it is understandable that caregivers and perhaps some family members may fear the possibility of causing patients harm or increasing suffering when an advance directive to withhold assisted feeding is invoked, particularly when the resident still seems to cooperate or enjoy being fed. One could readily imagine concern about the possibility that the demented resident feels hunger or thirst, or possibly feels abandoned when others are being fed and he or she can smell food. As an alternative to either completely ignoring the directive to withhold hand feeding or fully complying with those instructions, some suggest a temporary "half-way" measure known as comfort feeding only (CFO).⁶⁵

CFO was proposed as a means to facilitate a change in focus from maintaining adequate nutrition to sustain and support health, to bringing comfort or palliation to the patient by providing foods that seem **simply**

⁶² *State Operations Manual: Appendix Q – Guidelines for Determining Immediate Jeopardy*, CMS, https://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/downloads/som107ap_q_immedjeopardy.pdf (last modified May 21, 2004).

⁶³ Paul T. Menzel & M. Colette Chandler-Cramer, *Advance Directives, Dementia, and Withholding Food and Water by Mouth*, 44 HASTINGS CTR. REP. 23 (2014).

⁶⁴ *Id.* at 26-27.

⁶⁵ Eric J. Palecek et al., *Comfort Feeding Only: A Proposal to Bring Clarity to Decision-Making Regarding Difficulty with Eating for Persons with Advanced Dementia*, 58 J. AM. GERIATRIC SOC'Y 580 (2010), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2872797/pdf/nihms-200335.pdf>.

to be enjoyed. This involves two steps. The first step consists of gently spoon-feeding patients until they resist or otherwise indicate they no longer “want” to eat, or appear physically distressed as evidenced by coughing or choking, or refusing to participate in being fed. The second step involves the ongoing provision of a comforting presence and human interaction during mealtimes such as quiet talking, gentle stroking, or other caring interventions. As Menzel and Chandler-Cramer observe, CFO would challenge the notion that failing to provide adequate nutrition is morally equivalent to failing to provide necessary care and comfort to patients with advanced dementia.⁶⁶ They further suggest that, when supported by a patient’s advance directive, CFO could become a realistic practice in nursing homes.⁶⁷ I now include CFO as an option in the living will I provide to those with early AD [attached].

I am currently working with another patient who has an early stage of AD. I have met with him and his wife and his adult children on several occasions. The goal of these meetings is for Saul, the patient, to discuss with his family the treatment wishes he wants them to understand and honor, when he is no longer able to contemporaneously participate in such decisions. Like many persons who have vivid memories of the prolonged and miserable death that a beloved family member endured after living for years with AD in a nursing home, he wants his family to promise to care for him at home. He also has specifically and repeatedly told them that he does not want to be hand fed once he loses capacity and the ability to feed himself—even *if* he appears willing to be fed.

This was a very difficult request for his daughters to hear; one of his daughters cried openly after hearing her father’s plea. He insisted that, even if he seemed to “want” to eat, he told them they must not help him to eat. Losing his mind would be worse, he said, than dying. He completed the

⁶⁶ Menzel, *supra* 63

⁶⁷ *Id.*

living will I had given him that we had discussed on many previous occasions. Then, he gave each of his children a copy of the document.

Saul said that he does not want to have to wait until the last stage of AD to begin the process of fasting. He said stages 6 or 7 would be too late because by then he would no longer know his family, would be incapable of responding to those around him, and would be completely dependent upon others for all physical care. He has indicated in his directive that once he enters a “moderate” stage of AD and can no longer do the things that now give him pleasure, such as exercising outdoors, reading/comprehending sports magazines, watching the Yankees on TV, and engaging in the political conversations he enjoys with friends and family. He wants *out* and he wants his family to help him get there.

It may be that he will change his mind about these instructions before he loses decisional capacity. But in the meantime, I encourage him to get “buy-in” for his written direction to SED from as many other professionals in his life as he can, including the family attorney, spiritual advisor, and his long-term physician. The physician should know that Saul has been thinking about the final stages of this disease, and that physician should know the particular stages of AD he wants desperately to avoid. His physician might provide him with palliative support in his home, as he begins to SED, and perhaps will refer him to home hospice care once his death becomes imminent. His family would undoubtedly benefit from such support as well.

X. SUMMARY

As increasing numbers of Americans are diagnosed with an early stage of AD, it is to be expected that a small, but persistent, proportion of those individuals will seek information about choices that can facilitate the avoidance of the final stages of this disease. While they retain cognitive ability and decisional capacity, they can consider various EOL options for a hastened death, reflect upon the expected benefits and burdens of those options, and reach a conclusion about the best choice for them. Some of

these individuals may choose to stop all life-prolonging measures including food and fluid, with the intention of hastening their death while being able to make a contemporaneous decision to do so.

To achieve a hastened death by VSED in the absence of a terminal illness will require a decisionally capable person with a very determined will to control the timing of death, social/family and care-giving support, and ideally, access to hospice, palliative, or other medical oversight. The process of fasting unto death under these clinical circumstances may take several weeks. It remains a very challenging option.

Other individuals with an early stage of AD who want to avoid the final stages of severe dementia may choose to complete a comprehensive written directive that includes information about the particular stage of dementia when assisted feeding is to be stopped. An appointed healthcare agent and significant others will confirm that these written directions to forgo food and fluid under the patient's current stage of dementia are consistent with the verbal instructions and decisions previously made by the now incompetent patient. Such directions would conform with the NYS requirements regarding clear and convincing evidence of the now incompetent patient's prior autonomous choice.

Some of those patients with an early diagnosis of AD may choose to include instructions about receiving comfort feeding when they are in an advanced stage of dementia. It seems incredibly difficult to imagine how one would "*feel*", in a future advanced stage of dementia about receiving food or fluids. However, one can imagine that, while decisionally capable, one might realize that by agreeing to accept comfort feeding, one might relieve some of the distress that loved ones might experience by withholding all oral intake. Such feedings would be provided so long as the resident seemed to 'enjoy' the feedings, and does not in any way resist, cough, or choke while being fed.

There remain a number of issues of concern about the appropriateness of honoring an advance directive to SED under circumstances of advanced

dementia. As noted, some may question whether a person with advanced dementia who appears to cooperate while being fed might have changed his or her mind. This can be particularly challenging when the written directive offers no insight into whether the now incompetent patient previously considered such a possibility, and left no guidance to the caregiver about how to respond.

Others question whether a prospective choice to SED by advance directive would be legally enforceable for patients who are not yet in an advanced stage of dementia. Cantor states that there may be a “legally sound theoretical framework” for enforcing advance directives to SED so long as the assisted feeding can be classified as medical treatment necessitated by the associated pathology of *advanced* dementia. Yet, he concludes that too many hurdles currently exist to support an advance directive to SED for a moderately demented patient.

Under such uncertain circumstances, it may be necessary for all those who care for and care about this now voiceless patient to come together, review previous documents and statements, consider the patient’s current status and response to being fed, and attempt to determine what, with all things considered, is the best choice to make.

This article describes an innovative approach to “end of life” planning for patients with an early diagnosis of AD. It is true that there are, as yet, unresolved legal and ethical concerns about the appropriateness of honoring a comprehensive written directive created by an individual who desperately wants to avoid the final stages of this disease. There is neither a legal consensus nor a judicial ruling about whether such a carefully drafted advance directive should be honored when it stipulates that the now incompetent patient has reached the identified final stage of dementia. But, I expect there will be in the future.

In the meantime, the counsel I provide to New Yorkers with early AD who contact EOLCNY is based upon my conviction that an advance directive to SED should be viewed as an informed decision to forgo a life-

prolonging measure (oral nutrition and hydration) that can be refused like any other life-prolonging measure. Clearly, the directive must be comprehensive and clearly written, and be supported by an appointed health agent and family members and/or close friends. Ideally, the document should include instructions about whether to provide CFO when a moderately severe stage of AD occurs and the patient seems willing to be fed. I have included such a directive at the end of this article.

It may also be the case that the patient will not want any oral feedings provided when they reach an advanced stage of dementia. Whatever the autonomous choice about hand feeding previously made by the now incompetent patient, it ought to be respected and honored by caregivers and others.

XI. APPENDED ADVANCED DIRECTIVE

ADVANCE DIRECTIVE GUIDELINES (LIVING WILL)

I, _____ have prepared these guidelines for use by my health care agent (referred to herein as “my agent”), in the event that it becomes necessary to clarify my wishes, or if any physician, nurse or representative of any hospital or health care institution is reluctant to accept the decisions made by my agent.

I wish the treatment decisions described in these guidelines to be implemented if my physician believes that my clinical status fits any one of the five conditions described below or *any other condition that seems comparable*. If there is any disagreement among my caregivers, my agent is instructed to resolve any disagreement by using his or her best judgment as to what I would want for myself.

I wish these guidelines to be implemented if I am in a condition comparable to any of the following:

- (a) I am unconscious or in a coma or persistent vegetative state with no reasonable expectation that I will regain consciousness; or

- (b) I am in a so-called “minimally conscious state” or have brain damage or a brain disorder that is very unlikely to be reversible and that prevents my being able to recognize family members or close friends, or communicate understandably and care for myself, even though I am conscious and might be able to survive for an extended time in such condition; or

(c) It is likely that I will never again be able to live without mechanical ventilation and/or feeding tubes (artificial nutrition and hydration); or

Signature: _____ Date _____

(d) I am suffering from an incurable and progressive disease and/or a terminal illness that interferes with my ability to engage in thoughtful treatment decision-making and/or causes me great physical or emotional/spiritual suffering; or

(e) Despite being conscious, I am in an advanced stage of dementia* and, for this or any other reason, I am unable to communicate understandably, **or** recognize family members or friends, **or** am dependent upon others for my physical care **or** unable to feed myself

* by 'advanced stage' of dementia I mean, in addition to the above clinical description, stages 6 or 7 of the Functional Assessment Staging Test for Alzheimer's disease.

If my agent concludes, after reasonable medical consultation, that I am suffering from any of the foregoing conditions, I want a DNR order written and I wish all medication, all treatment, all **oral feeding by hand**, and all artificial nutrition and hydration that might prolong my life to be withheld or, if already begun, to be withdrawn. Other examples of procedures I do not want are: antibiotics, blood transfusions, kidney dialysis and invasive diagnostic

procedures; I do not want surgery, unless it is absolutely necessary to control pain. Any previously implanted cardiac devices are to be deactivated. The foregoing list is not exhaustive; it is my wish to have no procedure that would prolong my life under any of the conditions described above. If I am demented and appear to be willing to accept food offered by hand, my instructions as expressed herein are to prevail; I do not wish to be fed by hand in an advantage state of dementia even if I appear to cooperate in being fed.

Signature _____ Date _____

However, I do want to receive simple hygiene and measures to assure comfort to relieve pain and allay anxiety. I would like my lips and inner surface of my mouth to be kept moistened to minimize discomfort. I would like medication for pain and/or anxiety to be administered to me in sufficient dosage and with sufficient frequency to assure effective palliation and symptom relief, even though such medication might shorten my life. I particularly want sedation sufficiently strong to relieve any respiratory distress that I may be suffering. Under the conditions described above, life will have no value for me and I would want to die peacefully and quickly, avoiding a drawn-out death that would involve unnecessary suffering for me and/or for those whom I love.

I have tried to describe above the kinds of circumstances under which I would like life-sustaining treatment to be withdrawn or withheld. However, I cannot anticipate and describe every possibility, and I want my agent to be guided at all times by the principle of compassion and to demand withholding or withdrawal of life sustaining measures if my condition is comparable to the circumstances described above.

It is my wish to die at home, rather than in a hospital or other institution, provided that this does not impose an unreasonable burden on my family. If I am in a hospital, nursing home or other health care facility when my condition is judged to be as outlined above, I wish “Do Not Resuscitate” and “Do Not Intubate” and “Do not hand feed” orders to be written and I would like my agent to ascertain whether that facility will honor my wishes as set forth in these guidelines. If not, I would like to be removed from such facility and placed under hospice care in my own home or in some other setting where capable staff will provide compassionate

Signature _____ Date _____

end-of-life care in accordance with these guidelines.

It is my intention that my agent’s instructions be honored by everyone, including my family, my physician and all others concerned with my care. I expect all such persons to be legally and morally bound to act in accord with my wishes, as set forth on my behalf by my agent.

The question may arise as to whether I may have had a change of mind. It is my direction that, absent a written revocation of this document, it must be presumed that I have not had a change of mind, no matter how much time may have elapsed between the execution of this document and its enforcement.

I have subscribed to this declaration in the presence of witnesses and, in a separate document, I have designated my health care agent, to whom I have communicated the decisions set forth above and upon whom I have conferred the authority to communicate these decisions to all concerned.

Unless I revoke it, this set of guidelines to my agent shall remain in effect indefinitely

Signature _____ Date _____

Optional Addendum re comfort feeding: If I appear receptive and cooperate in eating and drinking (show signs of enjoyment or positive anticipation) I want comfort feeding provided. By this I mean, feed me any foods I appear to enjoy, in any texture that works, but please stop when I no longer indicate enjoyment or willingness to eat or drink – or if I begin to cough or choke – or if I appear indifferent to being fed. I do not want to be cajoled, harassed, or in any way forced to eat or drink. I do want to receive comfort care and palliative medications for any signs of anxiety, agitation, insomnia or pain.

Signature _____ Date _____

We, whose names are hereto subscribed, declare that the person who signed all 3 pages of this document is personally known to us, appears to be of sound mind and acting of his or her own free will, and signed this document in our presence.

Witness 1:

Signature _____ Date _____

Print name _____

Address _____

Witness 2:

Signature _____ Date _____

Address _____