Approaching the Limits of Advanced Directives: Refusing Offers of Food and Water When Demented

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The use of Advanced Directives is well-established, but does this exercise of "precedent autonomy" include the right to instruct that no food or water be offered to the patient when in a future demented condition?

Learning Outcomes

1. Explain the role of Advanced Directives in Advanced Care Planning.
2. Articulate the ethical arguments regarding refusing offers of food and water when demented.
3. Explore your own position on these ethical issues.
For Your Reflection...

- Would you complete an AHD in which you declined oral feeding if severely demented?
- Would you as a healthcare agent decline oral feeding for your severely demented friend or loved one?
- Would you as a caregiver comply with a request to stop all feeding?

Patient Choices and Dying Today

- Goals of Care Choices (Aggressive Life-Sustaining or Comfort Focus)
- Limiting Life-Sustaining Medical Treatments (e.g., Intubation, CPR, Medically Provided Fluids and Nutrition, Antibiotics)
- Voluntarily Stopping Eating and Drinking (VSED)
- Advance Healthcare Directives to Appoint an Agent and to Guide Medical Choices When Incapacitated

Advance Healthcare Directives

- What are they?
- Who uses them?
- Why are they important?
- Are they effective?
Frontiers for AHD's

• Physician-Assisted Dying in the US
  – Only available to currently capacitated patients

• MAiD in Canada
  – Must a person’s choice be contemporaneous with the action?
  – Should AHD's requesting MAiD be respected when the patient is incapacitated?

• Dementia and Withholding Life-Sustaining Treatment

AHD's and Dementia

“More than one-third of Americans ages seventy-one and older have dementia and cognitive impairment without dementia. Dementia, usually defined as memory and other cognitive deficits that are sufficient to cause limitations in daily functioning, is often under-recognized as a terminal, progressive condition. This may result in end-of-life care for people with dementia that can be burdensome, painful, costly, and unlikely to improve their quality of life or chance of survival.”


Merely naming a proxy decision maker has not been found to be associated with less aggressive care in a national sample of Medicare beneficiaries. Thus, efforts to educate both patients and their families at the initial diagnosis about dementia and its progression may be necessary to prompt surrogates to learn about a patient’s preferences and prognosis in a timely manner.

Nicholas, et.al.
Alzheimer’s Dementia

- Of the top 10 diseases that we die from (Alzheimer’s dementia is number 6), it is the only one that can’t be prevented, slowed or treated.
- In MN, currently there are thought to be approximately 94,000 individuals with dementia and that number will increase almost 30% to 120,000 by 2025.
- $341,840 is the estimated lifetime cost of caring for an individual with dementia.

* 2017-18 Alzheimer’s Disease facts and figures from the Alzheimer’s Association.

Alzheimer’s Dementia

Alzheimer’s Disease is a continuum wherein decline occurs over 2-20 years with an average lifespan of 5-8 years.

- Brain changes due to Alzheimer’s without symptoms
- Mild Cognitive Impairment
- Mild, Moderate and Severe disease

* 2017-18 Alzheimer’s Disease facts and figures from the Alzheimer’s Association.

Disease Course

Disease course from Living Well at the End of Life, 2005.
**Dementia Scales**

- “ROSA” (Relevant Outcome Scale) in Germany
- “ABC-DS” (ABC Dementia Scale) in Japan
- FAST (Functional Assessment Staging) in the U.S. (Barry Reisberg, MD NYU)

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**FAST Scale**

- Stage 1: Normal
- Stage 2: Age related forgetfulness
- Stage 3: Mild Cognitive Impairment
- Stage 4: Mild Alzheimer’s Dementia
- Stage 5: Moderate Alzheimer’s Dementia
- Stage 6: Moderate-Severe Alzheimer’s
- Stage 7: Severe Alzheimer’s

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**Dementia Scales - FAST SCALE**

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>6a</td>
<td>Cannot dress without assistance; occasionally or more frequently</td>
</tr>
<tr>
<td>6b</td>
<td>Cannot bathe without assistance; occasionally or more frequently</td>
</tr>
<tr>
<td>6c</td>
<td>Cannot toilet without assistance; occasionally or more frequently</td>
</tr>
<tr>
<td>6d</td>
<td>Incontinence of urine; occasionally or frequently</td>
</tr>
<tr>
<td>6e</td>
<td>Incontinence of bowel; occasionally or frequently</td>
</tr>
<tr>
<td>7a</td>
<td>Speech limited to fewer than six intelligible words during an average day</td>
</tr>
<tr>
<td>7b</td>
<td>Speech limited to single intelligible word during an average day</td>
</tr>
<tr>
<td>7c</td>
<td>Unable to ambulate independently</td>
</tr>
<tr>
<td>7d</td>
<td>Cannot sit up independently</td>
</tr>
<tr>
<td>7e</td>
<td>Cannot walk</td>
</tr>
<tr>
<td>7f</td>
<td>Cannot hold head up independently</td>
</tr>
</tbody>
</table>
Dementia Scales

- Not good at predicting mortality (or for indicating hospice referral)
- Decline is often not linear
  - Physical and cognitive decline can be out of sync
- Can they be helpful in determining when a person would want to stop eating and drinking?

"Some people are trying to prevent living with advanced dementia by establishing advance directives/living wills that limit aggressive medical interventions, usually cardiopulmonary resuscitation, transfer to an acute care setting, use of feeding tubes, and treatment of generalized infections with antibiotics. However, even if these advance directives are honored, they may not prevent living with advanced dementia because some people do not require any of these interventions for survival. That led to some people considering suicide when they were still able to do it, for example, the first 'patient' of Dr. Kevorkian, Janet Adkins. Such action deprives them of living with mild dementia for some years that they can still enjoy."


What are the greatest end-of-life fears?
- Days to weeks of unending, unbearable pain and suffering.
- Months to years of lingering in Advanced Dementia.
Worse: you may suffer from BOTH.
This book’s brief review shows traditional Living Wills do NOT remove these fears.
Yet two legal rights let you forgo spoon feeding—if someday you suffer from Advanced Dementia. Refusing life-sustaining treatment is a well-accepted choice, but this decision alone cannot help patients whose devastated brains are in healthy bodies. What can? Natural Dying, which includes forgoing spoon feeding while receiving all Comfort Care.
Some argue spoon feeding is basic care and thus obligatory. This book [Peaceful Transitions] presents clinical reasons why spoon feeding is medical treatment. A Catholic priest/health ethicist’s guest essay explains why religious patients may refuse spoon feeding if a condition makes treatment extraordinary or disproportionate. —Comforting arguments, if you wish to respect the sanctity of life but do not want to prolong dying if there is no other life-sustaining treatment to forgo.

MINNESOTA ADVANCE PSYCHIATRIC AND HEALTH CARE DIRECTIVE
To My Doctors, Health Care Providers, Family and Friends:

I, ____________________________________, am a competent adult. I willfully and voluntarily make the following health care instructions, to be followed if I become incapable of making sound decisions about my health care.

I understand that I have the right to make medical, mental health, and other health care decisions for myself as long as I am capable of doing so. I understand that I have the right to revoke this document or any part of it at any time as long as I am mentally capable of doing so.

I understand that any agent or proxy appointed by me is under no legal duty to act. However, those persons appointed by me have agreed to act as my agent or proxy. It is my intention that anyone appointed by me must act consistent with my instructions as stated in this document and any wishes as otherwise made known by me.

I. INSTRUCTIONS ABOUT MY MENTAL HEALTH CARE
A. My Beliefs, Concerns and Preferences about my mental health care.

I am telling you what my beliefs, preferences and concerns are about my mental health problems and my care. I am giving you this information because I want my choices to be honored, and I want you to help me have as much control over my life as possible while I work on my recovery and managing my illness.

ALZHEIMER’S DISEASE/DEMENTIA MENTAL HEALTH ADVANCE DIRECTIVE OF [Print your name here]

As a person with capacity, I willfully and voluntarily execute this mental health advance directive, so that my choices regarding my mental health care and Alzheimer/Dementia care will be carried out in circumstances when I am unable to express my instructions and preferences regarding my future care. If I live in a state that has not adopted laws that provide me with the legal rights to make this advance directive, then I want this document to be used as a guide for those who make decisions on my behalf when I am no longer capable of making them for myself.

I understand that nothing in this directive, including any refusal of treatment that I consent to, authorizes any health care provider, professional person, health care facility, or agent appointed in this directive to use or threaten to use abuse, neglect, financial exploitation, or abandonment to carry out my directive.

I intend this Alzheimer’s Disease/Dementia Mental Health Directive to take precedence over any other mental health directives I have previously executed, to the extent that they are inconsistent with this Alzheimer’s Disease/Dementia Mental Health Advance Directive.

I understand that there are some circumstances where my provider may not have to follow my directive, specifically if compliance would be in violation of the law or accepted standards of care.
MY INSTRUCTIONS FOR ORAL FEEDING AND DRINKING

I am making this document because I want my medical and long-term care providers, caregivers, family, and other loved ones to honor my wishes regarding oral feeding and drinking.

If I become unable to make decisions about my health care and I stop feeding myself due to Alzheimer’s Disease or other progressive dementia, I want oral food and fluids to be provided to me under certain circumstances.

If I accept food and drink (comfort feeding) when they’re offered to me, I want them. I request that oral food and fluids be stopped if, because of dementia, any of the following conditions occur:

• I appear to be indifferent to being fed.
• I no longer appear to desire to eat or drink.
• I do not willingly open my mouth.
• I turn my head away or try to avoid being fed or given fluids in any other way.
• I spit out food or fluids.
• I begin a pattern of coughing, gagging, or choking on or aspirating (inhaling) food or fluids.
• I exhibit other signs of discomfort or symptoms of continued feeding and drinking, as determined by a qualified medical provider, outweigh the benefits.

I want the instructions in this directive followed even if the person who has the right to make decisions for me and my caregivers judge that my quality of life, in their opinion, is satisfactory and I appear to them to be comfortable. I have given considerable thought to this decision and want my wishes to be followed.

No matter what my condition appears to be, I do not want to be cajoled, harassed, or forced to eat or drink. I do not want the reflexive opening of my mouth to be interpreted as giving my consent to being fed or given drink or misinterpreted as a desire for food or drink.

Before I am admitted to a long-term care facility, I want that facility to affirm its willingness to honor these instructions. If the long-term care facility where I already reside will not honor these instructions, I want to be transferred to one that will.

The directive for receiving assisted oral feedings has two options:

• **Option A** refuses all oral assisted feedings once the patient is in an advanced stage of dementia and the ability to self-feed and make decisions has been lost.

• **Option B** permits assisted oral feeding in advanced dementia but limits that provision to comfort-focused feeding that must be stopped when the patient becomes disinterested or unwilling to be fed.

The chosen feeding option would be implemented only when the appointed health care agent and primary care physician agree that the patient is now suffering from an “advanced” dementia, understood as Stages 6 or 7 (the last two stages) of the widely used Functional Assessment Staging Tool (FAST). When dementia becomes advanced, patients would be unable to feed themselves or make health care decisions. EOLCNY developed this advance directive to provide clear documentation that the patient decided, while still mentally capable, to refuse all life-prolonging measures, including assisted oral feedings, once their dementia became advanced.
Case of VSED

- Mr. Indy Pendent is an 80-year-old man with a past medical history significant for mild cognitive impairment, advanced prostate cancer, hypertension, pulmonary embolism, and ckd stage 4.
- He told his family that he “knows what is coming” and it is not congruent with the “arc” of his life.
- Very successful business man, a leader and someone who was always in charge.

Case of VSED

- He had many conversations with family and friends expressing his wishes not to progress to the dementia phase of his disease.
- Family and friends were all on board.
- He lived independently, stopped eating/drinking on his own, was supported by family/friends and died 5 days later.

Family Facilitated Stopping Eating and Drinking

- Mr. Big Mac is a 90-year-old gentleman with past medical history significant for advanced dementia (Alzheimer type), prostate cancer, hypertension, DVT, and trigeminal neuralgia.
- He has been bedbound for the past 4 years. He is non-verbal and dependent on staff for all of his ADLs. PPS 10%, Fast 7F
• In his directive, signed in June 1996, Mr. Big Mac states that he does "not want to remain alive or be kept in a living condition unless I can do so without the assistance of any kind of life-sustaining treatment if I am diagnosed to have a terminal condition." His directive further indicates that he does not want to be sustained by "any equipment or machinery" nor by "artificially administered sustenance."

• All the children agreed that the patient was vocal before he got ill about not wanting to prolong his life if he was in a significantly debilitated state.

• "The patient somewhat reflexively opens his mouth whenever somebody comes into the room and the caregivers have been feeding him routinely. He is even getting high caloric supplemental drinks in the morning. The caregiving staff also give him baked goods in the form of cakes and cookies and the granddaughter feeds him his favorite meal— a Big Mac!"

• Family believed it was consistent with his wishes as expressed in his directive to stop feeding him. Patient had a Big Mac for his last meal.

• He lived for one week.

AHD, Dementia and Withholding Food and Water by Mouth Case

The Advance Directive for Dementia of Colette Chandler-Cramer

I know the gift of life is precious. However, I believe death is a natural part of our life journey and the timing of death has its own rhythm. When either my body or my mind is worn out and beyond repair, I am ready to die without medical intervention.

For the circumstance in which I develop severe dementia, I define that stage in two ways. First, by stages 6 and 7 of the Functional Assessment Staging Test. Second, I include my personal definition: when I am no longer able to recognize family or friends, am no longer engaged in the life activities listed above or any new activities, and no longer demonstrate enthusiasm or joy. I understand that my proxy will need to use judgment regarding when I have reached severe dementia.

If I enter into severe dementia, I do not want the following measures to keep me alive: heart resuscitation (CPR or defibrillation), artificial breathing (ventilation), antibiotics for infections, artificial hydration (IV fluids or nasogastric tube), artificial nutrition (nasogastric tube, PEG tube or jejunostomy tube).

Regarding eating and drinking once I am in severe dementia:

• If I am receptive to eating and drinking (i.e., show signs of anticipation and enjoyment), I want comfort feeding only. It is OK to spoon feed me any foods I like—and any texture that works—but please stop when I indicate I want no further food or drink or if I begin to choke or cough. I do want not to be cajoled, harassed, or in any way forced to eat.
• If I decline or resist food and water, please stop food and water and continue comfort care.
• If I am indifferent to food and water, please stop food and water and continue comfort care.
• In the circumstances where I have indicated above that I want not to be fed, if I then show distress, please do not resume feeding, but use distress-relieving drugs.

Lastly, if I need to be placed in a care facility, please verify before admission that my end-of-life wishes, whether expressed in this directive or elsewhere, will be respected.

AHD’s, Dementia, Fluids and Nutrition: Ethical Issues

• Medically provided treatments can be refused based on the autonomy of the capacitated patient.
• Should AHD’s preserve all of the rights of the previously capacitated person?
• What does “medically provided fluids and nutrition” include? Tube feeding and hand feeding by caregivers?
  – Is oral feeding a basic form of human caregiving?

Precedent Autonomy

• “...a patient’s autonomy right to accept or reject medical intervention is not vitiated by the onset of mental incapacity...if a person has articulated choices regarding future medical interventions, those preferences must be respected...
• “Prior expressions thus serve as the means to project a once-competent patient’s autonomy rights into a post-competence setting.”

“This wish to hasten my post-competence demise is not based on prospective suffering or distress, but rather on my personal vision of intolerable indignity and degradation associated with cognitive dysfunction. For me, it is critical to shape the post-mortem recollections of my loved ones and to preserve the lifetime image as a vital, critically thinking individual that I have strived to cultivate. In addition, it is important to me to avoid being an emotional, physical, or financial burden on my family and friends, even if they would willingly assume such burdens.

“I fully understand that my determination to avoid prolonged, progressive debilitation could prompt my demise even though I might appear content in my debilitated condition. I am exercising my prerogatives of self-determination and bodily integrity to shape my lifetime narrative, including my dying process, in accord with my strong aversions to mental dysfunction and to dependence on others.”


Challenges to Precedent Autonomy

The assumption is that the present self is the same self as the future, demented self. If the wants of the future self are different than those of the present self (e.g., values different experiences, wants food and water), then why should the latter self’s diminished capacities be overridden?

• Is the demented future person the same self as the prior self?

Theories of Personal Identity

• Physical/bodily continuity
• Psychological continuity (memory)
• Narrative continuity (thematic continuity)
• How are the individual and social constructs of the self related?
• Which view(s) support precedent autonomy?
Challenges

- Withholding food and water from an incompetent patient is an affront to human dignity and is inhumane.
- The present self would be discriminating against the future disabled self.
- The future self’s best interests should prevail over the wishes of the present self.
- Caregivers cannot help patients kill themselves.


AHD’s and Advanced Dementia: Issues and Problems - Timing

- Individual choices are embedded in social practices and relationships
- Caregivers’ moral responsibilities and integrity may limit the range of individual choices
- Care environments pose limitations on choices
- Equitable access to end-of-life care
  — Concierge dying?
Location, Location, Location

The setting in which the request to stop offering food and water is being evaluated will likely play a large role in whether the request is honored:

• Facility: Nursing Home or Assisted Living
• Home: Family and/or Home Health Care

How would socioeconomic factors then affect the actual prospects for the current self to make decisions for the future self?

• Are basic moral rights (autonomy) contingent on socioeconomic status?

• If justice requires equity but not all can afford the same range of choices at end of life, what are the ethical implications?

ADH’s and Advanced Dementia: Issues and Problems

• The Minnesota Department of Health (MDH) recently announced that it will add Alzheimer’s disease as a new qualifying condition for the state’s medical cannabis program. Under state law, the new condition will take effect in August 2019.

• “Any policy decisions about cannabis are difficult due to the relative lack of published scientific evidence,” said Minnesota Commissioner of Health Jan Malcolm. “However, there is some evidence for potential benefits of medical cannabis to improve the mood, sleep and behavior of patients suffering from Alzheimer’s disease.”
Mismatch between what the future self on marijuana wants...

and what the future self gets...

The Way From Here...
If an AHD is to be used to direct that oral feeding be withheld from a future demented self...

• This AHD is most similar to a Psychiatric AHD
• The present self and the future self must be seen as continuous
• The present self has moral priority and authority over the future self (precedent autonomy)
• One's agent must be willing to implement it
• Caregivers must be willing to accept its limitations
• Society must accept this way of dying as not being neglect or abuse
You can’t always get what you want...

Which self will not get what it wants, the present intact self or the future demented self?

That depends on...

Discussion

• Would you complete an AHD in which you declined oral feeding if severely demented?
• Would you as a healthcare agent decline oral feeding for your severely demented friend or loved one?
• Would you as a caregiver comply with a request to stop all feeding?