Learning Objectives for the session on “VSED by Advance Directive”:

1. To understand the questionable legal status and legal potential of advance directives for stopping eating and drinking.

2. To know the advisable elements of a plausible directive to withhold food and water, including the difference between withholding food and water and withholding assistance with eating and drinking while offering food and fluid.

3. To recognize the difficulties encountered by caregivers in implementing advance directives to stop eating and drinking.

4. To understand reasons for and against including basic personal care, not only medical treatment, within the scope of advance directives.

5. To learn what end-of-life options are available to patients who do not want to wait until their advanced dementia has progressed to the point where they no longer can self-feed.

6. To be aware of the end-of-life options that may be available for advanced dementia patients who lack a clear, specific advance directive but who have the active concern of several people who knew them well before they lost capacity.

[PTM, 3 Oct 2016]
Two Barriers to VSED by Advance Directive: Change of Mind, Basic Personal Care
Paul T. Menzel, PhD

Abstract

Two legal realities about VSED and advance directives create the possibility of a controversial third. (1) Any competent person has the right to VSED. (2) In becoming incompetent people do not lose their rights; they preserve their ability to exercise them by advance directives. (3) Then people by sufficiently clear directive for their later incompetence ought to be able to have food and water withheld, just as they can refuse lifesaving medical treatment.

Ought such advance directives for stopping eating and drinking (ADs for SED) to have the same normative force as more typical directives to refuse lifesaving medical treatment? The propositional logic above, that 1 + 2 implies 3, says they should, but legal, moral, and clinical barriers intrude. This presentation addresses two of them.

(A) Willingness to eat as a change of mind. In their later incompetence (severe dementia, e.g.) some persons with ADs for SED will still accept food and water by mouth. Does that constitute a change of mind about the directive, removing its normative force?

(B) Food and water are basic personal care, not medical treatment. Even if such acceptance of food and fluids does not constitute a relevant change of mind, food and water are different than medical treatment. As basic personal care, they are not amenable to control by advance directive. Caregivers may not be restricted by ADs in the basic personal care they are obligated to provide, as they ought to be restricted in providing medical care.

I argue that though each of these objections is cogent, neither constitutes persuasive grounds for refusing to implement an AD for SED. The first can be correct; physically accepting food and water could constitute a relevant change of mind, but with a sufficiently clear directive it will not. The second objection fails once we examine the fundamental reasons why directives have normative force at all. Those reasons hold for basic personal care as well.

Most Important Sources


Barriers to VSED by Advance Directive: Change of Mind, Basic Personal Care

Paul Menzel, PhD
Pacific Lutheran University (emeritus)

Hastening Death by Voluntarily Stopping Eating and Drinking,
a conference at Seattle University School of Law
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Presentation Structure

I. The core argument – powerful but problematic

II. Advance directives (ADs)
   • the then-self vs. now-self problem
   • its solution in case of severe dementia

III. Change of mind – what kind alters the force of a directive? Desire to eat?

IV. Basic personal care vs. medical care – for ADs, is the distinction relevant?

Conclusion and alternatives
Part I. The Core Argument

1. Competent persons have a moral-legal right to refuse food and water by mouth.

2. No one loses their rights in becoming incompetent – just exercised by others per AD/proxy.

3. By clear directive, ought to be able to refuse food and water by mouth – an AD for (V)SED.

Some greatly object to having their life extend into years of severe dementia at least as much as they wish to control for pain and suffering – thus ADs for SED as important as for refusing lifesaving treatment.

But how much may an AD control? When a person’s interests change? Food & water, not just med. tr.?

Part II. Advance Directives (ADs)

ADs’ recognized authority is wide:

- Refuse any medical treatment, including
  - acute lifesaving treatment
  - medically administered food & water, the refusal of which ensures death
  - whether or not illness is terminal

Powerful arguments for ADs’ normative weight:

- Self-determination, self-ownership
- Continuing narrative identity
Importance of Clarity

- AD must be valid: informed, uncoerced
- Must be applicable – the conditions intended for its directions to apply must now be present.
  But then AD must state the conditions meant to trigger implementation.
- AD should also convey reasons for its directions, so potential “change of mind” can be accurately discerned.

Characteristics of a Clear Directive for Dementia

- Knowledgeable about stages and affective dimensions of dementia
- Clear about the stage of dementia that the person wants to trigger implementation.
- If AD specifies withholding oral food or feeding assistance, be clear how to handle an apparent desire to eat.
Then-self vs. Now-self Problem

- Person who wrote AD (then-self) may radically change – e.g., in dementia
  - doesn’t remember writing the AD
  - doesn’t care about autonomy
  - may not now find her diminished life unbearable

- What gives the then-self authority over the now-self?

- Critics say: scrap autonomy, focus on best interests of patient as she is now.

Response

- To focus only on interests of now-self treats someone as if she had never been competent – unacceptable (N. Rhoden).

- Narrative identity – combination of bodily continuity and “story” of our lives over time:
  - previous self hasn’t disappeared – “… not here any more, but she is still our Mom ….”
  - The “whole-life” self still has continuing interests that count in weighing up what’s in the current patient’s overall best interest.
  - a difficult balancing, but sometimes the AD wins
Two Kinds of Interests (R. Dworkin)

- “Experiential” interests, derived from first-order desires – non-reflective, we just have them.
- “Critical” interests, derived from second-order desires (desires about other desires). It is these that create the enduring values of a whole life.
- In severe dementia, experiential interests change, but critical interests remain the same (those expressed in an AD, for example). Like posthumous interests (damage to reputation, e.g.), they exist even when not now experienced.
- Puts argument on critics’ own ground – patient best interest.

Best Interest and Survival

Balance critical & experiential interests:

- AD has little authority where person is actively engaged and values her life.
- Power of AD increases as present subjective value of survival diminishes.
- As dementia deepens, person
  - no longer anticipates being alive in the future
  - no longer remembers yesterday (having surv’d)
  - value of life to the person whose life it is becomes minimal and is outweighed by the person’s critical interests conveyed in the AD.
Part III. Change of Mind

- More recent AD supercedes earlier one.
- Revocation or change of mind removes us from then-self/now-self conflict.
- In even moderately severe dementia, no capacity to reconsider. Berghmans:

  The irony of dementia is that “...at the time you would...‘change your mind’ [about your AD because you’ve adapted], you do not have enough mind left to change.”*


Relevant Change of Mind Still Possible

My claim: even after there’s not enough of a mind to revoke a directive or write a new one, a relevant change of mind can still occur that alters the force of an AD.

- The attitudes and desires that were the reasons for the AD may change.
- When that’s the case, if we do not follow the AD, we are not disrespecting the person who wrote it.
Change of Mind: Two Cases

- **Andrew***: moderate/severe Alzheimer’s, does not recognize individuals but enjoys life. AD says no life-extending care when he no longer recognizes…. Contracts pneumonia – treat?

- **Margot Bentley**: 84, former nurse, strong clear AD for no food/water in severe dementia, which she now has. Now she accepts food, somewhat discriminatingly. Stop feeding?

Is Andrew’s enjoyment of life or Margot Bentley’s willingness to eat a relevant change of mind?


Andrew: Two Versions

- **Andrew’s** key reason for AD was that he viewed life with Alzheimer’s when he would no longer recognize individuals as a life he would not enjoy. He was a very social person.

- Now, however, though unable to recognize people as specific individuals, he is not distressed, smiles often, appears to enjoy life.

- An attitude that was a key reason for his AD has changed. Without this basis, why should we follow his directive? Not following it can still take him and his directive seriously.
Andrew: Two Versions (cont'd)

Revised Andrew’s different reasons for the same request:

- Life lacking this capacity is not the kind he lived for and encouraged others to thrive on.
- Preferred resources go to things he cared about much more strongly than continuing to live in such a condition, even if happy.
- Wanted loved ones not to have to care for him for years, with likely result he would not be remembered as clearly or fondly.

These reasons have not changed. They are not the sort that he can any longer change.

Margot Bentley

- What does opening her mouth to accept some foods, but not others, constitute?
  - Her consent to eat?
    - Probably not, though B.C. court said it did.
  - A relevant change of mind about her AD?
    - No. Her reason was not that she thought she would not accept food or not want to eat.
  - An expression of desire to live?
    - Doubtful. Does she have much capacity for such desire if she cannot now anticipate surviving or remember having survived?
Part IV. Basic Personal Care

- If basic personal care, in contrast to medical treatment, is not the sort of thing a person may properly control by AD, we don’t need to find a solution to the then-self/now-self problem in the case of an AD for SED, and we don’t need to look for a person’s possible change of mind.

- Focus is then directly on what basic personal care caregivers are obligated to provide, independent of any AD.

Should caregiver obligations be insulated from patient ADs?

Reasons for ADs’ Moral Weight

- Self-ownership: the life of Jane with dementia is still her life, and still her body.

- Self-determination: the person to whom the care is most important is the person who gets the care. She should have control of it – its primary effects are on her.

- Desert, prerogative, narrative identity:
  "A person, by nurturing and developing a body, character, and relationships has earned a prerogative to shape a life narrative – including the medical fate of a succeeding incompetent persona." *

* N. Cantor: //blogs.harvard.edu/billofhealth/2015/12/02/is-it-immoral-for-me-to-dictate-an-accelerated-death-for-my-future-demented-self/
Applied to ADs for Personal Care

- Some people want to control food and water as much as medical treatment.
- Self-ownership applies equally – it’s her life that’s sustained whether by Rx or F&W.
- Self-determination applies equally.
- Narrative life and the desert/prerogative that go with it apply equally.
- “Mental Health ADs” can be written for many non-medical matters.
- Bodily intrusion may be different, but the right to VSED is already acknowledged.

Caregiver Obligations

But are caregivers’ obligations re feeding absolute, unconditioned by patient ADs?

- Same question can be asked of lifesaving Rx. There we say ADs shape caregiver obligations. Caregivers have accepted that.
- Basic moral reasons behind ADs apply to food and water as much as to lifesaving Rx.
- Then why should caregiver obligations re food and water be any less conditioned by ADs?
- In absence of AD, caregiver obligations re Rx and food and water remain just as strong.
- Cultural transition time is needed.
Not Living Long into Dementia – Options

Goal: not living into years of severe dementia

- **AD for medical treatment** – effectiveness contingent on circumstance
- **AD for SED** – likelihood of implementation dependent on various factors, including
  - clarity of the AD, esp. re dementia and SED, and reiterated in early dementia
  - savvy and persistent appointed proxy
- **Pre-emptive VSED**, patient still decisive – difficult to discern, lost good time
- **Pre-emptive suicide** – lost good time, little support from caregivers
When Will ADs to Withhold Food and Water by Mouth Become Acceptable?

- When Comfort Feeding Only has come to be regarded as good care for dementia patients as they develop problems with eating.

- A clarifying legal case arises:
  - AD is clear re dementia and SED
  - AD was reiterated close to time of incompetence
  - proxy is persistent
  - caregivers refuse to carry out AD

- Courts see basic personal care within AD scope.

Medicare and Medicaid

Withholding food & water can be neglect or abuse that removes Medicare and Medicaid eligibility.

But “failure to provide adequate nutrition & hydration to support and maintain health” is explicitly conditioned on the absence of an AD to withhold food and water.*

Beyond Voluntarily Stopping Eating & Drinking: Options to Help Patients Avoid Prolonged Dying in Advanced Dementia including “Natural Dying.”

Stanley A. Terman, PhD, M.D.
Board Certified in Psychiatry
Medical Director and CEO, Caring Advocates

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