Understanding New and Emerging Issues Regarding Medical Decision-Making for Incapacitated Patients

Table of Contents

I. Advance Directives

A. Definition and Purpose

1. While individuals have decision making capacity, they can control their own healthcare. However, many individuals eventually lose decision-making capacity with illnesses, injuries, and aging.

2. To control their post-autonomy healthcare, individuals can complete advance directives. Minn. Stat § 145C ("Health Care Directives"); Minn. Stat. § 144.651(10) ("Health Care Bill of Rights").

3. Advance directives are combination documents that offer individuals two ways to assert their prospective autonomy. They allow individuals to leave specific healthcare instructions and/or to appoint a healthcare agent who can make healthcare decisions on their behalf.

B. Limits

1. Despite numerous educational campaigns and even despite enhanced Medicare reimbursement for ACP, advance directive completion rates remain mediocre in Minnesota. K.N. Yadav et al., *Approximately One in Three US Adults Completes Any Type of Advance Directive for End-of-Life Care,* 36(7) Health Affairs 1244-1251 (2017).

3. Moreover, even when completed, many advance directives are not found or available when needed.

3. Moreover, even when both completed and available, many advance directives are too vague. They often fail to provide adequate guidance either to surrogates or to healthcare providers.

II. Advance Directives & Dementia

A. Traditional Advance Directives

1. Most advance directives address post-1950s medical technology interventions such as dialysis, mechanical ventilation, feeding tubes, and CPR. These interventions are explicitly included on the suggested form. Minn. Stat § 145C.16.

2. Traditional advance directives focus on opting-out of the default pathway, which is the deployment of life-sustaining treatment.

B. Dying from Dementia

1. 6 million Americans have Alzheimer's disease. That number is expected to increase to 14 million by 2050

2. Advanced dementia, including Alzheimer's disease, is the sixth leading cause of death in the United States. It is the fifth leading cause for people over 65, and the third for those over 85.

3. The lifetime risk of dementia for the cohort born in 1940, at age 70 is 31% for men and 37% for women. Ezra Fishman, *Risk of Developing Dementia at Older Ages in the United States*, 54(5) Demography 1897-1919 (2017).

4. Many individuals want to avoid living in the late stages of dementia (e.g. stage 7 Alzheimer's). People live well with dementia for several years, but when the disease has progressed to the point that they can no longer toilet, speak or swallow, many individuals feel the disease enters a time of needless suffering and indignity.

C. Limits of Traditional Advance Directives to Address Dying from Dementia

1. These individuals are not dependent upon any life-sustaining treatment. While they have a right to refuse medical care, there is nothing to "turn off" or "disconnect."

2. Therefore, traditional advance directives cannot help these individuals avoid living in states that they find intolerable. Barak Gaster et al., *Advance Directives for Dementia Meeting a Unique Challeng*e, 318(22) JAMA 2175-2176 (2017); Paula Span, *One Day Your Mind May Fade. At Least You'll Have a Plan*, N.Y. Times (Jan. 18, 2018).

3. These individuals need special advance directive provisions that address orally administered food and fluids. Thaddeus M. Pope & Lindsey Anderson, *Voluntarily Stopping Eating and Drinking: A Legal Treatment Option at the End of Life*, 17(2) Widener Law Review 363-428 (2011).

III. Severe Dementia Directives

A. Definition and Purpose

1. Severe dementia directives focus on healthcare in cases of dementia rather than on healthcare in critical or intensive care contexts.

2. A key provision in these directives directs the withholding of food and fluid by mouth. This is also known as withholding of hand feeding (upon which the individual is dependent in advanced dementia). This is also known as "advance VSED" (voluntarily stopping eating and drinking).

3. In her advance directive the patient specifies measurable conditions (a point in time) when she wants care-providers to stop hand feeding.

4. Once the patient stops consuming fluids, she will die from dehydration in 10 to 14 days. Timothy E. Quill et al., *Voluntarily Stopping Eating and Drinking Among Patients with Serious Advanced Illness—Clinical, Ethical, and Legal Aspects*, 178(1) JAMA Intern Med. 123-127 (2018).

5. Death from VSED is peaceful and comfortable. Thaddeus M. Pope, *Narrative Symposium: Patient, Family, and Clinician Experiences with Voluntarily Stopping Eating and Drinking (VSED)*, 6(2) Narrative Inquiry in Bioethics 75-126 (2016).

B. Prevalence

1. There is a growing interest in severe dementia directives. Jane E. Brody, *Alzheimer's? Your Paperwork May Not Be in Order*, N.Y. Times (April 30, 2018).

2. New forms and tools have been developed and published both by End-of-Life Choices New York and by End-of-Life Washington. EOLCNY, *Advanced Directive for Receiving Oral Foods and Fluids in Dementia,* http://endoflifechoicesny.org.

3. With a growing emphasis on medical aid in dying (now legal in eight U.S. jurisdictions) to control the timing and manner of death, there is growing recognition of the inability of MAID to help those with dementia. Those patients cannot concurrently satisfy two eligibility criteria at the same time: terminal illness and capacity. Thaddeus M. Pope, *Medical Aid in Dying: When Legal Safeguards Become Burdensome Obstacles*, ASCO Post (Dec. 25, 2017).

4. One of the most common questions during listening sessions on Minn. S.F. 1880 (2016) ("Minnesota Compassionate Care Act"), was "What about dementia?"

IV. Validity of Severe Dementia Directives in Minnesota

A. Individuals or their agents may refuse any "health care." Minn. Stat. § 144.651(10) ("Health Care Bill of Rights – Right to Refuse Care").

1. If the individual cannot refuse on her own behalf, she may refuse through instructions. Alternatively, her agent can refuse on her behalf.

2. "A health care directive may include one or more health care instructions to direct health care providers, others assisting with health care, family members, and a health care agent." Minn. Stat. 145C.02.

3. "A health care directive may include a health care power of attorney to appoint a health care agent to make health care decisions for the principal."

B. "Health care" is defined broadly in the Health Care Directives Act.

1. "'Health care' means any care, treatment, service, or procedure to maintain, diagnose, or otherwise affect a person's physical or mental condition." Minn. Stat. 145C.01(4).

2. Therefore, "health care" includes hand feeding, because hand feeding is a "service or procedure" that "affects a person's physical . . . condition."

C. Some states explicitly exclude oral food and fluids from the scope of advance directives. Minnesota does not make such an exclusion.

1. See, e.g., Wis. Stat. § 155.20; N.Y. Pub. Health Code § 2994a.

2. Minnesota used to have a similar exclusion in the 1989 Minn. Stat. 145B. But that statute was sunset in 1998. The new 1998 Minn. Stat. 145C does not include such an exclusion.

D. An increasing number of health care professional associations recognize VSED as a healthcare intervention with position statements or CPGs.

1. Royal Dutch Medical Association & Dutch Nurses Association (2015).
2. American Nurses Association (2017).
3. International Association of Hospice & Palliative Care (2017).
4. Austrian Palliative Society (2018).

E. There is an increasing amount of guidance for clinicians on how to manage VSED. J.W. Wax et al., *Voluntary Stopping Eating and Drinking.* 66(3) J. Am. Geriatrics Soc. 441-445 (2018).

F. Some tribunals have recently recognized VSED as a legitimate medical practice. *See, e.g., College of Physicians and Surgeons of British Columbia, Final Disposition Report of the Inquiry Committee,* CPS File No. IC2017-0836, Feb. 13, 2018

G. Even if hand feeding is not "health care," individuals can refuse "any" medical or non-medical intervention by a healthcare provider.

1. To administer intervention without consent is a tortious battery. Mohr v. Williams, 104 N.W. 12 (Minn. 1905).

V. Following a Severe Dementia Directive Does Not Constitute Assisted Suicide

A. Assisted suicide is a felony. Minn. Stat. 609.215.

B. Health care choices are not allowed under the Health Care Directives Act, if they would constitute assisted suicide.

C. Healthcare provider participation in VSED is not assisted suicide.

1. This is a passive, not active means of hastening death.

2. The clinician's participation is limited to palliation of symptoms. Such conduct is carved out of the scope of prohibition.

VI. Following a Severe Dementia Directive Does Not Contravene Regulatory Duties

A. Healthcare providers have duties to ensure patients and residents get sufficient fluid intake to maintain hydration. *See, e.g.,* 42 C.F.R. 483.25(j); CMS TagF327.

B. Healthcare providers are regularly sanctioned for violating these duties.

C. But patients and residents may voluntarily waive these rights. CMS Tag F242.

VII. Drafting Strategies for Severe Dementia Directives

A. Lessons from Litigated Cases

1. There have been few appellate cases interpreting the validity of dementia Directives. There have been none in Minnesota.

2. *Bentley v. Maplewood Seniors Care. Society*, 2014 BCSC 165. The court ruled that the facility did not need to honor the patient's advance directive.

3. *In re Nora Harris,* No. 13-017-G6 (Jackson County, Ore. 2016). The court ruled that the facility did not need to honor the patient's advance directive.

B. Be very clear and specific that the principal is refusing "oral" fluids.

1. In both the *Bentley* and *Harris* cases, the patients had not specifically identified hand feeding or orally administered fluids. Therefore, their references to "nutrition and hydration" were interpreted to refer to "artificial" measures, since that is what advance directives normally intend.

2. Principals making more "unusual" treatment instruction must make those instructions with extraordinary clarity and precision.

C. Be very clear and specific not only with respect to the content of the instruction but also with respect to showing that that the principal "understands" the instructions.

1. It is necessary but not sufficient that providers understand "what" the principal is instructing. Providers must also be sure that the principal understood the instructions.

2. Principals making more unusual treatment instruction must explain the reasons for making the instructions.

3. As with wills, supplementing the advance directive with a video can usefully provide assurance that principal voluntarily made the instructions in the advance directive.

D. Be very clear and specific on "when" the VSED should start.

1. Some directives may direct care during early and moderate stages of dementia. In contrast, Severe Dementia Directives focus on feeding options to be implemented only when a patient is diagnosed with moderate or severe dementia, defined as Stages 6 or 7 (the last two stages) of the widely used Functional Assessment Staging Tool (FAST). At those stages patients would be unable to feed themselves or make health care decisions.

2. The individual can specify the conditions that must be satisfied before the instructions would be triggered (e.g. inability to recognize friends or family, inability to toilet).

3. There are available tools to reflect and record these preferences. See, e.g. Stanley Terman, *My Way Cards.*

E. Include a Ulysses clause

1. In the *Bentley* case, the court found that the patient's swallowing of food (when a spoon was placed in her mouth) constituted a revocation of her advance directive. While Bentley was in stage 7 Alzheimer's at the time, capacity is decision specific. It does not require much capacity to know that one feels thirst or hunger.

2. This is probably wrong, because the patient did not appreciate the consequences of opening her mouth and swallowing, viz. undermining her prior plan to avoid severe dementia.

3. Still, patients can revoke prior advance directives with low levels of capacity. *See, e.g., Herzer v. Redstone,* No. B276191 (Cal. App. Jan. 2018).

F. What Is a Ulysses Clause?

1. The term refers to the pact that Ulysses (Odysseus) made with his men as they approached the Sirens. Ulysses wanted to hear the Sirens' song although he knew that doing so would render him incapable of rational thought. He put wax in his men's ears so that they could not hear. He had them tie him to the mast so that he could not jump into the sea. He ordered them not to change course under any circumstances, and to keep their swords upon him and to attack him if he should break free of his bonds.

2. NYEOLC offers this language: "all medications and treatments to prolong life be withheld or withdrawn and that the patient not be fed artificially or by hand "even if I appear to cooperate in being fed by opening my mouth." This contrasts with other sample language: "assisted oral feedings be done only when the patient appears receptive and cooperative and shows signs of enjoying eating and drinking."

3. "A health care directive may authorize a health care agent to make health care decisions for a principal even though the principal retains decision-making capacity." Minn. Stat. 145C.05(2)(c).