

References

- Marks, A. D., & Ahronheim, J. C. (2020). Advance Directive as Ulysses Contract: The Application of Stopping of Eating and Drinking by Advance Directive. *American Journal of Hospice & Palliative Medicine*, 37(11), 974–979. <https://doi.org/10.1177/1049909120912951>
- Pope, T. M. (2019). "Whether, When, and How to Honor Advance VSED Requests for End-Stage Dementia Patients." *The American Journal of Bioethics* 19(1): 90-92.
- Trowse, P. (2020). Voluntary stopping of eating and drinking in advance directives for adults with late-stage dementia. *Australasian Journal on Ageing*, 39(2), 142–147. <https://doi.org/10.1111/ajag.12737>

Advance Directive as Ulysses Contract: The Application of Stopping of Eating and Drinking by Advance Directive

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Abstract

Increased attention is being paid to “dementia directives,” advance directives tailored to persons with dementia that outline what treatments an individual with dementia might wish to receive or forgo should they lose capacity. Particular focus has been placed on the request to have assisted oral feedings withheld, the so-called Stopping of Eating and Drinking by Advance Directive (SED by AD), the purpose of which is to hasten death. This article reviews the available literature regarding the practice of SED by AD and explores the clinical and ethical aspects as they present at the bedside. Our review aims to show that practical, clinically applicable ways to approach such requests must be developed in order to balance the fundamental principles at play.

Keywords

voluntary stopping of eating and drinking, Stopping of Eating and Drinking by Advance Directive, palliative care, ethics

Therefore, pass these Sirens by, and stop your men’s ears with wax that none of them may hear; but if you like you can listen yourself, for you may get the men to bind you as you stand upright on a cross-piece half way up the mast, and they must lash the rope’s end to the mast itself, that you may have the pleasure of listening. If you beg and pray the men to unloose you, then they must bind you faster.¹

Introduction

In the classic epic poem, *The Odyssey*, Ulysses (Odysseus) makes a pact with his men to tie him to the mast of his ship in order to hear the compelling song of the sirens and instructs his crew to keep him tightly bound no matter how much he demands to be released. This tale has been embodied in clinical practice as a “Ulysses Contract,” a treatment agreement between patient and physician in which a competent patient documents in writing an enduring commitment to a particular treatment. Such an agreement might be considered for a condition such as mania, in which the patient could develop an altered state of mind and try to rescind agreement to that treatment.²

An analogous agreement has been proposed in the form of an advance directive to guarantee implementation of a person’s wish to refuse oral food and fluids in the event of future incapacity.³⁻⁶ Unlike a traditional advance directive that focuses on medical treatments, the proposed advance directive would guarantee a process currently available only to competent patients—voluntary stopping of eating and drinking (VSED).

Sometimes called “voluntary dehydration,” VSED is a practice in which a competent person deliberately stops eating and drinking in order to hasten death.^{7,8} Some have proposed that an incapacitated individual has the same right, through an advance directive, to request that oral hydration and nutrition be withheld,⁹⁻¹¹ the so-called Stopping of Eating and Drinking by Advance Directive (SED by AD).^{4,12} Most recently, this practice has been recognized in Nevada, amending the state’s statute governing Durable Power of Attorney for Health Care Decisions (DPAHC) to include a section that focuses specifically on treatment choices for persons with dementia.¹³

Although SED by AD is conceptually similar to VSED, the fact that the patient in question lacks capacity distinguishes it from VSED in clinical terms and therefore raises additional ethical and legal questions. Dementia-specific advance directives have been designed with the expectation that they would be implemented for the person at a point that incapacity or debility has been attained such that the person would no longer wish to live.^{5,6} Given that the majority of older adults residing in long-term care facilities lack capacity,¹⁴ and a large majority

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of those with severe dementia will develop significant eating problems,¹⁵ consideration of these circumstances requires particular attention. This article reviews the available literature regarding the practice of SED by AD and explores the clinical and ethical aspects as they present at the bedside. Certain aspects of SED by AD that remain controversial will no doubt remain unresolved in the foreseeable future. Therefore, our review aims to show that practical, clinically applicable ways to approach such requests must be developed in order to balance the fundamental principles at play.

Case Report

Mr S is an 88-year-old man whose past medical history includes Parkinson disease, frontotemporal dementia, coronary artery disease, mild congestive heart failure, and hypertension. Over the past several months, he has experienced a gradual decline, characterized by a decrease in physical function, repeated falls, and insufficient oral intake with a related weight loss of ~12% in 6 months. He has also had repeated hospitalizations for falls, urinary tract infections, and worsening confusion.

Most recently, Mr S was admitted for altered mental status. A workup at that time failed to reveal a cause for this most recent decline, though follow-up imaging suggested possible stroke. At this time, his family (2 daughters and a son; eldest daughter is the durable power of attorney) opted to forego further aggressive interventions and instead focus on comfort, and the decision is made to transfer him from his assisted living facility to a nearby inpatient hospice.

On arrival to the hospice facility, Mr S can answer simple questions, though he is only oriented to self. While he is bed-bound and sleeps for 15 to 18 hours a day, when awake he is noted by staff to be pleasant and appears to enjoy music, pet therapy, and visits from family and hospice volunteers. During this time, Mr S requires assistance from the hospice staff in the form of facilitated eating which he appears to tolerate without difficulty or distress. Although he typically consumes 20% to 50% of meals, he will occasionally accept offered snacks between meals.

After 2 weeks in the hospice facility, Mr S's children request a meeting with the medical director. During this meeting, they request that facilitated feeding be stopped. They cite their father's previously expressed wishes to "not linger" in a state of physical and cognitive impairment and that his express wish had been to not be fed if he couldn't feed himself. They further express their belief that their father "would never want to live like this" and believe he would be "horrified" if he were fully aware of his physical and cognitive state. There is no written documentation to this effect. Further exploration of their concerns reveals that although they do not believe their father is physically suffering, they express a belief that his "spirit" is suffering, given that he is existing in a state that he would have abhorred.

The nursing staff report that Mr S indicates interest when offered food, indicates when he is done eating, and appears to enjoy the physical and social aspects of eating. He shows no

signs of aspiration or dysphagia but continues to eat only 25% to 50% of meals and has progressively lost weight. Hospice staff express concern that by withholding hydration/nutrition, they will not only be hastening his death but will worsen his suffering by causing him hunger. They also feel that withholding food and drink from someone who is asking for it can be morally distressing for staff, several of whom express concern for "starving" the patient.

Discussion

What Are the Clinical Realities of Eating and Drinking in Severe Dementia?

In order to determine the best course of action, and to begin the discussion with family and staff, all involved need to understand the clinical implications of feeding or not feeding. Mr S has a history of progressive dementia with a superimposed acute event, possibly a stroke, that further compromised his neurocognitive function and may have complicated a feeding disorder developing in the natural course of his dementia. In progressive dementia, acceptance of food will gradually give way to its rejection in which the patient may push food away, clamp the mouth shut, or resist feeding in other ways. This process does not represent a studied, "conscious" rejection but rather an "aversive feeding behavior," one of a commonly encountered group of syndromes that develop in late-stage dementia.¹⁶ These behaviors eventually give way to oropharyngeal apraxia, in which the patient can no longer take in or process any food that is placed in the mouth. Oropharyngeal apraxia can be said to represent the terminal stage of dementia, in that death is certain unless artificial hydration and nutrition (ANH) is provided. However, most patients with severe dementia will die from comorbidities, usually pneumonia or other infections before that point is reached.¹⁷ These acute illnesses are generally accompanied by failure to eat and rapid onset of coma, enabling death to occur in a peaceful manner.

Mr S presently is not demonstrating aversive feeding behaviors, is still accepting food, and is sometimes even demonstrating pleasure from eating. Thus, assisted feeding appears to benefit him insofar as it provides him pleasure, whereas withholding assisted feeds appears to cause him distress. From this, several reasonable questions arise.

Can a Decision About Stopping Eating and Drinking Be Made by Proxy?

If a competent individual has the right to stop eating and drinking, proponents argue, then the same right should be guaranteed to incapacitated individuals through a legally recognized instrument, such as an advance directive.^{6,10,18} Thus, decisions about refusing food and fluids would be governed by the same rules as decisions to forgo ANH and other medical treatments, and the same rules for advance directives would apply. Honoring such requests respects an individual's autonomy and right to decide what constitutes an acceptable quality of life.¹⁰ In the

case of Mr S, the family strongly feels that the patient, when competent, held values that did not support the use of assisted feeding if it would prolong a life of severe cognitive debility and physical dependence, and he would want such feedings to be discontinued.

Mr S had conveyed his wishes to the family via an oral advance directive, which can be problematic even when explicit,¹⁹ with the most thoughtful individuals unable to predict the complexity of medical decisions their future self may face.²⁰ We know too that a person's values and goals change over time and that a living will completed years ago may no longer reflect a person's wishes.²¹ All of these considerations are magnified in the situation that confronts Mr S, his family, and his care providers.

When there is no advance directive and others must decide for the patient, specific standards are applied, including (1) substituted judgment in which a surrogate determines what the patient would decide under the present circumstances or (2) the best interests standard. A person's "best interests" are determined by assessing what would be appropriate in light of the patient's value system, including expectations for quality of life, and by balancing the burdens of a proposed treatment compared to its perceived benefits.^{22,23} Neither approach is a "gold standard," and even when rigorously applied, may contain a bias toward the values of the person actually making the decision. Notably, jurisdictions have varied widely in which standards may legally apply, to what extent, and even which treatments can or cannot be refused by others.²⁴

On top of all this, surrogate decision-making standards do not address the question of whether a patient's goals might have changed, and applying these standards with rule-like rigidity would seem short-sighted in certain circumstances. As advance directive law was evolving (a time of great ferment and debate about how to decide for others), one commentator proposed an alternative "revised best interests standard" that would take into consideration a patient's "experiential interests," whereby a patient could "obtain pleasure and enjoyment" from life even if restricted by a condition such as dementia.²⁰ Such a standard might allow for nonburdensome life-sustaining treatment in the context of a typical advance directive, which might otherwise reject such things and might, in a person such as Mr S, allow for assisted feeding, which would be pleasurable as well as nonburdensome. The question of SED by AD was not on the horizon when this "revised" standard was proposed, but the principle seems quite applicable to the newer question of whether a person can be made to stop eating and drinking by proxy.

"Past-Self" and "Now-Self": Whose Autonomy Rules?

A common question that arises in the use of advance directives is who has the moral authority to make decisions about medical treatments, the "past-self" who completed an advance directive or the "now-self" whose values and preferences may have changed?⁴ This years-old conundrum^{19,25,26} now looms over the newer issue of SED by AD. What are we to make of an

individual who previously asked to have assisted feedings stopped in the event of progressive incapacity, but like our patient Mr S, now indicates a willingness or desire to eat and drink? Does such an advance directive, as is recognized in Nevada, rise to the level of a "Ulysses contract" in which the person is compelled to carry out a vow that they no longer can uphold? Should we respect the autonomy of the past-self even if it goes against the perceived best interests—indeed, the apparent preferences—of the now-self?

The Nevada DPAHC statute had already provided for refusal of ANH. However, that provision contains language that is highly misleading from a clinical perspective, but potentially persuasive, stating that a decision to forgo tube feeding might lead to "death by starvation."²⁷ This apparent warning has long existed in that law, as well as advance directive laws in certain other states.²⁸ Ironically, no language warns about a decision to refuse food and water in the dementia amendment¹³ or elsewhere in the statute,²⁹ nor should such language appear in any advance directive law. Explanations about benefits and burdens of treatments belong in the hands of experienced medical professionals—specifically, a clinician who understands that certain interventions, such as tube feeding, may be counterpalliative, whereas others, such as comfort feeding, are recognized components of palliative care that a patient might elect if appropriately informed.³⁰

As is the case in our scenario, conflict commonly arises between a family that is understandably oriented toward the past-self and the medical team toward the now-self.³¹ Mr S's family members carry the conception of the past-self with them, when he was the "full moral agent" with whom they shared a relationship. How could they not feel a duty to honor that person's wishes?¹² In contrast, the medical team is unlikely to have known the past-self in the same fashion, if at all. All they have is the now-self and naturally would tend to place more weight on the interests of the incapacitated adult before them.

Most advance directives reflect the view that, as a person's dementia progresses, the value the past-self would place on continued existence diminishes, and the authority of that directive would likewise increase.⁴ But when the previous and current self are not aligned, difficult choices emerge. Some would place greater weight on the wishes espoused by the autonomous self of the past, who has established values or "critical interests"—those beliefs that are firmly held and theoretically enduring, and without which one would not consider theirs to be a "good" life.^{4,25} An example of a critical interest might be to maintain control of care in the event of future incompetence or severe disability. Others would place greater weight on the "experiential interests" of the current self, who, despite dementia, can appreciate a particular experience (eg, music, images, flavors), though unable to pinpoint its source or meaning.^{20,26} The conflict between Mr S's critical interest not to live in a debilitated state and his experiential interest of enjoying food or satisfying hunger or thirst is subject to these divergent ethical arguments, but as a practical matter, a way should be found to balance the autonomy of the patient's past with the

unanticipated interests of the present. This is not unreasonable, since one's critical interests are not predictive, and one's viewpoint might actually differ as time goes on, whereas experiential interests are those of the moment.²⁰

In the case of Mr S, who appears to derive pleasure from eating and drinking and distress when these are withheld, the medical team would opt to postpone implementation of the family's request until such time that the food ceases to provide apparent benefit to the patient and withholding it no longer appears to cause distress. This "not yet" approach aligns both with a "sliding scale" of moral authority⁴ and with the natural course of events at the end of life, when the patient stops eating and drinking, whether due to acute illness or a neurodegenerative feeding disorder or both. Moreover, this approach closely aligns with a larger hospice philosophy of care, which makes the patient's comfort the overriding goal. Indeed, such "comfort feeding" measures³⁰ are the standard in hospice patients such as Mr S, wherein food is provided not with a primary goal of nutrition or hydration but instead to maximize the comfort of the patient.

Can a Person With Severe Dementia Override His or Her Advance Directive?

If the rules of advance directives apply to refusal of assisted feeding, as the practice of SED by AD would demand, then patients should be permitted to override their previous instructions if they have the capacity to do so.

Determination of decisional capacity to consent for treatment generally includes 4 criteria: "the ability to communicate a choice, understand the relevant information, appreciate the medical consequences of the situation, and reason about treatment choices."³² Capacity is specific to the decision at hand—therefore, someone whose capacity is narrowed by disease or disability might be able to decide on issues that are relatively simple, and criteria for determining a specific capacity might likewise narrow.

Informed consent in the context of medical treatments generally involves express consent, "consent that is clearly and unmistakably stated,"³³ which can be provided by the patient or by proxy. In some situations, consent can be implied—that is, "inferred from one's conduct rather than from one's direct expression."³³ Thus, when a patient cannot communicate a preference, acceptance or rejection of a particular intervention, such as feeding, may be shown in other ways. As in the case of Mr S, his apparent interest in and pleasure elicited from oral intake appear to meet this criterion of implied consent.

Common sense must also play a role. One example appears during an examination of a patient with advanced dementia: The patient is mute and the clinician does not attempt to ask permission before pulling down the sheet, exposing the patient's body. The patient promptly pulls the sheet back up, her behavior clearly demonstrating a desire not to be exposed in such a way; this is a clear signal to the clinician that he or she will hopefully heed. Refusal was not verbally expressed but was implied by the patient's behavior.

The concept of implied consent also applies to eating and drinking. Cognitively intact people who forswear certain aspects of eating or drinking often change their minds or at least their behavior. For example, a person previously vowed not to eat sweets for dietary reasons, but if offered one, the dieter might accept it because of the urge to obtain pleasure from it, having chosen to ignore and override the previous vow. If the person offering the sweets knows about the vow but offers the sweets anyway, the dieter has the option to refuse, but if she chooses to accept and eats it, her consent is implied by that behavior. Similarly, feeding someone who might be hungry or thirsty but is unable to state a preference and instead of resisting readily accepts the food or drink has demonstrated implied consent.

No one can determine exactly what a patient with severe dementia experiences when he or she accepts or rejects food and can only judge by the person's behavior. Whether acceptance represents hunger or thirst, a "reflex" response or a cognitive one³⁴ and whether one calls this "consent," "assent," or merely "acceptance" are theoretical questions that are immaterial and distract from clinical decisions that must be made regarding the patient's current needs. Therefore, when parties disagree on how to proceed, the clinical realities must be made clear from the outset.

In a legal or ethical conflict, this acceptance of food and water should be seen as implied consent, and it should be permitted to override advance instructions to the contrary.³⁵ One critic suggests that this "test of capacity" is too low to be acceptable in a court of law,³⁴ as it does not comport with the traditional legal test.³² However, those with dementia who accept food and drink are not overriding a prior rejection of a complex intervention such as gastrostomy placement or ANH. Accepting food does not constitute the classic "change of mind" in a deliberative sense that would nullify an advance directive aimed at complex interventions³⁶; however, it does respect the patient's apparent desires and experiential interests²⁰ and would justify delaying implementation of the directive, the "not yet" approach taken by the medical team in our case of Mr S.³⁷

Is It Wrong to Offer Food and Fluids to a Patient Who Does Not Appear to Refuse it?

Commentators have asserted that feeding or merely presenting food/fluids to someone who has rejected this in an advance directive but now lacks capacity could constitute a battery.^{34,38} In general, battery is defined as "unwanted touching" or contact that is harmful or offensive, even if the outcome is perceived to be desirable. In the medical context, treatment without proper informed consent could have this result—for example, performing cardiopulmonary resuscitation despite an order not to resuscitate,³⁹ and such a charge could also extend to unwanted feeding by tube.^{40,41} However, the argument that this

applies to personally assisted eating and drinking is controversial at best.

The law recognizes the clinical burdens of “forced feeding,” that is, “forced intrusion that causes discomfort or restraint,” such as struggling to open a patient’s mouth, forcibly restraining patients to prevent them from removing a feeding tube, or surgically implanting a gastrostomy or jejunostomy tube.⁴² However, these illustrative examples in no way resemble ready acceptance of food and water by a patient with cognitive dysfunction, as described in our case above.

One cannot predict whether a court would find a battery in the dilemma described in this article—if food or fluids were offered to a patient with severe dementia who appeared hungry or thirsty, and readily accepted. A lower court in Oregon denied one guardian’s request to prevent staff from assisting such person in eating, despite her wish to refuse it as stated on a previously written document.^{43,44} In Canada, an appellate court rejected the finding of battery in a similar situation, finding that the patient’s acceptance of food constituted a valid consent, overriding instructions on her advance directive.⁴⁵ In the Canadian case, the patient was described as having severe dementia (“stage 7 of 7”) and required “prodding” and “prompting” to eat,⁴⁵ which would suggest to the reader an aversive feeding behavior bordering on oral dyspraxia. If a comfort feeding approach had been offered and discussed carefully with the family, perhaps an advance directive debate and year-long legal wrangling could have been avoided.

Conclusion

In SED by AD, a sort of Ulysses contract involving a patient tied down not by physical bonds but by mental incapacity, has gained increasing attention, and though controversial, surrogate refusal of food and water was recently incorporated as an amendment governing persons with dementia in Nevada’s advance directive statute.¹³ The significance of that amendment remains to be seen, as the clinical significance of the “refusal” could and should be interpreted at the bedside. However, in the United States, a legally protected right for an incapacitated patient to broadly refuse food and fluids through a surrogate would be a major move beyond the established right to refuse ANH.

Although based on the principle of autonomy, SED by AD may cause tension between families who wish to honor the instructions made by the person’s past-self and clinicians who want to support the clinical interests of the patient before them, the “now-self.” These values are best balanced by thoroughly educating staff and carefully informing families about the clinical realities of progressive dementia, which ultimately necessitate feeding decisions whether there is an advance directive or not.

Patients in the future may have sweeping freedom to choose the precise manner and time of their death, on their own or by proxy. At present, a legal right to refuse comfort feeding in advance of an uncertain future, and an accompanying

responsibility of health-care providers to adhere to this instruction made years before, must include the following:

- patient and surrogate understanding about the advance decision when made and the clinical implications of the choice,
- thorough knowledge of the clinical implications by any professional who assists in filling out the advance directive,
- thorough education of nursing staff who will assist the patient whether at home or in an institution,
- resolution of moral conflicts that such a practice might produce, and
- resolution of legal conflicts such as regulations about feeding,⁴⁶ on the one hand, and advance directive law, on the other.⁴⁷

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References

1. Homer, Murray AT. *The Odyssey*. London, UK: W. Heinemann; G.P. Putnam’s Sons; 1919.
2. Spellecy R. Reviving Ulysses contracts. *Kennedy Inst Ethics J*. 2004;13(4):373-392.
3. Gaster B, Larson EB, Curtis JR. Advance directives for dementia: meeting a unique challenge. *JAMA*. 2017;318(22):2175-2176.
4. Menzel PT, Cramer MC. Advance directives, dementia, and withholding food and fluid by mouth. *Hastings Cent Rep*. 2014;44(3):23-37.
5. Health Directive for Dementia. 2017. <https://static1.squarespace.com/static/5a0128cf8fd4d22ca11a405d/t/5cd9efd571c10b87cbaf4676/1557786582104/dementia-directive.pdf>. Accessed November 2019.
6. End of Life Washington. *My instructions for oral eating and drinking*. 2017. <https://endoflifewa.org/wp-content/uploads/2017/10/Instructions-for-oral-food-and-water-FINAL-10-2-17.pdf>. Accessed November 2019.
7. Quill TE, Ganzini L, Truog RD, Pope TM. Voluntary stopping of eating and drinking among patients with serious advanced illness: clinical, ethical and legal aspects. *JAMA*. 2018;178(1):123-127.
8. Lachman VD. Voluntary stopping of eating and drinking: an ethical alternative to physician-assisted suicide. *Med Surg Nurs J*. 2015;24(1):56-59.
9. Steinbock B, Menzel PT. Advance directive for refusing life-sustaining treatment in dementia. *Hasting Cent Rep*. 2018;48(5):75-79.

10. Pope TM. Whether, when, and how to honor advance VSED requests for end-stage dementia patients. *Am J Bioeth.* 2019; 19(1):90-92.
11. Menzel PT. Justifying a surrogate's request to forego oral feeding. *Am J Bioeth.* 2019;19(1):92-94.
12. Dresser R. Toward a humane death with dementia. *Hastings Cent Rep.* 2014;44(3):38-40.
13. *Power of Attorney for Health Care for an Adult With Any Form of Dementia: Form.* Nev. Rev. Stat. §162A.870 (eff. Oct 1, 2019).
14. Darby RR, Dickerson BC. Dementia, decision making, and capacity. *Harv Rev Psychiatry.* 2017;25(6):270-278.
15. Mitchell SL, Teno JM, Kiely DK, et al. The clinical course of advanced dementia. *N Engl J Med.* 2009;361(16):1529-1538.
16. Blandford G. *Eating disorders.* In: Tallis RC, Fillit M ed. *Brocklehurst's Textbook of Geriatric Medicine and Gerontology.* 6th ed. London, UK: Churchill Livingstone (Elsevier Science Limited); 2003:1381-1390.
17. Ahronheim JC, Morrison RS, Morris J, Baskin SA, Meier DE. Palliative care in advanced dementia: a randomized controlled trial and descriptive analysis. *J Palliat Med.* 2000;3(3):265-273.
18. Schwarz JK. Death by voluntary dehydration: suicide or the right to refuse a life-prolonging measure? *Widener Law Rev.* 2011; 17(351):351-361.
19. Rhoden NK. The limits of legal objectivity. *N C L Rev.* 1990; 68(5):845-865.
20. Dresser R. Missing persons: legal perceptions of incompetent patients. *Rutgers Law Rev* 1994;46(2):609-719.
21. Kim SYH. Improving medical decisions for incapacitated persons: does focusing on "accurate predictions" lead to an inaccurate picture? *J Med Philos.* 2014;39(2):187-195.
22. Cantor NL. Twenty-five years after Quinlan: a review of the jurisprudence of death and dying. *J Law Med Ethics.* 2001; 29(2):182-196.
23. Torke AM, Alexander GC, Lantos J. Substituted judgement: the limitations in autonomy in surrogate decision making. *J of Gen Int Med.* 2008;23(9):1514-1517.
24. American Bar Association. *Commission on Law and Aging. State-Specific Advance Planning Forms.* Chicago, IL; 2019. https://www.americanbar.org/content/dam/aba/administrative/law_aging/2018-lnks-to-st-spcific-advnc-drectv-frms.pdf. Accessed February 13, 2020.
25. Dworkin R. *Life's dominion.* London, United Kingdom: Harper Collins Publishers; 1993: 228-229, 258 n20.
26. Dresser R. Dworkin on dementia. Elegant theory, questionable policy. *Hastings Cent Rep.* 1995;25(6):32-38.
27. *Nev Rev Stat.* §162A.860.
28. Sieger C, Arnold J, Ahronheim JC. Refusing artificial nutrition and hydration: does statutory law send the wrong message? *J Am Geriatr Soc.* 2002;50(3):544-550.
29. *Power of attorney for adult with intellectual disability: Form.* Nev Rev Stat. §162A.865.
30. Palecek EJ, Teno JM, Casarett DJ, Hanson LC, Rhodes RL, Mitchell SL. Comfort feeding only: a proposal to bring clarity to decision-making regarding difficulty with eating for persons with advanced dementia. *J Am Geriatr Soc.* 2010;58(3):580-584.
31. Aleccia J. Should patients with dementia be able to decline spoon-feeding? NPR. 2017. <https://www.npr.org/sections/health-shots/2017/11/03/561393940/should-dementia-patients-be-able-to-decline-spoon-feeding>. Accessed November 2019.
32. Appelbaum PS. Clinical practice. Assessment of patients' competence to consent to treatment. *N Engl J Med.* 2007;357(18): 1834-1840.
33. Garner BA ed. *Black's Law Dictionary.* St Paul, MI: Second Pocket Edition West Group; 2001.
34. Pope TM, West A. Legal briefing: voluntary stopping of eating and drinking. *J Clin Ethics.* 2014;25(1):68-80.
35. Shaw LC. *Bentley v Maplewood: Consenting to Live.* TheCourt.ca; 2015. <http://www.thecourt.ca/bentley-v-maplewood-consenting-to-live/>. Accessed November 2019.
36. Loewy EH. Changing one's mind: when is Odysseus to be believed? *J Gen Intern Med.* 1988;3(1):54-58.
37. Menzel PT. Three barriers to VSED by advance directive: a critical assessment. *Seattle J Soc Just.* 2017;15(3):673-700.
38. Pope TM, Anderson LE. Voluntarily stopping of eating and drinking: a legal treatment option at the end of life. *Widener Law Rev.* 2011;17:363-427.
39. Anderson, Admr, Appellee V. St. Francis-St. George Hospital, Inc. 77 Ohio St. 3d 82. *North East Rep Second Ser.* 1992;614:841-847.
40. *Cruzan v. Dir, Mo. Dep't of Health* 497 U.S. 261:269 (1990).
41. *Bouvia v Superior Court of Los Angeles County.* 179 Cal. App. 3d 1127 1138.
42. *Cruzan v. Dir., Mo. Dep't of Health* 497 U.S. 261, at 287-9 (O'Connor concurring).
43. Aleccia J. August 21, 2017. *Despite advance directive, dementia patient denied last wish, says spouse.* Kaiser Health News KHN. <https://khn.org/news/despite-advance-directive-dementia-patient-denied-last-wish-says-spouse/>. Accessed November 2019.
44. Circuit Court of the State of Oregon for the County of Jackson. Case No. 13-107-G6 2016. <https://www.documentcloud.org/documents/3921692-Harris-Order-Denied.html>. Accessed November 2019.
45. *Bentley v Fraser Health (Appellate Opening Brief).* http://www.thaddeuspope.com/images/Factum_Final.pdf. Accessed December 2019.
46. Centers for Medicare & Medicaid Services, HHS CFR § 483.25. Quality of Care. <https://www.govinfo.gov/content/pkg/CFR-2011-title42-vol5/pdf/CFR-2011-title42-vol5-sec483-25.pdf>. Accessed December 2, 2019.
47. Centers for Medicare & Medicaid Services, HHS CFR § 483.10—Resident rights. <https://www.govinfo.gov/app/details/CFR-2011-title42-vol5/CFR-2011-title42-vol5-sec483-10>. Accessed December 2019.

Whether, When, and How to Honor Advance VSED Requests for End-Stage Dementia Patients

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The Director of Nursing at the Pleasant Valley Nursing Home has requested an ethics consultation for guidance on whether the staff should follow the directions of a resident's health care agent. Rhea, the agent, has asked the staff to stop spoon feeding Gertrude. Gertrude has end-stage dementia. Rhea explains that Gertrude did not want any orally or artificially ingested food or fluids under those circumstances.

The ethics consultant should ask (and answer) at least six questions:

1. Is the advance directive valid?
2. Who is the decision maker?
3. Has Gertrude, in fact, requested forgoing spoon feeding?
4. Does Rhea have authority to direct forgoing spoon feeding?
5. Is Rhea complying with applicable decision-making standards?
6. Does Gertrude's opening and swallowing trump contrary instructions?

IS THE ADVANCE DIRECTIVE VALID?

Clinicians should presume that a health care directive is legally sufficient absent actual knowledge to the contrary. Here, although Gertrude's advance directive is 10 years old, there is no evidence (such as a separation of the partners) to suggest that Rhea's agency is invalid. First, Gertrude and Rhea lived together for 15 years. Apparently, they would still be living together but for Gertrude's admission to the nursing home. Second, Rhea appears to be an involved and caring agent. She visits regularly and is reasonably available to make health care decisions on Gertrude's behalf.

WHO IS THE DECISION MAKER?

Presumptively, the patient makes her own health care decisions. Clinicians must presume that patients have decision-making capacity until they can rebut that presumption. Moreover, even if the patient, in fact, lacks capacity,

clinicians should restore it, if possible, so that the patient can make her own decisions. That does not seem possible here. Gertrude lacks capacity, and there is no way to restore it. Given the advanced stage of her dementia, Gertrude lacks the ability to understand the significant benefits, risks, and alternatives to proposed health care. And she lacks the ability to make or communicate a health care decision.

Since Gertrude lacks capacity, her advance directive is activated. Through her advance directive, Gertrude has appointed Rhea as her health care agent. Therefore, Rhea is the legally authorized decision maker for Gertrude. Without an advance directive, Rhea's status as a non-spouse partner might have been either inferior or unclear relative to Gertrude's siblings, relatives, and friends. But Gertrude has an advance directive. Therefore, Rhea's authority is superior, even exclusive (Pope 2012).

HAS GERTRUDE, IN FACT, REQUESTED FORGOING SPOON FEEDING?

In her advance directive, Gertrude has written: "Do not feed me if I can't recognize anyone! I would rather be dead." The triggering condition in this instruction has obtained. Gertrude cannot recognize anyone. But what exactly does Gertrude want? Unfortunately, we cannot be sure. "Do not feed me" is ambiguous. Is she referring to artificial nutrition and hydration? Or is she referring to spoon feeding? Because Gertrude completed the advance directive 6 years before her dementia diagnosis, it is unclear whether "cannot recognize anyone" refers to dementia or whether it refers to being in a coma, persistent vegetative state (PVS), or minimally conscious state (MCS).

When interpreting similar language in other advance directives, courts have held that the patient was probably referring to artificial nutrition and hydration, because that is what patients typically address in advance directives (Pope and Richards 2015). Therefore, without more

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explicit reference to food and fluid “by mouth” or to “spoon feeding,” it is unclear (perhaps even unlikely) that Gertrude has, in fact, requested forgoing spoon feeding.

This conclusion is bolstered by the fact that the staff members at Pleasant Valley Nursing Home never noticed this language on Gertrude’s admission. The staff clearly read Gertrude’s advance directive and prepared medical orders to implement her other wishes. But the “do not feed me” language did not convey to staff that Gertrude was asking for what Rhea is now directing.

But that is not the end of the analysis. As Gertrude’s agent, Rhea is authorized to interpret the advance directive. After all, if advance directives were self-executing, then there would be no need for agents. Of course, advance directives are rarely self-executing. By appointing Rhea, Gertrude entrusted her to make health care decisions not definitively answered by the advance directive’s written instructions. As agent, Rhea gets to resolve the ambiguity and interpret the advance directive. Ideally, Rhea has evidence other than the advance directive itself (such as conversations or, ideally, video) that Gertrude wanted to forgo spoon feeding when she reached end-stage dementia.

DOES RHEA HAVE AUTHORITY TO DIRECT FORGOING SPOON FEEDING?

It is unclear where the Pleasant Valley Nursing Home is located. But in some U.S. states Rhea would lack legal authority to direct staff to forgo spoon feeding (Pope and Anderson 2011). For example, the Wisconsin statute defining the powers and duties of health care agents provides that an agent “may not consent to the withholding or withdrawal of orally ingested nutrition or hydration unless provision of the nutrition or hydration is medically contraindicated.” Other states place similar limits on the scope of permissible health care decisions in an advance directive or by an agent.

There is a growing literature on whether clinical ethics consultants should limit their advice to clearly legally permissible options. But, typically, the law does (and should) constrain the available options. The ethics consultant should confirm with the nursing home’s risk manager or general counsel whether health care agents in their jurisdiction may direct the forgoing of spoon feeding. If state law prohibits agents from making such requests, then Rhea might consider transferring Gertrude to a facility in another jurisdiction.

IS RHEA COMPLYING WITH APPLICABLE DECISION-MAKING STANDARDS?

Assume that Pleasant Valley Nursing Home is not located in a jurisdiction like Wisconsin. Assume that there is no direct legal constraint on Rhea’s authority to direct forgoing spoon feeding. Rhea must still comply with applicable decision-making standards. In virtually every state, Rhea’s duty as agent is to exercise substituted judgment if possible. Because Gertrude’s advance directive is ambiguous, it is

difficult to know whether Rhea is complying with substituted judgment unless she has further evidence of Gertrude’s wishes.

If Rhea has little or no evidence of Gertrude’s wishes regarding spoon feeding beyond the advance directive itself, then Rhea’s duty is to act in Gertrude’s best interest. Typically, these seven factors guide the application of the best interest standard: (1) the patient’s present level of physical, sensory, emotional, and cognitive functioning; (2) quality of life, life expectancy, and prognosis for recovery with and without treatment; (3) the various treatment options and the risks, side effects, and benefits of each; (4) the nature and degree of physical pain or suffering resulting from the medical condition; (5) whether the medical treatment being provided is causing or may cause pain, suffering, or serious complications; (6) the pain or suffering to the patient if the medical treatment is withdrawn; and (7) whether any particular treatment would be proportionate or disproportionate in terms of the benefits to be gained by the patient versus the burdens caused to the patient (Pope 2012).

The staff may disagree with Rhea that forgoing spoon feeding is in Gertrude’s best interest. But as Gertrude’s agent, Rhea is authorized to determine Gertrude’s best interest in close call situations (Pope 2018b). Here, the balancing of benefits and burdens is not lopsided. Rhea’s determination is not obviously unreasonable. Consequently, it appears that Rhea is complying with applicable decision-making standards.

DOES GERTRUDE’S OPENING AND SWALLOWING TRUMP CONTRARY INSTRUCTIONS?

We have a valid advance directive. Rhea has made a legitimate request to forgo spoon feeding. Normally, clinicians should comply with the directions of a health care agent. But has Gertrude revoked her earlier instructions? Is she now vetoing Rhea’s directions?

When the nursing home staff puts a spoon of food or thickened liquids to Gertrude’s mouth, she opens her mouth and swallows. Since capacity is a decision-specific inquiry, some might argue that even in end-stage dementia Gertrude knows she wants to eat and is expressing that wish. But Gertrude does not appreciate the consequences of consuming food and fluids. She does not understand that would prolong life in a state that she found abhorrent. While a capacitated decision by Gertrude would trump both her advance directive and Rhea’s directions, Gertrude’s “request” for spoon feeding lacks capacity. Therefore, Rhea’s direction remains valid.

CONCLUSION

Clinicians and health care societies have increasingly accepted voluntarily stopping eating and drinking (VSED) as an appropriate end-of-life exit option (Pope 2018a; Quill et al. 2018). If capacitated patients may hasten their deaths with VSED, then incapacitated patients

should be able to exercise that same choice through an advance directive or health care agent. An increasing number of tools and resources are available to help individuals exert that control (Pope 2018c). ■

REFERENCES

- Pope, T. 2012. Legal fundamentals of surrogate decision making. *Chest* 141(4): 1074–1081.
- Pope, T. 2018a. Law and ethics in oncology: Voluntarily stopping eating and drinking is a legal and ethical exit option. *ASCO Post* (June 25, 2018).
- Pope, T. 2018b. The best interest standard for health care decision making: Definition and defense. *The American Journal of Bioethics* : 18(8): 36–38.
- Pope, T. 2018c. VSED resources. Available at: <http://thaddeuspope.com/vsed.html>.
- Pope, T., and L. Anderson. 2011. Voluntarily stopping eating and drinking: A legal treatment option at the end of life. *Widener Law Review* 17(2): 363–428.
- Pope, T. M., and B. J. Richards. 2015. Prospective autonomy and dementia: Ulysses contracts for VSED. *Journal of Bioethical Inquiry* 12(3): 389–394. doi: 10.1007/s11673-015-9652-6.
- Quill, T., L. Ganzini, R. Truog, and T. Pope. 2018. Voluntarily stopping eating and drinking among patients with serious advanced illness—clinical, ethical, and legal aspects. *JAMA Internal Medicine* 178(1): 123–127.

Justifying a Surrogate's Request to Forego Oral Feeding

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Gertrude's advance directive (AD) is coherent. It speaks to end-stage as well as terminal conditions, and why shouldn't it, if Gertrude is equally concerned that her life not continue for years with an end-stage but not yet "terminal" chronic illness? It also includes withholding oral feeding, not just life-prolonging medical interventions. Again, why not, if her primary point in withholding any medical intervention is that her life not be prolonged in the relevant conditions she specifies? Her goal in withholding oral feeding is undoubtedly identical.

Of course the directive will hardly always be clear. Sometimes her agent Rhea may not know exactly what Gertrude wanted. ADs inevitably labor under such weakness. Patients therefore appoint health care agents whom they trust to use discretion on their behalf. When agents know patients well and have had long-standing close relationships with them, we fail to respect patients if we do not follow the appointed, trusted agent. An agent's decision-making role, to be sure, like a directive's substantive instructions, may need interpretation and can be tempered if the agent is now not very connected to or concerned about the patient or there is distinct conflict of interest.

Gertrude's partner Rhea is not compromised in any such ways. She visits far more often than anyone else. She and the nursing-home health care team agree on the major timing element of Gertrude's substantive instructions: end-stage dementia, no longer recognizing anyone. And "do not feed me [in those

circumstances]" would have to include stopping spoon feeding when that is the only way oral feeding can take place—what else could "do not feed me" mean in such situations?

A good reason for resisting Rhea's request will have to be something else. Three candidates are (1) a direct challenge to the ethical basis for ADs known as the "then-self versus now-self" problem, (2) interpreting Gertrude's swallowing when spoon-fed to constitute a change of mind about her directive, and (3) caregivers' obligation to feed because oral feeding, unlike medical treatment, does not fall within the proper scope of an AD. None of these, I argue, is an ethically sound reason for not following Rhea's request.

THEN-SELF VERSUS NOW-SELF

The basic case for ADs is intuitive and direct: Whose life is it, anyway? The competent individual has the moral authority to make decisions about medical treatment, including for situations when the person has lost decision-making capacity. There, too, the life at stake is still her life. It is certainly not anyone else's.

ADs, nonetheless, face a fundamental challenge. The very situation the directive's writer wishes to avoid can change the person whom it afflicts. When she wrote her directive, she may have regarded extreme cognitive impairment and failure to recognize individuals as contrary to her dignity, her values, and her strongest desires about the last stage of her life; she badly wants it not to

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Voluntary stopping of eating and drinking in advance directives for adults with late-stage dementia

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Abstract

Objective: The objective of this paper is to explore the ethical and legal validity of advance directives that request the voluntary stopping of eating and drinking against a backdrop of late-stage dementia.

Method: Doctrinal research and analysis of primary and secondary materials, including Australian legislation, Australian case law and journal articles, was undertaken.

Results: There is legal uncertainty in Australia around whether an advance directive to voluntarily stop eating and drinking will be followed should the adult become incompetent.

Conclusion: Voluntary stopping of eating and drinking should be viewed in law as a form of “treatment” that competent adults can nominate in advance directives, thereby providing dementia patients with the opportunity to choose in advance, if they wish, to end their life legally, with dignity and comfort, and in a manner that does not implicate others in criminal behaviour such as assisted suicide, acceleration of death or euthanasia.

KEYWORDS

advance care planning, advance directives, dementia, withholding treatment

1 | INTRODUCTION

Dementia is a seriously debilitating condition that impacts upon the person, carers and family members. It is not part of the normal ageing process, although age is one of the strongest risk factors.¹ Dementia is a chronic, progressive condition caused by a variety of diseases that affect ‘*memory, thinking, behaviour and the ability to perform everyday activities.*’ [2; p.2] People suffering from dementia eventually lose capacity to make decisions about their health care. If a person reaches late-stage dementia, care is left entirely to others until the end of their life. This may include a requirement to be hand-fed. (This term is used to include the provision of nutrition and hydration via the hand of a person caring for the individual.) Some adults, especially

those with friends or relatives suffering from late-stage dementia, may not want to live to this point should they have the misfortune of succumbing to the illness themselves.³

If a competent person decides life is no longer worth living because of intolerable pain, overly compromised dignity, painful and invasive procedures or any other reason, the person can choose to end his or her life by refusing treatment that might otherwise sustain it. This includes the refusal of nutrition and hydration, and has been termed ‘*voluntary stopping of eating and drinking.*’ [4; p.376] An adult who voluntarily stops eating and drinking should receive palliative care in order to ‘*address pain, suffering and symptoms that may be experienced by the individual as he or she approaches death.*’ [4; p.376] This is known as ‘*voluntary palliated starvation.*’ [4; p.376]

Julian Savulescu asserts that the decision made by adults with capacity to voluntarily stop eating and drinking with medical support should extend to decisions made in advance.

Disclaimer: The views expressed in this article are my own views and not an official position of the Queensland University of Technology.

He observes that ‘*the person who has the most right to decide whether life is tolerable is the person who must live that life.*’ [6; p.112] Therefore, individuals who do not want to be hand-fed in the future should be able to express their wishes in an advance directive and those wishes should be respected when the person loses capacity to make health-care decisions. If the person has not executed an advance directive, it follows that proxy decision-makers, such as those holding an enduring power of attorney or a statutory health attorney, should be able to request voluntary stopping of eating and drinking if that reflects the individual's wishes.⁷ The discussion in this article is limited to the execution of advance directives only. Advance directives are also known as “advance health directives,” “advance care directives” and “living wills.” For consistency, the term “advance directive” is used throughout this paper.⁸

It is acknowledged that there are philosophical and ethical issues surrounding the voluntary stopping of eating and drinking where an individual lacks capacity. Health-care professionals and carers may not be comfortable implementing such action because the provision of food and water is viewed as nursing care or palliation. However, this must be weighed against the autonomous right to self-determination.

2 | METHODOLOGY

Doctrinal research and analysis of primary material was undertaken, including state and territory legislation governing advance directives and guardianship law. Legislation was identified by accessing electronic legal databases. Common law decisions that relate to and/or explain the legislation were also identified by searching electronic legal databases to further elucidate the meaning and operation of key legislative principles. Searches were carried out on the following databases: AustLII and Lexis Advance Pacific. Search terms included “advance directive,” “health directive,” “advance health directive,” “guardianship” and “living will.” Additionally, doctrinal research and analysis of secondary material including journal articles relating to advance directives, voluntary stopping of eating and drinking, and dementia was undertaken. Searches were carried out on the following databases: EBSCOhost (including CINAHL and PubMed). Search terms included “voluntary stopping of eating and drinking,” “voluntary palliated starvation,” “right to refuse food and water,” “hand feeding” and “dementia.”

3 | RESULTS

The competent refusal of nutrition and hydration is ethically and legally acceptable.^{4,5} However, it is unclear whether such refusal can be made in advance and implemented legally through an advance directive. The following sections address

Policy Impact

The law surrounding the validity of advance directives must be clear. Competent adults must be confident that their choices will be respected if they lose capacity. Health professionals and carers must be confident they are acting within the law if they follow a request in an advance directive.

Practice Impact

For some adults, the idea of being hand-fed is undignified, is humiliating and unnecessarily prolongs an inevitable death. Health professionals and carers need to know with clarity whether it is lawful to follow an advance directive that directs the voluntary stopping of eating and drinking, and patients need to be confident that their directives will be implemented.

this issue and illustrate its complexity by applying the various state and territorial laws in Australia that govern advance directives to a case study.

3.1 | Competent refusal of nutrition and hydration

There is significant research around the ethics of voluntary stopping of eating and drinking by an adult with capacity and correlations with physician assisted suicide and voluntary active euthanasia.⁴ Nonetheless, provided the person requesting to voluntarily stop eating and drinking has capacity to make the decision, it is legally accepted as a means utilised by individuals to hasten death.⁹

The voluntary stopping of eating and drinking by an adult with capacity was held to be lawful in the South Australian case of *H Ltd v J*.^{10,11} It was further held that there is no common law duty of care on health-care providers to deliver sustenance to a competent adult who refuses to accept it.¹⁰ While the refusal of food and water would bring about death, it is not considered suicide; rather, it is an exercise of the right to self-determination, and those responding to the patient's wishes, such as health professionals and carers, have not engaged in assisted suicide.

3.2 | Refusal of treatment and advance directives

There is uncertainty in Australia about whether a competent adult can make an advance directive to voluntarily stop eating and drinking, and whether such a directive, if made, would be binding. This is important because health professionals and carers need to know with clarity whether it is lawful to

follow an advance directive requesting the voluntary stopping of eating and drinking, and patients need to be confident that their directives will be implemented.

An adult with capacity can complete an advance directive instructing health professionals to withhold treatment such as the provision of artificial nutrition and hydration should it become necessary, and the instruction will be honoured. However, it is uncertain whether the same directive can be given in relation to nutrition and hydration that is provided naturally.

Arguments against advance requests for voluntary stopping of eating and drinking include strong comparisons to passive euthanasia. However as noted by Christensen, this argument starts from the premise that an individual with capacity who requests that nutrition and hydration cease is committing suicide.⁷ There is both literature and case law that asserts this is not the case.^{4-6,10,11} Advance requests for voluntary stopping of eating and drinking have also been criticised because there is no ability for the individual to change their mind.⁷ However, this is also the case with withdrawal and withholding of artificial nutrition and hydration. Both cases result in the passing of the individual, the only difference being the method through which the nutrition and hydration is refused. Furthermore, instruction and education about the impact and expectations of an advance request to voluntarily stop eating and drinking must be provided before such a directive is executed.^{12,13}

One problematic aspect of advance requests for voluntary stopping of eating and drinking is where there is active involvement from the individual being fed. While they are unable or unwilling to feed themselves, if a spoonful of food (usually in a pureed state) or liquid is placed against their lips they may open their mouths. The Ethics Committee of the Society for Post-Acute and Long Term Care Medicine (AMDA) in the United States recommends a policy of comfort feeding for patients with advanced dementia, notwithstanding an advance directive providing otherwise. Comfort feeding is aimed at the provision of pleasure in food rather than sustenance. The Society asserts that greater injustice is done by ending a person's life in circumstances where they wish to eat, drink and live, than violating their autonomous right to self-determination. Ostensibly, this is correct, but the legal question in this context is whether or not circumstances have changed sufficiently for the directive to not be followed, or, alternatively, whether the situation that initiates the operation of the instruction has in fact arisen.

Clearly, there are situations where the patient actively chooses to accept nutrition and hydration and, in those cases, if there is an indication that the patient has actually changed their mind about their advance directive, or has not yet reached the point where nutrition and hydration are irrelevant activities in their lives, the directive is not operative and

should not be followed. However, there are cases where the person's willingness to accept food in the late stages of dementia is a reflex action only.⁷ There is a difference between a patient who robotically opens their mouth when food is placed against their lips and one who cries out for sustenance. Other aspects of the person's life must be observed—for example, whether they are enjoying their food and showing interest when it is placed before them, the patient's general attitude and responsiveness to their surroundings and consideration of previous discussions or assertions about or in relation to medical treatment that the person made when they had capacity.⁷

This is important in the context of dementia because the very symptoms these terminally ill patients seek to avoid, such as pain, suffering, humiliation and loss of dignity, may be experienced at a point when they have lost capacity and can no longer make decisions in relation to their health care. As a result, they are unable to give directions to withhold nutrition and hydration. Patients suffering from late-stage dementia are vulnerable and cannot advocate for themselves. They have no voice, yet they are dignified human beings who once expressed their autonomy. Unless there are clear indications to the contrary, their advance directions or previously expressed wishes should be accommodated.

3.3 | Lack of clarity in the law

Unfortunately, there is a lack of clarity in the law, which creates uncertainty for patients who may wish to make requests in advance to voluntarily stop eating and drinking in circumstances such as late-stage dementia. Further and significantly, it is important for health professionals and carers to know whether an advance directive is valid and should therefore be implemented so that the wishes of the patient, who now lacks capacity, can be followed; or whether following the instructions provided in the document would constitute illegal conduct.

The law relating to advance directives is governed by state and territory legislation and is not uniform throughout the various Australian jurisdictions. Definitions and requirements differ among the states and territories so that a request for voluntary stopping of eating and drinking in one jurisdiction may have a different affect in another.

The following hypothetical case study exemplifies the problem.

3.3.1 | Case example

A 90-year-old woman is suffering from end-stage dementia caused by vascular disease. She is incontinent, is immobile and has lost interest in and the ability to feed herself, although she will allow the nursing staff to “spoon-feed” her. She does not recognise friends or family and regularly

appears confused, frightened, anxious and emotional. She wears a pain patch but cannot articulate whether she is experiencing any pain relief.

When she had capacity, she completed an advance directive and ticked and initialled all options stating “I do not want artificial hydration” and “I do not want artificial nutrition.” She also added a request stating “I do not want to be hand fed.”

At this point in time, the patient does not require artificial nutrition and hydration but she does require hand feeding.

The uncertainty in the law and therefore the challenges facing health professionals and carers faced with this situation are exemplified below.

- In Victoria, there are two types of directives—an instructional directive, which takes effect as if the person completing the directive has provided valid consent; and a value directive, which is a statement of preferences. The legislation provides that “palliative care” includes the provision of food and water and that a directive that concerns palliative care is treated as a “value directive.” Health professionals are required to take value directives into consideration when they are providing health care, but they are not obliged to follow them. Therefore, it is uncertain whether a patient's advance directive to refuse food and water would be followed in Victoria.¹⁴
- The reasonable provision of food and water is also considered palliative care in the Australian Capital Territory; however, the legislation governing advance directives in that jurisdiction does not apply to palliative care. In addition, a health professional must not withhold treatment from a person unless the health professional believes the direction complies with the legislation. Therefore, the refusal of food and water is outside the ambit of the legislation, unless the provision of food and water is considered to be unreasonable, thereby creating uncertainty about whether a directive to voluntarily stop eating and drinking would be binding.¹⁵
- In South Australia, an advance directive refusing food and water will be binding if the provision of food and water constitutes “health care.” If the provision of food and water is not considered to be “health care,” the direction will be non-binding,¹⁶ again creating uncertainty about whether it should be followed. Interestingly, one of the principles of the South Australian legislation is that ‘*a competent adult can decide what constitutes quality of life ... and can express that in advance in an advance care directive.*’ [17; p. 7] This suggests a desire in the legislation to prioritise the autonomous decision of the patient rather than whether the decision is considered reasonable by health professionals.
- The situation is particularly complex in Queensland. There

is legislation that governs the withdrawal and withholding of life-sustaining measures in certain circumstances.

- The first issue is whether hand feeding is a *life-sustaining measure*. The definition of a *life-sustaining measure* includes health care intended to maintain the operation of vital bodily functions that are permanently incapable of independent operation.¹⁷ It is arguable that hand feeding maintains a bodily function (the intake of nutrition and hydration) that the patient is unable to achieve independently, and is therefore a life-sustaining measure.¹⁷
- A direction to withdraw or withhold life-sustaining measures cannot operate unless one of the following applies (emphasis added):
 - a) The patient has a *terminal illness* or condition that is *incurable or irreversible* and in the opinion of two doctors may reasonably be expected to *die within 1 year*;
 - b) The patient is in a *persistent vegetative state*;
 - c) The patient is *permanently unconscious*; and
 - d) The patient has an illness of such severity that there is *no reasonable prospect that the patient will recover* to the extent that the patient's life can be sustained without the continued application of *life-sustaining measures*.¹⁸
- In the case example, the patient is not in a *vegetative state* or *permanently unconscious*, and, although her condition is *terminal, incurable and irreversible*, the doctors cannot attest that she is expected to die in the near future. They do not know how long she will live. However, she might have an illness of *such severity* that there is *no reasonable prospect that she will recover without the continued application of life-sustaining measures*.
- In Queensland, a life-sustaining measure can only be withheld or withdrawn if commencement or continuation of that measure would be inconsistent with good medical practice.¹⁸ Good medical practice is defined in the legislation and is focussed on the medical and ethical standards, the practices and procedures of the medical profession, and not the wishes and expectations of the patient.¹⁹ Therefore, if the medical team treating the patient is not of the view it would be inconsistent with good medical practice to continue hand feeding, it cannot be withdrawn.
- If hand feeding is not recognised as a life-sustaining measure under the Queensland legislation because it is not “health care,” then the advance directive does not comply with the legislation and the common law could be applicable.^{20,21}

A further complexity in Queensland (and Western Australia) is that it is a criminal offence for a person in charge of another, to deprive that person of the necessities of life—such as nutrition and hydration.²² In *Brightwater Care Group v Rossiter*,²³ the

court recognised that the provision of nutrition and hydration through a percutaneous endoscopic gastrostomy to Mr Rossiter, who was unable to move due to permanent injury, could be withdrawn without committing an offence because Mr Rossiter retained the mental capacity to make informed decisions; therefore, he was not “within the charge” of the facility caring for him. Unlike Mr Rossiter, the patient in the case study does not have capacity to make health-care decisions. However, it is submitted that the obligation to provide necessities would be extinguished in circumstances where an advance directive operates, just as it is where the directive requires the withholding nutrition and hydration that is provided artificially.

These brief applications of the law indicate a lack of certainty. The law should clearly provide that an adult without capacity can voluntarily stop eating and drinking through the choice and direction made in advance when the adult had capacity, as indicated in their advance directive. If the adult has reached late-stage dementia where there is no reasonable prospect of recovery and their life cannot be sustained without being hand-fed, the directive should be activated to allow the patient to stop eating and drinking, succumb to voluntary palliated starvation, and die peacefully and with dignity.

Because the legislation governing advance directives is state- and territory-based, legislative changes that would allow for voluntary stopping of eating and drinking directives to be made in advance will vary. However, one initial response would be to re-define terms such as “medical treatment,” “health care” and “life-sustaining measures” to include the provision of nutrition and hydration by hand.

4 | CONCLUSIONS

An individual with capacity can make a decision to voluntarily stop eating and drinking, and that decision will be followed both legally and ethically out of respect for the person's autonomous rights. It is recommended that the same respect should be afforded to the person when they no longer have capacity and that voluntary stopping of eating and drinking in cases of late-stage dementia should be a form of “treatment” that an adult with capacity can direct in advance, thereby providing dementia patients with the opportunity to choose, if they wish, to end their life legally, with dignity and comfort, and in a manner that does not implicate others in criminal behaviour such as assisted suicide, acceleration of death or euthanasia.

It is important that Australians complete advance directives in order to protect their autonomy and dignity should they lose capacity in the future to make decisions about their health care. With this in mind, there is a need for patients, health professionals and carers to be confident about the validity of, and associated responsibilities and liabilities

attaching to advance directives that request the voluntary stopping of eating and drinking. Clarity in the law also allows for the development of policies around the law to ensure the patient receives adequate palliative care, dies with dignity and is free of pain, discomfort and humiliation.

Voluntarily stopping of eating and drinking followed by voluntary palliated starvation may not be the path of choice for everyone, but for those who wish to go down this avenue and for those involved in its implementation, the path should be clear and unobstructed.

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REFERENCES

1. World Health Organisation. *Global action plan on the public health response to dementia 2017–2025*. [Cited 2017]. <https://apps.who.int/iris/bitstream/handle/10665/259615/9789241513487-eng.pdf;jsessionid=B965AF7AEBCB40A8B19A3779EB02C8C2?sequence=1>
2. World Health Organisation and Alzheimer's Disease International. *Dementia A Public Health Priority*. 2. [Cited 2012] https://www.who.int/mental_health/publications/dementia_report_2012/en
3. Steinbock B, Menzel PT. Advance directives for refusing life-sustaining treatment in dementia. *Hastings Cent Rep*. 2018; 48: 75-79.
4. White BP, Willmott L, Savulescu J. Voluntary palliated starvation: A lawful and ethical way to die? *J Law Med*. 2014; 22: 376-386.
5. McGee A, Miller FG. Advice and care for patients who die by voluntarily stopping eating and drinking is not assisted suicide. *BMC Med*. 2017; 15: 222.
6. Savulescu J. A simple solution to the puzzles of end of life? Voluntary palliated starvation. *J Med Ethics* 2014; 40(2): 110-113.
7. Christensen J. An ethical discussion on voluntarily stopping eating and drinking by proxy decision maker or by advance directive. *J Hosp Palliat Nurs*. 2019; 21(3): 15-16.
8. White B, McDonald F, Willmott L. *Health Law in Australia*, 9th edn. New South Wales, Australia: Lawbook Co, 2018.
9. Ivanovic N, Buche D, Fringer A. Voluntary stopping of eating and drinking at the end of life - a ‘systematic search and review’ giving insight into an option of hastening death in capacitated adults at the end of life. *BMC Palliat Care*. 2014; 13(1): 1-8.
10. *H Ltd v J* [2010] SASC 176 [98].
11. *Re E (Medical Treatment Anorexia)* [2012] EWHC 1639.
12. Lachman V. Voluntary stopping of eating and drinking: An ethical alternative to physician-assisted suicide. *Medsurg Nurs*. 2015; 24(1): 56-59.
13. *Re T (adult: refusal of medical treatment)* [1992] 4 All ER 649.
14. *Medical Treatment Planning and Decisions Act 2016* (VIC) ss5, 6, 12(3) (c), 60.
15. *Medical Treatment (Health Decisions) Act 2006* (ACT) ss3, 7(1), 6, 12.
16. *Advance Care Directives Act 2013* (SA) ss3, 4, 10(b).
17. *Guardianship and Administration Act 2000* (Qld) Schedule 2, Section 5A.
18. *Powers of Attorney Act 1998* (Qld) s 36(2).

19. *Guardianship and Administration Act 2000* (Qld) Schedule 2, Section 5B.
20. *Powers of Attorney Act 1998* (Qld) s 35(1).
21. White B, Willmott L. Will you do as I ask? Compliance with instructions about health care in Queensland. *Law Justice J.* 2004; 4(1): 77-87.
22. *Criminal Code Act 1899* (Qld) s 285.
23. *Brightwater Care Group v Rossiter* (2009) 40 WAR 84; *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88; *H Ltd v J* [2010] SASC 176.

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