Advance Directives for Refusing Life-Sustaining Treatment in Dementia

BY BONNIE STEINBOCK AND PAUL T. MENZEL

Since the 1960s, there has been increasing acceptance in American law and society of the right of individuals to participate in and, within limits, control their medical treatment. Such participation and control reflect a rejection of medical paternalism and support for autonomy and respect for persons.

In the 1970s, the ability of competent individuals to control medical interventions led to support for advance directives that enabled individuals, either through living wills or health care proxies, to express their values and preferences about medical treatment when they would no longer be competent to make decisions. In the landmark case *in re Quinlan*, the New Jersey Supreme Court found that "Karen's choice [to decline medical treatment], if she were competent to make it, would be vindicated by the law" and "should not be discarded solely because her condition prevents her conscious exercise of the choice."[1]

The *Quinlan* judicial precedent was soon augmented by "living will" statutes, the first in 1975 in California. All fifty states followed in their various ways. Fairly quickly there was a backlash, with critics arguing that living wills were too imprecise a tool for carrying out someone's preferences.[2] It is difficult enough to know what treatments one is willing to accept in a particular situation and almost impossible to know in advance which treatments one would want to refuse years later. Health care proxies, however—individuals whom people appoint to carry out their wishes on the basis of the proxies' knowledge of their values and preferences—have been viewed as avoiding many of the pitfalls.[3]

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The rise of advance directives was shortly followed by growing support for another means for controlling the end of life, physician-assisted death. At present, physician-assisted suicide, or, as it is often called, aid in dying, is legal by judicial decision in Montana and by statute in six other U.S. jurisdictions, Oregon, Washington, Vermont, Colorado, California, and the District of Columbia; come January 2019, it will be legal by statute in Hawaii as well. Medical assistance in dying (MAID) is also legal in Canada following a Canadian Supreme Court decision and subsequent implementation legislation.

Aid-in-dying laws in the United States have two important restrictions. First, only patients who are terminally ill, defined as having a prognosis of six months or less to live, qualify. Second, at the time the patients take the lethal medication, they must be competent to make medical decisions. This means that an advance directive requesting aid in dying for a later time when the patient lacks decision-making capacity would be invalid. However, many people are more concerned about avoiding living into severe dementia for years—a time when they will lack decision-making capacity—than they are about preventing suffering or the loss of dignity or autonomy for a few months at the end of life.

Gillian Bennett is an example of someone determined not to live into severe dementia. She opted for preemptive suicide in 2014, explaining why in a letter she posted online:

> Every day I lose bits of myself, and it's obvious that I am heading toward the state that all dementia patients eventually get to: not knowing who I am and requiring full-time care. I know as I write these words that within six months, or nine months, or twelve months, I, Gillian, will no longer be here. What is to be done

with my carcass? It will be physically alive, but there will be no one inside.[4]

Bennett did not want to have "a minder" to care for her "mindless body." As a Canadian, she did not want her country to expend tens of thousands of dollars a year on her care for perhaps a decade. She did not want to impose the burdens such care would entail on her family. And she wanted her family and friends to remember her as she was, not as a body empty of her person. She preferred to take her own life rather than to allow that to happen.

In 2014, Canada had not yet legalized medical assistance in dying; it became legal two years later. Even if it had been legal in 2014, however, it is not at all clear that Bennett would have qualified. She was not yet in "an *advanced* state of irreversible decline in capability" (emphasis added), her natural death had not yet "become reasonably foreseeable," and it is debatable whether her state of decline was already causing her "enduring physical or psychological suffering."[5] Nor could she have relied on an advance directive to dictate that she be given active medical assistance in dying when she would be in such an advanced state; that would contravene the requirement of contemporary competence. Similarly, in the United States, Bennett would not have been "death eligible" had she lived in a state where aid in dying is legal. Thus, legalized aid in dying is not a solution for those wishing to avoid living into severe dementia.

Bennett's solution to avoiding living into severe dementia was preemptive suicide.[6] A major problem with this solution, however, is that the individual is likely thereby to be giving up some "good time." Obviously, judging from the letter Bennett wrote, she was not yet severely impaired, even if she was forgetful. She was still Gillian.

A legal alternative to preemptive suicide is to create an advance directive stating the circumstances under which one wants not to receive any lifesaving or life-sustaining treatment, even the most basic and noninvasive.[7] This option is our focus in this paper: how to create effective advance directives to avoid living into severe dementia. To be relevant to progressive dementia, the directive would need to state what kinds of care should be withheld and when. At the same time, advance directives for severe dementia face serious challenges. Before addressing these, we review the normative force of directives themselves.

The Moral Case for Advance Directives

The case for advance directives is simple and eloquent: whose life is it, anyway? Surely it is the competent individual herself who has the moral authority to decide on what medical treatment is acceptable, as well as when enough is enough. Even when the person lacks decision-making capacity, the life at stake is still *her life*.

At the same time, there is a fundamental challenge to advance directives, which is particularly strong in the case of progressive dementia. The very situation that the writer of the directive wishes to avoid also changes the person on whom it is carried out. When she writes her directive, she regards nearly losing her mind or having her family (or perhaps her country) burdened with her care as contrary to her dignity and deepest values. But when she enters severe dementia, neither of these things will matter to her anymore, nor will she remember writing the directive.

In the literature on precedent autonomy, this is often called the "then-self/now-self problem." The writer of the directive, the competent individual, is the then-self; the present incompetent individual is the now-self. Since the now-self doesn't care about the things that the then-self cared about, what justifies withholding treatment that would now save the person's life? What justifies prioritizing the contrasting concerns of the then-self? Caregivers should not look to advance directives to determine what medical treatment should be given, but should focus entirely on the needs and interests of their patient and loved one *as she is now*.[8]

Supporting this approach are several associated considerations: the disability critique, adaptation, and the possibility of a change of mind. We argue that none of these constitutes a persuasive rejection of advance directives for advanced dementia.

The disability critique. According to this line of criticism, when individuals claim they would not want to live with a particular disabling condition, including cognitive impairment, their judgment on the subjective quality of life may be distorted by ignorance and prejudicial attitudes, captured by the word "ableism." With appropriate, compassionate care, even people in severe dementia can have relatively happy—at least not unhappy—lives.

We do not dispute this. Moreover, we acknowledge that for many people, such care is precisely what they want. They do not want to create an advance directive specifying when in dementia life-sustaining treatment should be withheld. They want to receive good life-sustaining care as long as their life does not involve unbearable pain and suffering, which severe dementia rarely imposes.

Not everyone, however, shares this view. Many badly want their life not to be marked by a final stage with chronic loss of cognition, memory, and recognition of family and loved ones; for them, this is quintessentially not what *their life* is about. We deny that such a view of a person's own life is necessarily bigoted. Nor is it necessarily ignorant; many who hold this view hold it, in fact, precisely because they are intimately familiar with this kind of last stage of life from having cared for someone they loved.

Adaptation. The phenomenon of adaptation is well documented in the disability literature. The claim here is

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not that the desire not to live with profound cognitive loss may stem from ignorance or prejudice. Rather, the claim is that the desire will diminish or even cease as the individual adapts to her new reality.

Essentially, the argument from adaptation is a restatement of the then-self/now-self problem—the now-self has adapted. We acknowledge that the concerns of the then-self are not the concerns of the now-self, but we think that the then-self has significant moral authority in determining what is done when the individual is no longer competent. Why? Because the alternative would deny competent adults a strong voice in what medical treatment they regard as "worth it," preventing them from having any say in the way they die. As Nancy Rhoden eloquently expressed it, "Something is wrong . . . when we treat formerly competent patients as if they were never competent. . . . One . . . component of treating persons with respect [is] that we view them as they view themselves. If we are to do this, we must not ignore their prior choices and values."[9]

Changes of mind. It might be argued that the person in severe dementia has changed her mind about what makes her life worth living. She has not merely adapted to her new circumstances; she no longer regards them as intolerable. Someone who once prized her intellectual ability might now find simpler pursuits, such as gardening, simple crafts, or singing familiar songs, to have value that makes life worth living. Someone who says, "Yes, I might change, but I don't want to become that person—I'd rather die first," is essentially denying herself the right to change her mind. What justifies holding someone to values she once held dear, but no longer does?

Two responses are in order. The first was made by Rhoden, who admitted limits to the authority of advance directives for precisely this kind of reason: "People make prior directives to avoid being tethered to medical technology when unconscious or in a state such as Claire Conroy's [minimal consciousness]. When they start saying, 'If I can't do higher mathematics, kill me,' we will have to worry in earnest about the limits of precedent autonomy."[10] The authority of an advance directive is not unlimited.

The second is one we made in an earlier paper.[11] The values of an individual can indeed change in the early and middle stages of dementia. At some point in the progression into severe dementia, however, the individual no longer has enough of a mind to change, and certainly not enough of a mind to change the advance directive itself. It is reasonable, though not rationally required, to wish that one not survive into such a state. If one's stated wishes, whether written in a directive or made clear in other ways to one's health care proxy, are likely to be, in effect, ignored, then the only alternative left to the person who does not want to survive into severe dementia will be preemptive suicide or voluntarily stopping eating and drinking (VSED). Such preemptive actions likely involve, as they did with Gillian Bennett, dying while one still has some good time left.

We are thus back to advance directives, given how much more attractive they are than preemptive suicide. How might they be used effectively to avoid living into the advanced stages of dementia that a person does not want?

Effective Directives for Hastening Death in Dementia

In addition to being *valid* (made voluntarily and with sufficient understanding of the things to which it speaks), any advance directive, to be implemented, needs to be *applicable*—the conditions to which the person intended it to apply must now obtain. Many of the directives people write are undoubtedly not clear and substantive enough to be applicable, because they are not clear either about what is to be withheld or about when—that is, in what conditions.

Much precision regarding what and when may not be possible; one simply cannot know all the circumstances as far in advance as a directive that would address severe progressive dementia will need to be written. Designating a proxy trusted to represent one's values can fill in some of that substance, but to some extent both *what* and *when* should still be meaningfully spoken to in the directive. On both scores, major choices need to be made.

Deciding what is to be withheld is perhaps easier. Does it include the most basic and nonintrusive treatments, such as an antibiotic for pneumonia? Those whose goal is not to live long into severe dementia will likely want to say explicitly that even the most basic, routine, noninvasive treatment should be withheld. Other potentially controversial categories, such as medically delivered food and fluids, will also need to be addressed.

Stipulating when such care is to be withheld is likely to be more difficult. A relatively easy aspect of writing the directive is describing the stage of dementia into which one does not want to live. One can, for example, use any of the seven clinically defined stages of the Reisberg Functional Assessment Staging (FAST) scale, a tool for evaluating people at moderate and severe stages of dementia and whose stages can be conveyed in colloquial terms.[12] If one's goal is not to live into severe dementia, however, describing simply the stage into which one wants not to live will hardly be sufficient, for one can have no assurance that the opportunity to hasten death by withholding lifesaving treatment will ever present itself. Some people with progressive dementia will never need life-sustaining or acute lifesaving treatment. To be sure, eventually, if they do not die from something else, they will die of the neurological degradation of dementia itself, but that will typically be years into the advanced stages, when they do not recognize their closest loved ones and have little if any engagement with surrounding stimuli. If a window of opportunity to die by forgoing life-sustaining treatment comes earlier, taking it may be a very good bet. Some life worth living may thereby be sacrificed, but a lot less than with preemptive suicide or VSED. On balance, seizing such a window of opportunity may be eminently rational given the risk that it will not come along again in time.

How should one write the directive to capture such "windows of death" at a reasonable time before severe dementia? One could give earlier stage-of-dementia markers, or one could simply note the issue in one's directive and state firmly that one wants the proxy not to miss what she would regard as a reasonable opportunity to die by forgoing life-sustaining treatment if such an opportunity comes along before severe dementia itself has arrived.

None of these choices is easy for either the person writing the directive or the designated proxy implementing it, but that should hardly lead those who feel strongly about the matter to throw up their hands and only hope for the best. To be sure, even with a clear and strong directive that squarely addresses the what- and when-to-withhold issues, including capturing an early window of death, one will still need to hope that such an opportunity comes along. Yet it would be foolish to ignore the fact that one can improve the odds of not living into years of severe dementia by having a clear directive to withhold medical treatment and a trusted proxy to carry it out.

No Perfect Solutions

Two other kinds of advance directives than those for refusing life-sustaining treatment may seem to provide greater assurance of not living into severe dementia, but they are either not legally permitted or are legally problematic. Physician-assisted death could be made accessible by advance directive, as in the Netherlands and Belgium, but no legalization of active aid in dying in the United States or Canada permits its use by those who are not contemporaneously competent. Another kind of advance directive—to withhold oral feeding—would also seem to provide greater assurance that one will not live into severe dementia, for with withholding oral feeding, unlike with withholding lifesaving treatment, a patient or caregiver does not have to wait for a window of opportunity to present itself. However, while in ideal circumstances implementation of a directive to forgo oral feeding arguably is legally permissible, legal, ethical, and institutional barriers to implementing such directives are still significant.[13]

Over the decades, the pressure to develop and refine advance directives to help patients accomplish their desire not to live into years of severe dementia will likely intensify. Convictions about how life should end or not end will continue to be important to many with certain deeply held values and a strong sense of identity. Preemptive suicide and preemptive VSED are the only options that can guarantee that one will not live into severe dementia, but they are unlikely to be attractive to many. Fortunately, people can gain a considerable degree of control over when they die by creating clear advance directives. They are not a perfect solution, but they are an established legal option.

That said, the potential for using such directives to hasten death in dementia should not be inflated. Strong, maximally effective directives to withhold life-sustaining treatment are challenging to think through and write; proxies are not always sufficiently persistent and forthright to effectively implement them; and always, good care of all sorts should be accessible to the increasing number of people with progressive dementia. Even with the prospect of the best of care, however, some will want not to live into severe dementia. Their convictions should be respected.

1. In the Matter of Karen Quinlan, An Alleged Incompetent, 355 A.2d. at 644, 1976. The subsequent development of U.S. case law on refusing life-sustaining treatment, both contemporaneously and by advance directive, is reviewed by N. L. Cantor, "Twenty-Five Years after *Quinlan*: A Review of the Jurisprudence of Death and Dying," *Journal of Law, Medicine & Ethics* 29, no. 2 (2001): 182-96.

2. A. Fagerlin and C. E. Schneider, "Enough: The Failure of the Living Will," *Hastings Center Report* 34, no. 2 (2004): 30-42.

3. Ibid., 39.

4. G. Bennett, "Goodbye and Good Luck!," August 18, 2014, http://www.deadatnoon.com/page2.html.

5. Parliament of Canada, An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying), Bill C-14, June 17, 2016, http://www.laws-lois.justice.gc.ca/pdf/2016_3.pdf, p. 6. The Canadian medical assistance in dying eligibility criteria are succinctly summarized in J. Downie, "An Alternative to Medical Assistance in Dying? The Legal Status of Voluntary Stopping Eating and Drinking (VSED)," *Canadian Journal of Bioethics* 1, no. 2 (2018): 48-58, at 48-49.

6. The case for preemptive suicide is sympathetically explored by D. Davis, "Alzheimer Disease and Pre-emptive Suicide," *Journal of Medical Ethics* 29, no. 8 (2014): 543-49.

7. N. L. Cantor, "On Avoiding Deep Dementia," *Hastings Center Report* 48, no. 4 (2018): 15-24, at 17.

8. R. Dresser and J. S. Robertson, "Quality of Life and Non-treatment Decisions for Incompetent Patients," *Law, Medicine & Health Care* 17, no. 3 (1989): 234-44.

9. N. Rhoden, "The Limits of Legal Objectivity," *North Carolina Law Review* 68, no. 5 (1990): 845-65, at 860.

10. Rhoden, "Limits of Legal Objectivity," 860.

11. P. T. Menzel and B. Steinbock, "Advance Directives, Dementia, and Physician-Assisted Death," *Journal of Law, Medicine & Ethics* 41, no. 2 (2013): 484-500.

12. Medical Care Corporation, "Functional Assessment Staging Test," 2010, https://www.mccare.com/pdf/fast.pdf; B. Reisberg, "Functional Assessment Staging Test (FAST)," *Psychopharmacology Bulletin* 24 (1988): 653-59. A three-stage division (mild, moderate, severe) is used by Barak Gaster, Eric B. Larson, and J. Randolph Curtis (see their article "Advance Directives for Dementia: Meeting a Unique Challenge," *Journal of the American Medical Association* 318, no. 22 [2017]: 2175-76). A format for directives using three stages that also explicitly walks the reader through a process of consideration is available at www.dementia-directive.org. An extremely comprehensive "Alzheimer's Disease and Dementia Mental Health Advance Directive" is provided by Lisa Brodoff and End of Life Washington at https://endoflifewa.org/alzheimers-diseasedementia-advance-directive/.

13. P. T. Menzel, "What Barriers Inhibit the Use of Advance Directives for Voluntarily Stopping Eating and Drinking (VSED)?," *Medical Law Perspectives*, March 2018. For a recent exploration of the ethical and psychological barriers, see D. S. Davis, "Avoiding Dementia, Causing Distress," *Bioethics Forum* (blog), August 29, 2018, https://www.thehastingscenter.org/avoiding-dementia-causing-moral-distress/. Specific formats for writing an advance directive to forgo oral feeding are available from End of Life Choices New York and End of Life Washington at, respectively, http://endoflifechoicesny.org/wp-content/uploads/2018/03/3_24_18-Dementia-adv-dir-w-logo-no-donation-language.pdf and https://endoflifewa.org/wp-content/uploads/2017/10/Instructions-for-oral-food-and-water-FINAL-10-2-17.pdf. These directives also address the option of "comfort feeding only" that is often relevant in the end stages of dementia.