Changing the Paradigm of Advance Directives to Avoid Prolonged Dementia

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To Avoid Prolonged Dementia

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In the early days of living wills -- the 1970's and 1980's -- a major objective was to avoid being maintained on burdensome medical machinery in a highly debilitated status at the end stage of a fatal affliction. The contemporaneous legislation endorsing advance directives was typically geared to "terminal illness" (meaning likely death within 6 months). The distasteful specter was a moribund patient tethered to burdensome interventions like a respirator or a dialysis machine despite an unavoidable, looming demise. A common short-form living will rejected life support that "only prolongs the dying process" for a patient in "a terminal condition."

Another specter was being medically sustained in an utterly dismal quality of life -- such as permanent unconsciousness without awareness or interaction with one's environment. The contemporaneous legislation explicitly authorized advance directives seeking to avoid medical maintenance in a permanently vegetative state. And several landmark cases authorizing surrogate end-of-life determinations involved permanently unconscious patients. See Quinlan (N.J. 1976); Brophy, (Mass. 1986); Browning (Fla. 1990); Schiavo (Fla. 2005).

With the increasing prevalence of Alzheimer's disease and similar degenerative dementias, the focus of advance directives has changed for some people. The primary specter is neither an unavoidable looming demise nor the insensate limbo of permanent unconsciousness. Rather, the emerging concern is protracted maintenance during progressively increasing cognitive dysfunction and helplessness. For some, being mired in a demented state is an intolerably degrading prospect well before the advanced stage when the person no longer recognizes loved ones and is totally uncomprehending.

For people like me who see even moderate dementia as an intolerably demeaning status staining their life image, their advance directive may seek to facilitate death by declining even simplistic medical interventions like antibiotics. Our hope is that death will soon ensue when an infection is left untreated or when artificial nutrition and hydration is withheld in the face of an eating disorder.

This new paradigm for an advance directive -- avoidance of prolonged dementia -- seeks to accomplish the demise of persons who, without such a directive, would surely be medically sustained. For a dignity-focused advance directive envisions hastening the demise of a demented person who may not perceptibly be suffering, who may be getting some rudimentary satisfaction from a debilitated life, and who
may no longer recall the directive's underlying preoccupation with a personal vision of intolerable indignity. Can and should such an advance directive be implemented?

Some medico-legal commentators express moral compunctions about surrogates allowing an uncomprehending, ostensibly content individual to die. These commentators focus on the experiential interests of the now-incompetent person. For them, the demented person's previous dignity-based concerns have been forgotten and are now irrelevant. For them, a surrogate's moral obligation is to prevent the "harm" of avoidable death for a non-suffering, demented patient – regardless of contrary advance instructions.

For me, these moral claims are both unconvincing and counter to the prevailing legal frameworks. Overriding clear, considered advance instructions declining medical intervention at a point of self-defined intolerable indignity is itself a serious harm – even if the now-incompetent patient can no longer comprehend the violation of previous wishes.

American law and custom respect prospective autonomy (or precedent autonomy) in various contexts. These contexts include the disposition of property via contract, irrevocable trust, or last will and testament, as well as organ and tissue donation and disposal of mortal remains. And they include a prerogative of a competent person to shape the medical fate of their future demented persona according to personal values and visions of intolerable indignity. (That is the central function of an advance directive).

I have argued elsewhere that prospective control of a later, helpless persona is not immoral. While a later, demented self may have a very different character, personality, and memory set than a prior competent self, the 2 personas constitute a single person whose life narrative is unfolding in successive stages. The demented persona has the same body, the same spouse, the same relatives, the same property, the same religion, and (I argue) the same principles as its competent predecessor. The self-determination prerogative (dominion over the medical fate of a future persona) has, I contend, been earned by the competent person who nurtured and developed the body, character, relationships, and lifetime images associated with the later, incompetent persona.

American law upholds efforts of competent persons to control the medical fate of their subsequent incompetent personas. Starting with Quinlan in 1976, landmark opinions have established a fundamental right of competent persons to reject (or accept) life-sustaining medical interventions. This right is grounded in self-determination and bodily integrity and is anchored by various courts in the common law, state constitutional provisions, or the liberty clause of the 14th Amendment of the federal constitution. Importantly, the same courts declare that a competent person's right to control medical intervention is not lost by onset of incompetency. If the now-incompetent patient has left clear instructions regarding post-competence medical
handling, those instructions effectuate the patient's right to control medical intervention. The widely prevalent legal standard for surrogate medical decisionmaking – substituted judgment – dictates adherence to prior instructions and thus secures for an incompetent patient "the same panoply of rights and choices" as accorded to competent persons. Moreover, prevailing medical ethics also dictate upholding a now-incompetent patient's prior treatment choices even in the face of a physician's differing value judgment about remaining quality of life.

That an advance instruction withholding life-sustaining medical intervention from a helpless, non-suffering demented person is both lawful and moral does not mean that it will be readily implemented. The medical treatment of an incompetent patient is in the hands of a designated agent (or other surrogate) along with attendant care providers. For them, it cannot be easy to allow the preventable death of an individual who still derives some rudimentary satisfaction from life, even if that was the patient's express wish.

It will take a resolute, committed agent or surrogate to secure implementation of the contemplated dignity-based instructions. The declarant in an advance directive cannot rely on legal sanctions to enforce the advance instructions. Courts are not likely to punish surrogate decision makers or care providers for failure to facilitate the death of a non-suffering patient who no longer recalls his or her dignity-based instructions. The damage flowing from maintenance of life contra to prior instructions is not readily calculable in monetary terms.

Even without an efficient enforcement mechanism, a declarant can include advance directive provisions that enhance the prospects for implementation of dignity-grounded instructions. The following is my own, revised advance directive geared to avoiding prolongation of life in a demented state that I deem intolerably undignified. It invokes my common-law and constitutional prerogatives to shape my post-competence medical fate. It includes provisions that should reinforce the resolve of my decision-making agent and should assist that agent in overcoming any resistance from care providers or others.

**My Revised Advance Directive**

I have witnessed the ravages that Alzheimer's disease and similar progressive dementias produce. I wish to be allowed to die upon reaching a degree of permanent mental dysfunction that I deem to be intolerably demeaning. For me, this means mental deterioration to a point when I can no longer read and understand written material such as a newspaper or financial records such as a checkbook.

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

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

My determination not to prolong my life at the described point of debilitation includes rejection of any and all life-sustaining means. This includes simplistic medical interventions such as antibiotics, blood transfusions, and antiarythmias, as well as more complex interventions like CPR, mechanical ventilation, dialysis, and artificial nutrition and hydration. Indeed, if my dementia or any other affliction has produced inability or unwillingness to feed myself – for example, because of swallowing difficulties, or other eating disorders, or just indifference to eating -- I instruct that my caregivers refrain from hand feeding unless I appear receptive to eating and drinking (show signs of enjoyment or positive anticipation). If I am indifferent or resistant to hand feeding, I do not want to be cajoled, harassed, or in any way impelled to eat or drink.

The only limitation on my advance rejection of life-sustaining medical intervention is adherence to humane treatment. That is, I have no desire to subject my future incompetent persona to a torturous or agonizing dying process. I presume that palliative steps -- including medication for pain, anxiety, or agitation -- will be taken to ease my dying process.

The question may arise as to whether I have had a change of mind and revoked my advance directive. My wish is that no revocation be found unless I do so while still capable of a considered choice, including appreciation of all the major elements involved. I urge my decision-making agents to avoid the temptation of manipulating my future, incompetent persona to contradict or alter my advance instructions. And I direct that my original instructions be honored absent an aware, considered change of mind (as opposed to uncomprehending expressions by my demented persona).


355 A.2d 647 (N.J. 1976)


AMA Principles of Medical Ethics, Current Opinions of the Council on Ethical and Judicial Affairs, Sections 5.2(e) & 5.3 (2016).

There are occasional damage suits or administrative proceedings brought against medical personnel and institutions for violating advance directives rejecting life support. See T.M. Pope, Legal Briefing: New Penalties for Disregarding Advance Directives and DNR Orders, 28 J. Clin. Ethics 74 (Spring 2017). Such proceedings offer encouraging signs for enforcing implementation of advance directives, but they do not yet constitute a strong impetus to honor advance directives. This is so in part because some courts may insist that monetary damages, such as for pain and suffering or for costs of unwanted medical services, be set off against the presumed intrinsic value of extended human life. See generally H. Fernandez Lynch, M. Mathes, & N.N. Sawicki, Compliance with Advance Directives: Wrongful Living and Tort Law Incentives, 29 J. Legal Med. 133-78 (2008).

Because my directive is grounded in common-law and constitutional rights, it is not constricted by preconditions, such as a “terminal” condition, contained in some living will legislation. Such living will statutes cannot override constitutional prerogatives and they generally do not purport to. Most living will statutes contain a “savings” provision preserving the existing common-law and constitutional prerogatives that a patient has, including the prerogative to leave advance medical instructions. See K.L. Cerminara & J.R. Kadis, Give Me Liberty to Choose (A Better) Death: Respecting Autonomy More Fully in Advance Directive Statutes, 10 J. Health L. & Policy 67, 70-73 (2016).