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A Role for Law in Preparing for Death

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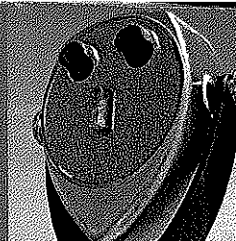


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By Barbara A. Noah

A Role for Law in Preparing for Death

Advance care planning may help prevent conflicts

“Timor mortis conturbat me.” (The fear of death distresses me.)

End-of-life law, though flawed, offers an opportunity to express individual values and preferences, via advance directives, health care proxies and other documents, to prepare for death before it's imminent. Yet, many people avoid the thinking process that's necessary to make these preparations, because the thought of death is uncomfortable to confront. Most decide, consciously or unconsciously, not to decide. If this decision is the result of a voluntary and considered choice to accept mortality by relinquishing attempts to exert control over death and the dying process, then perhaps all is well, at least for the dying individual. If, however, the non-decision arises out of a reluctance to confront death, then the non-deciders do themselves a disservice, not only at the time of death, but also throughout the life that precedes it.

Modern medical technology exacerbates this problem. In this era of highly technological care, physicians and patients often feel complementarily reluctant to engage in discussions about the patient's values, preferences and concerns or, worse, even to acknowledge the fact of the patient's dying.

Medicalization of Dying

The law is, of course, an imperfect tool to prevent end-of-life disputes and avoid over-use of life-prolonging technology. Physicians also bear their share of responsibility in promoting communication about complex

issues concerning the risks and benefits of continued treatment. The advent of modern technologies enables physicians to keep patients alive when their bodies would otherwise succumb to their underlying disease or injury. When life-sustaining technologies are used to assist a patient through a difficult illness or injury and return to health, there's rarely any question about their appropriateness. When, however, a patient's illness has progressed to the point where there's no hope of cure or even improvement, the use of these technologies in a way that merely prolongs dying poses vexing questions of ethical futility and proper use of limited medical resources. It's in such situations that conflicts arise, as the protracted legal dispute and public debate over the life and death of Theresa Schiavo so painfully illustrated.²

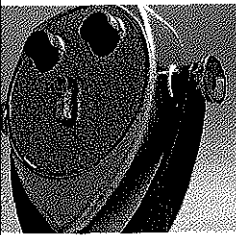
But, the medicalization of dying has created more than just conundrums about the appropriate use of medical technology. The emphasis on technology as the primary mechanism of medical care has gradually supplanted, or at least marginalized, other fundamental aspects of caregiving, such as communication and spending time with grieving patients and their families. Physicians lament the lost art of caregiving as technology takes over and leaves little time for addressing each patient's emotional needs. Many patients, experiencing fear and confusion about the nature of their condition and its treatment or simply sensing that their physicians are pressed for time, hesitate to ask questions or express their sense of despair or fear.

Advance Care Planning

Modern medical technology has created a lacuna of end-of-life dilemmas, which has triggered a need for legal intervention in the decision-making process. Optimally, there would be no need for law, except to acknowledge and defend the presumption of individual choice. In fact, the law of decisionmaking at the end



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of life is, in a broad sense, well settled. Nevertheless, because patients often don't or can't choose, conflicts about the use of technologies at the end of life arise, and these conflicts take a substantial toll on families, health care providers and society. To avoid these clashes, individuals can "practice death;" that is, acknowledge the certainty of death, make and articulate choices about end-of-life preferences, discuss these preferences with their family members, physicians and attorneys and revisit these choices on a regular basis via some form of advance care planning document or health care proxy. The mere act of routinely considering and discussing end-of-life choices will do more to prevent conflicts and

Some commentators have suggested abandoning efforts to encourage the use of advance directives altogether.

over-use of life-sustaining technology than any statute.³

Still, the irony persists that clients often make elaborate plans about how their worldly goods will be distributed after their death, while remaining reluctant to articulate preferences about their own journey. As death isn't optional, estate-planning attorneys have both an opportunity and an obligation to advise clients of the importance of advance care planning, along with plans for the disposition of their estates. By doing so, attorneys can achieve several goals: 1) informing clients of their right to make decisions about life-prolonging care, including the right to refuse care; 2) making clients aware of the various mechanisms to document their choices in advance, including living wills, the appointment of health care proxies and Physician Orders for Life Sustaining Treatment (POLST) forms that allow patients to request that physicians withhold life-sustaining treatments and less aggressive interventions and record their preferences regarding resuscitation, artificial nutrition and hydration and hospital transfer;⁴ 3) discussing with clients the risks of not documenting their preferences or, at least,

appointing a trusted person to speak on their behalf should they be unable to speak for themselves; and 4) creating a relationship with clients that demystifies and normalizes discussion of mortality by asking clients to think about what values are most important to them. No amount of legislation can serve to cajole or compel individuals to confront these issues, but attorneys have some opportunity to help their clients to do so.

End-of-Life Law

In the United States, we have a multi-layered legal system designed to protect our health care decision-making rights through a combination of federal and state statutes and judicial decisions. It's well settled that end-of-life law in the United States protects an individual's right of decisionmaking about health care (including the right to ignore the topic), though it does little to promote the decisionmaking itself. These legal rights are grounded in the ethical principle of autonomy and include the right to refuse treatment, whether or not one is terminally ill, the right to continue receiving life-prolonging treatment even when terminally ill (though this value becomes subject to dispute if the treatment appears futile) and, in some states, the right to hasten death with the assistance of a physician.

Advance Directives

Advance directives promote autonomy because they formalize an individual's wishes about treatment choices, and they can serve as a guide to the treating physician and the family about how to proceed if the individual is unable to speak for himself. These documents can give patients a sense of control over their health care should they lose decisional capacity. In many respects, however, this sense of control is an illusion. Advance directives may have limited application under state law, and more seriously, they may not be accurate predictors of what a now-capacitated individual would really choose under the exact circumstances when later incapacitated by illness. They're frequently inaccessible at key decision-making points, insufficiently specific to address the actual medical decision at hand and overruled by family members or ignored by health care providers. Family pressures and societal expectations about what individuals should choose may also influence those who make advance directives. With these problems in mind, some commentators have



suggested abandoning efforts to encourage the use of advance directives altogether.⁵

There is, however, a compelling argument in favor of continuing and expanding the practice; namely, the inherent and immediate benefit to the individual of thinking about and executing an advance directive or discussing preferences with a health care proxy. Laws encouraging advance directives provide a structural context in which individuals can consider and articulate to themselves and others their values and preferences about how they wish to live, as well as how they wish to die. Diligently considering death prospectively and discussing it in detail with family members or an attorney may seem unappealing to many people. Surveys suggest that no more than 20 percent of adults have completed advance directives.⁶ Even so, advance care planning, with all of its flaws in content and implementation, helps provide guidance to family members and health care providers and provides important ancillary benefits for the individual who takes on the task.

Ideally, when a patient can no longer articulate his wishes, the decision should center on whether continued treatment would be the patient's authentic choice; that is, the choice that reflects careful thought, self-knowledge and reflection and that acknowledges the external influences that shape an individual's identity. Autonomy means more than possessing a choice—it means exercising that choice in a way that holistically reflects the patient's values, preferences and beliefs within the context of her current, and evolving, life circumstances. It requires the confrontation of death, its inevitability and the possibility that, in some cases, death will become preferable to continued life.⁷

Ethical Dilemmas

Complicating matters further, the ethical principle of autonomy coexists in an uneasy détente with the principle of beneficence, which requires that physicians provide medical care that's in their patients' best interests. When a patient's wishes are unclear, determining "best interests" is often difficult. The co-existence of principles of autonomy and beneficence creates disagreements about futility: whether and when further treatment or life-sustaining measures are no longer medically or ethically appropriate.⁸ Without guidance about a patient's preferences regarding continued life-

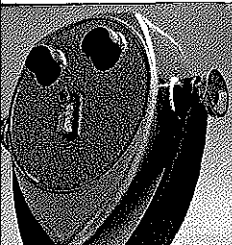
supportive measures, it's difficult to know when to cease providing support to a person whose condition won't improve. In such circumstances, the U.S. health care system and its providers are often reluctant to opine about an incapacitated patient's best interests and, generally, will revert to erring on the side of continued treatment.

With the evolution of life-supportive technologies and interventions, we add to our arsenal for delaying death—we almost always can do something more. We've all heard grieving families assure others that "the doctors did everything they could." "Doing everything" may help assuage feelings of helplessness on the part of fami-

Our culture discourages self-examination as part of the process of preparing for death.

lies and caregivers, but it's not necessarily in the patient's best interests, nor does it always reflect the patient's authentic choice. One important aspect of the futility question concerns quality of life. Even if a treatment or technology extends life, should physicians provide it if the patient will experience no added benefit in the form of improved function?

Choosing to "err on the side of life" to avoid difficult conversations about quality of life has created a further ethical dilemma when coupled with broadly available medical technologies designed to sustain life. As a society, we're equally reluctant to consider explicitly or to discuss the cost of end-of-life care as we evaluate whether and when to cease life-supportive measures and therapeutic interventions.⁹ Similarly, patients frequently misunderstand or fail to receive information about the potential success of various treatments and interventions. Statistical fallacies and unreasonable optimism lead patients to request and physicians to provide treatments that offer little or no real benefit and to discount the potential harm of such care.¹⁰ Physicians also tend to overestimate the remaining life spans of seriously ill patients and to convey overly optimistic prognoses.¹¹ Even worse, a surprising number of



physicians acknowledge deliberate deception of patients in discussing their prognoses. In a recent survey of physicians, one in 10 admitted to lying to a patient within the previous year, while over half acknowledged that they had been unreasonably optimistic about a patient's prognosis.¹²

Cultural Factors

The willingness to engage in the kind of self-examination that's consistent with making advance directives depends on both cultural factors and individual characteristics. For multiple reasons, we collectively have little appetite to address end-of-life issues before they arise in crisis form. The luxury of time, in the form of longer life spans, together with the promise of advanced therapies, has created the illusion that there's time to delay confronting mortality. Unlike the rest of the animal kingdom, we are, however, conscious of our mortality. Our superiority in this regard brings with it fear of death. Philosopher Ernst Becker has captured the paradox quite elegantly:

Man is literally split in two: he has an awareness of his own splendid uniqueness in that he sticks out of nature with a towering majesty, and yet he goes back into the ground a few feet in order blindly and dumbly to rot and disappear forever.¹³

As Becker observes, this "existential dualism makes an impossible situation, an excruciating dilemma."¹⁴


Cultural portrayals of older people exacerbate our ambivalence about aging. As the average life span lengthens, we hear phrases like "50 is the new 30" and see advertisements for "adult communities" (no longer "retirement communities" or "elder housing") depicting smiling, vigorous people playing tennis or golf. We also increasingly deny the reality of aging and dying. As one commentator wryly observed, "[o]nce regarded as an unyielding, utterly unforgiving, brute feature of existence, death is increasingly portrayed as a bad lifestyle option."¹⁵

Unsurprisingly, some medical researchers already talk of doubling the human life span, even of a "cure for death," and of aging as a disease that should be treated. Paradoxically, alongside these anti-aging, age-defying cultural sentiments, we've made an industry of death and dying. In the United States and elsewhere, there are multitudes of death memoirs and manuals, sharing

websites and blogs on the experience and process of terminal illness. Death memoirs are nothing new, but they appear to have multiplied in recent decades. Some of these memoirs contemplate what it means to be a patient captive to medicine and disease or describe a brave battle and its consequent appreciation of life. Others explain the experience of terminal illness as casting the sufferer into the role of an outsider, no longer a member of society. This modern tendency to share the intimate thoughts and experiences of illness via blogs and specialized social networks seems diametrically opposed to our general unwillingness to engage in advance care planning or to acknowledge and accept aging and the prospect of death.

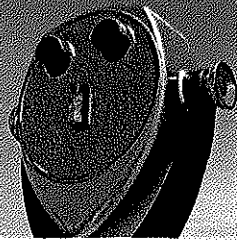
So what, if anything, does all of this have to do with law? The short answer is: despite the multiplicity of state and federal statutes and judicial decisions on end-of-life decision making, not much. The problem we confront runs much deeper than what any law can solve. Our culture discourages self-examination as a part of the process of preparing for death. We unconsciously, or sometimes deliberately, decide not to make choices that are ours to make. Yet, our legal rights regarding end-of-life decisionmaking only have their fullest impact in preventing unwanted suffering at the end of life if we address death and dying before a serious illness forces the issue.

Considering the Future

Although advance directives are only occasionally consulted in making treatment decisions for patients who've lost decisional capacity, the process of thinking about the issues to which a good advance directive demands attention is inherently valuable, not only as an opportunity to exercise some choice over how we die, but also as a means of enhancing all remaining life. The process of thinking about an advance directive, revising it and discussing it with an attorney, physician and family presents an opportunity for each individual to reorient himself individually to goals and ways of living that provide meaning on a personal level. Ultimately, advance directives are about living, not dying. 

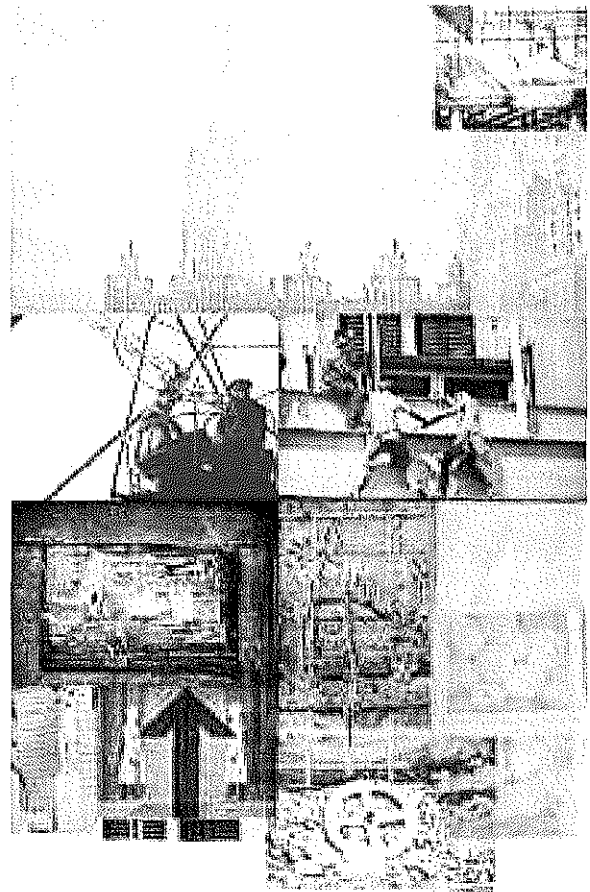
Endnotes

1. Many medieval poems included the saying: "Timor mortis conturbat me" ("The fear of death distresses me"). The phrase comes from a responsory of the Catholic Office of the Dead in the third Nocturne of Matins. Richard L. Greene, "A Middle English 'Timor Mortis' Poem," *Modern Language Review*, Vol. 28 (1933) at pp. 234-38.



2. Barbara A. Noah, "Politicizing the End of Life: Lessons from the Schiavo Controversy," *Univ. Miami Law Rev.*, Vol. 59 (2005) at pp. 107-34; Barbara A. Noah, "The Role of Religion in the Schiavo Controversy," *Houston Journal Health Law & Policy*, Vol. 6 (2006) at pp. 319-46.
3. In the absence of advance care planning, the law requires that families, health care providers and, sometimes, the courts attempt to ascertain the wishes of the dying patient regarding life-prolonging treatment via "substituted judgment." This process asks the decisionmaker to choose what he believes that patient would choose if able to speak for himself.
4. For a discussion of the utility of Physician Orders for Life Sustaining Treatment (POLST), see Susan E. Hickman, et al., "The POLST (Physician Orders for Life Sustaining Treatment) Paradigm to Improve End of Life Care: Potential State Legal Barriers to Implementation," *Journal of Law, Medicine & Ethics*, Vol. 36 (2008) at p. 119.
5. Angela Fagerlin and Carl E. Schneider, "Enough: The Failure of the Living Will," *Hastings Center Report* (March/April 2004) at p. 31; John A. Robertson, "Second Thoughts on Living Wills," *Hastings Center Report* (November/December 1991) at pp. 6-7 (acknowledging the benefits, at least superficially, of living wills but questioning whether they actually provide valid guidance as to the later-incompetent patient's wishes and interests).
6. Fagerlin and Schneider, *ibid.*, at pp. 32, 36 (noting that less than 20 percent of Americans have living wills). This statistic doesn't reflect the recent move in many states to implement POLST-type documents that patients complete with physicians upon admission to a hospital and in response to a particular illness.
7. Norman L. Cantor, "Making Advance Directives Meaningful," *Psychiatry Public Policy & Law*, Vol. 4 (1998) at pp. 639-41 (discussing how a declarant can "effectively communicate the degree of deterioration at which death would, for that person, be preferable to continued existence").
8. Futility questions arise in two categories: 1) questions about the subjective value of the medical intervention; and 2) questions about the probability that the medical intervention will be successful. Robert D. Truog, et al., "The Problem with Futility," *New England Journal of Med.*, Vol. 326 (1992) at p. 1561.
9. It's well documented that one-third of medical expenses in the last year of life are spent in the final month, with aggressive treatments in that month accounting for 80 percent of those costs. Baohui Zang, et al., "Health Care Costs in the Last Week of Life: Associations with End-of-Life Conversations," *Archives Internal Med.*, Vol. 169 (2009) at p. 480. Moreover, 30 percent of Medicare dollars spent goes to care for the 5 percent of Medicare beneficiaries who die each year. Amber E. Barnato, et al., "Trends in Inpatient Treatment Intensity Among Medicare Beneficiaries at the End of Life," *Health Services Research*, Vol. 39 (2004) at pp. 363-4.
10. Lynn A. Jansen, et al., "Unrealistic Optimism in Early-Phase Oncology Trials," *IRB: Ethics and Human Research*, Vol. 33 (2001) at p. 4 (concluding that, despite disclosures in informed consent about the early-stage cancer trials in which they were enrolled, patients tended to underestimate the risks to themselves and overestimate the prospective benefit).
11. Nicholas A. Christakis and Elizabeth B. Lamont, "Extent and Determinants

- of Error in Doctors—Prognoses in Terminally Ill Patients," *British Med. J.*, Vol. 320 (2000) at pp. 470-71 (finding that in predicting patients' remaining life expectancies, physicians were correct only 20 percent of the time and overoptimistic 63 percent of the time and concluding that a closer doctor-patient relationship was associated with over-optimistic predictions).
12. Lisa I. Iezzoni, et al., "Survey Shows That at Least Some Physicians Are Not Always Open or Honest with Patients," *Health Affairs*, Vol. 31 (2012) at pp. 383-88.
13. Ernst Becker, *The Denial of Death* 26 (Simon & Schuster, New York, 1973).
14. *Ibid.* at p. 27.
15. Leigh Turner, "Antiaging," *JAMA*, Vol. 292 (2004) at p. 2155.



SPOT LIGHT

Juxtaposition

"Soviet/American Array VII" (78³/₄ in. by 51 in.) by Robert Rauschenberg, sold for \$23,750 at Christie's recent Prints and Multiples Sale in New York on July 15, 2014.

The Texas-born Rauschenberg was a painter and graphic artist whose early works anticipated the Pop Art Movement.