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### In Denial: The Role of Law in Preparing for Death

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## IN DENIAL: THE ROLE OF LAW IN PREPARING FOR DEATH

*Barbara A. Noah*

*Only approximately 20% of Americans have engaged in any form of advance care planning and, even among older Americans, the process frequently is delayed until an acute illness provides sufficient pressure to act. End of life law, though flawed, offers some opportunity to express individual values and preferences via advance directives of various kinds in order to prepare for death before it is imminent. Yet many people avoid making these preparations because the thought of death is uncomfortable to confront. This Article considers the utility of existing law in preventing and resolving end of life disputes and avoiding over-utilization of life-prolonging technology and the law's inevitable failure to address complex issues concerning quality of life and communication about this inevitable but usually unpredictable event.*

*The so-called technological imperative and the cultural admiration of those who "fight" and "do everything" to defeat illness have created an atmosphere in which physicians and patients often feel complementarily reluctant to engage in thoughtful discussions about the patient's values, preferences, and concerns or, worse, even to acknowledge openly the fact of the patient's dying. In addition, the presumption in favor of continued treatment for patients who have lost decisional capacity has created a situation in which patients are frequently subjected to multiple therapeutic and life-supportive technologies that they would not wish for if they could make the choice. This lacuna of unconsidered choices suggests a significant need for formal expressions*

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*of end of life preferences, or at least serious conversation with family and health care providers about one’s preferences. The law allows individuals to express their preferences on these matters, but creates little incentive to do so.*

*As other commentators have noted, advance directives rarely resolve end of life disputes—these commentators have therefore suggested abandoning efforts to encourage the utilization of advance directives. There is, however, a compelling argument in favor of continuing and expanding the practice—namely, the inherent and immediate benefit to the individual of carefully and systematically thinking about and executing an advance directive or, at least, discussing preferences with a health care proxy. Laws encouraging advance directives provide a structural context in which individuals can acknowledge their mortality and make the effort to consider and articulate to themselves and others their values and preferences, resulting in much potential benefit to themselves, their families and their health care providers, not only at the end of life but throughout life. Regularizing this practice throughout adulthood may gradually reduce the impact of the technology juggernaut on the dying process. This Article concludes by examining the ways in which end of life law and the medical education system might be reformed to promote individual reflection and conversations between patients and physicians in order to prepare for death.*

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**I. Introduction**

End of life law, though flawed, offers some opportunity to express one’s values and preferences via advance directives, health care proxies, and other such mechanisms, in order to prepare for death before it is imminent. Yet many people avoid the thinking process that is necessary to make these preparations because the thought of death is uncomfortable to confront. Most decide, consciously or unconsciously, not to decide. If the decision not to decide 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, though the medical technology juggernaut may result in

an undesirable prolongation of the process. If, however, the non-decision arises out of a reluctance and fear to confront death, then the non-deciders do themselves a disservice, not only at the time of death, but throughout the life that precedes it.

Modern medical technology has brought to a boil matters which have simmered in the collective human consciousness for many centuries. Beginning in the mid to late nineteenth century, dying was transformed from an accepted, albeit generally unwelcome, life passage to a medical crisis with the resultant medicalization of the death bed.<sup>1</sup> Around the middle of the nineteenth century, “[t]he most apparent manifestation of the medicalization of death took place when the doctor replaced the priest as master of ceremonies.”<sup>2</sup> Before then, it was common for physicians to leave their dying patients in the care of family members and clergy when they could no longer offer any useful treatment. By the mid-1800s, expectations and practices changed and physicians often remained with their dying patients until the end. Although this change in practice predated any new ability to treat dying patients, cultural attitudes toward the death bed were shifting. Despite their inability to provide any curative care, physicians began to believe that they “had a responsibility to hold out some, even if very limited, course of action to the dying patient, to help her overcome a sense of helplessness.”<sup>3</sup>

Well into the twentieth century, the advent of modern life-supportive technologies and therapies enabled physicians to keep patients alive when their bodies would otherwise succumb to their un-

1. Shai Lavi, *How Dying Became a “Life Crisis,”* 137 *DAEDALUS* 57, 58 (2008); see also ELIZABETH KUBLER-ROSS, *ON DEATH AND DYING* 19–20 (1969); Ivan Illich, *Death Undefeated*, 311 *BRIT. MED. J.* 1652, 1652 (1995) (observing “how difficult medicalisation made the task of family, friends, or chaplain: to arouse the dying person’s willingness to accept the inevitable, to find strength in the beauty of memories, and to take leave of this world.”).

2. Lavi, *supra* note 1, at 61.

3. *Id.* As Joan Didion also has observed, modern death differs tremendously from that of a century ago. At the turn of the twentieth century, the act of dying had not yet been professionalized. It did not typically involve hospitals. . . . At the time [Emily Post] undertook her book of etiquette, there would have been few American households untouched by the influenza pandemic of 1918. Death was up close, at home. The average adult was expected to deal competently, and also sensitively, with its aftermath.

JOAN DIDION, *THE YEAR OF MAGICAL THINKING* 60–61 (2005). The same is true, though more recently, with the medicalization of the process of childbirth.

derlying disease, injury, or disability.<sup>4</sup> When life-sustaining technologies are used to assist a patient through a difficult illness or injury and return to health, there is rarely any conflict about their appropriateness. When, however, a patient's chronic or acute illness has progressed to the point where there is no hope of cure or even improvement, the use of these technologies in a situation that merely prolongs dying poses complex questions of ethical futility, not to mention wise use of limited medical resources.<sup>5</sup> It is in such situations that conflict arises as, for example, the protracted legal dispute and public debate over the life and death of Theresa Schiavo so painfully illustrated.<sup>6</sup> In such cases, the law requires that families, health care providers and, sometimes, courts attempt to ascertain the wishes of the dying patient regarding life-prolonging measures in order to carry out the patient's autonomous choices.<sup>7</sup>

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 the technology of medicine takes over and leaves little time for addressing each patient's emotional needs.<sup>8</sup> Many patients—experiencing fear and confusion about the nature of their disease or injury and its treatment, or simply sensing that their physicians are

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4. See Lavi, *supra* note 1, at 59 ("The growing use of antibiotics, surgery, and other technological advances, including life-sustaining machinery, had transformed mortality statistics. But extending life had the unintended but inevitable consequence of prolonging dying and suffering.").

5. As commentators have observed, it is paradoxical that the ever-increasing technological ability to sustain life has led to significant support for physician-assisted suicide. See Charles J. Sabatino, *Reflections on the Meaning of Care*, 6 NURSING ETHICS 374, 377 (1999).

6. See Barbara A. Noah, *Politicizing the End of Life: Lessons from the Schiavo Controversy*, 59 U. MIAMI L. REV. 107, 107–34 (2005) [hereinafter *Politicizing the End of Life*]; Barbara A. Noah, *The Role of Religion in the Schiavo Controversy*, 6 HOUSTON J. HEALTH L. & POL'Y 319, 319–46 (2006) [hereinafter *Role of Religion*].

7. See *infra* notes 21–48 and accompanying text.

8. See Arthur Kleinman, *Forum: On Caregiving*, HARV. MAG. July–Aug. 2010 at 29 ("If the ancient Chinese perception is right that we are not born fully human, but only become so as we cultivate ourselves and our relations with others—and that we must do so in a threatening world where things often go terribly wrong and where what we are able to control is very limited—then caregiving is one of those relationships and practices of self-cultivation that make us, even as we experience our limits and failures, more human.").

pressed for time—hesitate to ask questions or to express their sense of despair or fear.<sup>9</sup> In this era of highly technological medical care, physicians and patients often feel complementarily reluctant to engage in thoughtful discussions about the patient's values, preferences, and concerns or, worse, even to acknowledge openly the fact of the patient's dying.<sup>10</sup>

Modern medical technology has created a lacuna of end of life dilemmas, which have triggered a need for legal intervention in end of life decision making (including an important role for advance directives or, at least, serious conversations with family and health care providers about individual preferences in these matters).<sup>11</sup> In an optimal situation, there would be no need for law except to acknowledge and defend the presumption of individual choice.<sup>12</sup> In fact, the law of decision making at the end of life is, in a broad sense, well settled.<sup>13</sup> Nevertheless, because patients often do not or cannot choose, conflicts about the use of technologies at the end of life do arise and these conflicts take a substantial toll on families, health care providers, and society more broadly.

To avoid such conflicts (and their accompanying negative impact on end of life care, loved ones, health care providers, and societal costs), individuals can "practice death"—that is, acknowledge the certainty of death, make and articulate choices about end of life preferences early in adulthood, discuss their preferences with relevant family members, and revisit these choices on a regular basis via some form

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9. *Id.* at 25 (explaining that "[t]he structure of training and of service delivery discourages and even disables the art.").

10. See Timothy E. Quill, *Initiating End-of-Life Discussions with Seriously Ill Patients: Addressing the "Elephant in the Room,"* 284 JAMA 2502, 2503 (2000).

11. The same medical technology also created a need for the law to define "death" for various legal and medical purposes (homicide, estates and trusts law, organ harvesting, and more). See *A Definition of Irreversible Coma: Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death*, 205 JAMA 85 (1968); see also Roger N. Rosenberg, *Consciousness, Coma, and Brain Death—2009*, 301 JAMA 1172, 1173 (2009) (explaining that in the last twenty years, permanent vegetative state and minimal consciousness have been further defined as separate from coma and brain death); Seema K. Shah & Franklin G. Miller, *Can We Handle the Truth? Legal Fictions in the Determination of Death*, 36 AM. J. L. MED. 540, 541 (2010).

12. There are also good arguments for placing some limits on individual autonomy, though this discussion is beyond the scope of this article. See, e.g., Alexander McCall Smith, *Beyond Autonomy*, 14 J. CONTEMP. HEALTH L. & POL'Y 23 (1997).

13. See *infra* notes 21–36 and accompanying text.

of advance care planning document or proxy.<sup>14</sup> For a variety of reasons, many individuals in our society appear unwilling to do so, even though (in the current system) advance planning is crucial to preserve individual choice should a patient lose decisional capacity. At the same time, physicians have an obligation to encourage such conversations and to provide a frank and full picture of the patient's situation so that the conversation reflects the medical reality. The act of considering and discussing end of life choices, whether via a formal document or conversations with family members and physicians, will do more to prevent end of life conflicts and over-utilization of life-sustaining technology than any new or revised statute.

To be fair, while those who espouse advance care planning frequently argue that such preparations often would avoid much grief for all those involved, this is not invariably true. Commentary on the *Schiavo* case bemoaned the fact that Theresa Schiavo had not completed an advance directive indicating her preferences about health care should she lose decisional capacity.<sup>15</sup> In retrospect, it is doubtful that an advance directive would have made much difference in Theresa Schiavo's case<sup>16</sup> because it became a *cause célèbre* in the culture wars.<sup>17</sup> But, in many cases, advance care planning can help indicate that the

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14. Advance care planning documents (also sometimes referred to collectively as "individual instructions for health care") include advance directives, values history forms, do-not-resuscitate orders, appointments of health care proxy decision makers, and POLST (Physician Orders for Life Sustaining Treatment) and related documents. Depending on the law of the state in which it was executed, an advance directive may apply only when a patient is terminally ill, or it may also apply to patients in persistent vegetative states, irreversible coma, or other "non-terminal" conditions. See BARRY R. FURROW ET AL., *BIOETHICS: HEALTH CARE LAW AND ETHICS* 294–95 (6th ed. 2008).

15. See, e.g., Lois Shepherd, *Terri Schiavo: Unsettling the Settled*, 37 *LOY. U. CHIC. L.J.* 297, 315 (2006) (explaining that if Theresa Schiavo had executed a living will "clearly expressing a desire not to continue feeding in a permanent vegetative state, that might have sufficed to overcome the deference to [a] proxy's decision to continue treatment, but mere oral evidence would unlikely have been enough."). For background on the events of the Schiavo dispute, see *Role of Religion*, *supra* note 6 at 320–29.

16. See *infra* notes 57–58 and accompanying text. Those who sought to keep Theresa alive would have argued that she had not anticipated the particular circumstances that she found herself in (permanent unconsciousness but not actively dying) or that, as a good Catholic, she would defer to the papal declaration denouncing the withdrawal of artificial nutrition from patients such as herself. See *Role of Religion*, *supra* note 6 at 339–40 (describing and discussing the papal pronouncement that artificial nourishment constitutes "minimal care" for the patient and that death by starvation from its withdrawal would be "euthanasia by omission").

17. See *infra* notes 57–58 and accompanying text.

patient has given some thought to end of life issues. In its absence, the default position of continuing care may do as much harm as good, and therefore deserves careful scrutiny.

The *Schiavo* case certainly did not end the collective struggle with decision making for incapacitated patients, particularly those who are not terminally ill and actively dying. It therefore seems useful to consider why such conflicts arise in the first place and why they are likely to recur in the future. First, at risk of stating the obvious, in disputes or public debate over decision making for incapacitated patients, we often fail to acknowledge societal discomfort with the subjects of death and dying. Second, a major cause of disputes is confusion—not only about how to answer the question of what a decisionally incapacitated person would choose—but more fundamentally about whether this is the question we should be asking in the first place.<sup>18</sup> The end of life laws in the United States do little to address this confusion. End of life disputes arise from a cluster of cultural issues—including a default position in favor of the utilization of technology, discomfort with conversations about death and dying, and the influence of the pro-life culture wars. Ultimately, however, no amount of legislation can serve to cajole or compel individuals to confront these issues.

This Article considers the utility of existing law in preventing and resolving end of life disputes and avoiding over-utilization of life-prolonging technology.<sup>19</sup> It also examines the law's inevitable failure to address complex issues concerning quality of life, communication about death, and the unwillingness of many individuals to acknowledge the reality of mortality, and to plan for that unavoidable but usually unpredictable event. As other commentators have noted, advance directives rarely resolve end of life disputes—therefore they have suggested abandoning efforts to encourage the utilization of advance directives.<sup>20</sup> There is, however, a compelling argument in favor

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18. See generally Daniel Brudney, *Choosing for Another: Beyond Autonomy and Best Interests*, HASTINGS CENTER REP., Mar.–Apr. 2009, at 31 (discussing differences among concepts of autonomy, self-determination, and authenticity in making decisions for patients who have lost decisional capacity).

19. The next paper in this series considers an alternative to the current approach, which focuses so heavily on patient autonomy as the principle to resolve end of life disputes. See Barbara A. Noah, *Medical Autonomy and Pragmatism* (forthcoming 2013) (manuscript on file with author).

20. See, e.g., Angela Fagerlin & Carl E. Schneider, *Enough: The Failure of the Living Will*, HASTINGS CENTER REP., Mar.–Apr. 2004, at 31 ("In an attempt to extend



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 template through which individuals can make an effort to consider and articulate to themselves and others their values and preferences. In doing so, they provide a structural context in which individuals can address their mortality, resulting in much potential benefit to themselves, their families and their health care providers, not only at the end of life but throughout life. This Article ends with an examination of the ways in which end of life law and the medical education system might be reformed to promote individual reflection and conversations between patients and physicians in order to prepare for death.

## II. Death and Dying in the Post-Modern (Legal) World

In the United States, we have a vast and multi-layered legal instrumentarium designed to articulate and protect our health care decision making rights through a combination of federal and state statutes and judicial decisions. It is well settled that end of life law in the United States protects an individual's right of decision making about health care (including the right to ignore the topic), though it does little to promote the making of those decisions. Virtually every state has enacted statutes permitting (but not requiring) individuals to assert their wishes via some form of advance directive.<sup>21</sup>

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patients' exercise of autonomy beyond their span of competence, resources have been lavished to make living wills routine and even universal. This policy has not produced results that recompense its costs, and it should therefore be renounced."); John A. Robertson, *Second Thoughts on Living Wills*, HASTINGS CENTER REP., Nov.–Dec. 1991, at 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).

21. In addition to laws dealing with advance directives, most states have enacted statutes that formally permit individuals to appoint a health care proxy decision maker via a durable power of attorney for health care decision making. A formally appointed health care proxy must make decisions either based on the patient's separately-executed advance directive, or if none is available, based on the patient's values and preferences as the proxy understands them. See Charles P. Sabatino, *The Legal and Functional Status of the Medical Proxy: Suggestions for Statutory Reform*, 27 J. L. MED. & ETHICS 52, 58–59 (1999) (providing a summary of state provisions). Merely appointing a health care proxy, however, even a spouse, does not ensure that the parties have communicated with any specificity about preferences with regard to end of life care. See Sara M. Moorman et al., *Do Older Adults Know Their Spouses' End-of-Life Treatment Preferences?*, 31 RES. ON AGING 463 (2009) (finding that spouses as surrogate decision makers state their spouses' preferences

States clearly struggle with the issue of advance directives, their enforceability, and even their desirability. Some states expressly forbid requiring advance directives,<sup>22</sup> but others have taken a variety of steps to encourage their citizens to complete an advance directive by simplifying the process and recognizing the validity of out of state documents.<sup>23</sup> In recent years, some states have attempted to encourage health care providers to consult existing advance directives by creating registries that make these documents more easily accessible to providers, especially in emergencies.<sup>24</sup> Still other states have expanded the contexts in which advance directives are applicable, including legislation that recognizes the Physician Order for Life Sustaining Treatment (POLST) form, which allows patients to request that physicians withhold life-sustaining treatments and less aggressive interventions such as antibiotics, and also includes patient preferences for resuscitation, artificial nutrition and hydration, and hospital transfer.<sup>25</sup>

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incorrectly in end of life scenarios 13% of the time with respect to cognitive impairment and 26% of the time with respect to pain management); David Shalowitz et al., *The Accuracy of Surrogate Decision Makers*, 166 ARCHIVES INTERNAL MED. 493, 495 (2006) (finding that surrogate decision makers incorrectly predicted patients' preferences in one-third of cases studied).

22. See, e.g., CONN. GEN. STAT. ANN. § 19a-580a-580e West, Westlaw through the 2012 Feb. Regular Session and June 12 Special Session (2012) (prohibiting the requirement of an advance directive).

23. For example, North Carolina's statute explicitly recognizes advance directives created in other states as long as they were valid pursuant to the law of the state where they were created. See N.C.G.S. § 90-321(1) (2012) and N.C.G.S. § 32A-24(d) (2012); see also NEV. REV. STAT. §§ 450b.400-590 (2012) (requiring advance directives that conform to other states' laws to be upheld in Nevada); UTAH CODE §§ 75-2a-104, 121 (2012) (simplifying the process by allowing for written or oral advance directives and making a presumption of capacity).

24. See, e.g., NEV. REV. STAT. §§ 449.920-449.925 (2011) (establishing a registry of advance directives); OR. REV. STAT. § 127.666 (2011) (establishing a registry of advance directives and Physician Orders for Life-Sustaining Treatment (POLST) forms); cf. James Wallace & Norman A. Desbiens, *Evaluation of a Labeling System to Indicate the Presence of an Advance Directive in a Hospital Medical Record*, 16 INT'L J. FOR QUALITY IN HEALTH CARE 333, 334-35 (2004) (finding that only 3% of the studied inpatient population had an advance directive in their medical record and only 46 of 121 medical records studied had a label indicating the presence of an advance directive elsewhere and that many of these labels were inaccurate); see also Thaddeaus Mason Pope, *Legal Briefing: Advance Care Planning*, 20 J. CLINICAL ETHICS 362, 365 (2009) (explaining that a total of eleven state legislatures have enacted legislation requiring an electronic registry to store health care directives in order to make these documents readily available to health care providers).

25. See, e.g., IDAHO CODE ANN. § 39-4510 West, Westlaw through end of 2012 2nd Reg. Session of the 61st Legis. (2012) (adding a POLST option); MD Health Gen. § 5-602 (adding a POLST option); N.C. GEN. STAT. § 90-21.17 (2012) (adding a POLST option); see also California POLST Form (2011), available at <http://www.calpolst.org/>

In addition to these state law efforts, commentators have urged the development of a simple and effective form that will comply with the legal requirements of all states.<sup>26</sup> Most who favor reform agree that legislatures should design laws that make the execution of advance directives simple and affordable for their citizens.<sup>27</sup> In addition to making the format readily available, legislatures should recognize the legal validity of directives that are executed in proper form without the assistance of an attorney.<sup>28</sup>

The Uniform Health-Care Decisions Act provides a template for state laws relating to advance directives and durable powers of attorney for health care decisions.<sup>29</sup> It includes a suggested statutory form for advance directives but also encourages their completion by permitting individual variations of form,<sup>30</sup> by not requiring witnesses or notarization,<sup>31</sup> and by making the advance directive valid regardless of when and where it was executed.<sup>32</sup> In addition, a variety of federal laws have attempted to encourage individuals to formalize their end of life preferences, all with little success.<sup>33</sup>

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[www.capolst.org/documents/CAPOLSTform2011v13web\\_005.pdf](http://www.capolst.org/documents/CAPOLSTform2011v13web_005.pdf) (last visited Mar. 12, 2013). For more discussion of the utility of POLSTs, see generally 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*, 36 J. L. MED. & ETHICS 119 (2008); Susan E. Hickman et al., *Use of the Physician Orders for Life-Sustaining Treatment (POLST) Paradigm Program in the Hospice Setting*, 12 J. PALLIATIVE MED. 133, 133-41 (2010).

26. Some suggest that the "Five Wishes" document accomplishes this goal. See FURROW ET AL., *supra* note 14, at 298. The "Five Wishes" document is available at *Five Wishes*, AGING WITH DIGNITY, [www.agingwithdignity.org/five-wishes.php](http://www.agingwithdignity.org/five-wishes.php) (last visited Mar. 12, 2013).

27. See, e.g., Dorothy D. Nachman, *Living Wills: Is It Time to Pull the Plug?*, 18 ELDER L.J. 289, 317-18 (2011) (describing a U.S. Senate bill which includes funding of legal services for advance care planning for low-income people and expands the portability of validly-executed advance directives from state to state).

28. Although requiring witnesses to the executor's signature makes sense to reduce the risk of fraud, there seems to be little reason to require the services of a notary public to validate these documents. See UNIFORM HEALTH-CARE DECISIONS ACT (1993), available at [http://www.uniformlaws.org/shared/docs/health%20care%20decisions/uhcda\\_final\\_93.pdf](http://www.uniformlaws.org/shared/docs/health%20care%20decisions/uhcda_final_93.pdf) ("An advance health-care directive is valid for purposes of this [Act] if it complies with this [Act], regardless of when or where executed or communicated.").

29. See *id.* at § 2(h). As of this writing, some version of this Act has been adopted in approximately six states. See *id.* (citing legislative factsheet).

30. See *id.* at § 4.

31. *Id.* at § 2, § 4 and cmts. (explaining that witness signatures are optional).

32. *Id.* at § 2(h).

33. For example, the Patient Self-Determination Act, has had very limited effectiveness in increasing the rate at which adults complete advance directives. See U.S. GOV'T ACCOUNTABILITY OFFICE, GAO/HEHS-95-135, PATIENT SELF-DETERMINATION ACT: PROVIDERS OFFER INFORMATION ON ADVANCE DIRECTIVES

Finally, judicial decisions at the state and federal level have added a further common law layer to the state statutes by resolving individual disputes about end of life care. Many of these disputes involve uncertainty about the quality or quantity of evidence of a now-incompetent patient's assumed wishes, either because the patient has no advance directive,<sup>34</sup> or a family member is disputing the appropriateness of a health care proxy decision maker, or the relevance of an advance directive.<sup>35</sup> In addition, the U.S. Supreme Court has addressed issues surrounding end of life choices on multiple occasions, though mainly to opine in one form or another that these are matters best left to the states for regulation.<sup>36</sup>

Ultimately, as the discussion that follows will illustrate, it seems to be of little practical importance what the law says about advance directives beyond acknowledging their legal validity when they exist. These directives and related attempts to announce patient preferences (such as documents appointing health care proxies) are frequently inaccessible at key decision-making points, irrelevant or insufficiently specific to address the actual medical decision at hand, overruled by family members, or ignored by health care providers. Despite all of these pitfalls, however, the process of making an advance directive can provide important ancillary benefits—which not only accrue directly for the individual and his or her loved ones, but also more indirectly for health care providers and society.

Our legal rights of decision-making are grounded in the ethical principle of autonomy and include the right to refuse treatment even if one is not terminally ill.<sup>37</sup> These rights also include the right to re-

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BUT EFFECTIVENESS UNCERTAIN 2 (1995) (concluding that "advance directives have been advocated more than they have been used" and that "in general, only 10 to 25 percent of Americans have documented their end of life choices or appointed a health care agent."); see also Fagerlin & Schneider, *supra* note 20, at 32 (commenting on the empirical studies that demonstrate the PSDA's lack of effectiveness).

34. See, e.g., *In re Schiavo*, 780 So.2d 176; *In re Quinlan*, 355 A.2d 647 (1976).

35. See, e.g., *In re Guardianship of Schiavo*, 780 So.2d 176 (2001) (disputing, among other things, whether it was appropriate for the patient's husband to continue to serve as her surrogate decision-maker). Other disputes concern the best interests of never-capacitated patients such as infants. See, e.g., *In re Baby "K."*, 16 F.3d 590 (4th Cir. 1994).

36. See, e.g., *Cruzan v. Director, Missouri Dept. of Health*, 497 U.S. 261 (1990); *Vacco v. Quill*, 521 U.S. 793 (1997); *Washington v. Glucksberg*, 521 U.S. 702 (1997).

37. See, e.g., *Bouvia v. Superior Ct.*, 179 Cal. App. 3d 1127, 1135 (1986) ("Petitioner sought to enforce only a right which was exclusively hers and over which neither the medical profession nor the judiciary have any veto power. The trial court could but recognize and protect her exercise of that right.").

fuse treatment when 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 one’s death with the assistance of a physician.<sup>38</sup>

Advance directives, the orthodox argument goes, promote autonomy because they formalize an individual’s wishes about treatment choices and serve as a guide to the treating physician and the family about how to proceed if the individual is unable to speak for herself. These documents can give patients who complete them a sense of control over their health care, should they lose decisional capacity.<sup>39</sup> In multiple respects, this sense of control is an illusion. First, these documents may have limited application under state law.<sup>40</sup> Second, they are not necessarily accurate predictors of what an individual would really choose under the particular circumstances when decisionally-incapacitated by illness.<sup>41</sup> Furthermore, advance directives are seldom made and seldom followed.<sup>42</sup>

In fact, advance directives and the laws which authorize them may protect patient *autonomy* (i.e. they can announce a patient’s choice to accept or reject cardiopulmonary resuscitation, for example, or to decline artificial nutrition or ventilation), but they do little to promote *authenticity* in decision making. Individuals frequently do not know what they want, what choices are theirs, or how to articulate their

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38. See Oregon Death with Dignity Act of 1994, OR. REV. STAT. § 127.800-995 (2011); Washington Death with Dignity Act, WASH. REV. CODE § 70.245 (2012); *Baxter v. Montana*, 224 P.3d 1211 (2009).

39. See Robertson, *supra* note 20 (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).

40. States frequently limit applicability of advance directives to terminal illness, leaving patients who suffer from chronic and debilitating disease with more limited options, such as the appointment of a health care proxy. See *id.* at 6.

41. See *id.* at 8 (noting that those who execute advance directives are “rarely . . . told that the directive they make reflects their current interests and may not be a good indicator of their interests as an incompetent patient.”); see also Fagerlin & Schneider, *supra* note 20, at 33 (arguing that people will have difficulty predicting their preferences in advance because they misunderstand illnesses and treatments, think about their “choices” only superficially, and change their minds over time).

42. See Fagerlin & Schneider, *supra* note 20, at 32, 36 (noting that less than 20% of Americans have living wills, and studies suggest that living wills rarely influence the level of medical care; at least a quarter of patients with living wills receive care that is inconsistent with their instructions).

wishes.<sup>43</sup> These are not the sorts of questions that can be answered in an attorney's office or hospital admissions desk with a few moments of reflection. These questions require far more contemplation and in more detail than one can achieve by simply ticking boxes on a one-size-fits-all form. For confluence of autonomy and authenticity, it is the responsibility of each individual to think carefully about the various possible scenarios<sup>44</sup> and to make some decisions about what sort of care the individual wishes to have and what life-prolonging measures that person might wish to avoid.

Diligently considering these future scenarios and discussing them in detail with family members may seem unappealing to many people. An authentic decision requires a reasonably detailed understanding of the relevant options and their projected impact on the patient's prognosis and quality of life in the context of the patient's values and goals. Even those individuals who do confront these questions and document their wishes risk being influenced, consciously or unconsciously, by family and societal expectations about what they should choose and when. 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 serves a salutary purpose for the individual who willingly takes on the task, preferably before serious illness or injury arises.

The ethical principle of autonomy coexists in an uneasy *détente* with the ethical principle of beneficence, which requires that physicians provide that care which is in their patients' best interests.<sup>45</sup> When a patient's wishes are unclear, defining "best interests" is often difficult. Ideally, when a patient can no longer articulate his wishes, the decision should center around whether continued treatment would be the patient's authentic choice—that is, the choice that reflects careful thought, self-knowledge, and reflection, and that

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43. *Id.* at 33–35 (noting the difficulty of predicting preferences for future unspecified illnesses with unspecified treatments, adding that people do not understand treatments well enough to make an informed choice, and usually cannot write clearly enough to express preferences in detail even if they understood them).

44. Such scenarios might include, "what if I become mentally incapacitated?," "what if I become unable to care for myself?," "what if I develop a medical condition that leaves me in intractable pain or causes me to suffer from continuous shortness of breath?," and "what if I become permanently unconscious?"

45. See JOHN C. FLETCHER, ET AL., INTRODUCTION TO CLINICAL ETHICS 12 (2d ed. 1997) (describing beneficence as the "obligation to benefit patients . . . and to further their welfare and interests").

acknowledges the external influences that shape an individual's identity.<sup>46</sup> Autonomy ideally means more than possessing a choice—it means exercising that choice in a meaningful way which reflects holistically the patient's values, preferences, and beliefs within the context of her current, and evolving, life circumstances.<sup>47</sup> Advance directives drafted with this goal in mind must, therefore, speak with specificity about the writer's instructions for care when he or she suffers from a self-defined "intolerable indignity" as a result of a medical condition.<sup>48</sup> It requires the confrontation of death, its inevitability, and even, eventually, its possible desirability.

The co-existence of principles of autonomy and beneficence creates disagreements about the futility of life-supportive medical technology, and these disputes are embedded into many end of life conflicts. Physicians, patients, or families may question whether and when further treatment or life-sustaining measures are no longer medically or ethically appropriate.<sup>49</sup> New technologies also create new ethical dilemmas.<sup>50</sup> The futility conundrum is obvious—futility

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46. For a thorough discussion of different perspectives on the meaning of autonomy, see M. Gregg Bloche, *Beyond Autonomy: Coercion and Morality in Clinical Relationships*, 6 HEALTH MATRIX 229, 276–91 (1996).

47. See Brudney, *supra* note 18, at 33 (discussing the concept of autonomy as self-determination and suggesting that focusing on the distinction between desire and choice is helpful in understanding autonomy—we desire certain things that we may choose not to act on).

48. See Norman L. Cantor, *Making Advance Directives Meaningful*, 4 PSYCHOL. PUB. POL'Y & L. 629, 639–41 (1998) (discussing how a declarant can "effectively communicate the degree of deterioration at which death would, for that person, be preferable to continued existence.").

49. Futility questions arise in two categories—questions of the subjective value of the medical intervention and questions about the probability that the medical intervention will be successful. See Robert D. Truog et al., *The Problem with Futility*, 326 NEW ENG. J. MED. 1560, 1561 (1992).

50. In one recent case, a patient who had a left ventricular assist device (LVAD) implanted to supplement his heart's ability to circulate blood later requested that the pump be shut off because he found life intolerable with his profound disability. A bioethicist, commenting on the case, wrote that disabling the LVAD would be "tantamount to removing the patient's heart." See Rob Stein, *Heart Pump Creates Life-Death Ethical Dilemmas*, WASH. POST, Apr. 24, 2008, at A1. Such drastic statements perpetuate the misimpression that one has an ethical obligation to stick with life-sustaining technologies once they are started. New brain imaging technologies such as functional magnetic resonance imaging (fMRI) pose different but equally vexing dilemmas. fMRI technology allows physicians to identify localized neural activity in the brain that was previously undetectable through observable patient responses. These scans have called into question the accuracy of diagnoses of permanent vegetative state, raising questions about the consequent appropriateness of withdrawal of life-sustaining measures from these patients. See J. Andrew Billings et al., *Severe Brain Injury and the Subjective Life*, HASTINGS CENTER REP., May–June 2010, at 17, 18–20.

is in the eye of the beholder, so that families, patients, and health care providers may fail to agree on an appropriate point to discontinue technological interventions. Without guidance about an individual patient's beliefs regarding continued life-supportive measures, it is difficult to know when to cease providing support to a person whose condition will not improve. In such circumstances, the U.S. health care system and its providers are reluctant to opine about an incapacitated patient's best interests, and generally will revert to erring on the side of continued treatment.<sup>51</sup>

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 have 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 families and care givers, but it is not necessarily in the patient's best interests, nor does it necessarily reflect the patient's authentic choice.<sup>52</sup> 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? As a society, we experience serious discomfort when considering quality of life as a factor in resolving disputes about the continuation of arguably futile care. Rather than address uncomfortable quality of life questions, however, we “err on the side of life” even when all sentience is permanently gone.

As *Schiavo* and other cases of its type illustrate, many individuals take the position that our end-of-life laws should default on the side of continued treatment whenever a patient's choice or best interest is in dispute and decline to assess the quality of that life in doing so.<sup>53</sup> Giv-

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51. See, e.g., *Cruzan v. Missouri Dep't of Health*, 497 U.S. 261, 283 (1990) (discussing the risks of an erroneous decision to withdraw life-support from a patient who lacks decisional capacity).

52. Cf. Sean Palfrey, *Daring to Practice Low-Cost Medicine in a High-Tech Era*, *NEW ENG. J. MED.*, at e21(1), e21(1) (2011), available at <http://www.nejm.org/doi/pdf/10.1056/NEJMp1101392?source=hcrc> (commenting on the mistaken belief that “‘doing everything’ is the best practice and the way to prevent harm”).

53. See, e.g., *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 282 (1990) (“[A] state may properly decline to make judgments about the ‘quality’ of life that a particular person may enjoy and simply assert an unqualified interest in the preservation of human life to be weighed against the constitutionally protected interests of the individual.”); *Wendland v. Wendland*, 28 P.3d 151, 174 (Cal. 2001) (upholding a trial court decision to continue life-sustaining treatment despite a proxy decision maker's request to withdraw it because the proxy “offered no basis for such a finding other than her own subjective judgment that the conservatee did not enjoy a



en that several opinion polls establish that the majority of people say they would prefer not to continue living in a permanent vegetative state,<sup>54</sup> and given the astonishing amount of health care resources we use in the final months of our lives,<sup>55</sup> why does the law presume that, when a patient's wishes are unknown, that patient would wish to continue treatment or life-supportive measures? Part of the answer is, of course, that keeping a patient alive "in error" is capable of correction in the future, should additional information about the patient's wishes or condition become available. Implicit in this "err on the side of life" mentality is an unwillingness to make quality of life assessments. A biologic view of life is a binary view—that a person is either "alive" or "dead." It fails to account for the range of intermediate levels of unconsciousness or other sorts of disability or suffering in which a person with decisional capacity might choose to forego additional life-prolonging treatment. A purely biologic view of life certainly presents an easy to apply bright-line rule for courts.<sup>56</sup> But for persons to whom this approach is applied, the presumption in favor of continued treatment risks demeaning the individual or disregarding his preferences.

Much of the commentary on the *Schiavo* case also noted the inappropriate influences of politics, religion, and the so-called "culture wars" on the resolution of this dispute.<sup>57</sup> During the final years before

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satisfactory quality of life and legally insufficient evidence to the effect that he would have wished to die"); *In re* Conservatorship of Helga M. Wanglie, No. PX-91-283, Dist. Ct. Prob. Ct. Div. (Minn. 1989) (upholding the surrogate's request for continued treatment of the patient, who was in a persistent vegetative state and who died more than a year later of sepsis).

54. See, e.g., Kelly Gullo, ed., Harris Interactive Health Care Poll, *By a Near Four-to-One Margin, U.S. Adults Favor Not Taking Additional Steps to Prolong the Lives of Patients in a Persistent Vegetative State*, Apr. 12, 2005 (copy on file with author); Lydia Saad, *Americans Choose Death Over Vegetative State*, GALLUP (Mar. 29, 2005), <http://www.gallup.com/poll/15448/americans-choose-death-over-vegetative-state.aspx>.

55. Cf. Andrew Stern, *Discussing End-of-Life Care Lowers Cost—U.S. Study*, REUTERS (Mar. 9, 2009), available at <http://www.reuters.com/article/latestCrisis/idUSN06415881>.

56. Cf. *In re* Baby K, 16 F.3d 590 (4th Cir. 1994) (resolving, on technical statutory grounds, a dispute about continued life supportive measures for an anencephalic infant and thus defaulting to protection of purely biologic life).

57. See, e.g., George J. Annas, "I Want to Live": *Medicine Betrayed by Ideology in the Political Debate Over Terri Schiavo*, 35 STETSON L. REV. 49 (2005); Kathy L. Cerminara, *Collateral Damage: The Aftermath of the Political Culture Wars in Schiavo*, 29 W. NEW ENG. L. REV. 279 (2007); *Politicizing the End of Life*, *supra* note 6, at 107; John A. Robertson, *Schiavo and Its (In)Significance*, 35 STETSON L. REV. 101 (2005); Shepherd, *supra* note 15, at 297.

Theresa Schiavo died, there was an astonishing outpouring of passionate public sentiment (both supportive and condemnatory) at the court's decision to order the removal of her feeding tube.<sup>58</sup> The dispute over Theresa Schiavo's care provided a worst-case scenario for resolving an ethical conflict at the end of life. For politicians to impose a presumption of continued life at all costs when it is inconsistent with the individual patient's preferences represents the worst kind of potential harm because the presumption, in many cases, will fundamentally violate principles of autonomy and beneficence. The *Schiavo* battle, which pitted political and religious conservatives against Theresa's husband and the courts which had agreed with him that she would have chosen to forego continued life support, presented an uncomfortable cultural irony: the pro-life religious organizations which battled to keep Theresa alive at all costs were keeping her, a communicant of the Catholic church, from achieving the peace that her faith promises.

Choosing to "err on the side of life" as a default in order to avoid difficult conversations about quality of life has created a further ethical dilemma when coupled with broadly available medical technologies designed to sustain (biological) life. As a society, we are 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. Although it is well documented that "one-third of expenses in the last year of life are spent in the final month . . . with aggressive treatments in the final month accounting for 80 percent of those costs,"<sup>59</sup> we often persist in "doing everything" and we celebrate those patients who "fight until the end." Similarly, we, as patients, frequently misunderstand or simply fail to receive statistical information about the potential success of various treatments and interventions.<sup>60</sup> Statistical fallacies and unreasonable optimism lead patients to request and physicians to provide treatments that offer little or no real promise of benefit and to discount the potential and often probable harms of such care.<sup>61</sup> Physicians also tend to over-

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58. See *Role of Religion*, *supra* note 6, at 327–29 (describing last ditch efforts by interest groups and politicians to intervene in the *Schiavo* case).

59. Stern, *supra* note 55.

60. See Lynn A. Jansen et al., *Unrealistic Optimism in Early-Phase Oncology Trials*, 33 IRB: ETHICS & HUM. RES. 1, 2–7 (2011).

61. See *id.* (concluding that, despite disclosures in informed consent about the early-stage cancer trials that they were enrolled in, patients tended to underestimate the risks to themselves and overestimate the prospective benefit).

estimate the remaining life spans of seriously ill patients and to convey prognosis in overly optimistic terms.<sup>62</sup>

In fact, those patients who opt against therapeutic care in the face of severe chronic or terminal illness capture our attention and remind us that, sometimes, “doing everything” is not the best option for the patient, particularly when the adverse effects associated with treatment interfere with the patient’s ability to enjoy life and provide little added time.<sup>63</sup> Recent research confirms this conclusion. In a study of over 600 patients with advanced cancer, those patients who had end of life planning discussions with their physicians expended significantly less in health care costs in the final week of life and experienced less psychological and physical distress than those who did not discuss options with their physicians.<sup>64</sup> Survival times between the two studied groups were equal on average, but higher health care spending at the end of life was associated with poorer quality of life in the last weeks before death.<sup>65</sup> The study suggests “that increasing communication between patients and their physicians is associated

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62. See Nicholas A. Christakis & Elizabeth B. Lamont, *Extent and Determinants of Error in Doctors’ Prognoses in Terminally Ill Patients*, 320 BRIT. MED. J. 469, 470–71 (2000) (finding that, in predicting patients’ remaining life expectancies, physicians were correct only 20% of the time and were over-optimistic 63% of the time and concluding that a closer doctor-patient relationship was associated with over-optimistic predictions); see also Lisa I. Iezzoni et al., *Survey Shows That at Least Some Physicians Are Not Always Open or Honest with Patients*, 31 HEALTH AFFAIRS 383, 383–88 (2012) (discussing a survey finding that one-in-ten physicians admitted to lying to a patient within the previous year and over half of those surveyed acknowledged that they had been unrealistically optimistic about a patient’s prognosis).

63. See, e.g., PETER NOLL, IN THE FACE OF DEATH (Hans Noll Trans., 1989) (memoir detailing the author’s decision to forego treatment for his bladder cancer in order to enjoy the remainder of his life without the burden of surgery’s and radiation’s adverse effects); Amy Berman, *Can Good Care Produce Bad Health?*, HEALTH AGENDA (Jan. 11, 2011, 3:19 PM), <http://www.jhartfound.org/blog/?p=2765> (discussing the author’s decision not to seek treatment for her incurable stage IV breast cancer and the health care system’s bias in favor of quantity rather than quality of life); Greg A. Sachs, *Sometimes Dying Still Stings*, 284 JAMA 2423, 2423 (2000) (describing the death of a family member who opted for no cancer therapy and remained relatively well until the last two days of his life).

64. Baohui Zhang et al., *Health Care Costs in the Last Week of Life: Associations With End-of-Life Conversations*, 169 ARCHIVES INTERNAL MED. 480, 482–84 (2009) (finding that the average expenditure in the final week for patients who discussed end of life options with their physicians was \$1,876 compared with \$2,917 for those who did not).

65. *Id.* (finding that patients did not experience any shortening of life as a result of their decisions not to use intensive interventions such as ventilator support).

with better outcomes and with less expensive medical care.”<sup>66</sup> In fact, a growing body of evidence demonstrates that an emphasis on palliative care rather than aggressive therapy can improve patients’ quality of life and even prolong survival.<sup>67</sup> Continuing aggressive care also poses risks of iatrogenic harm and additional pain or discomfort, often with no discernable off-setting physical benefit. Prolonging therapy when it offers only speculative benefit to the patient also needlessly increases costs in a health care system that is already straining to meet its obligations.<sup>68</sup>

### III. Denial of Mortality

The willingness to engage in the kind of self-examination that is consistent with making advance directives depends in part on cultural factors, and in part on 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 new therapies, has created the illusion that there is time to procrastinate, to delay confronting mortality, perhaps even the hope of postponing death indefinitely.

Until relatively recently, religious faith played a dominant role in the lives of many, if not most people. Most faiths, including Christianity, offer the promise of life after bodily death, at least if the individual has taken the appropriate steps to achieve salvation. For those who have faith, the promise of salvation must surely provide some

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66. *Id.* at 487. Without regard to having end of life discussions with their physicians, the raw numbers of patients whose treatment preferences favored aggressive interventions despite having advanced cancer were substantial: 158 out of 603 patients stated that they valued life possible extension over comfort, 142 of the 603 preferred ventilator use to extend life, and 122 of 603 stated that they preferred everything possible to extend life for a few days. *Id.* at 483 tbl.1.

67. “Palliative care” refers to medical care intended to alleviate symptoms associated with illness, whatever the patient’s prognosis. Such care may address pain, shortness of breath, insomnia, depression, nausea and lack of appetite, among other symptoms. See Lise M. Stevens, *Palliative Care*, 296 JAMA 1428, 1428 (2006).

68. It is well documented that one-third of medical expenses for the last year of life are spent in the final month and that aggressive therapies and technologies in that final month account for nearly 80% of these costs. See Zhang, *supra* note 64, at 480. Moreover, 30% of Medicare dollars spent go to care for the 5% of Medicare beneficiaries who die each year. See Amber E. Barnato et al., *Trends in Inpatient Treatment Intensity Among Medicare Beneficiaries at the End of Life*, 39 HEALTH SERVICES RES. 363, 363–64 (2004).

comfort in the face of death.<sup>69</sup> Yet, Christianity also acknowledges the fear of death.<sup>70</sup> When society had all the rituals of organized religion, there was a pre-approved homogenous pathway, a set of instructions about how to live right and, finally, enter Paradise. Surprisingly, some recent research suggests that religious beliefs and traditions do not decrease fear of death,<sup>71</sup> and a recent study in fact indicates that terminally ill patients who profess some sort of religious faith or practice are more likely than agnostic or atheist patients to seek aggressive care at the end of life.<sup>72</sup>

Today, in a more secular age, many individuals lack the framework of religious belief to navigate the prospect death and dying. As one commentator noted, “[f]or the last two millennia at least, tight-rope-walking theists have been keenly aware that, should the safety net of resurrection fail, there is nothing between them and the solid ground of mortalism.”<sup>73</sup> For many people, the pathway of organized religion no longer exists. With that safety net of formal religion gone, the fear of death may be grounded in the realization that it is up to the

69. As Henry Scott Holland, Canon of St. Paul’s Cathedral, wrote, “Death is nothing at all / I have only slipped away into the next room / I am I and you are you / Whatever we were to each other / That we are still / . . . Life means all that it ever meant. / It is the same that it ever was / . . . I am waiting for you / for an interval / Somewhere very near / Just around the corner / All is well.” Henry Scott Holland, *Death is Nothing at All*, (published in *Facts of the Faith*, 1919), available at <http://www.poeticexpressions.co.uk/POEMS/Death%20is%20nothing%20at%20all%20-%20Canon%20Henry%20Scott-Holland.htm> (last visited Mar. 12, 2013).

70. Many medieval poems included the phrase “*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 Nocturn of Matins. See Richard L. Greene, *A Middle English “Timor Mortis” Poem*, 28 MODERN LANGUAGE REV. 234, 234–38 (1933). The Book of Psalms contains a plea for more time before the singer confronts his death: “Hear my prayer, O Lord, and give ear unto my cry; hold not thy peace at my tears: for I am a stranger with thee, and a sojourner, as all my fathers were. O spare me, that I may recover strength, before I go hence, and be no more.” *Psalms* 39:12–13 (King James).

71. See Timothy P. Daaleman & Larry VandeCreek, *Placing Religion and Spirituality in End-of-Life Care*, 284 JAMA 2514, 2514 (2000) (noting that the research into this question has generated “controversial results”).

72. See Andrea C. Phelps et al., *Religious Coping and Use of Intensive Life-Prolonging Care Near Death in Patients with Advanced Cancer*, 301 JAMA 1140, 1144 (2009) (concluding that high levels of religious coping were strongly associated with a preference for intensive life-prolonging care at the end of life, including ventilation and resuscitation). The authors of the study were unable to explain the association between religiousness and the preference for aggressive care at the end of life. *Id.* at 1141. The authors speculate that perhaps these preferences arise from a sense that the sanctity of life requires all available efforts to prolong it and that suffering at death furthers a religious purpose. *Id.* at 1145.

73. PETER D. HEINEGG, MORTALISM: READINGS ON THE MEANING OF LIFE 10 (2003).

individual to determine how to live life well and thus reconcile herself to mortality.

Unlike the rest of the animals, we are 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."<sup>74</sup> As Becker observes, this "existential dualism makes an impossible situation, an excruciating dilemma."<sup>75</sup> Thus, man resorts to a form of "blind obliviousness with social games, psychological tricks, personal preoccupations so far removed from the reality of his situation that they are forms of madness."<sup>76</sup> Much of how some individuals occupy their days serves either to deny that death is real or to somehow make its reality, when unavoidably glimpsed, more palatable.<sup>77</sup>

These individual, intimately personal struggles are reinforced at a societal level in a variety of ways. For one, the conflict between the conservative, pro-life religious movement and our rule of law's fundamental respect for individual autonomy has devolved into an extremely polarizing conflict between faith and science. In recent years, the United States has seen political and religious conservatives intentionally reject and undermine meaningful discussion about end of life care in favor of appealing to their base with superficial or false and misleading characterizations of issues.<sup>78</sup> Sarah Palin's fear-monger rhetoric about government-sponsored "death panels" provides a

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74. ERNST BECKER, *THE DENIAL OF DEATH* 26 (1973).

75. *Id.* at 27.

76. *Id.*

77. Philosopher Søren Kierkegaard's concept of busyness seems to explain quite a lot of what we do to avoid thinking about difficult truths. See SØREN KIERKEGAARD, *PURITY OF HEART IS TO WILL ONE THING* 108 (1847) ("But the reason may need to be explained . . . why, in the press of busyness, there is neither time nor quiet to win the transparency that is indispensable if a man is to come to understand himself . . . . Nay, the press of busyness into which one steadily enters further and further, and the noise in which the truth continually slips more and more into oblivion, and the mass of connections, stimuli, and hindrances, these make it ever more impossible for one to win any deeper knowledge of himself.").

78. Cf. Rudy Ruiz, *Commentary, Open Your Minds, America*, CNN.COM (Sept. 3, 2009), [http://articles.cnn.com/2009-09-03/politics/ruiz.closed.minds\\_1\\_health-care-listening-labels?\\_s=PM:POLITICS](http://articles.cnn.com/2009-09-03/politics/ruiz.closed.minds_1_health-care-listening-labels?_s=PM:POLITICS) (suggesting that, with the health care debate, we should be listening to differing opinions and acknowledge that changing one's mind in the face of new information is not a character flaw).

memorable example.<sup>79</sup> These sorts of careless and ill-advised pronouncements frustrate any reasonable attempts to engage in careful discussion and necessary debate about ethically complex end of life issues.<sup>80</sup>

In a different realm, cultural portrayals of older people in this society further exacerbate feelings of ambivalence about aging. As the average life span lengthens, we hear phrases like “fifty is the new thirty” and advertisements for “adult communities” (no longer “retirement communities” or “elder housing”) depict smiling, vigorous, nimble people playing golf and tennis.<sup>81</sup> As a society, we also deny the reality of aging and death by celebrating youth and physical perfection and by seeking it for ourselves.<sup>82</sup> We cut, plump, inject with

79. See Sarah Palin, *Statement on the Current Health Care Debate*, FACEBOOK (Aug. 7, 2009, 3:25 PM), [http://www.facebook.com/note.php?note\\_id=113851103434](http://www.facebook.com/note.php?note_id=113851103434) (“The America I know and love is not one in which my parents or my baby with Down Syndrome will have to stand in front of Obama’s ‘death panel’ so his bureaucrats can decide, based on a subjective judgment of their ‘level of productivity in society,’ whether they are worthy of health care.”). Palin’s statement actually referred to a proposal in President Obama’s health care reform legislation to provide Medicare beneficiaries with *optional* and free counseling on end of life decision making, including the *option* of making an advance directive to announce the individual’s preferences about life supportive care. See Michelle Andrews, *Rather Than Creating ‘Death Panels,’ New Law Adds to End-of-Life Options*, WASH. POST, Sept. 7, 2010, at HE5 (explaining that, in the wake of the outcry, legislators abandoned the provision). The damage created by these lies (a very effective, though mad, form of busyness) was significant. In a Kaiser Family Foundation poll of Medicare-eligible senior citizens, more than one-third believed that the health reform bill would allow government panels to make decisions about end of life care for Medicare recipients. See *Kaiser Health Tracking Poll*, KAISER FAMILY FOUND. (July 2010), [www.kff.org/kaiserpolls/8084.cfm?RenderForPrint=1](http://www.kff.org/kaiserpolls/8084.cfm?RenderForPrint=1).

80. Conflict about the sanctity of life may have more to do with political power and profiteering or with psychological displacement than any genuine concern about the merits of the arguments. It is, at least in part, another distraction from mortality, another manifestation of Kierkegaard’s busyness.

81. Cf. Mark D. Bauer, “Peter Pan” as Public Policy: Should Fifty-Five-Plus Age-Restricted Communities Continue to be Exempt from Civil Rights Laws and Substantive Federal Regulation?, 21 ELDER L.J. 33, 36, 42–43 (2013) (describing the amenities and shortcomings of 55+ communities).

82. We are bombarded constantly with images and promises of youth and rejuvenation. Airline magazine advertisements, for example, tout pills and hormone treatments for all sorts of ills associated with aging: a “brain oxygen-boosting miracle energizes mind, mood and memory . . . sharpens focus, clears away brain fog, erases 15 years of lost memory power!”; an exhortation to “choose life, grow young with HGH” (human growth hormone); and another program that promises that its “balanced combination of nutrition, exercise and hormone optimization” will “reverse[] the signs and symptoms of aging” including “decreased risk of age-related disease . . . increased energy, increased sex drive, sharper thinking.” (Copies on file with author); see also Thomas H. Perls et al., *Provision or Distribution of Growth Hormone for “Antiaging,”* 294 JAMA 2086, 2086 (2005) (describ-

muscle-paralyzing toxins and much more in the pursuit of physical perfection and perpetual youth.<sup>83</sup> 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.”<sup>84</sup>

In the tradition of the best hucksters selling wonder potions and elixirs on the American frontier, some researchers now talk of doubling the human life span, even of a “cure for death,”<sup>85</sup> and of aging as a “disease” that should be “treated.”<sup>86</sup> Research is underway to eliminate error rate in cell division at the molecular level in order to postpone death or evade it altogether.<sup>87</sup> Although commentators have eloquently questioned the research imperative and its unintended consequences,<sup>88</sup> so-called “cures for death,” and strategies to reduce

ing the proliferation of websites marketing HGH and commenting on the multi-million dollar and growing “antiaging” industry).

83. See LAURIE ESSIG, *AMERICAN PLASTIC: BOOB JOBS, CREDIT CARDS, AND OUR QUEST FOR PERFECTION*, at xiii, 84 (2010) (noting that the rate of plastic surgery has increased by 465% in the past decade and discussing the American woman’s battle against “ordinary ugliness” with plastic surgery and the underlying causes for failure to accept the effects of aging’s normal wear and tear on the body such as “stretch marks, cellulite, wrinkles, the downward pull of gravity . . .”).

84. Leigh Turner, *Antiaging*, 292 *JAMA* 2155, 2155 (2004).

85. *Closing in on the Cure for Death*, FIGHT AGING! (Sept. 2, 2003), <http://www.fighting.org/archives/2003/09/closing-in-on-the-cure-for-death.php>; see also Penni Crabtree, *Fountain of Youth with Just a Shot in the Arm?*, *SAN DIEGO UNION-TRIBUNE*, July 25, 2005, at A1 (describing the Institute’s claims and explaining that mainstream science has debunked anti-aging claims as “hucksterism” that offers little or no benefit but poses potentially serious health risks).

86. See Daniel Callahan, *Death and the Research Imperative*, 342 *NEW ENG. J. MED.* 654, 654–55 (2000) (quoting William Haseltine, then CEO of Human Genome Sciences as saying that “[d]eath is a series of preventable diseases” and arguing that research “should not, even implicitly, have eradication of death as its goal” because it supplants emphasis on the importance of relieving suffering at the end of life and it “promotes the idea among the public and physicians that death represents a failure of medicine.”).

87. See, e.g., Mariela Jaskelioff et al., *Telomerase Reactivation Reverses Tissue Degeneration in Aged Telomerase-Deficient Mice*, 469 *NATURE* 102, 104 (2010) (concluding, astonishingly, that correcting degeneration of the telomeres at the ends of mouse chromosomes, which are responsible for mutations during cell division, not only halted aging in mice but also reversed previous age-related degeneration of the brain). Similar research is supported by the Methusaleh Foundation, which sponsors a competition for researchers to develop technologies that break the world record for mouse longevity and mouse rejuvenation. See METHUSALEH FOUNDATION, [www.mprize.org](http://www.mprize.org) (last visited Mar. 22, 2013).

88. As Daniel Callahan succinctly explains,

Medical technology seems to know no boundaries because it is hard to say just what bodily failings and lethal threats we should be willing to accept. The medical research agenda now goes after all lethal diseases, but it also goes after human enhancements and wish fulfill-



morbidity in old age continue with little regard for the cultural consequences of the utterly distorted and absurd message it sends. This quest for a fountain of youth denies the reality of mortality, not to mention the fact that more days or years of life do not necessarily guarantee more quality of life or more happiness.

Paradoxically, alongside this anti-aging research juggernaut, we have at the same time 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.<sup>89</sup> 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.<sup>90</sup> Others explain the experience of terminal illness as casting the sufferer into the role of an outsider, no longer a member of society in the usual sense.<sup>91</sup> The modern tendency to share one's innermost thoughts and experiences of illness via blogs and specialized social networks seems paradoxical when juxtaposed with the unwillingness

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ment. Death itself is made to seem an accidental, contingent event. Why do we now die? Not because of the inherent finitude of the human body, as most people thought for most of human history. We die, it is said, because we engage in unhealthy lifestyles, or because research has not yet found a cure for our diseases.

Daniel Callahan, *Too Much of a Good Thing: How Splendid Technologies Can Go Wrong*, HASTINGS CENTER REP., Mar.-Apr. 2003, at 21.

89. The German language even has a compound noun for such books—"Krebsbüchlein" or, roughly translated, "little cancer book."

90. See, e.g., EDWARD E. ROSENBAUM, *A TASTE OF MY OWN MEDICINE* (1988); JOHN GUNTHER, *DEATH BE NOT PROUD* (1949) (telling the story of the author's son's struggle with a brain tumor and his death at age seventeen).

91. See PETER NOLL, *IN THE FACE OF DEATH* 3-5 (Hans Noll, trans., 1984). Peter Noll's book provides an intriguing and ultimately disturbing explanation of how he sees his outsider role as a logical continuation of what he has done all his life. In it, he explains his refusal of aggressive treatment for his cancer, not for religious reasons (although his father was a cleric) but for reasons of individual humanity and autonomy, a carefully considered decision to choose what is right and correct for himself, rather than to take any kind of public stance on end of life care. The author, upon deciding to refuse surgery to resect his bladder cancer, comments that

[n]aturally it is appropriate to show a patient who chooses metastasis instead of the technological prolongation of death a certain admiration, even though, strictly speaking, he hardly deserves it, for he really has only a choice between two evils, and it is almost purely a question of taste as to which he prefers.

*Id.* at 3-4.

to engage in advance care planning or to acknowledge and accept aging and the prospect of death.

#### IV. The Role of Law in Confronting Death

So what, if anything, does all of this have to do with law? The short answer: despite the multiplicity of state and federal statutes and judicial decisions that address 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 dying and death. We unconsciously (or sometimes deliberately) decide not to make choices that are ours to make. Yet, our legal rights regarding end of life decision making only have their fullest impact and meaning if we confront end of life issues long before a crisis of trauma or illness forces the issue.

Although advance directives are only occasionally consulted in making treatment decisions for patients who have 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 the manner of one's death but also as a means of enhancing life. The process itself—thinking about an advance directive, revising it, and discussing it with physician and family—presents an opportunity for each individual to reorient himself individually to goals and ways of living that have meaning on a very personal level. Ultimately, advance directives are about living, not dying.

In addition to the reforms discussed above that focus on regularizing the process of making advance directives and promoting interstate recognition, states should publicize the purposes and availability of these documents and should promote them as part of the daily business of being a citizen of the state. Although the idea of mandating advance directives raises serious concerns about privacy and autonomy, there seems no reason to discourage states from promoting the execution of these documents. Just as we ask people to indicate their willingness to be organ donors on their driving licenses, general practitioners could similarly make an annual inquiry about memorializing end of life preferences, though physicians already struggle to care for patients during the limited time allocated for an annual exam. Unfortunately, the design of our health care system does not foster

long-term relationships between physicians and patients.<sup>92</sup> Those individuals who are fortunate enough to have health insurance still are likely to change general practitioners fairly frequently, particularly when they change employment.<sup>93</sup> When serious illness occurs, specialists become involved in care, often omitting to include general practitioners in the conversation or to maintain a seamless exchange of information among themselves.

States also should educate their citizens about the value of periodic review and encourage individuals to revisit their choices as their values, experiences, and circumstances change.<sup>94</sup> States might even consider including information about end of life issues and end of life rights in their public school health curricula. Teaching young adults about these issues (along with safe sexual practices and good nutrition) would likely help to improve their comfort level with thinking about and discussing such matters throughout their lives. Over time, education about advance care planning and regularizing inquiries and updates could make advance directives as natural a part of citizenship as obtaining vehicle registration stickers or paying property taxes (and, at least superficially, far less burdensome than either of these).

Still, it seems likely that many people, perhaps the vast majority, would choose to postpone addressing end of life issues, perhaps for some of the same reasons that people refuse to consider organ donation in the face of concerted government action to encourage it.<sup>95</sup> All

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92. Cf. Quill, *supra* note 10, at 2504 (quoting a clinician who felt that she had "lost [her patient] in the system" after he was transferred to a long-term care facility where he would likely die, rather than dying at home with hospice, where she could be part of the ending).

93. Most insured individuals in the United States outside of the Medicare population receive their health insurance as an employee benefit. See BARRY R. FURROW ET AL., *THE LAW OF HEALTH CARE ORGANIZATION AND FINANCE* 347 n.1 (6th ed. 2008); cf. Ann S. O'Malley et al., *Coordination of Care by Primary Care Practices: Strategies, Lessons and Implications*, CTR. FOR STUDYING HEALTH SYSTEM CHANGE, Apr. 2009, at 1, 3, available at <http://www.hschange.com/CONTENT/1058/>.

94. At least a few states have chosen to put some resources into education. For example, in 2007 New York created a program to educate the public about the need for advance directives and health care proxies. See N.Y. PUB. HEALTH LAW § 207 (Consol. 2012); see also CAL. HEALTH & SAFETY CODE § 442.5 (2012) (requiring that if a health care provider diagnoses a patient with a terminal condition, the provider must provide the patient with information regarding end of life options); VT. STAT. ANN. 18 § 1871 (2012, Westlaw through the laws of the Adjourned Session on the 2011–2012 Vermont General Assembly) (same).

95. Concerns about making organ documents of gift and concerns about making advance directives sometimes arise from the misperception that physicians will make less effort to preserve the lives of potential organ donors or those who

of these suggested reforms to the law only go part of the way to addressing the inevitable struggle with end of life issues. The broader, unanswered question is what else, outside of the legal system, can encourage individuals to address these questions on a personal level before the critical moment arrives? Autonomy does not have much meaning without the courage and foresight to think about what is important to us as individuals—whether it is achieving the longest life possible, minimizing life with disability, or perhaps tolerating disability so long as cognitive abilities remain unimpaired—and to memorialize these preferences through serious conversations with family members or via a written document. Of course, there is also the option to ignore reality and to pretend that we are immortal. This denial injures not only ourselves but also those around us by raising the risk of conflicts within families or between families and health care providers and by potentially imposing the burden of deciding on a family member.

From the perspective of health care providers, these conversations are also difficult. Physicians have long struggled with feelings of powerlessness, grief, or failure when patients die.<sup>96</sup> Educating physicians and medical students about effective patient communication can foster participatory decision making and meaningful conversation. The medical literature suggests that the goal of quality communication has received more attention recently, though time constraints and individual predispositions probably limit it overall.<sup>97</sup> Discussions about the imminence of death and the patient's preferences regarding

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indicate preferences to refuse life-sustaining treatment. See generally Symposium, *Precious Commodities: The Supply & Demand of Body Parts*, 55 DEPAUL L. REV. 793 (2006).

96. See R. S. Kane, *The Defeat of Aging Versus the Importance of Death*, 44 J. AM. GERIATRIC SOC. 321, 321–22 (1996); Diane E. Meier et al., *The Inner Life of Physicians and Care of the Seriously Ill*, 286 JAMA 3007, 3007–08 (2001) (encouraging physicians to be self-aware, to acknowledge their emotions as they care for dying patients in order to improve quality of care, and to guard the physician's own well-being).

97. See Ronald M. Epstein et al., *Communicating Evidence for Participatory Decision Making*, 291 JAMA 2359, 2362 (2004) (reviewing the literature to identify research that guides physicians in communicating with their patients about end of life choices and recommending five communication steps to facilitate good discussion between physician and patient); Dale G. Larson & Daniel R. Tobin, *End-of-Life Conversations: Evolving Practice and Theory*, 284 JAMA 1573, 1576–77 (2000) (urging that end of life conversations become a routine part of health care and that advance care planning function as a key aspect of these discussions); Quill, *supra* note 10, at 2503 (explaining that “[t]imely, sensitive discussions with seriously ill patients regarding medical, psychosocial, and spiritual needs at the end of life are both an obligation of and privilege for every physician.”).

care are too frequently delayed.<sup>98</sup> Perhaps most significantly, health care providers express frustration and even anguish that they do not have the time to spend with patients to address their patients' feelings of shock, depression, or helplessness.<sup>99</sup> Thus, encouraging physicians to talk with patients (even younger adult patients) about end of life matters can help to make this process a routine aspect of general and preventive health care and, in fact, is explicitly encouraged by the American Medical Association.<sup>100</sup> Somewhat paradoxically, however, physicians appear resistant to such recommendations.<sup>101</sup>

Moreover, medical education should teach new physicians clearly and unequivocally that medical care is not necessarily always about prolonging life. The common training of physicians focuses on fighting disease, remaining detached, continuing to search for a solution to a problem, but perhaps at the cost of also losing sight of the pa-

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98. See Quill, *supra* note 10, at 2503–04 (providing a list of clinical indications for discussing end of life care, including imminent death, talk about wanting to die, inquiries about hospice, recent hospitalization for severe progressive illness, severe suffering, discussing prognosis, discussing treatment with low probability of success, discussing hopes and fears, and in cases where the physician would not be surprised if the patient died within six to twelve months). These indications for initiating end of life discussions, while useful, are primarily reactive to imminent death, not proactive in any way that would assist a person with coming to terms with mortality while still healthy.

99. See Charles J. Sabatino, *Reflections on the Meaning of Care*, 6 NURSING ETHICS 374, 374–76 (1999) (explaining that the dramatic growth of technologies in medical care creates a danger “that care will lose its primary focus on the well-being of the whole person”).

100. As one commentator has noted, “discussing palliative care issues while disease-remitting treatments are continued without creating a perception of abandonment requires the utmost empathy and skill.” See Larson & Tobin, *supra* note 97, at 1575. Why not discuss while the patient is well, as part of primary and preventive care? In fact, these authors recommend precisely that. See *id.* at 1576. Encouraging patients to discuss preferences is already happening, but does not appear to have had widespread effect. See *Opinion 8.081 – Surrogate Decision Making*, AM. MED. ASS'N, <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion8081.page> (last visited Mar. 26, 2013) (“Physicians should encourage their patients to document their treatment preferences or to appoint a health care proxy with whom they can discuss their values regarding health care and treatment in advance. Because documented advance directives are often not available in emergency situations, physicians should emphasize to patients the importance of discussing treatment preferences with individuals who are likely to act as their surrogates.”).

101. See Nancy L. Keating et al., *Physician Factors Associated With Discussions About End-of-Life Care*, 116 CANCER 998, 1001 (2010) (concluding that most physicians surveyed indicated that they would not discuss end of life decisions and choices with terminally ill patients until they exhibited symptoms or there are no remaining treatments available).

tient and her goals as an individual.<sup>102</sup> By reorienting the notion of caring to include the possibility of stopping therapeutic care and focusing on the alleviation of suffering, young physicians in training can learn to rein in their technological imperative impulses and offer the patient other sorts of care to ease the dying process.<sup>103</sup> Unfortunately, physicians who care for dying patients quite frequently experience resistance from patients' families or their own colleagues when they recommend withholding or withdrawing life-sustaining care—such recommendations often are referred to as “euthanasia,” “killing,” or “murder.”<sup>104</sup>

This society has endorsed the idea that it is acceptable, even desirable, to suppress the fear of death rather than confronting it, to take massive measures to fight death, even to deny its inevitability. The instinctive desire of physicians, patients, and families to “do everything possible” comports with this broader cultural attitude. This perspective perpetuates the belief that maximal utilization of life-prolonging measures constitutes “good health care.”<sup>105</sup> Although the attitude among health care providers is shifting, not long ago it was common to interpret good care as demanding every available, relevant treatment.<sup>106</sup> Now, more voices are speaking against the uncriti-

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102. See generally Symposium, *Patient-Centered Law and Ethics*, 45 WAKE FOREST L. REV. 1427 (2010) (containing multiple articles that address the value of providing medical care that places the individual patient at the center of health care delivery, rather than letting insurance companies, pharmaceutical companies, or even medical organizations drive).

103. It is important to acknowledge at this point the flaws in the palliative and hospice system that impact the quality of end of life care, particularly the problems of access and late referrals, although this matter falls outside the scope of this Article. In this regard, as with communication with patients about their end of life preferences, medicine is making significant progress.

104. See Nathan E. Goldstein et al., *Prevalence of Formal Accusations of Murder and Euthanasia Against Physicians*, 15 J. PALLIATIVE MED. 334, 334–39 (2012) (finding that more than half of physicians surveyed had their recommendations characterized as euthanasia, murder, or killing within the previous five years and that 4% of physicians surveyed reported being formally investigated for hastening a patient's death when using aggressive pain management techniques and discontinuing ventilator support).

105. Cf. Albert R. Jonsen, *The God Squad and the Origins of Transplantation Ethics and Policy*, 35 J. L. MED. & ETHICS 238, 239 (2007) (“The problem that looms behind transplantation medicine is the incessant desire, or rather, demand, that life must be salvaged at all costs.”).

106. See *id.* at 377 (adding that it is not unusual to “offer a great deal of expensive care trying to put off the inevitability of death, even when it may be in vain to continue doing so.”).

cal presumption in favor of utilizing medical technology simply because it is available.<sup>107</sup>

## V. Conclusion

There is a fundamental difference between acknowledging futile treatment and advocating euthanasia, abandoning effective medical treatments for serious illness, or any other dire interpretation that alarmists might ascribe to the reflections on law and dying in this essay. It is difficult to imagine a downside to educating individuals about their rights and choices, including their right to refuse unwanted medical treatment. It is also essential to ensure that choices really do exist and that individual preference is respected, the more so in situations where care givers, institutions, family members, and even politicians or religious leaders are attempting to hijack individual choice. Thinking about and discussing end of life choices explicitly while there is still healthy life ahead can reduce the incidence of end of life conflicts and family anguish about stopping treatment and foster a culture of respect for individual choice. Reforming the law represents only a small step towards helping individuals make peace with death. Meanwhile, modern medicine, longer life spans, and life-sustaining technology make it possible to postpone end of life decision-making.

Acknowledging and embracing mortality is not a tragedy—it is a life-long opportunity. It is impossible to develop any collective majoritarian default position on how to deal with death on an individual level. When an individual decides for herself how to live right, and moves forward with the assurance that she is living well, she can let go of the fear of death. Making peace with how one lives—in preparation for how one dies—should be an ongoing process, an opportuni-

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107. As Daniel Callahan has so ably argued, medical research should focus on reducing morbidity in the final years of life and assuring that people receive excellent care as they die in order to reduce suffering. Daniel Callahan, *supra* note 86, at 655–56; see also DANIEL CALLAHAN, SETTING LIMITS: MEDICAL GOALS IN AN AGING SOCIETY 53–58 (1987); DANIEL CALLAHAN, TAMING THE BELOVED BEAST 152–55 (2009) (arguing that “death itself, part of our biological nature, ought not to be seen as the primary target for health care, particularly when most of us now have the chance to live a full life” and observing that, paradoxically, as our society has become healthier, we have begun to worry more about health and to spend more technological resources on maintaining it); see also James F. Fries, *Ageing, Natural Death, and the Compression of Morbidity*, 303 NEW ENG. J. MED. 130, 130–31 (1980) (discussing the goal of “[e]xtension of adult vigor far into a fixed life span [in order to] compress[] the period of senescence near the end of life.”).

ty to be seized rather than postponed. This is not a novel observation. H.L. Mencken, in a letter to the woman whom he later married, argued that it is better to acknowledge the sorrows of life (including the inevitability of death) in order to savor its joys. Mencken advocates cynicism as “the most comforting of philosophies. You will get over your present difficulties only to run into something worse, and so on, until the last sad scene. Make up your mind to it—and then make the best of it. . . . Biological necessities keep us going. It is the feeling of exerting effort that exhilarates us, as a grasshopper is exhilarated by jumping. A hard job, full of impediments, is thus more satisfying than an easy job.”<sup>108</sup>

Obviously, there are no simple solutions to the problems described here. Perhaps, at a societal level, these problems are insuperable. Individuals can, however, take responsibility for that moment which, when it comes, is ours alone to face.<sup>109</sup> In this sense, even advance care planning creates a false sense of control over the inevitability of death, because it addresses (and more often in theory than in practice) the externalities of dying, not the feelings of the individual approaching death. Finding ways to live beyond the daily activities necessary to sustain our bodies, and beyond simply seeking distraction, provides a sense of purpose. Much of what we experience at the end of our lives is within our exclusive control—our inner lives remain ours alone. As for our outer lives—specifically our bodies and what we may suffer—taking some control over this aspect of dying requires an initial willingness to confront what lies within, and to make use of the law when it promotes our interests and those of the ones we love.

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108. Letter from H.L. Mencken to Sara P. Haardt (later his wife) while she was in a sanatorium receiving treatment for tuberculosis; quoted in Jacob A. Stein, *A Book on the Bus*, WASHINGTON LAWYER, Sept. 2008, [http://www.dcbbar.org/for\\_lawyers/resources/publications/washington\\_lawyer/september\\_2008/spectator.cfm](http://www.dcbbar.org/for_lawyers/resources/publications/washington_lawyer/september_2008/spectator.cfm).

109. In the words of Ivan Illich, “[t]he ordinary person suffers from the inability to die . . . Today, it is not sophisticated terminal treatment but lifelong training in misplaced concreteness that is the major obstacle to a bittersweet acceptance of our precarious existence and subsequent readiness to prepare for our own death.” Illich, *supra* note 1, at 1653.