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The End of End-of-Life Law

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THE END OF END-OF-LIFE LAW*

LOIS SHEPHERD**

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** Wallenborn Professor of Biomedical Ethics, Professor of Public Health Sciences and Professor of Law, University of Virginia. I wish to thank Professors Joan Krause and Richard Saver for inviting me to present and publish this Article as part of the North Carolina Law Review October 2013 symposium, *Health Care Decisions In the New Era of Health Care Reform*. The comments and questions of participants at the symposium have been valuable and much appreciated, as have those of participants in Temple Law School’s 2011 conference *Aging in the US: The Next Civil Rights Movement?* (organized by Professor Nancy Knauer), the meeting of the Blue Ridge Health Law Professors in 2013 (organized by Professor Mark Hall), and the 2013 annual meeting of the American Society of Bioethics and Humanities—each meeting in which the ideas presented here were first developed. I also thank Paul Shepherd and Stanley Terman for reading and commenting on prior drafts of the Article and Chad Anderson and the staff of the *North Carolina Law Review* for their helpful editing.

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INTRODUCTION

Over the last four decades, end-of-life law has had a life, so to speak, of its own. Through court decisions and statutes, state laws specify the medical conditions in which someone may refuse life-prolonging measures, the persons who can make refusal decisions when the patient lacks capacity, and the standards by which those decisions will be judged acceptable.¹ Some states have passed special laws requiring physicians to inform their patients of end-of-life options when the patient has a terminal condition.² The federal government has also been involved in end-of-life law: since 1990, hospitals that receive Medicare or Medicaid funding have been required to ask patients whether they have advance directives and to inform them of any hospital policies that would prevent their implementation.³ Early versions of the Affordable Care Act⁴

1. For a comprehensive explanation of the law of end-of-life decision making, see generally ALAN MEISEL & KATHY L. CERMINARA, *THE RIGHT TO DIE: THE LAW OF END-OF-LIFE DECISIONMAKING* (3d ed. 2004) (looseleaf text updated annually) (providing a broad overview of statutory and case law surrounding end-of-life decision making).

2. To date, four states have passed such laws: California, Michigan, New York, and Vermont. See CAL. HEALTH & SAFETY CODE § 442.5 (West Supp. 2014); MICH. COMP. LAWS ANN. §§ 333.5654-.5655 (West Supp. 2012); N.Y. PUB. HEALTH LAW § 2997-c (McKinney Supp. 2014); VT. STAT. ANN. tit. 18, § 1871 (Supp. 2012). Violation of the New York statute can result in monetary fines and even imprisonment. See *Questions and Answers About Palliative Care, Hospice, and the Palliative Care Information Act*, N.Y. ST. DEP'T HEALTH, http://www.health.ny.gov/professionals/patients/patient_rights/palliative_care/practitioners/questions_and_answers.htm#q_25 (last visited Jan. 30, 2014). See generally Sonia M. Suter, *The Politics of Information: Informed Consent in Abortion and End-of-Life Decision Making*, 39 AM. J.L. & MED. 7 (2013) (discussing and critiquing these statutes).

3. Patient Self-Determination Act, Pub. L. No. 101-508, §§ 4206, 4751, 104 Stat. 1388, 1388-115, 1388-204 (1990) (codified in scattered sections of 42 U.S.C.).

promised more—physician reimbursement for advance care planning with Medicare beneficiaries.⁵ The entire health insurance reform effort floundered and nearly failed when Sarah Palin charged that the reimbursement provision would empower “death panels” to ration life-sustaining treatment and deny care to the elderly and disabled; it was eliminated before the Act’s final passage.⁶ Distortion and fear-mongering are not new to end-of-life law. Since the 1970s, this area of law has been a hotbed of controversy—from early cases brought by families to allow their permanently unconscious or dying relatives to be removed from ventilators,⁷ to later cases involving patients in similar conditions but a different form of life support (artificial nutrition and hydration⁸), to the now increasingly common case in which it is health care providers, not families, who are insisting it is time to let the patient die.⁹

Today we have multiple complex legal rules that treat decisions about medical treatment at the end of life differently than other important decisions about medical treatment. Many of the special rules for end-of-life decision making insist on legally exact and increasingly complex documentation; depend on idealized, unrealistic

4. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119 (2010) (codified as amended in scattered sections of 26 U.S.C. and 29 U.S.C.).

5. H.R. 3200, 111th Cong. § 1233 (2009), available at <https://www.govtrack.us/congress/bills/111/hr3200/text> (text as of Oct 14, 2009).

6. See generally Brendan Nyhan, *Why the “Death Panel” Myth Wouldn’t Die: Misinformation in the Health Care Reform Debate*, 8 FORUM 1, 1 (2010) (tracing the origin and spread of the “death panel myth”).

7. See, e.g., *In re Quinlan*, 355 A.2d 647, 671 (N.J. 1976) (holding that patients, such as Karen Ann Quinlan, who was in a permanent vegetative state, have a federal constitutional right to refuse extraordinary treatment and allowing her family to render their best judgment about what she would want done). Death and dying jurisprudence actually predates *Quinlan*, but *Quinlan* was a landmark decision. See generally Norman L. Cantor, *Twenty-Five Years After Quinlan: A Review of the Jurisprudence of Death and Dying*, 29 J.L. MED. & ETHICS 182 (2001) (explaining that some courts relied on a constitutional right, others a common law right, and some both, in uniformly establishing that competent patients have a right to refuse life-sustaining treatment).

8. *Cruzan v. Dir., Mo. Dep’t of Health*, 497 U.S. 261, 286–87 (1990) (upholding Missouri’s prohibition against removing artificial nutrition and hydration unless there was clear and convincing evidence that this was what Nancy Cruzan—who was in a permanent vegetative state—would have wanted, based on her own statements to that effect).

9. See Thaddeus Mason Pope, *Surrogate Selection: An Increasingly Viable, but Limited, Solution to Intractable Futility Disputes*, 3 ST. LOUIS U. J. HEALTH L. & POL’Y 183, 204 (2010) (“Futility disputes are regularly identified as the single biggest ethical dilemma facing North American hospitals.”); see also Ruth A. Mickelsen et al., *The Barnes Case: Taking Difficult Futility Cases Public*, 41 J.L. MED. & ETHICS 374, 374 (2013) (describing dispute between a health care agent and a hospital over the “futility” of continued aggressive medical treatment for a patient); *infra* Part II.A (discussing the Hanford Pinette case).

notions of patient autonomy; and are driven by political ideology rather than concern for patients.¹⁰ There is little evidence that such rules produce good and some evidence that they produce harm, impeding rather than honoring patients' wishes, values, interests, and relationships.¹¹

How we got here is understandable. The early cases had no precedent, and courts struggled to develop constitutional and common law standards to address the new controversies brought about by medical advances that could save and extend life.¹² State legislatures responded by developing "safe harbor" statutes that would let patients, families, physicians, and hospitals know when forgoing life-sustaining treatment was legally acceptable, and allow these matters to be decided outside the traumatic and contentious arena of the courtroom.¹³

But the time has come to abandon this way of thinking—to put an end to end-of-life law—and there is good evidence that a necessary shift is already underway. This Article argues that questions about medical care at the end of life should be approached like other important questions about medical care—with consideration to patients' wishes, values, interests, and relationships, and without special laws, special burdens of proof, or unique requirements for documentation. Reducing legal distinctions between end-of-life decisions and other health care decisions can bring efficacious changes to both sorts of decision making processes. On the one hand, we can import good legal and ethical practices in caring for patients generally to caring for them when they are dying. At the same time, we can bring important lessons learned from decades of end-of-life law and ethics to the care of patients at any stage of life and health.

Before charting this course, a word about terminology is in order. This Article will use the terms "life-prolonging measures," "life-sustaining treatment," and similar terms interchangeably, as well as

10. See *infra* Part II and notes 34–41 and accompanying text.

11. See *infra* Part II and notes 34–41 and accompanying text.

12. See generally WILLIAM H. COLBY, LONG GOODBYE: THE DEATHS OF NANCY CRUZAN (2002) (detailing the legal landscape and advocacy surrounding the *Cruzan* case); Cantor, *supra* note 7 (providing an overview of end-of-life law after *Quinlan*); Annette E. Clark, *The Right to Die: The Broken Road from Quinlan to Schiavo*, 37 LOY. U. CHI. L.J. 385 (2006) (reviewing landmark end-of-life court decisions).

13. See, e.g., ALA. CODE § 26-1-2(g)(8) (LexisNexis Supp. 2011) (immunity for appointed proxy); *id.* § 22-8A-7(c) (LexisNexis 2006) (immunity for health care providers); *id.* § 22-8A-1(h) (LexisNexis 2006) (immunity for surrogate decision maker from statutory default list). See generally MEISEL & CERMINARA, *supra* note 1, at § 7.10[E] & [F], §§ 8.01, 8.09, 11.11[B] (providing an overview of statutory immunity for health care providers and surrogate decision makers).

“surrogate decision maker,” “proxy,” or “health care agent,” and “living will” or “instructional advance directive.” State laws define and use these terms with some precision, but they do not always share meanings across states. Most of the times that these terms are used in the Article, they are not used to make a point about a particular statutory meaning; when they are, care is taken to indicate that.

Part I provides a brief overview of the current law of end-of-life decision making. Part II then discusses, in some detail, two stories that reveal some of the many problems the current legal approach engenders. Part III explains why end-of-life decisions should be treated like other important medical decisions. Part IV provides a blueprint for reform through eight general principles that should guide the law relating to all health care decisions, including those we now think of as end-of-life decisions.

I. THE LAY OF THE LAND

Much of the special legal environment surrounding what we think of as end-of-life decisions focuses on narrow conceptions of the fundamental obligations we owe one another. This is in large part because the law has developed through recognition of patients’ rights rather than provider, family, or societal responsibilities. In the language of constitutional law, these are framed as rights to self-determination, bodily integrity, and life.¹⁴ In the context of health care decisions, these rights are more likely to be described as *respect for patients’ autonomy* and *protection of patients’ best interests*.¹⁵

Respect for patients’ autonomy is given great weight, or at least that is what many legal decisions intend to do, and some may actually achieve that goal. When an individual has decision-making capacity, her right to refuse medical treatment is nearly absolute, even if

14. See, e.g., *Cruzan v. Dir., Mo. Dep’t of Health*, 497 U.S. 261, 278 (1990) (determining that prior cases support a constitutional liberty interest in refusing unwanted medical treatment based on notions of bodily integrity); *Conservatorship of Wendland v. Wendland*, 28 P.3d 151, 166–75 (Cal. 2001) (discussing conscious conservatee’s right to life); *In re Fiori*, 673 A.2d 905, 910 (Pa. 1996) (basing right to refuse treatment on the individual’s right to self-determination). But see *Washington v. Glucksberg*, 521 U.S. 702, 725 (1997) (rejecting a constitutional right to physician-assisted suicide and emphasizing that the right assumed in *Cruzan* was not based on abstract concepts of personal autonomy); *Schiavo ex rel. Schindler v. Schiavo*, 358 F. Supp. 2d 1161, 1168 (M.D. Fla. 2005) (rejecting Fourteenth Amendment substantive due process claim of a “right to life”), *aff’d*, 403 F.3d 1289, 1302 (11th Cir. 2005).

15. See generally TOM L. BEAUCHAMP AND JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* (7th ed. 2013) (discussing the now-standard approach for analyzing ethical questions in medicine through the four principles of respect for autonomy, beneficence, non-maleficence, and justice).

treatment is relatively non-invasive, most likely curative, and forgoing it would jeopardize the patient's health or even lead to death.¹⁶ Why competent patients¹⁷ might wish to refuse treatment does not ultimately matter—they do not have to justify their health care decisions on the basis of religious beliefs, moral convictions, or anything of the sort.¹⁸ For patients with decision-making capacity, the law governing decisions about life-sustaining treatment is no different than the law governing other medical decisions—deference to the patient's desires is almost complete.¹⁹

16. See, e.g., *Bouvia v. Superior Court*, 225 Cal. Rptr. 297, 305 (Cal. Ct. App. 1986) (holding that a woman with disabilities was allowed to refuse a feeding tube in the hospital); *State v. McAfee*, 385 S.E.2d 651, 652 (Ga. 1989) (holding that a man with quadriplegia had the right to be removed from ventilator); *Lane v. Candura*, 376 N.E.2d 1232, 1235–36 (Mass. App. Ct. 1978) (holding that a competent woman could refuse amputation of her gangrenous leg); *McKay v. Bergstedt*, 801 P.2d 617, 624 (Nev. 1990) (holding that a man with quadriplegia had the right to withdrawal of respirator). As Norman Cantor explains in his history of death and dying jurisprudence, “courts have uniformly upheld an adult’s prerogative to reject a blood transfusion.” Cantor, *supra* note 7, at 194 n.7 (citing *Fosmire v. Nicoleau*, 551 N.E.2d 77 (N.Y. 1990); *Pub. Health Trust v. Wons*, 541 So. 2d 96 (Fla. 1989)).

17. This Article will sometimes use the terms “competent” or “incompetent” to reflect a patient’s capacity to make important medical decisions. Many of the court decisions use these terms. Principle 7, however, emphasizes the importance of carefully determining and monitoring capacity and allowing patients to make, or be involved in, as many decisions as they can. See *infra* Part IV.G.

18. See *Bouvia*, 225 Cal. Rptr. at 305 (determining that Bouvia’s decision to forgo medical treatment “is a moral and philosophical decision that, being a competent adult, is [hers] alone”). But see Paul K. Longmore, *Elizabeth Bouvia, Assisted Suicide and Social Prejudice*, 3 ISSUES L. & MED. 141, 158 (1987) (critically reviewing the *Bouvia* opinion from a disability rights perspective and pointing out that, despite the court’s insistence that the decision was Bouvia’s alone to make, the court assessed for itself the quality of Bouvia’s life and determined that it was not worth living).

19. One condition in which competent patients do not receive complete respect for their autonomous decisions is pregnancy. See Julie D. Cantor, *Court-Ordered Care—A Complication of Pregnancy to Avoid*, 366 NEW ENG. J. MED. 2237, 2237 (2012) (discussing case of Samantha Burton, a pregnant Florida woman subject to a court order to follow doctor’s orders for hospitalization and, ultimately, a cesarean section). For an example in the end-of-life context, see *In re A.C.*, 573 A.2d 1235, 1252 (D.C. Cir. 1990) (reversing trial court order of cesarean section for terminally ill woman of uncertain capacity over the objections of family). The appellate court in *In re A.C.* held that the trial court should have expressly determined the patient’s competency. *Id.* It left open the possibility that even if a patient is found to be competent, there may be “extremely rare and truly exceptional” cases in which the patient’s decisions about medical treatment may be overridden. *Id.* See generally April L. Cherry, *The Free Exercise Rights of Pregnant Women Who Refuse Medical Treatment*, 69 TENN. L. REV. 563, 564 (2002) (explaining that “the overwhelming sense among medical, legal, and ethics scholars is that judicial action is inappropriate and unwarranted” to compel pregnant women to undergo particular medical treatments). State intrusions into the decision making—medical or otherwise—of pregnant women appear to be on the rise. See generally R. Alta Charo, *Physicians and the (Woman’s) Body Politic*, 370 NEW ENG. J. MED. 193 (2014) (criticizing legislatures’

To what extent we must respect the autonomy of patients without decision-making capacity, however, is not as straightforward. Generally, respect for the autonomy of patients who previously had, but have now lost, capacity is understood as respect for their prior decisions—whether these were fully formed expressed preferences (as in, “if I am ever in a persistent vegetative state, I would not wish to have my life prolonged by a feeding tube”) or were instead a series of choices made in the course of their pre-incapacity lives from which we draw conclusions about what they would have decided if faced with the exact question now considered.²⁰ The law does not generally promote respect for autonomy as including respect for choices that benefit others’ interests over the patient’s interests, even if a competent patient could freely make such decisions.²¹ In this way,

intrusions into the practice of medicine, especially involving pregnant women); Lynn M. Paltrow & Jeanne Flavin, *Arrests of and Forced Interventions on Pregnant Women in the United States, 1973-2005: Implications for Women’s Legal Status and Public Health*, 38 J. HEALTH POL. POL’Y & L. 299 (2013) (reporting and analyzing 413 cases). Another limitation on the fulfillment of competent patients’ medical decisions is posed by conscience clause legislation that allows health care providers to refuse to honor patient or surrogate directives if they conflict with the provider’s religious or moral beliefs. See Howard Brody et al., *Artificial Nutrition and Hydration: The Evolution of Ethics, Evidence, and Policy*, 26 J. GEN. INTERNAL MED. 1053, 1055–56 (2011) (discussing such clauses in the context of patients’ options to refuse artificial nutrition and hydration).

20. See Alan Meisel, *Suppose the Schindlers Had Won the Schiavo Case*, 61 U. MIAMI L. REV. 733, 744–45 (2007) (describing the substituted judgment standard, which was adopted in *Quinlan* and has become the predominant standard). According to Meisel, “Put most simply, the substituted judgment standard seeks to determine the now-incompetent patient’s *probable* wishes concerning treatment.” *Id.*; see also PRESIDENT’S COMM’N FOR THE STUDY OF ETHICAL PROBLEMS IN MED. AND BIOMED. AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT 132 (1983) [hereinafter PRESIDENT’S COMM’N] (“The substituted judgment standard requires that a surrogate attempt to reach the decision that the incapacitated person would make if he or she were able to choose.”).

21. It is true that there is some indication in several court opinions that, in determining what the incompetent person’s choice would be, it may be appropriate to consider the impact of the decision on the patient’s family. See, e.g., *Barber v. Superior Court*, 195 Cal. Rptr. 484, 493 (Cal. Ct. App. 1983) (“[S]ince most people are concerned about the well-being of their loved ones, the surrogate may take into account the impact of the decision on those people closest to the patient.” (citing PRESIDENT’S COMM’N, *supra* note 20, at 134–35)); *In re R.H.*, 622 N.E.2d 1071, 1076 (Mass. App. Ct. 1993) (noting that in determining what an incompetent patient’s choice would be, a judge should consider, among other things, “the impact on the patient’s family”). However, in neither of those cases was the primary determinant of the substituted judgment decision the patient’s putative regard for the interests of others. See MEISEL & CERMINARA, *supra* note 1, § 4.03[B] (citing *In re Doe*, 583 N.E.2d 1263, 1269 n.15 (Mass. 1992)) (“Even those courts that consider a broad array of factors under the aegis of the substituted judgment standard are unwilling, at least overtly, to consider the financial cost of the care.”); see also RELATIONAL AUTONOMY: FEMINIST PERSPECTIVES ON AUTONOMY, AGENCY, AND THE SOCIAL SELF (CATRIONA MACKENZIE & NATALIE STOLJAR, eds., 2000) (collection

autonomy is de-contextualized or de-relationalized. So, for example, it would be unusual to see a living will that explicitly directed that life-sustaining treatment be either discontinued or continued for the benefit of another (as in, “if I am ever in a persistent vegetative state, I would like my husband to choose what to do on the basis of what is best for our children”). Such language is far removed from the typical language of living wills.²² Even if that statement were written into a personalized living will, a court would likely be flummoxed to know what to do with it.²³

The law also looks to protect an incompetent patient’s best interests. But in the context of decisions about life-sustaining treatment, continued life, if it is possible, is almost always seen to be objectively in a person’s best interests. While it is possible to hear people make assessments that death is preferable to some forms of living—where suffering is intense and pleasure absent, and both of these permanently so—this is seldom the position taken by the law.²⁴ Instead, continued life, if it is possible, is almost always seen to be presumptively in a person’s best interests.²⁵ It is true that in some

of essays on contemporary feminist theory that offer accounts of autonomy that are “relational” and that recognize individuals as socially interdependent); Sue Campbell, *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self* (Review), 17 *HYPATIA* 165, 165 (2002) (describing this volume as offering “accounts of autonomy capable of recognizing and supporting commitments to others”).

22. See, e.g., FLA. STAT. ANN. § 765.303 (West 2010) (suggesting a standard form for living wills); OKLA. STAT. ANN. tit. 63, § 3101.4 (West Supp. 2013) (same).

23. See *supra* note 21 and accompanying text.

24. For a related line of jurisprudence, see the “wrongful life” cases, in which a child born ill or disabled claims that he or she would not have been born (and thus suffered injury) but for the negligence of the defendant health care provider in failing to properly advise the child’s parents of the risk of disability or illness before the child’s birth. Only three jurisdictions have recognized such claims; the majority of jurisdictions have rejected them, generally determining that, as a matter of law, life with an illness or disability is better than never having been born at all. See *Turpin v. Sortini*, 643 P.2d 954, 966 (Cal. 1982) (accepting the “wrongful life” cause of action); *Procanik v. Cillo*, 478 A.2d 755, 760 (N.J. 1984) (same); *Harbeson v. Parke-Davis, Inc.*, 656 P.2d 483, 488 (Wash. 1983) (same). But see *Kassama v. Magat*, 792 A.2d 1102, 1123 (Md. 2002) (rejecting claim and reviewing twenty-year history of wrongful birth and wrongful life claims). See generally Mark Strasser, *Wrongful Life, Wrongful Birth, Wrongful Death, and the Right to Refuse Treatment: Can Reasonable Jurisdictions Recognize All But One?*, 64 *MO. L. REV.* 29, 64–67 (1999) (comparing wrongful life, wrongful birth, wrongful death, and treatment refusal—sometimes called “wrongful living”—claims).

25. See, e.g., *In re Estate of Longeway v. Cmty. Convelscent Ctr.*, 549 N.E.2d 292, 299 (Ill. 1989) (“The problem with the best-interests test is that it lets another make a determination of a patient’s quality of life, thereby undermining the foundation of self-determination and inviolability of the person upon which the right to refuse medical treatment stands While not passing on the viability of the best-interests theory in Illinois, we decline to adopt it in this case because we believe the record demonstrates the relevancy of the substituted-judgment theory.”); *In re Guardianship of L.W.*, 482 N.W.2d

states (but not all) life support may be withdrawn on the basis of a person's best interests,²⁶ but the discretion to do so is not as broad as it might first appear. The standard has generally been found to be inapplicable to patients in a permanent vegetative state (since they cannot experience any burdens from continued treatment or life),²⁷ and is often available only when the person's medical condition is such that, no matter what interventions are pursued, he or she is going to die fairly shortly anyway and attempting to extend life would severely impair its quality.

Due to the presumption that continued life is nearly always in a person's best interests, the structure of much of the law relating to withholding or withdrawing life-sustaining treatment begins with a default position in favor of continued life. State statutes grant immunity to providers and surrogate decision makers who make decisions to withhold or withdraw life-sustaining treatment only under certain circumstances.²⁸ Generally, the patient must be terminally ill (some of the statutes require that death be "imminent")

60, 75 (Wis. 1992) ("[T]he presumption is that continued life is in the best interests of the ward, and the burden rests upon the guardian to show . . . that the decision to withhold or withdraw treatment is in the ward's best interests and was made in good faith."); MEISEL & CERMINARA, *supra* note 1, § 4.07[B] (noting that some courts have accepted the best interests standard for decisions about life-sustaining treatment, although only a few have applied it, and that some have rejected it).

26. See MEISEL & CERMINARA, *supra* note 1, § 8.08 (noting inconsistent statutory support for the best interests standard); *id.* § 4.07[B] (discussing variability among courts about the permissibility of using the best interests standard).

27. See, e.g., *DeGrella v. Elston*, 858 S.W.2d 698, 705 (Ky. 1993) (stating that the best interests analysis would not be adopted); *Mack v. Mack*, 618 A.2d 744, 759 (Md. 1993) ("A best interest test applied to . . . any patient who is in a persistent vegetative state, who is not in pain, and who is not terminally ill, requires this Court to make a quality-of-life judgment under judicially adopted standards, without legislative guidelines."); *In re M. Peter*, 529 A.2d 419, 425 (N.J. 1987) ("[A] benefits-burden analysis . . . is essentially impossible with patients in a persistent vegetative state."); see also 73 Op. Att'y Gen. 162, 189-90 (1988) ("The balancing of costs and benefits to the patient that a surrogate must undertake for a terminally ill patient cannot be done in the same way for a patient who is permanently unconscious.").

28. See, e.g., ALA. CODE § 26-1-2(g)(8) (LexisNexis Supp. 2011) (immunity for appointed proxy); *id.* § 22-8A-7(c) (LexisNexis 2006) (immunity for health care providers); *id.* § 22-8A-1(h) (immunity for surrogate decision maker from statutory default list); FLA. STAT. ANN. § 765.305 (West 2010) (providing circumstances under which life-prolonging procedures can be withheld or withdrawn in the absence of a living will); *id.* § 765.109 (providing immunity for health care providers, surrogates, and proxies for actions taken in accordance with the provisions of Chapter 765). The structure of these statutes as immunity statutes does not mean that life-sustaining treatment cannot be withheld or withdrawn outside of these conditions, and many of them contain a "savings" provision that explicitly provides that the common law and constitutional rights of the patient are preserved. See Cantor, *supra* note 7, at 190; see also, e.g., FLA. STAT. ANN. § 765.106 (preservation of existing rights).

or permanently unconscious.²⁹ Some states, like Florida and Maryland, permit life-sustaining treatment to also be withheld or withdrawn when the patient is in an "end-stage condition," like end-stage renal disease or advanced dementia.³⁰ Only a few, like Virginia, do not restrict authority for forgoing life-sustaining treatment to any particular medical condition.³¹

Generally, surrogate decision makers must base their decision on the expressed preferences of the patient first, then on the patient's values through a "substituted judgment" process.³² As noted above, if there is no information of this kind upon which to base a decision to forgo life-sustaining treatment, surrogates in some states can make a decision on the basis of the patient's best interests, although this is by far the less preferred option.³³ Written instructions (such as a living will) are generally privileged over oral instructions, and both are strongly preferred over a mere understanding of a person's values. A few states have required clearly expressed (written or oral) preferences about withholding or withdrawing life-sustaining treatment in a situation like the one the patient is in and eschew decisions made on a more generalized understanding of a patient's

29. See, e.g., ME. REV. STAT. ANN. tit. 18-A, § 5-805(a) (Supp. 2012) (granting immunity where patient has a terminal condition or is in a persistent vegetative state); OHIO REV. CODE ANN. § 2133.08(A)(1)(a) (LexisNexis 2011) (granting immunity where patient has a terminal condition or is in a permanently unconscious state). These conditions are usually those that are also specified as conditions under which a patient's living will, or instructional directive, would be operative.

30. FLA. STAT. ANN. § 765.303 (suggesting a standard form for living wills); *id.* § 765.305 (stating that, in the absence of a written advance directive, a surrogate may only exercise an incompetent patient's right to forgo treatment when "[t]he patient has an end-stage condition, the patient is in a persistent vegetative state, or the patient's physical condition is terminal"). An "end-stage condition" is "an irreversible condition that is caused by injury, disease, or illness which has resulted in progressively severe and permanent deterioration, and which, to a reasonable degree of medical probability, treatment of the condition would be ineffective." *Id.* § 765.101(4). This term is commonly understood to embrace advanced dementia, such as that caused by Alzheimer's, which is steadily progressive, incurable, and ultimately fatal. See 85 Op. Md. Att'y Gen. 318, 328 (2000) (interpreting a statute similar to Florida's).

31. See VA. CODE ANN. § 54.1-2981 to -2993 (2013).

32. See *supra* note 20 and accompanying text.

33. See MEISEL & CERMINARA, *supra* note 1, § 8.08 (noting inconsistent statutory support for best interests standard); *id.* § 4.07[B] (discussing variability among courts about the permissibility of using the best interests standard); see also Kim Dayton, *Standards for Health Care Decision-Making: Legal and Practical Considerations*, 2012 UTAH L. REV. 1329, 1343 (arguing that even if guardianship statutes explicitly require a best interests standard, this must be understood in light of court decisions establishing constitutional rights and therefore be interpreted to require substituted judgment, if feasible).

values.³⁴ In some states, written authorization by the patient is required to forgo artificial nutrition and hydration, at least for some conditions.³⁵

Finally, in many states, the evidence supporting the surrogate's decision must be "clear and convincing."³⁶ This is an intermediate standard of evidentiary proof, higher than the usual standard for civil

34. See Alan Meisel, Lois Snyder & Timothy Quill, *Seven Legal Barriers to End of Life Care: Myths, Realities, and Grains of Truth*, 284 J. AM. MED. ASS'N 2495, 2497 (2000) (explaining that at that time, New York, Missouri, Michigan, and Wisconsin required evidence of an incompetent patient's actual wish to forego treatment under some circumstances). New York's law has since been revised by passage of the Family Health Care Decisions Act in 2010. N.Y. PUB. HEALTH LAW §§ 2994-a to -u (McKinney 2012). Missouri may also have backed away from its strict requirement of prior patient expressions in case law subsequent to *Cruzan*. See MEISEL & CERMINARA, *supra* note 1, § 4.06[A]. The standard requiring actual prior expressions by the patient is sometimes called the "subjective standard" in contrast to the substituted judgment standard. See Meisel, *supra* note 20, at 745 (explaining that "[t]his standard requires knowledge of the patient's actual wishes about treatment rather than the substituted judgment standard's determination of probable wishes").

35. See, e.g., ARIZ. REV. STAT. ANN. § 36-3206(H) (Supp. 2012) (creating rebuttable presumption that a permanently unconscious patient has directed that medically supplied nutrition and hydration continue unless the patient's instructional directive instructs otherwise or other narrow exceptions apply); KY. REV. STAT. ANN. §§ 311.631, 311.629 (LexisNexis 2011) (allowing surrogate decision makers to authorize the forgoing of artificial nutrition and hydration only if the patient's death is expected within a few days or if the patient is permanently unconscious and has executed an advance directive authorizing its withholding or withdrawal, or artificial nutrition and hydration cannot be physically assimilated or its burdens outweigh its benefits); N.D. CENT. CODE § 23-06.5-09(6) (2012) (stating that in the absence of a patient's health care directive specifying the withholding or withdrawal of artificial nutrition and hydration, either or both may be withheld or withdrawn if the attending physician determines "the nutrition or hydration cannot be physically assimilated by the principal or would be physically harmful or would cause unreasonable physical pain to the principal"); see also discussion *infra* Part II.B (discussing North Carolina law). See generally Brody et al., *supra* note 19, at 1056 (noting that "[p]atients' options to refuse ANH [artificial nutrition and hydration] may . . . be restricted by laws either directly prohibiting such refusals or allowing health care facilities to refuse to honor the refusals"—the latter referring to "conscience clauses" in many state statutes that allow health care providers to refuse to honor patient or surrogate directives if they conflict with the provider's religious or moral beliefs).

36. MEISEL & CERMINARA, *supra* note 1, § 3.27[A] (" 'Clear and convincing evidence' . . . has become the clearly dominant accepted standard of proof in end-of-life cases. Clearly, it applies in court cases; it similarly appears that this standard of proof is to be used in nonjudicial review of end-of-life decisionmaking." (citations omitted)); see also, e.g., FLA. STAT. ANN. § 765.401(3) (West 2010) (specifying the "clear and convincing" evidence standard for default surrogates); *In re Guardianship of M. Browning*, 568 So. 2d 4, 16 (Fla. 1990) (suggesting that the "clear and convincing" standard would apply equally to health care agents whether the agents are appointed or determined by statutory hierarchy, although this is not entirely clear); *In re Storar*, 420 N.E.2d 64, 72 (N.Y. 1981) (determining that "[c]lear and convincing proof should also be required in cases where it is claimed that a person, now incompetent, left instructions to terminate life sustaining procedures when there is no hope of recovery").

cases of "preponderance of the evidence" and lower than the criminal law standard of "beyond a reasonable doubt."³⁷ This means that the surrogate who wishes to refuse treatment must be able to substantiate his or her decision, while those who wish to begin or continue life-sustaining treatment do not.³⁸ The clear and convincing evidence standard contributed to Nancy Cruzan's parents' loss in the 1990 Supreme Court decision considering their request to discontinue artificial nutrition and hydration for their daughter, who was permanently unconscious.³⁹ The evidence offered in the lower court hearing did not satisfy Missouri's requirement that a patient in Cruzan's condition have previously expressed a wish to discontinue treatment.⁴⁰ The majority upheld Missouri's strict standard that such preferences be proven by clear and convincing evidence of past expressions on the grounds that it is better to err on the side of life.⁴¹

The combination of these many requirements and the complexities involved in meeting them can result in decisions that do not adequately honor or protect a patient's preferences and interests, especially when decisions are made about life-sustaining treatment for patients lacking capacity.

37. The majority opinion in *Cruzan* noted that clear and convincing evidence was that which

produces in the mind of the trier of fact a firm belief or conviction as to the truth of the allegations sought to be established, evidence so clear, direct and weighty and convincing as to enable [the factfinder] to come to a clear conviction, without hesitancy, of the truth of the precise facts in issue.

Cruzan v. Dir., Mo. Dep't of Health, 497 U.S. 261, 285 n.11 (1990) (alteration in original) (citations omitted) (internal quotation marks omitted).

38. How meaningful this evidentiary standard is in practice is unknown, as the vast majority of these decisions are made outside of court review. See Clark, *supra* note 12, at 404 ("At present, there is an enormous disconnect between the kind of evidence courts require to authorize withdrawal of treatment and what is happening every day at patients' bedsides when the family and health care providers are in agreement that life-sustaining procedures should be discontinued. Should we be concerned about parallel decision-making systems, one administered by the courts and the other administered in private at the hospital or nursing home bedside?").

39. *Cruzan*, 497 U.S. at 268.

40. *Id.*

41. See *id.* at 283 ("We believe that Missouri may permissibly place an increased risk of an erroneous decision on those seeking to terminate an incompetent individual's life-sustaining treatment.").

II. EVEN IF YOU DO EVERYTHING RIGHT, THE LAW IS STILL A PROBLEM

There are a number of statutes and court decisions that could be used to illustrate how our special rules for end-of-life contexts can prevent or corrupt good, reasonable, and well-intentioned decision making and that we would be better off treating medical decisions at the end of life like we treat medical decisions generally.⁴² But the two stories chosen for this Part are uniquely well-suited to the task because the individuals involved were doing or had done everything right by the standards of end-of-life law: they were on top of things, educated about their options, and trying to act responsibly.

The first story involves a problematic case decision while the second involves a problematic statute. The first illustration is a case in which the treatment may have been withdrawn earlier than it should have been and the second when the law might require treatment when it is not wanted. Thus, the “errors” can go in either direction.

A. *The Pinettes*

In 2004, seventy-three-year-old Hanford (“Hank”) Pinette was hospitalized for congestive heart failure and sustained by life support systems as his respiratory, circulatory, and renal systems failed.⁴³ Six years earlier, Mr. Pinette had appointed his wife as his health care agent and had executed a living will.⁴⁴ When he was admitted to the hospital, his wife presented both documents to hospital personnel⁴⁵—an action long urged by health care advocates but often neglected by patients and families.⁴⁶

At some point during his admission, doctors at the hospital believed Mr. Pinette’s condition had reached the point where life-

42. See *infra* notes 86–90 and accompanying text (discussing statutes imposing special restrictions on removing artificial nutrition and hydration) and notes 238–40 and accompanying text (discussing case of Sheila Pouliot).

43. LOIS SHEPHERD, IF THAT EVER HAPPENS TO ME: MAKING LIFE AND DEATH DECISIONS AFTER TERRI SCHIAVO 117–20 (2009) [hereinafter SHEPHERD, IF THAT EVER HAPPENS TO ME]; Lois Shepherd, *Shattering the Neutral Surrogate Myth in End-of-Life Decisionmaking: Terri Schiavo and Her Family*, 35 CUMB. L. REV. 575, 585–87 (2005) [hereinafter Shepherd, *Shattering the Myth*].

44. Shepherd, *Shattering the Myth*, *supra* note 43, at 585–86.

45. Anthony Colarossi, *Hospital, Wife Battle Over Patient's Life: A Hearing in Orange Will Consider the Fate of a Clermont Man Who Has a Living Will*, BIOETHICS.NET (Nov. 19, 2004), <http://www.bioethics.net/2004/11/a-more-dramatic-case-than-schiavo-major-story/>.

46. See Barbara A. Noah, *In Denial: The Role of Law in Preparing for Death*, 21 ELDER L.J. 1, 11 (2013).

prolonging procedures were only artificially prolonging the process of dying and that he should be allowed to “die naturally,” as stated in his living will.⁴⁷ They certified that Mr. Pinette was in a terminal condition and unresponsive, and sought Alice Pinette’s permission to remove life support.⁴⁸ Ms. Pinette, however, believed that her husband was still alert, that he would squeeze her hand in recognition of her company, and that he enjoyed watching sports on television with other family members.⁴⁹ When an agreement on life support could not be reached, the director of risk management for the hospital sought a court order to allow the hospital to remove it on the basis of the living will.⁵⁰

The Florida statutes were silent about how to resolve an apparent conflict between a living will and a duly-appointed health care agent’s decision.⁵¹ Nor had the Florida courts previously addressed the question. Following a hearing, the Circuit Court for Orange County determined that the living will dictated that treatment be discontinued and authorized the hospital to withdraw it against the wishes of Mr. Pinette’s wife and health care agent.⁵²

Although a newspaper photo of a crumpled and weary Alice Pinette revealed some of the personal toil of the court’s decision, the case appeared to be a triumph for those who have championed the living will as an instrument for choice and control in the dying process. After years of reports that people do not execute living wills in high percentages (less than twenty percent of Americans have one⁵³), that they are difficult to apply,⁵⁴ and that they are routinely

47. Colarossi, *supra* note 45.

48. *Id.*

49. *Id.*; Shepherd, *Shattering the Myth*, *supra* note 43, at 586.

50. Order Granting Petitioner the Right and Authority to Comply with the Wishes and Living Will of Hanford L. Pinette, *In re* Hanford L. Pinette, No. 48-2004-MH-1519-O, at 1 (Fla. Cir. Ct. Nov. 23, 2004), available at <http://mckinneylaw.iu.edu/instructors/orentlicher/healthlw/Pinette.htm> [hereinafter *Pinette Order*].

51. See FLA. STAT. ANN. § 765.303 (West 2010).

52. *Pinette Order*, *supra* note 50, at 1.

53. According to a recent report by the National Center for Health Statistics, estimates of complete advanced directives among adults in the United States have ranged from 5% to 15%. ADRIENNE L. JONES, ABIGAIL J. MOSS & LAUREN D. HARRIS-KOGETIN, U.S. DEPT OF HEALTH & HUM. SERVS., *USE OF ADVANCE DIRECTIVES IN LONG-TERM CARE POPULATIONS* 5 (2011). Use of advance directives among adults in long-term care populations is much higher: “28% of home health care patients, 65% of nursing home residents, and 88% of discharged hospice care patients had at least one advance directive.” *Id.* at 1 (including “do not resuscitate orders” as an advance directive in the study).

54. See Lesley S. Castillo et al., *Lost in Translation: The Unintended Consequences of Advance Directive Law on Clinical Care*, 154 ANNALS INTERNAL MED. 121, 121–28 (2011)

ignored⁵⁵—here was a case in which a living will had been signed and delivered, seemed fairly straightforward to apply, and hospital officials and health care providers, rather than ignoring the living will, were insisting that it be followed. The president of Aging with Dignity, a Florida-based national organization that advises people about the benefits of living wills, indicated that the lesson to be learned from the controversy was that family members may not make the best health care proxies because of their emotional involvement.⁵⁶ Indeed, the judge's own order stated that "[t]his case emphasizes the need for people to sign Living Wills expressing their last wishes."⁵⁷

But these conclusions are only persuasive if it is clear that honoring the living will to its letter respected Mr. Pinette's autonomy. The facts raise strong doubt about that conclusion. His concurrent appointment of Ms. Pinette as his proxy gave her full decision-making authority.⁵⁸ Which did he intend to carry the most weight? A number of studies have concluded that many people want their health care agents to take their "instructions" in living wills as "suggestions"—and to have leeway to respond as they think appropriate in the situation that comes to pass.⁵⁹ Mr. and Ms. Pinette had been married

(noting the difficulty physicians, patients, and families have shown in understanding the meaning of ambiguous terms such as "terminal" or "irreversible"); Rebecca Dresser, *Precommitment: A Misguided Strategy for Securing Death with Dignity*, 81 TEX. L. REV. 1823, 1829–37 (2003) ("[M]ost of the directives that are completed fail to convey meaningful information."); Angela Fagerlin & Carl Schneider, *Enough: The Failure of the Living Will*, HASTINGS CENTER REP., Mar.–April 2004, at 30, 30–42 (offering a thorough critique of living wills and arguing that it is a mistake to believe that better forms are the answer); Susan E. Hickman et al., *Hope for the Future: Achieving the Original Intent of Advance Directives*, HASTINGS CENTER REP. (SPECIAL REP.), Nov.–Dec., at S26, S26–S30 (detailing many of the often-repeated criticisms of traditional advance directives, including vagueness, lack of understanding, and a legalistic focus on refusing unwanted treatment rather than patient goals of clinical care); John A. Robertson, *Second Thoughts on Living Wills*, HASTINGS CENTER REP., Nov.–Dec. 1991, at 6, 6–7 (questioning the guidance living wills can offer).

55. Fagerlin & Schneider, *supra* note 54, at 32–33; *see also* Noah, *supra* note 46, at 11 (noting that advance directives "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").

56. *See* Colarossi, *supra* note 45.

57. *Pinette Order*, *supra* note 50, at 1.

58. While a copy of the durable power of attorney, like the living will, is not readily available, Colarossi reported that "[t]he power of attorney states her husband assigned her 'to decide for me [Hanford Pinette] any matters regarding my health care, including, but not limited to, consenting to withhold or withdraw life-prolonging procedures.'" Colarossi, *supra* note 45.

59. *See, e.g.*, Brenna Kelly, Annette Rid & David Wendler, *Systematic Review: Individuals' Goals for Surrogate Decision Making*, 60 J. AM. GERIATRICS SOC'Y 884, 892 (2012).

for at least fifty years.⁶⁰ She appeared devoted to him and committed to making decisions in his best interests.⁶¹ Neither the court order nor the newspaper accounts of the hearing suggested that he was in pain or otherwise suffering.⁶²

Moreover, the living will form he had signed could hardly be thought to have been specifically tailored to his individualized preferences. The news reports present a conflated view of Mr. Pinette's living will. For example, the use of language like "[Mr.] Pinette stated"⁶³ suggests that he had written a personalized living will, when in fact all of the language quoted suggests that the living will followed exactly the words of the Florida statutory living will form.⁶⁴ That form does not contain a menu of options.⁶⁵ Like many of the first generation forms (of which many are today still in use as state-endorsed forms), the only instruction available was to end life support.⁶⁶

Given these facts, it is reasonable to believe that Mr. Pinette would have preferred his wife to make this decision rather than have a court enforce the boilerplate conditions of his living will over her objection. Indeed, as is common, he may have executed the living will in an attempt to add *further protection* of his wife's decision-making power (providing her with documentary evidence to support treatment refusal if needed) rather than as a *limitation* upon it. If this is true, it is sadly ironic that, rather than the document helping her to avoid a legal battle, it caused her to become embroiled in one. In addition, advocates for advance directives commonly urge people to execute them in order to relieve loved ones of the burden of making these life and death decisions.⁶⁷ But here, as interpreted by the

60. Colarossi, *supra* note 45.

61. *See id.*

62. *Pinette Order*, *supra* note 50, at 1; Colarossi, *supra* note 45; *Hospital, Patient's Wife in Right-to-Die Dispute*, ST. PETERSBURG TIMES (Nov. 20, 2004), http://www.sptimes.com/2004/11/20/State/Hospital__patient_s_w.shtml.

63. *See Hospital, Patient's Wife in Right-to-Die Dispute*, *supra* note 62.

64. FLA. STAT. ANN. § 765.303 (West 2010).

65. *See id.*

66. *See id.* (suggested form of living will). For an example of a recently revised statutory form that contains more options, see N.C. GEN. STAT. § 90-321(d1) (2013).

67. *See, e.g., Advance Directives and Living Wills*, VANDERBILT-INGRAHM CANCER CENTER, <http://www.vicc.org/cancercare/advanced/directives.php> (last visited Jan. 26, 2014) ("[P]atients should keep in mind that avoiding these decisions when they are well will only place a heavier burden on them and their loved ones later on."); *Your Advance Directive*, COMPASSION & CHOICES, <http://www.compassionandchoices.org/what-we-do/advance-planning/advance-directive/> (last visited Jan. 26, 2014) ("Increase your own peace of mind and provide it to your family members by explaining what healthcare you would prefer if severely injured or terminally ill."). The evidence about the effect of

hospital and the court, the living will added an extra burden on his wife, even if Mr. Pinette's intention was to do the opposite.

About ten years ago, during a conference on end-of-life law, a physician confessed that although he had executed a living will to permit removal of life support in certain circumstances, he had deliberately chosen not to follow the popular advice of having it placed in one's medical record, or otherwise having it readily available. Instead, he kept it locked up in a safety deposit box. It was there if his wife needed it to support the decision that she felt was best to make, but he was taking care that it would not otherwise land in the hands of doctors or hospital administrators who might try to use it to convince her to make a decision they wanted. It is noteworthy that this admission came from a physician. Another physician, a colleague of mine, once similarly explained, in a matter-of-fact manner, that she had not signed a Durable Do Not Resuscitate Order⁶⁸ for her frail, incapacitated, and declining mother because the doctors would think it meant "Do Not Treat." Physicians and hospitals are not disinterested participants in these situations, even if we assume they are well-informed and well-intentioned. Significantly, one of the articles reporting on the Pinette case proclaimed that "[a]n Orlando hospital won the right Tuesday to honor Hanford Pinette's living will" ⁶⁹ It makes one wonder: who did Hanford Pinette's right to self-determination belong to, anyway?

advance directives or knowledge of patient preferences on surrogates' emotional burden in making end-of-life treatment decisions is mixed. David Wendler & Annette Rid, *Systematic Review: The Effect on Surrogates of Making Treatment Decisions for Others*, 155 ANNALS INTERNAL MED. 336, 343 (2011). According to a recent review article, two quantitative studies found that surrogate stress was substantially lower when an advance directive specified the patient's treatment preferences, although four other studies concluded that

having confidence in their knowledge of the patient's treatment preferences did not ease the burden for at least some surrogates. In addition, fourteen studies reported that surrogates experienced more negative emotional burden when the treatment that was thought to be in the patient's best interests differed from the treatment that . . . was what the patient would want.

Id.

68. In general, a Durable Do Not Resuscitate Order is an out-of-facility physician's order that prevents emergency personnel from administering cardio-pulmonary resuscitation efforts in the event of cardiac or respiratory arrest. *See, e.g.*, VA. CODE ANN. § 54.1-2987.1 (2013) (defining a Durable Do Not Resuscitate Order).

69. Anthony Colarossi, *Living-Will Ruling Means Man Can Die*, ORLANDO SENTINEL (Nov. 24, 2004), http://articles.orlandosentinel.com/2004-11-24/news/0411240296_1_pinette-alice-lucerne-hospital.

If our legal treatment of end-of-life decisions were more in line with our legal treatment of medical decisions generally, some flexibility and latitude would be possible. We would not be as ready to assume that a form document signed years before in a state of relative health can definitively answer what an ill and dying patient would want now if he or she could tell us. We would understand that patient autonomy is usually paramount, but that how to honor it is often not obvious, and that forms tell only part of a story. We would also better appreciate that patient autonomy is not the only thing that matters. In this case, a law originally designed to keep end-of-life decision making outside the courtroom did the opposite. The law created a special conflict—between forms and persons, between husband and wife—that would not have existed otherwise.

B. The U.C. Book Club

The second illustration involves recent revisions to the North Carolina statutes governing the appointment of health care agents and living wills. I became aware of these revisions when I was invited a few years ago to speak about the Terri Schiavo case⁷⁰ to a women's book club in North Carolina (the U.C. Book Club of Gaston County). Anticipating that members of the club—all of whom were over seventy-five-years-old—would have questions about advance care planning, I reviewed the North Carolina statutes to see what I might be able to tell them and found—despite recent revisions in 2007⁷¹—a number of problems that might encumber their own advance care planning and perhaps eventually their own care. The revisions appear

70. See generally SHEPHERD, IF THAT EVER HAPPENS TO ME, *supra* note 43 (describing the controversy surrounding the 2005 removal of artificial nutrition and hydration from Terri Schiavo, a Florida woman in a permanent vegetative state, which involved many years and more than one legal case).

71. Act of Aug. 30, 2007, ch. 502, 2007 N.C. Sess. Laws 1532 (codified as amended at N.C. GEN. STAT. § 90-321 (2013)). Prior to the revisions, North Carolina's Living Will Statute, adopted in 1977, allowed treatment withdrawal for patients whose medical condition was either: (1) "[t]erminal and incurable," or (2) "[d]iagnosed as [in] a persistent vegetative state." *Id.* § 90-321(b)(1), *repealed by* Act of Aug. 30, 2007, § 11(b), 2007 N.C. Sess. Laws at 1545. By contrast, North Carolina's Health Care Power of Attorney Statute, adopted in 1991, allowed individuals to authorize health care agents to withhold or withdraw treatment when the patient was terminally ill, was permanently in a coma, suffered severe dementia, or was in a persistent vegetative state. *Id.* § 32A-25(3)(G), *repealed by* Act of Aug. 30, 2007, § 6(a), 2007 N.C. Sess. Laws at 1536. The revisions were intended to align these two advance care planning mechanisms to apply to the same medical conditions. See Dorothy D. Nachman, *Living Wills: Is It Time to Pull the Plug?*, 18 ELDER L.J. 289, 319–21 (2011). Under the previous versions of the statutes, it was not clear whether an individual who had not appointed a health care agent could forego life-prolonging measures in a condition of severe dementia. See *id.* at 320.

to have been well-intended.⁷² They were aimed at clearing up some problematic inconsistencies and uncertainties in the statutes.⁷³ For example, they allowed individuals to indicate for themselves whether a health care agent's decisions or a living will should trump when there is a conflict (the Pinette type situation just discussed).⁷⁴ And they expanded and clarified the conditions that might be specified in an advance directive for allowing the withdrawal or withholding of life-prolonging measures.⁷⁵

The women in the book club, like Hanford Pinette, were taking care to fulfill their responsibilities through advance care planning, as urged for many years by countless health care and advocacy organizations and media. When I asked for a show of hands, most had advance directives. The possibility of eventually suffering from advanced dementia was on the minds of many of the women I spoke with that day. They had seen it; they had cared or were still caring for relatives with it. They knew about the possibility of placing feeding tubes in elderly individuals with advanced dementia; some of them had, in fact, conceded to the recommendations of health care providers to authorize it for the individuals for whom they now served as surrogate decision makers.⁷⁶ Some of them had witnessed the agitation and suffering such feeding tubes can sometimes bring to

72. See Nachman, *supra* note 71, at 317–20, 324–325.

73. See *id.* at 319–21.

74. N.C. GEN. STAT. § 90-321(d1). See generally Kenneth L. Burgess, *North Carolina General Assembly Overhauls Advance Directives Laws*, N.C. MED. SOC'Y, http://www.ncmedsoc.org/non_members/public_resources/genassembly-overhauls-endoflife.pdf (last visited Feb. 28, 2014) (explaining revisions).

75. See § 90-321(d1) (allowing individuals to specify in a living will that they wish to avoid life-prolonging measures if in a condition of advanced dementia). “Life-prolonging measures” in the revised statutes means

[m]edical procedures or interventions which in the judgment of the attending physician would serve only to postpone artificially the moment of death by sustaining, restoring, or supplanting a vital function, including mechanical ventilation, dialysis, antibiotics, artificial nutrition and hydration, and similar forms of treatment. Life-prolonging measures do not include care necessary to provide comfort or to alleviate pain.

Id. § 32A-16(4) (2013); see also *id.* § 90-321(a)(2a) (providing that life-prolonging measures are defined in G.S. 32A-16(4)).

76. See generally *Feeding Tubes in Advanced Dementia Position Statement*, J. AM. GERIATRICS SOC'Y (May 2013), <http://www.americangeriatrics.org/files/documents/feeding.tubes.advanced.dementia.pdf> (recommending against percutaneous feeding of older adults with advanced dementia and recommending hand feeding instead). According to the Position Statement, “[a]s many as 34% of US nursing home residents with advanced dementia have feeding tubes, two-thirds of which are inserted during an acute hospital stay. Caregivers report little conversation surrounding tube feeding decisions, and at times families feel pressure for its use.” *Id.* (citations omitted).

these patients.⁷⁷ A number of them clearly knew they did not want a feeding tube if they ever had advanced dementia.

But what could I tell them? Bad news: documents that they had drawn up just a few years before may not protect them against this possibility. While a *living will* in North Carolina could now specify the refusal of life-prolonging measures in a condition of advanced dementia,⁷⁸ it was not clear that such measures, including a feeding tube, could be avoided without such a special declaration.⁷⁹ In other words, an individual might not be protected against this possibility if she had a proxy appointment that did not specifically mention the agent's powers in the situation of advanced dementia or if she had an earlier generation living will that did not specify advanced dementia as a condition in which life-prolonging measures could be withheld because the law did not provide for that possibility before 2007.⁸⁰ These women's now out-of-date documents had required two witnesses who could not be related to them and notarization.⁸¹ The forms had likely been provided by lawyers. They would need to go through the entire process again.

Worse than these uncertainties, however, was the certainty that if a person did not have an advance directive, but was relying instead on the statutory hierarchy for surrogate decision makers (knowing for example, that one's daughters would serve as decision makers by

77. See generally Muriel R. Gillick, *Rethinking the Role of Tube Feeding in Patients with Advanced Dementia*, 342 NEW ENG. J. MED. 206 (2000) (discussing the overuse of feeding tubes in patients with advanced dementia, as well as the potential for harm and lack of benefit to their use).

78. § 90-321(d1).

79. See *id.* In the absence of an advance directive of any kind, the issue of whether artificial nutrition and hydration could be avoided would be determined by section 90-322, which does not include the condition of advanced dementia as one in which life-prolonging measures can be withheld or withdrawn. If instead a proxy appointment has been executed, but it does not grant authority for the proxy to withhold or withdraw life-prolonging measures in the condition of advanced dementia, then, again, no express authority would exist for this action. See *id.* § 32A-19(d) ("The powers and authority granted to the health care agent pursuant to a health care power of attorney shall be limited to the matters addressed in it, and, except as necessary to exercise such powers and authority relating to health care, shall not confer any power or authority with respect to the property or financial affairs of the principal."). Individuals, of course, have constitutional rights to refuse treatment which may be invoked, but with uncertain application here.

80. See *supra* note 71 and accompanying text.

81. § 32A-16(3), § 90-321(c)(2), (3). See generally Castillo et al., *supra* note 54, at 123 (discussing negative consequences of execution requirements; noting that "nearly all states require 2 witnesses to make advance directives legally valid, with 18 states permitting notarization as an alternative"; and stating that North Carolina and West Virginia require both).

default and being satisfied with that default position), then there was little to no protection against the imposition of a feeding tube in the condition of advanced dementia even if the individual would not want it and her daughters knew that.⁸² The daughters would be heeded only if doctors and hospitals would be willing to go outside the “safe harbor” of immunity created by the North Carolina statutes.⁸³

It is easy to think the answer to these problems can be found in laws that are more carefully drafted and take more care in specifying how things should be done. But North Carolina had just gone through that exercise.⁸⁴ And as a country, we have been revising end-of-life statutes for years, making them more comprehensive and more detailed—and along the way revising advance directive forms until they are ten pages long and barely understandable.⁸⁵ The answers to these difficult questions are not to be found in better forms (although better forms are better than worse forms) or other unrealistic quests to discover the Holy Grail for respecting patient autonomy.

It is also worth noting that end-of-life statutes provide a ready tableau for some state politicians to advance pro-life agendas. After the Terri Schiavo case, when special attention was focused on the

82. See § 90-322 (setting out the circumstances under which physicians may withhold or discontinue life-prolonging measures in the absence of a living will or health care power of attorney). The attending physician may follow the direction of an appropriate surrogate decision maker (from a statutory list) to withhold or discontinue life-prolonging measures “[i]f the attending physician determines, to a high degree of medical certainty, that a person lacks capacity to make or communicate health care decisions and the person will never regain that capacity,” and that the person “has as an incurable or irreversible condition that will result in the person’s death within a relatively short period of time; or . . . [i]s unconscious and, to a high degree of medical certainty, will never regain consciousness.” *Id.* § 90-322(a)(1a).

83. See *id.* § 90-322(d).

84. See *supra* note 71 and accompanying text.

85. See Nachman, *supra* note 71, at 324 (“Despite the legislature’s articulated goal of rendering the self-determination statutes more user-friendly and accessible, the new North Carolina law has created so many individual options and elections that one seeking to exercise his or her right to self-determination should do so with a *caveat patiens* approach.”). Kenneth Burgess, a North Carolina attorney, in an online explanation of the 2007 revisions, noted that “[a]lthough these additional choices promote patient choice, they also have the potential to increase confusion and result in patients selecting mutually inconsistent choices. Patients will need additional guidance with the new forms.” Burgess, *supra* note 74. For examples of other states’ forms, see *Advance Directives*, WIS. DEPT OF HEALTH SERVS., <http://www.dhs.wisconsin.gov/forms/advdirectives/ADFormsPOA.htm> (last visited March 14, 2014) (providing a nine page power of attorney document (including instructions) and a four-page living will (including instructions)); *Making Health Care Decisions in North Dakota*, N.D. DEPT OF HUM. SERVS. (Nov. 2012), <http://www.nd.gov/dhs/info/pubs/docs/aging/aging-healthcare-directives-guide.pdf> (publishing a thirty-one page booklet for residents on advance health care directives, including an eleven page advance directive form).

issue of artificial nutrition and hydration, many states introduced bills that would have essentially required patients to have a living will if they wanted to refuse artificial nutrition.⁸⁶ Otherwise, a feeding tube would have been almost always required.⁸⁷ What this would have meant was a wholesale rejection of patient autonomy. While the large majority of Americans do not have an advance directive, polls show that they would not want artificial nutrition and hydration if they were ever in a state of permanent unconsciousness.⁸⁸ Fortunately, nearly all of the bills failed, although some states do have laws that create special hurdles for withholding or withdrawing artificial nutrition and hydration.⁸⁹ A number of statutory living will forms allow individuals to express a preference for continuing artificial nutrition and hydration while refusing all other forms of life-prolonging measures,⁹⁰ opening the dangerous and untenable possibility that one might continue artificial nutrition and hydration but refuse medically necessary dialysis to accommodate it.

86. See, e.g., Alabama Starvation and Dehydration of Persons with Disabilities Prevention Act, H.B. 592, 2005 Reg. Sess. (Ala. 2005) (modeled on National Right to Life Committee's "model act" relating to artificially provided sustenance and hydration); H.B. 701, 107th Reg. Sess. (Fla. 2005) (same); S. 804, 2005 Leg., Reg. Sess. (Fla. 2005) (same); H.B. 1577, 23d Reg. Sess. (Haw. 2005) (same); Iowa Starvation and Dehydration of Persons with Disabilities Prevention Act, H. Study B. 302, 81st Gen. Assem., 1st Sess. (Iowa 2005). See generally MEISEL & CERMINARA, *supra* note 1, § 1A.03[C] (noting that most of these bills failed); Brody et al., *supra* note 19 (discussing historical and current landscape of law, ethics, and practice relating to medically supplied nutrition and hydration); Joshua E. Perry, *Biblical Biopolitics: Judicial Process, Religious Rhetoric, Terri Schiavo and Beyond*, 16 HEALTH MATRIX 553, 623–27 (2006) (discussing Alabama's proposal in particular, in the context of politicized religious advocacy); Lois Shepherd, *State Legislative Proposals Following Schiavo: What Are They Thinking?*, 15 TEMP. POL. & CIV. RTS. L. REV. 361 (2006) (critiquing the proposals and, in particular, the National Right to Life Committee's Model Starvation and Dehydration of Persons with Disabilities Prevention Act).

87. See Shepherd, *supra* note 86, at 373.

88. Cruzan v. Dir., Mo. Dep't of Health, 497 U.S. 261, 312 n.11 (1990) (Brennan, J., dissenting) ("[A] 1988 poll conducted by the Colorado University Graduate School of Public Affairs showed that 85% of those questioned would not want to have their own lives maintained with artificial nutrition and hydration if they became permanently unconscious."); Schulman, Ronca, & Bucuvalas, Inc., *SRBI/Time Magazine Poll # 2005-3500: Terri Schiavo*, ROPER CENTER FOR PUB. OPINION RES. (Mar. 22–24, 2005), http://roperweb.roperceneter.uconn.edu/cgi-bin/hsrun.exe/Roperweb/Catalog40/Catalog40.htm?start=summary_link?archno=USSRBI2005-3500 (indicating that 69% of Americans "would . . . want [their] guardian to remove [their] feeding tube").

89. See MEISEL & CERMINARA, *supra* note 1, § 1A.03[C]; see, e.g., ARIZ. REV. STAT. ANN. § 36-3206 (Supp. 2012); KY. REV. STAT. ANN. §§ 311.631, 311.629 (LexisNexis Supp. 2012); N.D. CENT. CODE § 23-06.5-09(6) (2012).

90. See, e.g., OKLA. STAT. tit. 63, § 3101.4 (Supp. 2013) (providing Oklahoma's statutory advance directive). Even the relatively liberal Uniform Health Care Decisions Act, discussed *infra* at text accompanying notes 124–30, offers this possibility.

Even North Carolina's revisions, billed generally as moderate changes to create consistency and clear up uncertainty in existing statutes, faced strong opposition from Life Tree, a pro-life Christian organization.⁹¹ Life Tree opposed, among other things, the addition of advanced dementia as a triggering condition for operation of a living will, although North Carolinians had, for years, been permitted through health care powers of attorney to authorize agents to make decisions to withhold or withdraw life-prolonging measures in the case of severe dementia.⁹²

Some conservatives tend to see every statutory clarification of rights that individuals almost certainly already possess—such as the right to refuse artificial nutrition and hydration in a condition of advanced dementia—as governmental efforts to encourage vulnerable, disabled, or elderly individuals to hasten their deaths.⁹³ This is nonsense. But so is the common liberal response, which is to think that as long as the power exists for educated people to protect themselves, the law is adequate. A quick internet search will pull up hundreds of websites explaining how a person can protect his or her rights and interests through advance care planning documents, with the more socially attuned sites adding information about the importance of having “conversations” about these documents.⁹⁴ But it is not easy to find any mainstream websites about how to navigate successfully the medical and legal labyrinth to protect a loved one's rights and interests when those documents have not been executed or, if executed, provide little guidance.

Instead of further attention on better forms and more detailed legal rules, the focus needs to turn toward allowing people *not* to engage in end-of-life advance care planning,⁹⁵ yet still permit medical decisions to be made that appropriately respect and care for patients.

91. Nachman, *supra* note 71, at 321–22.

92. *Id.* (describing the opposition the bill faced during its voyage through the North Carolina Senate and House). For a summary of Life Tree's objections to the revisions, see Elizabeth D. Wickham, *North Carolina Advance Directives Bill Is Not Pro-Life*, LIFE TREE (Apr. 29, 2007), http://www.lifetree.org/newsletter/04_07.html.

93. See Nachman, *supra* note 71, at 321–22; Wickham, *supra* note 92.

94. See, e.g., *Advance Directives and Living Wills*, *supra* note 67 (“A living will protects the patient's rights and removes the burden for making decisions from family, friends, and physicians.”); *Your Advance Directive*, *supra* note 67 (urging completion of advance care planning documents to “[i]ncrease your own peace of mind and provide it to your family members by explaining what healthcare you would prefer if severely injured or terminally ill”).

95. See generally CARL E. SCHNEIDER, *THE PRACTICE OF AUTONOMY* (1998) (challenging the prevailing bioethical assumption that individuals want to, and should, assume the full burden of medical decision making for themselves).

III. WHY “END-OF-LIFE” DECISIONS SHOULD BE TREATED LIKE OTHER IMPORTANT MEDICAL DECISIONS

The current legal framework for end-of-life decisions rests on a set of narrow assumptions that shape its form and limit its effectiveness. Built in response to a particular set of legal cases from the 1970s to 1990s, this legal framework envisions a certain kind of problem and a point at which a certain kind of decision has to be made.⁹⁶ The situation envisioned is one in which a hospitalized patient is no longer believed, by physicians, to be an appropriate candidate for “curative” therapy. He or she is either permanently unconscious or going to die soon, regardless of the medical interventions attempted. The surrogate decision maker is asked what the patient would want. If the patient has followed the urgings of the health care community and media, he or she has prepared an advance directive, which, if it follows the statutory living will form, most likely directs that life-sustaining treatment be withheld or withdrawn if it would only prolong the process of dying. If an instructional advance directive (living will) is absent, then the surrogate decision maker is asked what the patient would want. The surrogate decision maker is generally expected to relate that the patient would not want to continue living in his or her current burdened and hopeless condition.⁹⁷ Life support is then withdrawn, and the law provides immunity to all involved for following that course. If, contrary to expectations, the family wishes to continue treatment, then physicians may either honor that decision, believing continued treatment is a reasonable (or at least not unreasonable) choice because death is going to occur shortly anyway, or, if they believe continuing treatment is inappropriate, the physicians may begin to explore their options for transfer of the patient or discontinuation of treatment on the grounds of “futility”—a vague and problematic concept.⁹⁸ Except

96. See, e.g., *In re Jobes*, 529 A.2d 434, 434 (N.J. 1987) (holding that husband, as surrogate decision maker, could decide that artificial nutrition and hydration be withdrawn from wife, who was in a permanent vegetative state, following determination by two independent physicians of her condition); *In re Quinlan*, 355 A.2d 647, 670–71 (N.J. 1976) (holding that patients such as Karen Ann Quinlan, who was in a permanent vegetative state, have a federal constitutional right to refuse extraordinary treatment and allowing her family to render their best judgment about what she would want done).

97. Cf. Atul Gawande, *Letting Go*, NEW YORKER (Aug. 2, 2010), http://www.newyorker.com/reporting/2010/08/02/100802fa_fact_gawande?currentPage=1 (describing the dying experience of patients in hospitals).

98. See generally Daniel K. Sokol, *The Slipperiness of Futility*, 338 BRIT. MED. J. 2222 (2009) (describing the subjective nature of the concept of futility and different understanding of futility).

in those situations when the patient has entered a potentially long-term vegetative state or the medical treatment at issue is artificial nutrition and hydration—matters about which there is less likely to be agreement—by the time physicians start to pay close attention to advance directives and engage in careful conversation with surrogate decision makers and family members about patient preferences, there often is not much to decide.

At the same time, there are likely to have been many other important decisions made before that time—decisions that are not treated by the law with the same attention to patient preferences and family input. Contrary to the paradigm situation described above, the patient's prognosis is often not clear enough for a physician's certification of terminal illness or permanent unconsciousness.⁹⁹ Rather than one decision that must be made—to withhold or withdraw life-sustaining treatment—there are many, and those decisions must frequently be revisited as the patient's condition evolves or physicians obtain more clarity about it.

A final pair of assumptions is that patients have defined preferences about the decision to be made and that family members know them. Both of these assumptions are unlikely to be true, given the potential variability in, and likely uncertainty about, the patient's condition at different points in time when various potential treatment options are considered.¹⁰⁰

The decision by President Obama's grandmother to have a hip replacement reflects the broader context in which important medical care decisions such as these are made, decisions which can have permanent or life-ending consequences. In the fall of 2008, Madelyn Dunham, who was eighty-six years old, underwent hip replacement

99. See Joseph J. Fins, *Rethinking Disorders of Consciousness: New Research and Its Implications*, HASTINGS CENTER REP., Mar.–April 2005, at 22, 22; Gawande, *supra* note 97.

100. See *Mack v. Mack*, 618 A.2d 744, 771 (Md. 1993) (Chasanow, J., concurring in part and dissenting in part) (“[T]he inquiry at issue is not factual. It is an attempt to predict a choice that cannot be made.”). There are a number of studies that reveal the poor predictive ability of potential surrogate decision makers, such as family members, to choose the same treatment decisions as the relative for whom they may be asked to make choices. See generally David I. Shalowitz, Elizabeth Garrett-Mayer & David Wendler, *The Accuracy of Surrogate Decision-Makers: A Systemic Review*, 166 ARCH. INTERN. MED. 493 (2006) (reviewing studies that present patients and likely surrogates with hypothetical scenarios involving decisions about life-sustaining treatment and concluding that, on average, predictions by the surrogates were incorrect in one-third of cases and accuracy did not differ between patient-designated and next-of-kin surrogates or when prior discussions of treatment preferences had taken place).

surgery after a fall had caused a hip fracture.¹⁰¹ At the time of the surgery, doctors predicted that she had less than a year to live—possibly less than three months—because of terminal cancer.¹⁰² The idea appeared to be that the new hip would improve the quality of her remaining life, and therefore be worth the discomfort and risk of surgery posed by her heart condition and cancer. Instead, she died two weeks afterwards as a result of the surgery.¹⁰³ If the operation had been successful, Ms. Dunham may have been able to attend her grandson's inauguration; as it happened, she died one day before his election.¹⁰⁴ President Obama related the story in an interview as a way to begin a dialogue about the allocation of health care resources.¹⁰⁵ He said that, had the surgery not been covered by insurance, he would have paid for it himself, but that the situation did raise the question whether asking society to pay for such treatment is a "sustainable model."¹⁰⁶ He added, "So that's where I think you just get into some very difficult moral issues."¹⁰⁷

However, we do not need to get entangled in the controversial issue of health care rationing to understand a decision like this one as involving "some very difficult moral issues." As Joanne Kenen noted in a commentary soon after the President's interview was published, the more immediate and troubling questions concern the appropriateness of care Ms. Dunham received, not its cost.¹⁰⁸ Were less risky non-surgical options explored? Was the hip replacement necessary for her comfort and quality of life? "And above all," wrote Kenen, "was the care she got in keeping with her end-of-life goals and her personal values?"¹⁰⁹

The decision made in Ms. Dunham's case was not about withdrawing or withholding life-prolonging measures. Yet it was just as important as those decisions—with foreseeable consequences of a permanent and irrevocable nature. It involved, as do many of the decisions currently subject to special end-of-life rules, personal and

101. See Joanne Kenen, *HEALTH CARE: Obama's Grandmother and the National Conversation*, NEW AM. FOUND. (May 1, 2009, 3:31 PM), <http://www.newamerica.net/blog/new-health-dialogue/2009/health-care-obamas-grandmother-and-national-conversation-11479>.

102. David Leonhardt, *After the Great Recession*, N.Y. TIMES MAG., May 3, 2009, at 36, 76.

103. Kenen, *supra* note 101.

104. *Id.*

105. See Leonhardt, *supra* note 102, at 76.

106. *Id.*

107. *Id.*

108. Kenen, *supra* note 101.

109. *Id.*

subjective value judgments about acceptable levels of pain and disability, tolerance for risk, and whether life extension is more important than quality of life or vice versa.

For all of these important health care decisions, there must be established procedures and safeguards. The decisions should be made with the utmost care and by the right people.¹¹⁰ The decision makers, whether they are competent patients making decisions for themselves, as Ms. Dunham was, or are surrogates making decisions for others, must have access to all appropriate information. There are, in other words, basic principles and best practices that should guide how these decisions are made.¹¹¹ The law, however, should not distinguish between such decisions simply because one set involves patients who will die if certain treatment is forgone and the other involves patients who may die if treatment is accepted. At the very outset of the now nearly four decades of end-of-life law, the court in *In re Quinlan*¹¹² noted that reasonable decisions of the very sort it was called upon to approve were being made in hospitals with the agreement of “responsible people involved in medical care, patients and families” and with proper regard for patients.¹¹³ The thick and sometimes impenetrable end-of-life legal apparatus we have been almost continuously building in the meantime now creates distortions in that decision-making.

IV. GENERAL PRINCIPLES THAT SHOULD GUIDE LAW RELATING TO HEALTH CARE DECISIONS.

The remainder of this Article identifies and discusses eight general principles that should guide the law relating to health care decisions. This list is not meant to be exhaustive, although its scope is comprehensive. The principles listed are those that are likely to be implicated in what we now think of as an end-of-life situation in which end-of-life decisions are made, but they are principles that

110. See *infra* Part IV.B (Principle 2) (discussing rules and norms about surrogate decision makers); see also discussion of the Pinette case *supra* Part II.A (arguing that the decision to continue or discontinue life support measures for Hank Pinette should have rested with his wife and appointed agent rather than on the interpretation of his living will by the court, the hospital, and the hospital's risk management staff); *infra* text accompanying notes 255–58 (discussing Texas law's “futility” statute, which allows unilateral withdrawal of life-sustaining treatment by a Texas hospital over the objection of family and health care agents).

111. See *infra* Part IV (identifying eight general principles to guide the law relating to health care decisions).

112. 355 A.2d 647 (N.J. 1976).

113. *Id.* at 659.

govern, or should govern, other important health care decisions. Many of these principles, like much of end-of-life law, specifically address the situation of the incapacitated patient, in which decisions must be made on behalf of the patient by another. Patients who lack capacity, whether they at one time possessed it or not, are vulnerable. They need the law's protection. The principles described below do not lessen the degree of protection the law affords to such patients. Instead, the principles attempt to more clearly match the source of perceived vulnerability with an appropriate legal mechanism to provide protection against abuse, neglect, or disregard.

Nor do these principles lessen the degree to which we should honor patients' rights to self-determination. The pre-incapacity preferences of individuals, to the extent known, remain the most important indicator of what should be done, but past expressions should not crowd out every other consideration. For patients who have never had capacity to make medical treatment decisions, the principles acknowledge that there are still important questions about their preferences and values, their degree of understanding, and whether decision makers must secure the patient's assent to a course of action or at least honor their expressions of protest.

A. Principle 1: Respect and Care for the Patient Require Balancing Rather Than Rigidly Prioritizing Among Patient Instructions, Wishes, Values, and Interests

This is the first, foundational principle to guide health care decisions. The principles that follow it further specify how to put it into operation.

All health care decisions, including decisions about withholding or withdrawing life-sustaining treatment, should be made on the basis of respect and care for patients. Respect for patients includes more than respect for patients' autonomy; it embraces the idea that patients should be treated with respect for their equal human dignity, rather than treated as objects, and that their privacy should be respected, their confidences honored, and their relationships valued. "Care" goes beyond a calculation of an individual's best interests, and includes the notion of an attitude of care toward another and pays attention to how medical care is delivered. This means, for example, that when considering whether to tube feed a patient with advanced dementia, it would be neither appropriate nor sufficient to conclude that nutrition and hydration, even if artificially supplied, is always a

form of “basic care” that must be supplied if doing so can extend life.¹¹⁴ It would be necessary to consider how an individual person would experience the provision of nutrition and hydration in this manner—for example, whether it would cause discomfort or agitation.¹¹⁵

As discussed above, the current legal framework for end-of-life decision making gives great weight to a patient’s preferences, especially those expressed in writing.¹¹⁶ Often, however, people have not expressed in writing or even in clear oral statements what they would like in a particular medical situation. There are a lot of good reasons for this. People may not be able to anticipate the medical condition they will later find themselves in, or know what they would want done in that situation.¹¹⁷ They may rather trust family members to make medical decisions for them when the time for those decisions arrives.¹¹⁸ Respecting patients includes respecting their choice *not* to specify their medical treatment preferences in advance. It also means approaching standardized living will forms with less assurance that they provide answers about what to do. People may sign such forms because they believe they are required to in order to allow their loved ones to make reasonable decisions in the future about their care (and, as we saw with the North Carolina statute, they may be right). For this and other reasons—for example, the limited options offered on the forms, the use of terms not defined in the forms—these documents’ reflection of patient wishes may be weak.

When family members make other types of medical decisions for loved ones—decisions that do not involve “life-sustaining treatment”—they make decisions that they believe are in the best interests of, and consonant with, the values of the patient. They take into account the patient’s expressed preferences as well, such as a vow to refuse blood products on the basis of religious beliefs or other

114. During the controversy over the removal of Terri Schiavo’s feeding tube, Pope John Paul II issued an address that equated artificial nutrition and hydration of a person in a permanent vegetative state with “basic health care” and stated that it should be considered morally obligatory. The Vatican, Address to the Participants in the International Congress: Life-Sustaining Treatments and Vegetative State: Scientific Advances and Ethics Dilemmas (Mar. 20, 2004). See generally Brody et al., *supra* note 19 (discussing the complex and evolving position of Catholic teaching on this subject).

115. See Gillick, *supra* note 77, at 207–08.

116. See *supra* text accompanying notes 32–35.

117. See *supra* text accompanying notes 82–83.

118. See, e.g., Joanne Lynn, *Why I Don’t Have a Living Will*, 19 J. L. MED. & ETHICS 101, 103 (1991) (“I, and surely some other patients, prefer family choice *over* the opportunity to make our own choices in advance.”).

clearly stated preferences or aversions,¹¹⁹ but often there are no such expressions to take into account.

A patient's best interests may involve more than *medical best interests*. For example, in *Strunk v. Strunk*,¹²⁰ a court determined that it was in the best interests of an intellectually disabled man to donate one of his kidneys to his brother because, absent another source of donation, the brother would die and the man would suffer from the loss of his brother's companionship.¹²¹

Although careful consideration of the best interests of the patient is the norm for general medical decision making, in the case of decisions about forgoing life-sustaining treatment, a patient's best interests—or, to leave the legal language for a moment and be guided by considerations of “care,” *how best to take care of and care for a patient*—is given much less weight.

There is a good historical explanation for this. In the early days of end-of-life law, physicians were over-treating patients—insisting that patients' lives be sustained notwithstanding how intrusive the medical treatments might be, how ultimately unsuccessful they would

119. See Lisa J. Milligan & Mark C. Bellamy, *Anaesthesia and Critical Care of Jehovah's Witnesses*, 4 CONTINUING EDUC. IN ANAESTHESIA, CRITICAL CARE & PAIN 35, 35 (2004).

120. 445 S.W.2d 145 (Ky. Ct. App. 1969).

121. *Id.* at 146 (affirming lower court's decision that “under the peculiar circumstances of this case it would not only be beneficial to Tommy but also beneficial to Jerry because Jerry was greatly dependent upon Tommy, emotionally and psychologically, and that his well-being would be jeopardized more severely by the loss of his brother than by the removal of a kidney”). *But see In re Guardianship of Pescinski*, 226 N.W.2d 180, 182 (Wis. 1975) (prohibiting a man who lacked capacity to be a kidney donor for a sibling with whom he did not have a present relationship due to his mental illness because it would not serve his interests). Note that some courts, including *Strunk*, have referred to “substituted judgment” as the basis for making decisions for patients, such as Jerry Strunk, who have always lacked decision-making capacity. *Strunk*, 445 S.W.2d at 148. Current understanding of that standard, however, requires that decisions reflect the probable wishes of the patient; accordingly, the substituted judgment standard is generally not understood as appropriate for these patients, and the best interests standard is used instead. See Norman L. Cantor, *The Bane of Surrogate Decision-Making: Defining the Best Interests of Never-Competent Persons*, 26 J. LEGAL MED. 155, 158 (2005) (“[T]he bulk of commentators and courts have rejected application of a substituted judgment standard—a standard seeking to replicate the patient's own likely decision—in the context of a never-competent person.”). In fact, the court's reasoning in *Strunk* reveals that the best interests standard was used, although the opinion references the substituted judgment standard. See *id.* at 160 (describing *Strunk* as using a best interests standard, as is typical of the few judicial decisions purporting to use the substituted judgment standard for never-competent patients, and stating that “the courts purporting to apply a substituted judgment standard end up resolving the disabled patient's medical fate according to a projected weighing of the patient's future pleasure and pain. In other words, they apply a best interests of the patient standard”).

be in returning the patient to a condition of meaningful interaction with the world, or how much they were unwanted by family members speaking to what they believed their relative would want or benefit from.¹²² As courts began to recognize patients' rights to refuse treatment, they gave primary and almost exclusive weight to patient preferences in order to counter the paternalistic or vitalist tendencies of health care providers that would otherwise routinely understand continued life, in any condition, as being in the patient's best interests.¹²³ This emphasis on patient autonomy was also consistent with broader movements toward recognition of individual rights during this era.

Now that the law has firmly established that physicians cannot dictate that aggressive measures are always in a patient's interests, it is time to allow greater consideration of a more subjective, individualized best interests calculation by surrogates, families, and others involved in decision making. A strict ordering that grants the highest level of deference to expressed (especially written) preferences, mid-level deference to patient values, and the lowest consideration to a patient's individualized best interests should be abandoned in favor of allowing decisions to forgo or continue life-sustaining treatment to be justified on a reasonable combination of all factors relevant to the patient. Proof, especially to the degree of "clear and convincing evidence," of a now incapacitated patient's wishes should not be required to forgo any particular kind of treatment. Nor should the patient's medical condition have to fit within any particular category.

This approach is reflected in the Uniform Health-Care Decisions Act (the "UHCD" or "Act"),¹²⁴ which does not contain restrictions

122. See Robert Schwartz, *End-of-Life Care: Doctors' Complaints and Legal Restraints*, 53 ST. LOUIS U. L.J. 1115, 1157 (2009) ("At least from the turn of the twentieth century over a hundred years ago, American doctors have been enmeshed in a medical culture in which death is the enemy and the preservation of life, in any form, constitutes a victory over the enemy. American medicine was committed to using all of the resources available to save lives.").

123. See, e.g., *Bartling v. Superior Court*, 209 Cal. Rptr. 220, 220 (Cal. Ct. App. 1984) (upholding a man's right to have life support removed despite his physicians' insistence on preserving it).

124. UNIF. HEALTH-CARE DECISIONS ACT, 9 U.L.A. 83 (1993); see also Castillo et al., *supra* note 54, at 125–26 (arguing for reform "toward a flexible, relationship- and communication-based model" to advance care planning that would include "improving the readability of advance directives; eliminating surrogate restrictions; accepting oral and out-of-state advance directives; eradicating witness and notary requirements; and encouraging documentation of religious, cultural, and social beliefs"); Nachman, *supra* note 71, at 292 (discussing the shortcomings of instructional directives and arguing that "non-legally binding forms should be used to help the patient articulate his or her desires at end of life

on the withholding or withdrawal of life-sustaining treatment.¹²⁵ The Act, adopted by the National Conference of Commissioners on Uniform State Law in 1993, serves as a model for this needed reform, although to date it has only been adopted in six states.¹²⁶ The Act applies to all health care decisions, and not just those involving life-sustaining treatments.¹²⁷ It allows health care agents, whether appointed by a patient or granted authority through a default list of family members and others close to a patient, to make all but a few health care decisions for patients lacking capacity.¹²⁸ The Act requires the agent to make health-care decisions in accordance with the "principal's individual instructions, if any, and other wishes to the extent known to the agent."¹²⁹ Otherwise, decisions should be made "in accordance with the agent's determination of the principal's best interest. In determining the principal's best interests, the agent shall consider the principal's personal values to the extent known to the agent."¹³⁰

This approach is a sensible one if applied with the flexibility the Act's language implies.¹³¹ Patient preferences, to the extent they can

while giving the primary legal right to make end-of-life decisions to the health care agent and not a form, particularly when the patient is incapable of making coherent decisions").

125. See UNIF. HEALTH-CARE DECISIONS ACT, 9 U.L.A. 83. The Commentary for the UHCDA states: "Although case law imposes limitations on the withholding or withdrawal of life-sustaining treatment, attempts by the states to convert these limitations into statutory language have met with little success. The Act does not attempt to duplicate this failure." *Why States Should Adopt the UHCDA*, UNIFORM L. COMMISSION, <http://www.uniformlaws.org/Narrative.aspx?title=Why%20States%20Should%20Adopt%20UHCDA> (last visited Jan. 23, 2014).

126. According to the website of the Uniform Law Commission, as of November 22, 2013, UHCDA has been adopted in Alaska, Hawaii, Maine, Mississippi, New Mexico, and Wyoming. *Legislative Fact Sheet – Health-Care Decisions Act*, UNIFORM L. COMMISSION, <http://www.uniformlaws.org/LegislativeFactSheet.aspx?title=Health-Care%20Decisions%20Act> (last visited Jan. 23, 2014). Other states' laws may be influenced by the Uniform Health Care Decisions Act. See, e.g., VA. CODE ANN. § 54.1-2981 (2013).

127. UNIF. HEALTH-CARE DECISIONS ACT, *Prefatory Note*, 9 U.L.A. at 84 (describing the scope of the Act).

128. See *id.* These exceptions include decisions to commit an individual to a mental health facility, which are often subject to state procedural safeguards. *Id.* § 13(e), 9 U.L.A. at 125 ("This [Act] does not authorize an agent or surrogate to consent to the admission of an individual to a mental health-care institution unless the individual's written advance health-care directive expressly so provides." (alteration in original)); see *infra* Part IV.C (Principle 3).

129. UNIF. HEALTH-CARE DECISIONS ACT § 2(e), 9 U.L.A. at 94.

130. *Id.*

131. According to the Act's Commentary, "[t]he term 'individual instruction' . . . includes any type of written or oral direction concerning health-care treatment." *Id.* § 1 cmt., 9 U.L.A. at 90. Thus, the Act does not appear to grant exclusive priority to living wills.

be determined, should continue to be given the greatest weight among the various factors to be considered. Because this approach does not limit withholding and withdrawing treatment to certain medical conditions, patient preferences can in fact be given more weight than they typically have been given in the past in many states. At the same time, when patients' expressed preferences are general or contradictory, agents can look to patients' interests and values to understand and interpret them. Indeed, they should be encouraged to do so, rather than to read more than is warranted into a form document created by a state senate subcommittee or a years-old off-hand remark.¹³²

It should be noted that there is a cost to recognizing how little advance care planning documents or prior oral statements by the patient often tell us about what a patient would want. The current emphasis on advance care planning allows family members, surrogate decision makers, health care providers, and even ethics consultants, to believe that they are not making real-time decisions with life and death consequences, but that these decisions were made by the patient, perhaps long ago, and that they are merely the patient's messenger.¹³³ But this is mostly a fiction. If the burden of these decisions is made greater by recognizing that they are *current*, rather than *past* decisions, made by people today, rather than others in the past, then we need to work hard to figure out how to ease that burden, but in honest ways.

132. See generally Robert A. Burt, *The End of Autonomy*, HASTINGS CENTER REP. (SPECIAL REP.), Nov.-Dec. 2005, at S9, S9 (acknowledging the importance of protecting patient autonomy in these and other medical decisions but also concluding that "the facts are that applying the autonomy framework in end of life decision-making has had little practical effect and much fictitious posturing").

133. This fiction is encouraged by online materials like those published by the Missouri Attorney General's Office on the topic of advance care planning. Called "Life Choices," the publication begins: "Make important decisions now about your end-of-life needs. Your loved ones will not have to make those decisions for you if you become impaired." Chris Koster, *Life Choices*, OFF. MO. ATT'Y GEN. (March 2009), <http://ago.mo.gov/publications/lifechoices/lifechoices.pdf>. Court opinions also encourage this view. See *In re Guardianship of M. Browning*, 568 So. 2d 4, 13 (Fla. 1990) ("One does not exercise another's right of self-determination . . . by making a decision which the state, the family, or public opinion would prefer. The surrogate decisionmaker must be confident that he or she can and is voicing the *patient's* decision.").

B. Principle 2: All Patients Should Have a Surrogate Decision Maker, and the Same Standards of Decision Making Should Apply to All Surrogate Decision Makers

End-of-life law has taught us the importance of an identified surrogate decision maker. State statutes addressing life-sustaining treatment were, in many states, the first legislative attempts to clearly identify who had the authority to make medical decisions for the patient in the event of the patient's incapacity.¹³⁴ Similarly, advance directive statutes about life-sustaining treatment first established the idea of using a legal instrument to appoint an agent to make health care decisions for a person in the event of later incapacity.¹³⁵

Everyone should have a person¹³⁶ who can make medical decisions for him or her in the event of incapacity, whether questions of life-sustaining treatment are at issue or not. There are many situations in which a person may lose capacity, often just temporarily, but health care decisions must still be made.

Ideally, a patient would choose his or her own agent before one is needed, and this should be encouraged. Many Americans have not done so, however,¹³⁷ which may be due in part to the association of health care agency appointments with living wills and matters related to dying. This association might be traced to the federal Patient Self-Determination Act,¹³⁸ which is often considered to be a part of end-of-life law, although it is not explicitly so.¹³⁹ The Act requires most health care facilities to ask patients, upon admission, whether they have an advance directive (a living will or appointment of health care agent) and to document that answer in the patient's medical record.¹⁴⁰ The facility must also provide the patient with a written summary of the patient's health care decision-making rights and the facility's policies on recognizing, or refusing to follow, advance directives.¹⁴¹ In

134. See Schwartz, *supra* note 122, at 1158 (discussing history of surrogate decision-making statutes). Note that a few states still lack "default surrogate consent statutes" that specify who can make health care decisions for an incapacitated patient in the absence of a health care power of attorney. See, e.g., Eric D. Correia, *Why Rhode Island Needs Default Surrogate Consent Statutes*, R.I. B.J., Mar.-Apr. 2012, at 11, 11.

135. This instrument was originally known as a durable power of health care attorney. See Schwartz, *supra* note 122, at 1162.

136. Or *persons*. This Article does not take a position on the value of having a single surrogate decision maker or whether this responsibility might be shared.

137. See *supra* note 53 (providing statistics).

138. Pub. L. No. 101-508, 104 Stat. 1388 (1990) (codified in scattered sections of 42 U.S.C.).

139. See *id.* §§ 4206, 4751, 104 Stat. at 1388-115, 1388-204.

140. 42 U.S.C. § 1395cc(f)(B) (2012).

141. *Id.* § 1395cc(f)(1)(A)(i)-(ii).

practice, this has meant that facility inquiries about health care agents have been made at the same time as inquiries about whether the patient has documented decisions about withholding or withdrawing life-sustaining treatment.¹⁴² And, like many of the statutory forms, many of the forms offered by hospitals to patients for naming an agent include information about, and options for, documenting the withholding or withdrawal of life-sustaining treatment.¹⁴³ Patients often wish to avoid thinking about the latter issues—a completely understandable response for many situations. Imagine an otherwise healthy pregnant woman who arrives in labor to the hospital being asked, upon admission, whether she has a living will.

This reality means that the mechanism that many hospitals have in place to ask about and record health care agency designations fails to encourage them. While end-of-life legislation has led the way in demonstrating the importance of designating an agent, the method for doing so must now be de-coupled from living wills and the advance care planning associated with dying and death. There is some anecdotal evidence that some hospitals have begun an intentional effort to offer patients an opportunity to name an agent on a “short-form” document that does not focus on matters related to dire prognoses but instead anticipates that the need for a surrogate may arise in unanticipated circumstances and for temporary periods of incapacity.¹⁴⁴ In contrast to the current process, designating a health care agent should be simple and quick.¹⁴⁵

In keeping with the principle that everyone should have a surrogate decision maker (and preferably one appointed by the patient), greater efforts need to be made to ensure that no one is “unrepresented.” According to a recent article published by Thad

142. This is because both an appointment of a health care proxy and a living will are understood to be “advance directives.” *Id.* §1395cc(f)(3) (defining “advance directive”).

143. See, e.g., N.C. GEN. STAT. § 90-321(d1) (2013) (offering a combined statutory form); *Advance Directive*, VA. HOSP. CENTER, <http://extranet.acsysweb.com/vSiteManager/VirginiaHosp/Public/Upload/AdvancedDirectiveForm.pdf> (last visited Mar. 5, 2014) (combined form); *Patient and Family Guide to Advance Directives*, BRIGHAM & WOMEN'S HOSP., http://brighamandwomens.org/Patients_Visitors/pcs/ethics/AdvanceDirEnglish.pdf (last visited Mar. 5, 2014) (same).

144. See generally K. Michael Lipkin, *Identifying a Proxy for Health Care as Part of Routine Inquiry*, 21 J. GEN. INTERN. MED. 1188 (2006) (arguing for integrating proxy designations into routine medical care and reporting results of study showing feasibility of this approach); K. Michael Lipkin, *Advance Medical Planning*, 124 ANN. INTERN. MED. 1017 (1996) (urging that physicians routinely ask for a surrogate designation as an “informal advance directive” to be documented in the medical record). Such a short-form appointment document is available for use and promoted at the University of Virginia Health System, for example.

145. See *infra* Part IV.C (Principle 3).

Pope, as many as three to four percent of nursing home residents lack a legally recognized surrogate, as do five percent of patients who die in U.S. intensive care units.¹⁴⁶ While the law currently permits a guardian to be appointed by a court for such patients, often no one is available to serve in this role; indeed, even when one can be found, the process, according to Pope, is “too slow and cumbersome relative to the need for treatment decisions, it’s expensive, and guardians often lack time, given their heavy caseloads, to learn about the patient.”¹⁴⁷ Pope’s solution, when an appropriate surrogate cannot otherwise be found, is to allow an institutional, multidisciplinary (i.e., not “doctors only”) ethics committee to assume the role, preferably one that is external to the health care facility.¹⁴⁸ This proposal and others deserve serious consideration so that every patient has not only a decision maker but also an advocate.

Finally, there is the question of whether the scope of decision-making authority should be the same as between appointed agents and default surrogates selected from the statutory hierarchy (e.g., spouse, adult children, parents, etc.). Some state statutes explicitly give the appointed agent more authority than a default surrogate,¹⁴⁹ or greater authority may be inferred from language suggesting that an appointed agent can make the same type of decisions that the principal could have made while competent.¹⁵⁰ An argument in favor of granting greater authority to the appointed agent is that the patient trusted the agent enough to select him or her to make these decisions. But there are many reasons a patient may not appoint an agent—for example, a patient may be reluctant to discuss end-of-life matters and encounter few obvious opportunities to appoint a health care agent outside of the context of end-of-life discussions. Or a patient may not have appointed an agent because he or she knew about the statutory hierarchy and was comfortable with the person who would become the default surrogate. There is no compelling evidence to suggest that patients who have default surrogates trust them less than patients trust their appointed agents.¹⁵¹ But, more importantly, any limitations

146. Thaddeus M. Pope, *Making Medical Decisions for Patients Without Surrogates*, 369 NEW ENG. J. MED. 1976, 1976 (2013).

147. *Id.*

148. *Id.* at 1977.

149. For a discussion of North Carolina’s statutes, see *supra* Part II.B.

150. See MEISEL & CERMENARA, *supra* note 1, § 7.09[B] (“Other statutes reach the same result by authorizing the proxy to make decisions to the same extent that the principal could if the principal possessed decisionmaking capacity.”).

151. While I am not aware of any studies comparing the levels of trust principals have between appointed agents and default surrogates, there are studies showing that when

on the authority of default surrogates would be the sort of limitations discussed in connection with Principle 1¹⁵² that should be avoided because they create impediments to honoring patients' preferences and interests. In the absence of evidence that default surrogates perform their roles less responsibly than appointed agents, the scope of authority for each should be identical.

C. Principle 3: Requirements for Advance Documentation by Patients Should Be Minimal

Some instructions are generally better than none. But formal documentary requirements should be minimized to make it easier for people to express their preferences and, therefore, better allow surrogate decision makers and others to understand and honor their wishes. Moreover, the need for formal requirements, like witnesses and notarization, is reduced when we allow written instructions to be considered in the context of knowledge of patient values and interests¹⁵³ and reduce the need for people to make strong pre-commitments about certain treatment options.¹⁵⁴

The Uniform Health Care Decisions Act is a good model for application of this principle. The Act provides that "[an] instruction may be either oral or written."¹⁵⁵ There are no documentary requirements associated with it.¹⁵⁶ The Act provides an optional statutory instructional form that contains space for the signature of two witnesses, but a failure to have witnesses does not invalidate the document; a signature alone is sufficient.¹⁵⁷

Under the Uniform Health Care Decisions Act, a power of attorney for health care, while it must be in writing, need not be witnessed or acknowledged.¹⁵⁸ In addition, an individual may orally designate a surrogate "by personally informing the supervising health-care provider."¹⁵⁹ A surrogate designated in this way has the

asked hypothetical scenarios involving decisions about life-sustaining treatment, accuracy in predicting what the principal would want did not differ between patient-designated and next-of-kin surrogates. See Shalowitz et al., *supra* note 100, at 496.

152. See *supra* Part IV.A (Principle 1).

153. See *supra* Part IV.A (Principle 1).

154. See *infra* Part IV.D (Principle 4).

155. UNIF. HEALTH-CARE DECISIONS ACT § 2(a), 9 U.L.A. 83, 93 (1993).

156. *Id.* § 2 cmt., 9 U.L.A. at 95 ("Subsection (h) validates advance health-care directives which conform to the Act, regardless of when or where executed or communicated.").

157. *Id.* § 4 cmt., 9 U.L.A. at 106 ("The Act does not require witnessing.").

158. *Id.* § 2(b) & cmt., 9 U.L.A. at 93 ("The power must be in writing and signed by the principal.").

159. *Id.* § 5(b), 9 U.L.A. at 111; see also *id.* § 1(16), 9 U.L.A. at 90 ("Supervising

same powers with respect to health care decision making as an agent appointed through a power of attorney document.¹⁶⁰

These simple rules about documentation apply to revocations as well, so that a patient may revoke the written designation of an agent by personally informing the supervising health-care provider.¹⁶¹ Allowing patients to change their designation of surrogate with such ease provides some counterweight to concerns that a family member or another person may fraudulently produce an advance directive that gives him or her the power to make health care decisions for the patient. Taking special care to attend to incompetent patients' protests (see Principle 7)¹⁶² also reduces the likelihood that a person could successfully control the decision-making process against the will of the patient. Abuses of this nature are not likely to be common. Moreover, they can occur even with stringent witness and notarization requirements. Such requirements, for example, did not prevent the most notorious case of health care agency fraud in recent years—the *Barnes*¹⁶³ case—in which a wife pieced together two different documents prepared by a lawyer in order to produce an advance directive that deleted her husband's instructions and retained her prior, but later revoked, appointment as his proxy.¹⁶⁴

health-care provider' means the primary physician or, if there is no primary physician or the primary physician is not reasonably available, the health-care provider who has undertaken primary responsibility for an individual's health care.”).

160. *Id.* § 5 cmt., 9 U.L.A. at 113 (“Subsection (g) provides that a health-care decision made by a surrogate is effective without judicial approval. A similar provision applies to health-care decisions made by agents.”).

161. *Id.* § 3(a), 9 U.L.A. at 98.

162. *See infra* Part IV.G (Principle 7).

163. *In re* Emergency Guardianship of Barnes, No. 27-GC-PR-111-16 (Minn. Dist. Ct. Feb. 4, 2011), available at http://www.thaddeuspope.com/images/Barnes_Court_Ruling_02-04-11.pdf.

164. *Id.*; *see also* Ruth A. Mickelsen et al., *supra* note 9, at 374. One deficiency of the Uniform Health Care Decisions Act regarding surrogacy designation should be noted, which is that its default list does not recognize domestic partners. *See* UNIF. HEALTH-CARE DECISIONS ACT § 5(c), 9 U.L.A. at 111. The list it provides mirrors that of many states: spouse; adult child; parent; adult brother or sister; and, if none of the foregoing are reasonably available, “an adult who has exhibited special care and concern for the patient, who is familiar with the patient’s personal values, and who is reasonably available.” *Id.* Although the comment to this provision explains that the default rule “incorporates the presumed desires of a majority of those who find themselves [without a designated surrogate],” it would appear to fall short of that goal by allowing domestic partners to serve as surrogates only as a last resort through the final category of an unrelated adult. *See id.* § 5 cmt., 9 U.L.A. at 112. This means that a person in a non-traditional partnership who wishes to have health care decisions made by his or her companion will have to follow the procedures contained in the Act to appoint the companion through a health care power of attorney or designate him or her as surrogate. The latter, at least, is quite simple.

D. Principle 4: Binding Pre-Commitments Should Be Allowed Only Sparingly and for Compelling Reasons; They Should Not Be Required or Encouraged

As discussed above, one could reasonably understand Hanford Pinette's living will providing for a "natural death" to represent his attempt to grant authority to his wife to withhold or withdraw life-prolonging measures rather than to provide a directive for her to do so.¹⁶⁵ First generation living will and durable power of health care attorney forms have frequently failed to coordinate well with one another,¹⁶⁶ as seen in the example of the North Carolina statutes before the 2007 revisions.¹⁶⁷ Today, it has become much more commonplace for these forms to be combined,¹⁶⁸ and there appears to be an emerging trend to place more emphasis on the agency appointment rather than the instructions, and for agents to be given the *power* to make certain decisions without *requiring* that they make them in a way predetermined by the principal.¹⁶⁹

These reforms move end-of-life law in the right direction—away from requirements that a person pre-commit to a certain course of action or rules that encourage one to do so. There are, however, plenty of instances of statutory schemes and statutory living will forms that continue to require or encourage pre-commitment. For example, the Oklahoma statutory form¹⁷⁰ asks people to choose, for each of three conditions (terminal condition, persistent unconsciousness, and end-stage condition),¹⁷¹ whether they would like life-sustaining treatment or not, with separate, specific instructions

165. See *supra* Part II.A.

166. This is due, in part, to the fact that durable powers of health care attorney were generally authorized by state law several years after living wills were authorized. See Schwartz, *supra* note 122, at 1161–62 (explaining that living will legislation preceded legislation to allow the appointment of health care agents).

167. See *supra* Part II.B (discussing North Carolina's statutes).

168. See Schwartz, *supra* note 122, at 1162.

169. See, e.g., N.C. GEN. STAT. § 32A-25.1 (2013) (providing a statutory health care power of attorney form, which gives the agent broad powers but allows the principal to add specific limitations if desired); *id.* § 90-321(d1) (2013) (providing a living will form which, in paragraph six, allows the patient to state whether, in the event the patient has appointed a health care agent who gives instructions that differ from this form (living will), the living will instruction can or cannot be so overridden by the agent's instructions). The North Carolina forms are discussed in Part II.B, *supra*.

170. OKLA. STAT. ANN. tit. 63, § 3101.4 (West Supp. 2013).

171. "End-stage condition" is defined in the statutory form as "a condition caused by injury, disease, or illness, which results in severe and permanent deterioration indicated by incompetency and complete physical dependency for which . . . treatment of the irreversible condition would be medically ineffective." *Id.* § 3101.3(4).

about artificial nutrition and hydration.¹⁷² The form, which also allows for appointment of a health care proxy, makes clear that the proxy is only allowed to make decisions about life-sustaining treatment and artificially administered nutrition and hydration as instructed on the form, and emphasizes that the living will instructions are the “final expression of [the patient’s] legal right to choose or refuse” treatment and that the signer “accept[s] the consequences of such choice or refusal.”¹⁷³ Even the generally quite reasonable Uniform Health Care Decisions Act provides an advance directive form that allows a person to instruct that “artificial nutrition and hydration must be provided regardless of my condition” and regardless of other choices made about life-prolonging measures.¹⁷⁴

Health care decisions generally—and not just those relating to life-sustaining treatment—should be made close to the time they are to be implemented, so that those decisions can reflect the facts then existing. This is true whether those facts concern the patient’s medical condition and prognosis, the patient’s relationships, or the state of advancing medical knowledge. We must be especially cautious in following advance instructions that are contrary to a patient’s current, individualized best interests¹⁷⁵ or contrary to a patient’s current expressions, even if the patient’s decision-making capacity may appear diminished at the time. Certainly the law should not encourage patients to bind themselves to future treatment decisions that they have inadequate knowledge to make; nor should the law give expressions about such decisions a legal imprimatur they do not deserve.

That said, pre-commitment may be appropriate in some circumstances. For example, the legally recognized Durable Do Not Resuscitate Order involves a pre-commitment by a patient to refuse cardiopulmonary resuscitation (“CPR”) in the event of a cardiac or respiratory arrest.¹⁷⁶ Because the decision whether or not to initiate CPR must be made in seconds or minutes, emergency personnel must be able to follow it without engaging in lengthy, or really, any, conversation about whether this is truly what the arresting individual

172. *Id.* § 3101.4(C)(1)(1)–(3).

173. *Id.* § 3101.4(C)(IV)(d).

174. UNIF. HEALTH-CARE DECISIONS ACT § 4 explanation, 9 U.L.A. 83, 100 (1993).

175. *See generally* Dresser, *supra* note 54, at 1839–40 (discussing situations in which patient directives should be overridden when it would be detrimental to the incompetent patient).

176. *See, e.g.*, VA. CODE ANN. § 54.1-2987.1 (2013).

wants. If it were otherwise, people would not have a right to refuse CPR that they could effectively exercise.

Pre-commitment may also be appropriate for some mental health treatment decisions. Mental health advance directives allow individuals with severe mental illness, when in possession of decision-making capacity, to express their preferences about hospitalization, certain medications, and other potential treatments that can be honored in the event of a later lapse in capacity.¹⁷⁷ They have been hailed by many proponents “as a way to empower consumers to take a more active role in their own treatment, and as a way to avoid damaging, divisive conflicts over treatment and medication issues.”¹⁷⁸ Some states allow patients to include a “Ulysses clause” in their mental health advance directives, by which they consent to future treatment even in the event of their later protest.¹⁷⁹ These extraordinary clauses have a strong pre-commitment basis, and the extent to which they are legally binding is not yet clear.¹⁸⁰ They do not elicit the same concerns as end-of-life pre-commitment decisions when they are individualized, executed with the guidance of mental health professionals with whom a patient has an established relationship, and allow treatment that is in the best medical interests of the patient. They are also accompanied by extraordinary procedural safeguards, such as a capacity assessment and witness requirement by a physician at the time of signing.¹⁸¹ Such strong pre-commitment mechanisms should only be recognized in the most compelling and narrow of circumstances.

The most recent innovation in end-of-life law, the National Physician Orders for Life-Sustaining Treatment (“POLST”) Paradigm,¹⁸² deserves some mention here. The POLST Paradigm is a

177. See, e.g., *Advance Directives for Mental Health Treatment*, DEPRESSION & BIPOLAR SUPPORT ALLIANCE, http://www.dbsalliance.org/site/PageServer?pagename=urgent_advance_directives (last visited Jan. 22, 2014).

178. Ronald S. Honberg, *Advance Directives*, NAT’L ALLIANCE ON MENTAL ILLNESS, http://www.nami.org/Content/ContentGroups/Legal/Advance_Directives.htm (last visited Jan. 22, 2014).

179. See, e.g., § 54.1-2986.2(C).

180. See, e.g., Paul S. Appelbaum, *Psychiatric Advance Directives and the Treatment of Committed Patients*, 55 PSYCHIATRIC SERVS. 751, 752–53 (2004) (admitting that just how often legal issues will arise “remains to be seen”); Jeffrey W. Swanson et al., *Superseding Psychiatric Advance Directives: Ethical and Legal Considerations*, 34 J. AM. ACAD. PSYCHIATRY & L. 385, 393 (2006) (noting that it is “too soon to tell” what the future holds for these agreements).

181. See, e.g., § 54.1-2986.2(C).

182. The website of the National POLST Paradigm contains many useful resources. See *Resources*, POLST, <http://www.polst.org/educational-resources> (last visited Mar. 2, 2014); see also Susan E. Hickman et al., *The POLST (Physician Orders for Life-Sustaining*

program begun in Oregon in 1991 that allows physicians to document, in a simple one-page (back and front) form, orders about patients' end-of-life care decisions that other physicians and health care providers can follow across treatment settings.¹⁸³ The POLST form is intended for use in determining the care of seriously ill or frail persons.¹⁸⁴ The form is not an advance directive, but is rather an instrument that can translate the instructions of an advance directive or decisions of a surrogate decision maker or the patient him or herself, when competent, into actionable medical orders.¹⁸⁵ The treatment decisions documented in it should reflect the current goals of care and condition of the patient rather than decisions about distant, more hypothetical situations, and the orders in it can be relied upon by health care providers in emergent situations.¹⁸⁶ One premise of the program is that POLST forms will be reviewed whenever there is a change in the care facility or medical condition of the patient.¹⁸⁷ Then, or actually at any time, they can be revised by joint agreement of the patient, or surrogate decision maker, and physician.¹⁸⁸ For example, a chronically ill patient's first POLST form might document his wish (and his physician's corresponding order) for full treatment interventions, but, following a serious decline in medical condition, this earlier preference might change and the patient and physician together might create a new POLST form that orders only limited interventions and avoidance of hospital intensive care units. If and when a patient loses capacity, surrogate decision makers generally have the same power as the patient to seek similar, appropriate modification of the POLST form to respond to changes in the patient's condition.¹⁸⁹

Treatment) Paradigm to Improve End-of-Life Care: Potential State Legal Barriers to Implementation, 36 J.L. MED. & ETHICS 119, 119 (2008) (describing POLST program and detailing potential state law barriers to implementation, such as medical pre-conditions and witnessing requirements).

183. See *History*, POLST, <http://www.polst.org/about-the-national-polst-paradigm/history/> (last visited Mar. 2, 2014). For examples of state POLST forms, see *State-by-State POLST Forms*, EVERPLANS, <https://www.everplans.com/tools-and-resources/state-by-state-polst-forms> (last visited Mar. 2, 2014).

184. See *About the National POLST Paradigm*, POLST, <http://www.polst.org/about-the-national-polst-paradigm/> (last visited Jan. 22, 2014).

185. See *POLST and Advance Directives*, POLST, <http://www.polst.org/advance-care-planning/polst-and-advance-directives/> (last visited Jan. 22, 2014).

186. See *id.*

187. See *id.* (noting that POLST forms only cover medical orders for current treatment).

188. See *FAQ*, POLST, <http://www.polst.org/advance-care-planning/faq/> (last visited Jan. 22, 2014).

189. See, for example, the California and Oregon POLST forms, which can be found at

The POLST initiative is generally a positive one.¹⁹⁰ It is primarily a tool to communicate across a fragmented health care system. It can prevent an unwanted, traumatic, and high-intensity middle-of-the-night transfer to the hospital from a nursing home that might otherwise occur simply because a doctor has not issued a “do not hospitalize” order or specified “comfort measures only.”¹⁹¹ Physicians’ orders are a time-honored mechanism for physicians to direct other health care providers in caring for a patient in their absence. POLST forms allow that communication to occur between independent facilities.¹⁹²

E. Principle 5: Rushed Decisions That People Do Not or Should Not Want to “Live Like That” Should Be Avoided

Current end-of-life law’s enormous emphasis on asking and expecting surrogate decision makers to know *what the patient would want* has arguably contributed to a developing tendency for families to rush to certain and final conclusions to withhold or withdraw life-

State-by-State POLST Forms, *supra* note 183. Some of the POLST forms do include a somewhat troubling statement that any section not completed implies full treatment for the types of treatments specified in that section. *See, e.g., 2011 California POLST Form*, CAPOLST, http://www.capolst.org/documents/CAPOLSTform2011v13web_005.pdf (last visited Jan. 22, 2014); *Oregon POLST Form*, POLST OREGON, <http://www.oregonpolst.org/wp-content/uploads/2012/12/Printing-POLST.pdf> (last visited Jan. 22, 2014). This is not so much a problem of unnecessary pre-commitment, since the forms can and are expected to be revised over time, but is a problem of scripting choices. *See infra* Part IV.F (Principle 6). Rather than assume that incomplete sections imply treatment, it would be more reasonable to assume that no decision has been made by the patient (or surrogate, if appropriate) about the treatment option that was skipped in filling out the form. In other words, there should be no default—the decision has yet to be made.

190. For a critique of the POLST Paradigm, see Stanley A. Terman, *It Isn’t Easy Being Pink: Potential Problems with POLST Paradigm Forms*, 36 HAMLINE L. REV. 177, 178 (2013).

191. *See Scheible v. Joseph L. Morse Geriatric Ctr., Inc.*, 988 So. 2d 1130, 1131 (Fla. Dist. Ct. App. 2008) (explaining the situation of a nursing home resident who was transferred to a hospital, despite her living will that expressed contrary preferences). *See generally* Marshall B. Kapp, *Legal Anxieties and End-of-Life Care in Nursing Homes*, 19 ISSUES L. & MED. 111 (2003) (detailing the extent to which inappropriate transfers and other aggressive end-of-life measures occur in nursing homes because of anxiety about legal repercussions).

192. *See* Susan E. Hickman et al., *A Comparison of Methods to Communicate Treatment Preferences in Nursing Facilities: Traditional Practices Versus the Physician Orders for Life-Sustaining Treatment Program*, 58 J. AM. GERIATRICS SOC’Y 1241, 1246–47 (2010) (“The POLST program is built upon a coordinated system of care across treatment settings that includes emergency services, hospitals, primary care practices, hospices, and nursing facilities and relies on standardized, specific orders for a range of treatments, which makes the POLST program unique and may explain its apparent success.”).

sustaining treatment on the basis of quick and insistent beliefs that their family member would “not want to live like that,” meaning, generally, in some condition of impairment or with a loss of function. But “like that” is sometimes a condition in which objectively many people would in fact like to live—or at least would like to see how matters progress over the ensuing days, weeks, or months before making such an irrevocable decision. And while it would be reasonable in such circumstances to slow down the process, it is not clear that existing legal and ethical norms—which place great emphasis on “what the patient would want”—give physicians and others the tools to do that.

A recent *Atlantic* article by Ashwaq Masoodi describes one such scenario.¹⁹³ Joseph Brown, a thirty-six-year-old man, had become ill with necrotizing fasciitis (a flesh-eating infection).¹⁹⁴ While the prognosis was initially very poor, physicians came to believe that the patient would recover, although he would lose some or all of his limbs to amputation.¹⁹⁵ The family was told of this improved prognosis but insisted that, as a manual laborer, the man would not want to live if he could not have all his limbs.¹⁹⁶ They wanted doctors to disconnect his ventilator and allow him to die.¹⁹⁷ The *Atlantic* article describes the family as “adamant,” “unequivocal,” and “sure that he would prefer death to life with disability.”¹⁹⁸

The patient’s attending physician hesitated to follow this family’s instruction to discontinue life support.¹⁹⁹ He called an ethics consult.²⁰⁰ The consulting ethicist, Dr. Kenneth Prager, pointed to Brown’s improving prognosis and the uncertainty about what he would want: “He (Brown) could never have envisaged this,” Dr. Prager told Masoodi, “I don’t know how the relatives could possibly know what he would have wanted.”²⁰¹

During the delay caused by the ethics consultation, Brown’s condition continued to improve.²⁰² Nevertheless, and despite

193. Ashwaq Masoodi, *Make Your Wishes Known*, ATLANTIC (July 10, 2013, 10:46 AM), <http://www.theatlantic.com/health/archive/2013/07/make-your-wishes-known/277654/>.

194. *Id.*

195. *Id.*

196. *Id.*

197. *Id.*

198. *Id.*

199. *Id.*

200. *Id.*

201. *Id.*

202. *Id.*

hesitation on the part of the hospital's ethics committee, the family was ultimately given the option to discontinue mechanical ventilation.²⁰³ The family "feared that if the process were delayed, Brown would have a life of unwanted disability."²⁰⁴ The ventilator was removed, as the family requested, but Brown began breathing on his own.²⁰⁵ When he regained consciousness, Brown was asked what he wanted done in terms of further measures to extend his life.²⁰⁶ After being informed that amputation of his limbs was still likely, he said, contrary to his family's expectations, "Do whatever it takes."²⁰⁷

Another recent news story reveals a similar urgency on the part of a family to allow a patient to die.²⁰⁸ This story is somewhat different, however, in that the patient was brought out of sedation and asked what he would want done.²⁰⁹ Tim Bowers was a 32-year-old married man with a baby on the way.²¹⁰ A fall from a tree while hunting caused severe injuries to his spine.²¹¹ Physicians believed that he would be permanently paralyzed from the shoulders down and might always be dependent on a ventilator to breathe.²¹² The family believed they knew Bowers would not want to live like that, and asked if he could be brought out of sedation, told of his condition, and asked whether he wanted to live or die.²¹³ The physicians agreed to this plan.²¹⁴ Bowers, who had not suffered any brain injury, was brought to a state of alertness in which physicians felt he had decision-making capacity, told his prognosis, and asked if he wanted to continue with life support.²¹⁵ Bowers, according to his sister, "shook his head emphatically no," when asked, "Do you want this?"²¹⁶ Bowers was subsequently removed from the ventilator; he

203. *Id.*

204. *Id.*

205. *Id.*

206. *Id.*

207. *Id.*

208. Jeni O'Malley, *Indiana Hunter Paralyzed in Fall Chooses to End Life Support*, NBC NEWS (Nov. 5, 2013, 4:47 PM), <http://www.nbcnews.com/health/indiana-hunter-paralyzed-fall-chooses-end-life-support-8C11535734>.

209. *Id.*

210. *Id.*

211. *Id.*

212. *Id.*

213. *Id.*

214. *Id.*

215. *Id.*

216. *Id.* (internal quotation marks omitted).

died within a few hours.²¹⁷ The fall occurred on Saturday; Bowers was removed from life support and died on Sunday.²¹⁸

The speed with which this all occurred should make us uncomfortable. While patients have the right to make these choices, how quickly should they be asked to make them? Instead of bringing Mr. Bowers out of sedation to ask him if he wanted to die, would not it have been better to comfort him with the message that his life, though altered, could still bring him and others meaning and enjoyment? Above all, should he not be allowed more time to comprehend not only the limitations of his new condition, but the potential solutions or means of coping? Many people who have experienced severe loss of function later find life as satisfying or more satisfying than life before their accident or illness and experience happiness on par with people who do not have a severe disability.²¹⁹

These stories share at least two critical features in common. The first is a sense of urgency that there is a short window in which to make these sorts of decisions or some opportunity may be lost²²⁰ (what that opportunity is merits some review, as it is entangled in our preconceptions and sometimes misconceptions of disability). The second is a certainty about the wishes of another person that seems unsubstantiated and reasonably open to doubt. Important medical decisions tend to be complex; legal and ethical norms cannot allow them to be over-simplified. We need to develop guidelines and practices to allow physicians and hospitals to slow down and allow reconsideration of these quick judgments, without unduly impairing patient autonomy.²²¹ Realizing that we cannot understand patient autonomy to be appropriately represented by simple declarations (Principle 1)²²² may help us in this endeavor, although this way of thinking has been encouraged for some time.

217. *Id.*

218. *Id.*

219. See Adrienne Asch, *Recognizing Death While Affirming Life: Can End of Life Reform Uphold a Disabled Person's Interest in Continued Life?*, HASTINGS CENTER REP. (SPECIAL REP.), Nov.-Dec. 2005, at S31, S32.

220. See generally Thomas I. Cochrane, *Unnecessary Time Pressures in Refusal of Life-Sustaining Therapies: Fear of Missing the Opportunity to Die*, 9 AM. J. BIOETHICS 47 (2009) (discussing the dilemma some surrogate decision makers face in deciding whether to pursue treatment for a patient that may, if unsuccessful, result in a situation of severe disability but no plug to pull, so to speak).

221. See Burt, *supra* note 132, at S12-S13 (arguing for a continuation of life-sustaining treatment "until all affected participants (family members and clinicians)" engage in a consultative process in which they have a voice, but not a veto, about such decisions for both competent and incompetent patients).

222. See *supra* Part IV.A (Principle 1).

Disability rights organizations and scholars have long protested that many end-of-life decisions made in the name of patient autonomy rest on invalid and patronizing assumptions about the poor quality of life experienced by people with disabilities.²²³ They raise similar concerns about common practices in prenatal testing and the abortion of fetuses affected with genetic anomalies—practices that also are shaped by law.²²⁴ Many of their concerns are valid, and much work needs to be done in this area. There are promising signs that a “disability-conscious” approach to bioethics is emerging, in which concerns about disability discrimination have entered mainstream bioethics.²²⁵

F. Principle 6: Communication About Health Care Decisions Should Be Encouraged but Not Scripted by Law

It is never easy for the law to require or even encourage provider-patient communication about health care decisions without proposing a script for one, whether intentionally or not.²²⁶ This is especially so when communications are aimed at particular health care decisions, such as whether or not to have an abortion. Many recent state efforts, under the name of “Women’s Right to Know Acts,” do not even pretend to be neutral in requiring information to be provided to women in the form of descriptions of the developmental stage of the fetus or the showing of ultra-sound images.²²⁷

223. See Asch, *supra* note 219, at S32; Longmore, *supra* note 18, at 141; Adam A. Milani, *Better Off Dead Than Disabled?: Should Courts Recognize a “Wrongful Living” Cause of Action When Doctors Fail to Honor Patients’ Advance Directives?*, 54 WASH. & LEE L. REV. 149, 216–27 (1997).

224. See Adrienne Asch, *Disability Equality and Prenatal Testing: Contradictory or Compatible?*, 30 FLA. ST. U. L. REV. 315, 316 (2003); Martha A. Field, *Killing “The Handicapped”—Before and After Birth*, 16 HARV. WOMEN’S L.J. 79, 80–81 (1993); Erik Parens & Adrienne Asch, *The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations*, HASTINGS CENTER REP. (SPECIAL SUPPLEMENT), Sept.–Oct. 1999, at S1, S1–S2.

225. See ALICIA OUELLETTE, BIOETHICS AND DISABILITY: TOWARD A DISABILITY-CONSCIOUS BIOETHICS 10–11 (2011).

226. See Suter, *supra* note 2, at 51.

227. See *id.* at 44. In a recent ruling striking down North Carolina’s ultrasound law, codified at sections 90-21.80 through 90-21.92 of the North Carolina General Statutes, the U.S. District Court for the Middle District of North Carolina held that the First Amendment rights of the plaintiffs (physicians and other health care providers) were violated by the “speech-and-display provision” of the law, which required that a provider “must display ultrasound images so that the patient may view them and must describe the images to the patient.” *Stuart v. Loomis*, No. 1:11-CV-804, 2014 WL 186310, at *1 (M.D.N.C. Jan. 17, 2014). The opinion states,

Legislation relating to end-of-life decisions has been far less intentional in directing people toward certain choices,²²⁸ but it has nonetheless done so.²²⁹ As already noted, first generation living will forms did not present individuals with the option to document their wish for continued life-sustaining treatment, the assumption being that if continued treatment were desired, one would not have or need a living will.²³⁰ In response, some right-to-life groups have created living will forms that direct that life-prolonging measures always be continued.²³¹ While newer state-approved forms tend to allow either option, it would be preferable for states to get out of this business altogether. If states adopted fewer and less burdensome documentary requirements for people to communicate their preferences about life-sustaining treatment (Principle 3),²³² the need for state-approved forms would diminish.

As noted in the introduction to this Article, an early version of the Affordable Care Act included reimbursement for doctors undertaking conversations with their Medicare patients about advance care planning.²³³ While the conversation was not scripted per se, the provision did require that, to be eligible for reimbursement, certain topics had to be covered, including living wills, durable health care powers of attorney, the availability of hospice and palliative care, the roles and responsibilities of a health care agent, and “a list of national and state-specific resources to assist consumers and their families with advance care planning, including the national toll-free

The Supreme Court has never held that a state has the power to compel a health care provider to speak, in his or her own voice, the state’s ideological message in favor of carrying a pregnancy to term, and this Court declines to do so today. To the extent the Act is an effort by the state to require health care providers to deliver information in support of the state’s philosophic and social position discouraging abortion and encouraging childbirth, it is content-based, and it is not sufficiently narrowly tailored to survive strict scrutiny.

Id.

228. See Suter, *supra* note 2, at 49 (noting that there are currently no state mandates requiring the use of images or descriptions of various treatments like those required in the abortion context).

229. See *id.* at 29, 36 (explaining that “end-of-life informed consent statutes” in states such as California and Michigan have been criticized for intending to influence end-of-life decisions through disclosures of non-medical information).

230. See *supra* note 66 and accompanying text.

231. See NAT’L RIGHT TO LIFE COMM’N, <http://www.nrlc.org/medethics/willtolive/> (last visited Jan. 29, 2014) (operating like a living will but aiming to “protect your life”); see also Shepherd, *supra* note 86, at 380–81 & nn.103–06, 390–93 (describing the “Will to Live” and giving an example of the form in the appendix).

232. See *supra* Part IV.C (Principle 3).

233. See *supra* text accompanying notes 4–6.

hotline, the advance care planning clearinghouses, and State legal service organizations.”²³⁴ Critics’ distortion of this provision as creating a “death panel” was clearly dishonest.²³⁵ Medicare beneficiaries were not required to have such conversations and there was no indication that physicians were encouraged to use these conversations to convince patients to choose less aggressive medical care. Yet reasonable people might nevertheless have had some concerns about the degree to which the subject matter was dictated. State laws that mandate the provision of certain information in the end-of-life context, such as those recently enacted in California and New York can cause similar discomfort.²³⁶

In place of special incentives or requirements for conversations about certain topics (e.g., abortion, prenatal screening,²³⁷ diagnoses of terminal illness, and options for hospice), we should improve reimbursement and other incentives for conversation between providers and patients in all health care matters. This is especially appropriate given the increasing recognition that reimbursement rules contribute to our procedure-driven medical care system, as doing procedures is much more financially rewarding to providers than engaging in thoughtful conversations with patients about whether they should be done.

G. Principle 7: Appropriate Safeguards to Protect Patients with Diminished Capacity Are Needed

Much of end-of-life law is justified as protecting patients who are vulnerable because they have never had or have lost decision-making capacity and the opportunity for autonomous action. Until 2002, for example, New York, in the name of protecting vulnerable patients, prohibited surrogate decision makers from withholding or

234. H.R. 3200, 111th Cong. § 1233 (2009) (later revised).

235. See Nyhan, *supra* note 6, at 1.

236. See CAL. HEALTH & SAFETY CODE § 442.5 (West Supp. 2014); MICH. COMP. LAWS ANN. §§ 333.5654–.5655 (West Supp. 2012); N.Y. PUB. HEALTH LAW § 2997-c (McKinney Supp. 2014); VT. STAT. ANN. tit. 18, § 1871 (Supp. 2012); see also Steven E. Weinberger et al., *Legislative Interference with the Patient-Physician Relationship*, 367 NEW ENG. J. MED. 1557, 1557 (2012) (criticizing legislative attempts to “dictate the nature and content of patients’ interactions with their physicians,” including statutes requiring certain disclosures to terminally ill patients).

237. See CAL CODE REGS. tit. 17, § 6527(a) (2008) (requiring physicians to inform women about the availability of certain prenatal tests by using information in a format provided or approved by the Department of Health Services); Sonia M. Suter, *The Routinization of Prenatal Testing*, 28 AM. J.L. & MED. 233, 253 (2002) (describing how the California mandate caused physicians to overreach in persuading their patients to have the test, since having the test was “the clearest evidence of compliance”).

withdrawing life-sustaining treatment from anyone who had always lacked capacity to make health care decisions.²³⁸ In the famous case of Sheila Pouliot, this legal standard resulted in the imposition of treatments that prolonged suffering and were widely considered inhumane.²³⁹ Legal requirements for special documentation when a patient wishes to forgo artificial nutrition and hydration are similarly grounded in fear that feeding tubes will be denied to patients who want them, when in fact the opposite is true—feeding tubes are used far more often than medically beneficial or desired.²⁴⁰

Patients who lack decision-making capacity do need special protections, but those protections should be more carefully directed toward actual rather than imagined vulnerabilities. Here are three such safeguards.

First, the law should include clear procedures to enhance patient involvement in decision making. Most importantly, considerable care must be taken to ensure that surrogate decision makers are not asked to make decisions for individuals who actually still retain (or have re-attained) the capacity to make decisions for themselves. There is growing recognition that capacity can wax and wane, and that while individuals may lack capacity to make complex decisions, they may retain it to make simpler ones.²⁴¹ Even absent decision-making capacity, processes should be in place to involve patients in their health care treatment plans by providing information and opportunities for assent. In addition, processes should be in place to

238. See *In re Storar*, 420 N.E.2d 64, 73 (N.Y. 1981) (“A parent or guardian has a right to consent to medical treatment on behalf of an infant. The parent, however, may not deprive a child of life saving treatment, however well intentioned.”), *superseded by statute*, Health Care Decisions Act for Persons with Mental Retardation, ch. 500, § 3, 2002 N.Y. Laws 3375, 3376 (codified at N.Y. SURROGATE’S CT. PROC. ACT LAW § 1750-b (McKinney Supp. 2014)), *as recognized in In re M.B.*, 846 N.E.2d 794, 795 (N.Y. 2006). See generally Alicia R. Ouellette, *When Vitalism Is Dead Wrong: The Discrimination Against and Torture of Incompetent Patients by Compulsory Life-Sustaining Treatment*, 79 IND. L.J. 1, 13–18 (2004) (explaining prior New York law and describing the case of Sheila Pouliot in which the State of New York would not allow the surrogate of a woman, who had always lacked decision-making capacity, to authorize the withholding or withdrawal of artificial nutrition and hydration).

239. See generally OUELLETTE, *supra* note 225, at 13–18 (describing the Pouliot case). In response to Pouliot’s case, New York law now allows surrogates more discretion. See N.Y. SURR. CT. PROC. ACT LAW § 1750 (McKinney 2010).

240. See SHEPHERD, IF THAT EVER HAPPENS TO ME, *supra* note 43, at 155–57.

241. See COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS, AM. MED. ASS’N, CODE OF MEDICAL ETHICS, Opinion 8.081 (2012) (“In some instances, a patient with diminished or impaired decision-making capacity can participate in various aspects of health care decision making. The attending physician should promote the autonomy of such individuals by involving them to a degree commensurate with their capabilities.”).

take notice of and respect, to the extent feasible, incapacitated patients' protests about health care decisions.

Virginia law provides a good model on many of these fronts. Two physicians (or a physician and clinical psychologist) must determine that the patient lacks capacity before health care decisions may be made by a patient's agent, and those determinations must be documented in the medical record.²⁴² At least one of those physicians must be independent, meaning not involved in the care of the patient.²⁴³ The capacity determination is only good for 180 days and must be recertified after that time, except when the patient is "unconscious or experiencing a profound impairment of consciousness due to trauma, stroke, or other acute physiological condition."²⁴⁴ In addition, an attending physician must inform a patient, if she is able to understand, that a determination has been made that she lacks capacity and who will be making decisions on her behalf.²⁴⁵ A determination that the patient has regained capacity can be made by a single physician.²⁴⁶ When a patient who lacks decision-making capacity protests a health care decision, that protest must be heeded unless certain procedural and substantive standards are met.²⁴⁷

Second, we need special safeguards for contexts in which there is a strong record of past abuse. Many state laws carve out certain types of decisions that surrogate decision makers cannot make for others without meeting higher or different standards by which those decisions are judged.²⁴⁸ Some may require court review.²⁴⁹ A standard

242. VA. CODE ANN. § 54.1-2983.2(B) (2013). In addition, all adults are presumed capable of making health care decisions until determined otherwise, and "[n]o person shall be deemed incapable of making an informed decision based solely on a particular clinical diagnosis." *Id.* § 54.1-2983.2(A).

243. *Id.* § 54.1-2983.2(B). There is an exception if an independent capacity reviewer is not reasonably available. *Id.*

244. *Id.*

245. *Id.* § 54.1-2983.2(C).

246. *Id.* § 54.1-2983.2(D).

247. *See id.* § 54.1-2986.2.

248. *See, e.g.,* D.C. CODE § 21-2211 (2001) ("No person authorized to act pursuant to § 21-2210 [providing for surrogate decision making] shall have the power: (1) To consent to an abortion, sterilization or psycho-surgery, unless authorized by a court; or (2) To consent to convulsive therapy or behavior modification programs involving aversive stimuli, unless authorized by a court."); VA. CODE ANN. § 54.1-2983.3(B) ("The provisions of this article [the Health Care Decisions Act] shall not apply to authorization of nontherapeutic sterilization, abortion, or psychosurgery.").

249. KY. REV. STAT. ANN. § 387.660(3) (LexisNexis Supp. 2012) ("[A] guardian may not consent on behalf of a ward to an abortion, sterilization, psychosurgery, removal of a bodily organ, or amputation of a limb unless the procedure is first approved by order of

set of decisions should probably continue to be subject to special scrutiny because of past historical abuse.²⁵⁰ A number of states do not permit health care agents to commit an individual to a mental health facility or to agree to sterilization, abortion, or psychosurgery.²⁵¹ Constitutional guarantees may also require heightened protection for some of these decisions.²⁵²

Decisions about withholding or withdrawing life-sustaining treatment, however, should no longer fall into this category. The courts were right when they expressed, through the 1970s and 80s, that these decisions needed to be routinely made outside of court review.²⁵³ The fact that multiple parties—patients, surrogate decision makers, family members, physicians, nurses, hospital administrators, and sometimes ethics committees—are typically involved in making

the court or is necessary, in an emergency situation, to preserve the life or prevent serious impairment of the physical health of the ward.”); N.D. CENT. CODE § 23-12-13(4) (2012) (requiring “a mental health proceeding or other court order” for surrogate consent “for sterilization, abortion, or psychosurgery or for admission to a state mental health facility for a period of more than forty-five days”).

250. See, e.g., *Conservatorship of Valerie N. v. Valerie N.*, 707 P.2d 760, 764–71 (Cal. 1985) (describing history of eugenic sterilization and passage of subsequent laws in California to protect incompetent individuals from involuntary sterilization); Mike E. Jorgensen, *Is Today the Day We Free Electroconvulsive Therapy?*, 12 QUINNIPIAC HEALTH L.J. 1, 6 n.23 (2008) (discussing history of abusive practices in psychosurgery and electroconvulsive therapy); Paul A. Lombardo, *Taking Eugenics Seriously: Three Generations of ??? Are Enough?*, 30 FLA. ST. U. L. REV. 191, 194–202 (2003) (describing Virginia’s past eugenics sterilization laws and practices).

251. See *supra* note 248 (citing and quoting the Virginia and D.C. statutes).

252. See, e.g., *Mich. Prot. & Advocacy Serv. v. Kirkendall*, 841 F. Supp. 796, 801 (E.D. Mich. 1993) (“[T]he due process and equal protection clauses of the United States Constitution demand that any involuntary sterilization of [plaintiff, a mentally ill individual] or others similarly situated, occur only after a full evidentiary hearing has been held to determine the propriety of such an extreme measure in relation to the rights of the patient.”); see also Anne Tamar-Mattis, *Sterilization and Minors with Intersex Conditions in California Law*, 3 CALIF. L. REV. CIRCUIT 126, 130–31 (2012) (noting that the constitutional right to reproductive freedom likely requires judicial review of parental decision to sterilize minor with intersex condition); Bruce J. Winick, *The MacArthur Treatment Competence Study: Legal and Therapeutic Implications*, 2 PSYCHOL. PUB. POL’Y & L. 137, 147–48 (1996) (discussing constitutional protections regarding certain forms of involuntary mental health treatment such as electroconvulsive therapy and psychosurgery).

253. See *In re Jobes*, 529 A.2d 434, 449 (N.J. 1987) (“No matter how expedited, judicial intervention in this complex and sensitive area may take too long. Thus, it could infringe the very rights that we want to protect. The mere prospect of a cumbersome, intrusive and expensive court proceeding, during such an emotional and upsetting period in the lives of a patient and his or her loved ones, would undoubtedly deter many persons from deciding to discontinue treatment. And even if the patient or the family were willing to submit to such a proceeding, it is likely that the patient’s rights would nevertheless be frustrated by judicial deliberation. Too many patients have died before their right to reject treatment was vindicated in court.” (citations omitted)).

and executing important medical decisions provides an important, and usually adequate, check against inappropriate decisions.

But that does not mean that court review should not be available to parties who have a significant personal interest in the health care decision being made. Although decisions to forgo life-sustaining treatment should not *require* court review, *access* to courts should be available. Agreement among the various parties involved in such decisions cannot always be reached, and court review is an appropriate forum for resolving intractable disputes. Many end-of-life state laws explicitly provide a process for accessing such review.²⁵⁴

On the other hand, the Texas Advance Directives Act²⁵⁵ allows health care facilities to unilaterally discontinue life-sustaining treatment over a surrogate's objection without the opportunity for substantive court review.²⁵⁶ Under the provisions of the Act, unilateral termination of treatment can take place provided that the facility's ethics committee agrees, notice and an opportunity to participate in the ethics consultation process is provided to the family, and transfer of the patient to another facility is attempted.²⁵⁷ The Act allows a court to grant an order extending the time period for treatment only if a facility transfer appears possible; the court is not permitted to engage in a substantive review of the merits of the

254. See, e.g., FLA. STAT. ANN. § 765.105 (West 2010) (allowing health care agent's decisions to be challenged by the patient's family, the health care facility, the attending physician, or "any other interested person who may reasonably be expected to be directly affected by the . . . decision").

255. TEX. HEALTH & SAFETY CODE ANN. § 166.046 (West 2010).

256. *Id.* § 166.046(g) ("At the request of the patient or the person responsible for the health care decisions of the patient, the appropriate district or county court shall extend the time period provided under Subsection (e) only if the court finds, by a preponderance of the evidence, that there is a reasonable expectation that a physician or health care facility that will honor the patient's directive will be found if the time extension is granted."); *Nikolouzos v. St. Luke's Episcopal Hosp.*, 162 S.W.3d 678, 680 (Tex. App. 2005) ("Section 166.046 does not expressly provide a right to appeal the trial court's ruling on a request for extension of time for life sustaining treatment, thus indicating the legislature did not intend to permit such an appeal."); Thaddeus Mason Pope, *Medical Futility Statutes: No Safe Harbor to Unilaterally Refuse Life-Sustaining Treatment*, 75 TENN. L. REV. 1, 80 (2007) (explaining why Texas's statute, in contrast to others, is a "pure process approach"); Amir Halevy & Amy L. McGuire, *The History, Successes and Controversies of the Texas "Futility" Policy*, HOUS. LAWYER (May/June 2006), http://www.thehoustonlawyer.com/aa_may06/page38.htm ("The statute explicitly limits the ability of the courts to intervene in such cases. The courts' only role is the ability to grant an extension of the ten-day waiting period if the court finds, 'by a preponderance of the evidence, that there is a reasonable expectation that a physician or health care facility that will honor the patient's directive will be found if the time extension is granted.' There is no specific provision allowing a patient, family, or physician to appeal the decision of the hospital review committee in court.").

257. § 166.046.

facility's decision.²⁵⁸ The Act has faced sharp criticism,²⁵⁹ and rightly so, because the internal ethics committee—rather than an independent body governed by rules and precedent—is essentially the final arbiter of the decision.

When disputes wind up in court, we often take this as a sign of failure.²⁶⁰ And if all decisions to forgo life-sustaining treatment were resolved by courts, that conclusion would be apt. But sometimes courts are the best forum to bring clarity to a set of facts or to resolve disagreements over fundamental values. Efforts by state legislatures to avoid court involvement in end-of-life and other health care decisions may have gone too far. Statutes governing health care decisions, particularly those relating to life-sustaining treatment, have become more and more specific, as have advance directive forms, as if every potential conflict might be anticipated and resolved in advance. What to do when a spouse has been named as a health care agent but now the couple is separated? What to do when the instructional directive conflicts with the decisions of the appointed health care agent? Certainly, some of the legal mechanisms established by statute, such as health care powers of attorney and default surrogate statutes, have been helpful. But anticipating and definitively resolving in advance every combination of life circumstances is not only impossible, but legislative attempts to do so can create barriers to respecting and caring for patients.

H. Principle 8: Relief of Pain and Suffering Should Always Be Permitted and Considered an Important Goal of Care

For many years, terminally ill patients have had to choose either to continue aggressive, curative therapies or to choose palliative care and hospice.²⁶¹ As a matter of practice, hospital-based specialty palliative consults, which did not see widespread adoption until the early 2000s,²⁶² have often been seen as something to be done after the

258. See § 166.046.

259. See Robert D. Truog, *Tackling Medical Futility in Texas*, 357 NEW ENG. J. MED. 1, 2 (2007) (criticizing the Act and explaining that "the ethics committee is acting, under Texas law, as a surrogate judge and jury, with the statutory power to authorize clinicians to take actions against the wishes of a patient and family, with protection against civil and criminal liability").

260. See Alan Meisel, *The Role of Litigation in End of Life Care: A Reappraisal*, HASTINGS CENTER REP. (SPECIAL REP.), Nov.-Dec. 2005, at S47, S47 (discussing limitations and costs to end-of-life litigation).

261. See Alexi A. Wright & Ingrid T. Katz, *Letting Go of the Rope—Aggressive Treatment, Hospice Care, and Open Access*, 357 NEW ENG. J. MED. 324, 324 (2007).

262. See Stephen R. Connor, *Development of Hospice and Palliative Care in the United*

patient or family had decided that further aggressive therapies were unwanted.²⁶³ In some hospital settings, it was only then that serious attention would be paid to making the patient as comfortable as possible.²⁶⁴

Greater access to palliative care and hospice is becoming common, although these efforts are in their early stages. Importantly, the Affordable Care Act explicitly mandates that terminally ill children be allowed both curative therapies and palliative care.²⁶⁵

These are all steps in the right direction. In fact, this is one of the areas in which advances in how care is provided at the end of life should be translated to the delivery of health care generally. “Palliative care”—which focuses on the prevention and relief of pain and suffering²⁶⁶—should lose its association with care at the end of life and be an important part of all health care.²⁶⁷ A sign that this has occurred will be when it is no longer called by a special name.

CONCLUSION

The principles described above will not make health care decisions easier, but that is not their goal. The challenges of health care decision making—especially those that involve matters of life and death, pain, suffering, disability, dignity, and family—cannot and should not be simplified. But in a medical landscape that is constantly evolving in response to new technologies, treatments, knowledge, or

States, 56 OMEGA 89, 93 (2007).

263. Gawande, *supra* note 97 (discussing aggressive treatment versus palliative and hospice care).

264. *See id.* (discussing care of Sara Monopoli).

265. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 2302, 124 Stat. 119, 293 (2010) (codified as amended at 42 U.S.C. § 1396d(o)(1) (2012) (providing that a decision to accept hospice services for terminally ill children would not constitute a waiver of the right to payment for curative or treatment services from Medicaid or Children’s Health Insurance Program); *see Concurrent Care for Children*, NAT’L HOSPICE & PALLIATIVE CARE ORG., <http://www.nhpco.org/resources/concurrent-care-children> (last visited Jan. 27, 2014).

266. *See WHO Definition of Palliative Care*, WORLD HEALTH ORG., <http://www.who.int/cancer/palliative/definition/en/> (last visited Jan. 27, 2014) (defining palliative care as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”).

267. NANCY BERLINGER, BRUCE JENNINGS & SUSAN M. WOLF, THE HASTINGS CENTER GUIDELINES FOR DECISIONS ON LIFE-SUSTAINING TREATMENT AND CARE NEAR THE END OF LIFE 116–17 (2d ed. 2013) (recommending the integration of palliative care “into treatment and care plans in all care settings for all patients, including patients near the end of life”).

systems of care, these principles can help ensure that we remain focused on our duties to offer care and respect for every patient and every family. Special rules for decisions about withholding or withdrawing life-sustaining treatment may have been useful and even necessary at some point in the development of the law and ethics in this area, but their value has diminished and it is time to let them pass.