

## LIVING WILLS: IS IT TIME TO PULL THE PLUG?

*Dorothy D. Nachman*

Most of us were not afraid of death, only of the act of dying; and there were times when we overcame even this fear. At such moments we were free . . . it was the most complete experience of freedom that can be granted a man.

Arthur Koestler, *Dialogue with Death*

*Despite the high value that many Americans place on self-determination at the end of life, few actually have their end-of-life medical desires fulfilled due to the lack of adequate procedures and forms that ensure such wishes are carried out once a person is incompetent to make his or her own medical determinations. This Article addresses the shortcomings of current methods used to preserve a patient's desires at the end of life and advocates for uniform and consistent processes for recording a patient's end-of-life wishes, as well as open and honest conversations among the patient, the patient's health care agent, and health care provider regarding the patient's desires for future care. Reliance on forms, such as advance directives and living wills, should be replaced with dialogue that guides the patient's health care agent in making binding health care choices on behalf of the principal. Strong personal advocates are more effective in ensuring a patient's wishes are carried out than traditional legal forms, which have too long been used as a substitute for real conversations about the things that matter most at the end of life.*

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**I. Introduction**

Decisions about end-of-life care affect us all: as patients, spouses, parents and children. Most would agree that these decisions are intensely personal and should be guided predominately by a patient’s wishes, without interference from the state. In fact, our current law supports this notion as evidenced by the courts’ decisions in *In re Quinlan*,<sup>1</sup> and *Cruzan v. Director, Missouri Department of Health*.<sup>2</sup>

Although an intensely personal decision, there are numerous professionals and institutions that have a specific interest in the pa-

1. *In re Quinlan*, 355 A.2d 647, 669-70 (N.J. 1976) (holding that patient’s right to privacy was greater than the State’s interest in preserving human life).

2. *Cruzan v. Dir., Mo. Dep’t of Health*, 497 U.S. 261, 278 (1990) (stating that a competent person has a constitutionally protected right in refusing medical help).

tient's decision-making process; typically these professionals are not as concerned with *what* decision the patient makes as they are concerned with *how* the decision is made and documented. Family members are interested in the patient's desires for end-of-life care and treatment to ensure that any decisions a loved one has to make on behalf of their dying relative are consistent with the relative's desires. Doctors are interested in the patient's desires to ensure they are followed at suitable times and in accordance with a physician's medical judgment. Lawyers are interested in the patient's desires inasmuch as they are professionally positioned to help their clients preplan for these eventualities and navigate the necessary forms and statutes applicable to these decisions. Lawyers are also interested in the patient's desires when they represent physicians whose provision of care at the end of life may be subject to scrutiny by disgruntled family members, review boards, and insurance companies. Hospitals are interested in the patient's desires because many of these decisions play out in a hospital setting, requiring hospitals to have policies and procedures in place to protect themselves, as well as the doctors on their staff and patients in their care.<sup>3</sup>

The interests of these stakeholders combined with the ever-increasing "graying of America" give an urgency to the resolution of these matters. According to U.S. Census projections, the population of persons in the United States aged sixty-five or older is estimated to have reached thirty-seven million in 2008,<sup>4</sup> representing a growth of thirty-four million people in the sixty-five-and-over category during the twentieth century.<sup>5</sup> Additionally, the population of older Americans is expected to continue to increase significantly between the years of 2010 and 2030 as the Baby Boom Generation ages.<sup>6</sup> The challenge of advising clients about the intricacies of advance directive planning falls primarily to the estate planning and elder law attorney whose client population will increase proportionately to the aging

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3. SHARON R. KAUFMAN, *AND A TIME TO DIE: HOW AMERICAN HOSPITALS SHAPE THE END OF LIFE 25-60* (2005).

4. *American Community Survey Demographic and Housing Estimates: 2006-2008*, U.S. CENSUS BUREAU, [http://factfinder.census.gov/servlet/ADPTable?\\_bm=y&-qr\\_name=ACS\\_2008\\_3YR\\_G00\\_DP3YR5&-geo\\_id=01000US&-ds\\_name=ACS\\_2008\\_3YR\\_G00\\_-lang=en](http://factfinder.census.gov/servlet/ADPTable?_bm=y&-qr_name=ACS_2008_3YR_G00_DP3YR5&-geo_id=01000US&-ds_name=ACS_2008_3YR_G00_-lang=en) (last visited Oct. 31, 2010).

5. *Population*, AGINGSTATS.GOV, [http://www.aoa.gov/agingstatsdotnet/Main\\_Site/Data/2008\\_Documents/Population.aspx](http://www.aoa.gov/agingstatsdotnet/Main_Site/Data/2008_Documents/Population.aspx) (last visited Oct. 10, 2010).

6. *Id.*

population. Given the interests of the professional participants in end-of-life care planning and the personal decision making associated with end-of-life choices, the appropriate documentation of these decisions is imperative.

Despite the crucial need for clear, definitive, and acceptable means of communicating one's end-of-life care and treatment, the web of appropriate forms, elections, and orders to effectuate one's desires is tangled and messy, making effective client and patient advocacy nearly impossible. These administrative challenges are further burdened by the individual practices of doctors and other health care workers who struggle to incorporate the various authorized forms into their patient care and use them as tools to help patients and their families resolve end-of-life issues. Hospital administrators are laden with the task of creating policies and procedures for end-of-life treatment and care and advising doctors of the legally appropriate course of action in individual cases.<sup>7</sup>

One of the challenges of creating effective end-of-life decision-making policy is that there are two distinct goals that such policies are designed to address: 1) protecting an individual's right to determine the nature and scope of their end-of-life care and 2) protecting health care professionals from liability. It may be that these two goals cannot simultaneously be achieved successfully. As I will discuss below, statutory forms that seek to protect patient self-determination as well as health care professionals do neither successfully. The goal in end-of-life planning should be to encourage an open and honest conversation among the individual, his or her health care providers, and health care agent about the patient's desires at end of life. Attorneys and physicians should advocate the selection of a health care agent who is knowledgeable about the patient's desires at end of life and who is prepared to make the challenging decisions that are presented. Alternatively, non-legally binding forms should be used to help the patient articulate his or her desires at end of life 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.

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7. Carmel Marti Day, *The Why of Policies and Procedures; an Organization's Purpose or Mission Gives Rise to Policies, and from Policies Flow Procedures*, MED. LABORATORY OBSERVER, June 1985, available at [http://findarticles.com/p/articles/mi\\_m3230/is\\_v17/ai\\_3799313/](http://findarticles.com/p/articles/mi_m3230/is_v17/ai_3799313/).

Furthermore, if our society fervently believes that self-determination at the end of life is a hallmark of an evolved society, health care professionals, attorneys, and legislatures have a duty to work together to develop a clear and consistent process that allows clients and patients to choose their end-of-life care options with the confidence that their choices will satisfy underlying statutory law and hospital policies while supporting patient autonomy. By working together, professionals can understand the complex concerns of the other and work in tandem to create a reliable process that lawyers, doctors, and hospitals can accept to support the dying patient.

Supporting one reliable scheme for effectuating end-of-life care decisions, however, assumes that all professionals share a common goal. Much rhetoric has been made about the desire to guarantee, to the extent possible within the legal framework and existing professional codes, that end-of-life desires of clients and patients are upheld. For physicians, however, there is another competing, if not more compelling, goal of avoiding the medical liability associated with the removal or withdrawal of end-of-life care.<sup>8</sup> Failure to acknowledge this concern or relegating it to secondary status continues the myth that a series of forms can sufficiently protect physicians and bring about reliable care consistent with a patient's advance directives.

The chasm between these two goals frequently results in simultaneous processes by professionals: subcommittees of bar associations draft proposed legislation and bills to modify statutes regarding end-of-life care while subcommittees of medical associations draft forms and doctor's orders that seek to do the same thing.<sup>9</sup> Simultaneously, lawyers rely on statutes and statutory forms to help their clients designate end-of-life care and treatment choices while doctors rely on hospital policies, medical orders, and medical association-approved forms to help their patients designate end-of-life care and treatment

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8. See John M. Luce & Anna Alpers, *Legal Aspects of Withdrawing Life Support from Critically Ill Patients in the United States and Providing Palliative Care to Them*, 163 AM. J. RESPIRATORY CRITICAL CARE MED. 2029, 2031 (2001).

9. SUSAN E. HICKMAN ET AL., HASTINGS CTR. SPECIAL REPORT, IMPROVING END OF LIFE CARE: WHY HAS IT BEEN SO DIFFICULT?, 47-52 (2005) available at <http://www.scribd.com/doc/27571073/Improving-End-of-Life-Care-Why-Has-It-Been-So-Difficult>; *AMA Policy on End-of-Life Care*, AM. MED. ASS'N, <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/about-ethics-group/ethics-resource-center/end-of-life-care/ama-policy-end-of-life-care.shtml> (last visited Oct. 31, 2010).

choices.<sup>10</sup> This duplicitous process is not only burdensome to the family and patient, it also creates countless opportunities for inconsistencies and ambiguities regarding end-of-life wishes, thus creating unpredictability about the success of end-of-life choices. To add to the efforts of doctors, lawyers, and hospitals, patients' rights groups, religious organizations, and other advocacy organizations provide alternate forms designed to elicit and document patients' desires.<sup>11</sup> Although well-intentioned, these alternate forms may not be authorized by state law, approved by hospital administrators, or accepted by attending physicians.<sup>12</sup>

Ultimately, it is time to acknowledge the limitations of advance directives and focus end-of-life care efforts on conversation, dialogue, and preference selection to help guide the patient's agent when making binding health care choices on behalf of his or her principal.

Part II of this Article will review the hallmark cases on end-of-life care. Part III will consider medical literature and studies regarding the use of advance directives in a hospital setting. Part IV will highlight cases holding doctors liable for failure to comply with advance directives or, alternatively, complying with advance directives. Part V will consider independent initiatives by medical, legal, legislative, and ethics boards to address gaps in statutory options, specifically the evolution of the POST movement in America. Part VI will look at challenges one state recently encountered when it made changes to its advance directive laws. Part VII will discuss alternate forms for designating end-of-life decisions promoted by advocacy groups. Part VIII will offer recommendations to help ensure effective end-of-life decision making by surrogate decision-makers.

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10. Ray J. Koenig, III & MacKenzie Hyde, *Be Careful What You Wish for: Analyzing the "Five Wishes" Advance Directive*, 97 ILL. B.J. 242, 243 (2009).

11. Henry S. Perkins, *Controlling Death: The False Promise of Advance Directives*, 147 ANNALS INTERNAL MED. 51, 53-54 (2007); see *About Us*, AGING WITH DIGNITY, <http://www.agingwithdignity.org/about.php> (last visited Oct. 31, 2010); *Advance Medical Directive*, EWTN GLOBAL CATHOLIC NETWORK, <http://ewtn.com/expert/answers/Directive.pdf> (last visited Oct. 31, 2010).

12. See Koenig & Hyde, *supra* note 10, at 243 (stating that alternative forms are not authorized by eight states).

## II. The Legacy of Karen Ann Quinlan and Nancy Cruzan

Despite a long held belief that decisions about death and dying are within the purview of personal decision making, judicial acknowledgement of an individual's right to make end-of-life care decisions was not made until 1976 in the notable case of Karen Ann Quinlan.<sup>13</sup> At the age of twenty-one, "for reasons still unclear," Karen Ann Quinlan quit breathing and suffered subsequent severe brain damage.<sup>14</sup> Karen's life was maintained by a respirator, artificial food, and artificial hydration. When doctors treating Karen determined that she was in a persistent vegetative state, her father, Joseph T. Quinlan, petitioned to have Karen removed from the respirator.<sup>15</sup> In *In re Quinlan*, a court articulated, for the first time, a basis within the "unwritten constitutional right of privacy . . . a patient's decision to decline medical treatment."<sup>16</sup> This right was upheld despite the state's interest in the sanctity and preservation of human life. In balancing the state's long-standing interest in the preservation of human life against an individual's right to make end-of-life decisions, the court held that "the State's interest . . . weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims."<sup>17</sup> Having held that Karen, if competent, would have the right to avoid imposition of extraordinary medical care, the court next had to find that this right could be exercised on her behalf by a guardian. Answering this issue in the affirmative, the court ruled that Karen's father, as her court appointed guardian, had the right to exercise Karen's right to withdraw extraordinary medical care on her behalf.

Following the *Quinlan* decision, courts and legislatures began defining the scope of "death and dying jurisprudence," both in terms of the types of care that might be withheld or administered, as well as the evidentiary standard that would be required to determine an incompetent patient's desires regarding end-of-life care.<sup>18</sup> The right to

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13. See *In re Quinlan*, 355 A.2d 647, 647 (N.J. 1976).

14. *Id.* at 653-54. But see Norman L. Cantor, *Twenty-Five Years After Quinlan: A Review of the Jurisprudence of Death and Dying*, 29 J. L. MED. & ETHICS 182, 183 (2001) (citing a mix of alcohol and drugs as the reason for Karen's subsequent failure to breathe).

15. *Quinlan*, 355 A.2d at 653-57.

16. *Id.* at 663 (citing *Griswold v. Conn.*, 381 U.S. 479, 484 (1965)).

17. *Id.* at 664.

18. Cantor, *supra* note 14, at 182.

determine medical intervention would encompass the withdrawal of respirators, dialysis, food, and hydration, even though such acts result in certain and, possibly, a hastened death.<sup>19</sup> The right to determine medical care at end of life would not, however, be extended to physician-assisted suicide.<sup>20</sup> The right to determine medical intervention would encompass decisions by the competent patient and would also be extended to decisions by an incompetent patient's surrogate.<sup>21</sup> Decisions by a patient's surrogate, however, would be subject to a standard of review along a spectrum that includes an onerous "clear and convincing evidence" standard, "substituted judgment" standard, "best interests of the patient" standard, and "constructive preference" standard.<sup>22</sup> To satisfy the clear and convincing evidence standard, the surrogate must produce evidence that the patient would have wanted a particular course of action under the circumstances before the surrogate may opt to remove the patient from life prolonging treatments. Absent such clear and convincing evidence of the patient's desires, the surrogate may not make a decision to remove the patient from life support, regardless of how much the patient may be suffering.<sup>23</sup> Some courts however, have embraced a substitute judgment standard for surrogates desiring to remove incompetent patients from life support.<sup>24</sup>

The decision-making standard under the substituted judgment standard requires the surrogate to make the decisions his patient/principal would make were the principal competent to do so and aware of all relevant facts.<sup>25</sup> Written evidence by the principal, if available, would govern the surrogate's decision, but in the absence of such written evidence, the surrogate's decision could rely on the surrogate's knowledge of the patient's previous values.<sup>26</sup> In the absence of any reliable evidence of the patient's preferences, the jurisdiction

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19. *Id.*

20. *Id.* (with the exception of Oregon's authorization of physician-assisted suicide).

21. *Id.* at 190 (except for a small number of states that only allow surrogates to end life-prolonging measures if the patient has left "clear and convincing" evidence that he or she would have wanted the cessation of such treatment).

22. *Id.* at 190-92.

23. *Id.* at 190.

24. *Id.* at 191.

25. *Id.*

26. *Id.*



may require the surrogate to employ the best interests standard for surrogate decision making.<sup>27</sup>

The first United States Supreme Court case to tackle the issue of end-of-life care was *Cruzan v. Director, Missouri Department of Health*.<sup>28</sup> Nancy Cruzan suffered severe injuries in an automobile accident on the night of January 10, 1983.<sup>29</sup> In August, 1986, Joseph Cruzan, Nancy's father and appointed guardian, executed documents requesting that no cardiopulmonary resuscitation be administered to Nancy, as well as no "antibiotics, medications or medical treatments that might serve to prolong Nancy's life."<sup>30</sup> Joseph Cruzan wrote soon thereafter, "When medical technology has done all they can do and still leave no quality of life for a person, I believe it is absurd that society does not afford them a death with dignity without having to be involved in a lengthy court battle . . . ." <sup>31</sup>

In 1987, Joseph Cruzan presented a written request to the medical director at the Missouri Rehabilitation Center to remove his daughter from artificial food and hydration "aware that the consequence of this action will be her death."<sup>32</sup> Refusing to act without an order from the Missouri court, a petition was filed to remove Nancy from artificial food and hydration in late October, 1987.<sup>33</sup>

In July 1988,<sup>34</sup> the trial court rendered its decision in the matter which provided, in part:

There is a fundamental right expressed in our Constitution as the right to liberty which permits an individual to refuse or direct the withholding or withdrawal of artificial death prolonging procedures when the person has no more cognitive brain function

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27. *Id.*

28. *See Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261 (1990).

29. WILLIAM H. COLBY, LONG GOODBYE: THE DEATHS OF NANCY CRUZAN 7 (2002).

30. *Id.* at 42.

31. *Id.* at 43.

32. *Id.* at 47.

33. *See id.* at 89. Even before the petition was filed, the General Counsel for the Missouri Department of Health articulated that "[w]ithdrawing of death-prolonging procedures is designed to allow a natural death. Dehydration and starvation are not termed as natural death and it will, in my opinion, take a very, very strong argument to persuade a Missouri court to go this far." *Id.* at 50. The Missouri living will statute was narrower than the uniform law drafted by the National Conference of Commissioners on Uniform State Laws, primarily as a result of aggressive lobbying by the Missouri Catholic Conference. *Id.* at 91.

34. *See id.* at 231.

... The Respondents ... are directed to cause the request ... to withdraw nutrition or hydration to be carried out.<sup>35</sup>

The Missouri Supreme Court reversed by a divided vote.<sup>36</sup> In coming to its decision, the court considered the common law doctrine of informed consent and, alternatively, the right to refuse medical treatment.<sup>37</sup> They judicially recognized the right to privacy and the state's interests identified as "preservation of life, prevention of homicide and suicide, the protection of interests of innocent third parties and the maintenance of the ethical integrity of the medical profession."<sup>38</sup> Balancing these competing factors, the court held that since "Nancy is alive and that the burdens of her treatment are not excessive for her, we do not believe her right to refuse treatment ... outweighs the immense, clear fact of life in which the state maintains a vital interest."<sup>39</sup>

The United States Supreme Court granted certiorari to determine "whether Cruzan has a right under the United States Constitution which would require the hospital to withdraw life-sustaining treatment from her under these circumstances."<sup>40</sup> The decision to grant certiorari was not unanimous but received the four votes needed to accept the case for hearing.<sup>41</sup> Initially, the Solicitor General's ("SG") office, under the leadership of newly appointed Solicitor General Kenneth Starr, was expected to enter the case on behalf of the Cruzan family; however, the SG's office weighed in on behalf of the state of Missouri.<sup>42</sup> In a five-to-four decision, the Supreme Court ruled in favor of the state of Missouri by finding that Missouri's clear and convincing evidence standard of an incompetent's wishes as to the withdrawal of life-sustaining treatment was not in violation of the patient's due process right to refuse unwanted medical treatment and furthermore, that the state of Missouri was not required to accept the

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35. *Id.* at 232.

36. *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 268 (1990).

37. *Id.* at 268 (citing *Cruzan v. Harmon*, 760 S.W.2d 408, 416-17 (Mo. 1988)).

38. *Harmon*, 760 S.W.2d at 419.

39. *Id.* at 424.

40. *Cruzan*, 497 U.S. at 269.

41. COLBY, *supra* note 29, at 276 (citing released personal papers of Justice Thurgood Marshall: petition for certiorari denied by Rehnquist, Brennan, White, Marshall, O'Connor; petition for certiorari was granted by Blackmun, Stevens, Scalia and Kennedy).

42. *Id.* at 289.

substitute judgment of a family member in the absence of proof that their judgment reflects that of the patient.<sup>43</sup>

Thus, while the courts began to define the scope of a due process right to refuse treatment at end of life, proof of the patient's desires was critical in enforcing this right when the patient's condition prevented communication between the patient and doctor. The Supreme Court decision in *Cruzan* was devastating to the family of Nancy Cruzan, who had been unable to find evidence of Nancy's preferences for the withholding of treatment under the circumstances presented.<sup>44</sup> Before alternative legal attacks could be initiated, a local probate judge determined that there was evidence of Nancy's wishes for the discontinuance of life-sustaining treatment and ordered the feeding tubes removed.<sup>45</sup> On the backdrop of these seminal cases, patients' rights advocates sought to find effective ways for patients to articulate their preferences for end-of-life care.

### III. Efficacy of Advance Directives on End-of-Life Decision Making

The impact of advance directives on decisions regarding life-sustaining treatment is only as successful as (1) their rate of use by the public, (2) the physician's knowledge that advance directive documents have been executed, (3) the physician's willingness to comply with the patient's wishes as set forth in the advance directive documents, and (4) the physician's knowledge and understanding of the legalities of such documents. If obtaining appropriate end-of-life care and treatment is based primarily on these four elements, however, patients and their families are likely to be sorely disappointed by their end-of-life experience.

Statistically, researchers have placed the percentage of Americans whom have executed advance directive documents at a mere four to twenty-five percent.<sup>46</sup> Furthermore, even among those patients that have executed advance planning documents, many have failed to communicate the existence of these documents with their

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43. *Cruzan*, 497 U.S. at 263.

44. COLBY, *supra* note 29, at 322.

45. *Id.* at 361.

46. Perkins, *supra* note 11, at 52.

physicians.<sup>47</sup> Of those patients whom have communicated their desires to their physicians, there is still significant incidence of physician non-adherence.<sup>48</sup> Non-adherence may occur for several reasons: 1) questions arise regarding the patient's competence at the time of execution; 2) questions arise as to whether the circumstances invoking the advance directive exist; 3) physicians disregard advance directives that conflict with hospital policy, family preference, or practice standards; or 4) there is a misunderstanding by the physician about the patient's desires.<sup>49</sup> Finally, there is a belief among physicians that an advance directive needs to be translated into a doctor's order to be implemented.<sup>50</sup>

#### A. The Arkansas Study

In an early study (1987-1988) on physician attitudes toward the use of advance directives, investigators found that 79.2% of respondents had a positive general attitude toward advance directives while only 1.5% expressed a negative attitude.<sup>51</sup> Of particular interest was that 73.4% of responding physicians agreed with the statement: "I would worry less about legal consequences of limiting treatment if I were following an advance directive."<sup>52</sup> Likewise, seventy-nine per-

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47. Melinda Lee et al., *Physician Orders for Life-Sustaining Treatment (POLST): Outcomes in a PACE Program*, 48 J. AM. GERIATRICS SOC'Y 1219, 1224 (2000).

48. *Id.* at 1219. See also Marion Danis et al., *A Prospective Study of Advance Directives for Life-Sustaining Care*, 324 NEW ENG. J. MED. 882, 882-88 (1991); Sylvia McSkimming et al., *The Experience of Life-Threatening Illness: Patients' and Their Loved Ones' Perspectives*, 2 J. PALLIATIVE MED. 173, 180-82 (1999); Lawrence J. Schneiderman et al., *Relationship of General Advance Directive Instructions to Specific Life-Sustaining Treatment Preferences in Patients with Serious Illness*, 152 ARCHIVES INTERNAL MED. 2114, 2114-22 (1992).

49. Perkins, *supra* note 11, at 53.

50. Lee et al., *supra* note 47, at 1219.

51. Kent W. Davidson et al., *Physicians' Attitudes on Advance Directives*, 262 J. AM. MED. ASS'N 2415, 2418 (1989). Scientists at the University of Arkansas for Medical Sciences compiled survey results from 790 physicians in Arkansas (from an initial survey pool of 1293 physicians) engaged in general practice, internal medicine, or family medicine. *Id.* at 2417. The survey identified the most common arguments in existing literature in support of and in opposition to the use of advance directives, and physicians were asked to respond (on a five-point scale from strongly agree to strongly disagree) to fourteen statements based on these arguments for and against the use of advance directives. *Id.* The response rate was 65.2% among Arkansas physicians with a significantly higher response rate among physicians practicing internal medicine as opposed to those in general or family practice. *Id.*

52. *Id.* at 2416 tbl.3.

cent of respondents disagreed or strongly disagreed with the statement: "Advance directives represent unwarranted extension of the law into the practice of medicine."<sup>53</sup>

There were two statements with which physicians agreed or strongly agreed, both of which, if true, have implications for the appropriate use and drafting of advance directives. First, sixty-one percent of respondents agreed or strongly agreed with the statement: "Widespread acceptance of advance directives will lead to less aggressive treatment even of patients who do not have an advance directive."<sup>54</sup> While this may be a common perception among opponents of advance directives, the fact that sixty-one percent of physicians hold this belief is troubling. The researchers suggest that while this result may simply reflect physician attitudes that less aggressive treatment is generally a good consequence, it may also point to a more disturbing professional trend: that the more frequently care is appropriately withheld pursuant to an advance directive, the more easily care may be withheld from patients without advance directives.<sup>55</sup> While the presence of an advance directive seeks to prevent the presumption of imposition of unwanted medical care at the end of life, the absence of an advance directive should not allow for the presumption of the withdrawal of medical care at the end of life. To the extent that sixty-one percent of physicians believed less aggressive treatment to be a possible consequence of advance directives, additional safeguards and education are required.

Additionally, 32.4% of physicians agreed or strongly agreed with the statement: "The training and experience of physicians gives them greater authority than patients in decisions about withholding 'heroic' treatment."<sup>56</sup> Researchers observe that, superficially, this finding may "reflect a paternalistic position at odds with the respect for patient autonomy."<sup>57</sup> Researchers have found that one variable, physician's experience and use of such forms in critical situations, had a consistent and significant impact on a positive attitude toward the use of advance directives.<sup>58</sup> Additionally, physicians that employed advance

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53. *Id.*

54. *Id.*

55. *Id.* at 2419.

56. *See id.* at 2416 tbl.3.

57. *Id.* at 2419.

58. *Id.*

directives more frequently were more likely to have positive feelings toward their use.<sup>59</sup>

### B. The Pennsylvania Study

In addition to the question about physician attitudes towards the use of advance directives, the query must be made about the consistency between physician attitudes and physician actions in end-of-life decision making. In a 1990 study, researchers studied the actions of physicians practicing in the area of adult intensive care regarding the imposition or withdrawal of life-sustaining treatment and the impact, if any, of patient or surrogate wishes on end-of-life decision making.<sup>60</sup> Of particular inquiry in this study was the withholding or imposition of life-sustaining treatment in circumstances where the treatment is deemed to be medically futile. Medical futility may be defined as treatment that “preserves permanent unconsciousness or that fails to end total dependence on intensive medical care.”<sup>61</sup>

Ninety-six percent of survey respondents reported having withdrawn at least one type of life-sustaining treatment.<sup>62</sup> Thus, the experience of the survey pool in addressing the issues of withdrawal of life-sustaining treatments was quite high, and given the results of the Arkansas study, that experience should lead to a favorable use of and reliance on advance directives. Despite the large percentage of physicians who had withheld life-sustaining treatment, thirty-four percent of responding physicians also reported “that they had declined to

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59. *Id.*

60. David A. Asch et al., *Decisions to Limit or Continue Life-Sustaining Treatment by Critical Care Physicians in the United States: Conflicts Between Physicians' Practices and Patients' Wishes*, 151 AM. J. RESPIRATORY & CRITICAL CARE MED. 288, 288-92 (1995). Researchers compiled results from 879 physicians nationwide (from an initial survey pool of 1970 physicians) practicing in the area of adult intensive care. *Id.* This study was in response to the growing practice of foregoing life-sustaining treatment and the ongoing conversation among physicians and legal ethicists regarding whether physicians must always comply with patient requests to continue or limit life-sustaining treatment, even when physicians disagree with the requests. *Id.*

61. Lawrence J. Schneiderman et al., *Medical Futility: Its Meaning and Ethical Implications*, 112 ANNALS INTERNAL MED. 949, 952 (1990).

62. See Asch et al., *supra* note 60, at 290 tbl.3. Life-sustaining treatments were identified as mechanical ventilation, intravenous vasopressors, renal dialysis, blood or blood products, and artificial nutrition or hydration. *Id.*

withdraw mechanical ventilation at least once in the preceding year despite having been asked to do so by a patient or the surrogate.”<sup>63</sup>

Researchers found many physicians reported having withheld life-sustaining treatment without securing the consent of the patient or the patient’s family.<sup>64</sup> Moreover, some physicians reported having done so despite the lack of knowledge by the patient or the patient’s family members, with some having done so even over the objection of the patient or family member.<sup>65</sup> Whether a physician’s decision to withhold or withdraw treatment in circumstances of medical futility, without the knowledge or consent of the patient or surrogate, is based on a disagreement between the intended goals of treatment or the likely success of those goals was left unresolved by this study.<sup>66</sup> The authors observed that the practice of unilateral withdrawal or withholding of life-sustaining treatment, despite its statistical infrequency, may be a result of physician paternalism or the unwillingness or inability to have explicit conversations with patients about end-of-life care issues.<sup>67</sup> Regardless, either explanation is disturbing.

### C. The Teno Study

While physicians generally view the use of advance directives positively, their professional actions indicate some reluctance to fully respect the decisions of patients regarding their end-of-life care decision making. Frequently patients’ or surrogates’ wishes are merely one factor considered by physicians in making treatment decisions at the end of life. In a multi-center clinical trial conducted between 1992

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63. *Id.* at 240 (reporting the top five reasons given for having refused to withhold ventilation, in order of frequency: 1) physician believed the patient still had a reasonable chance to recover (seventy-seven percent), 2) physician believed the family might not be acting in the best interest of a patient who lacked decision making capacity (thirty-nine percent), 3) physician concerned about malpractice litigation (nineteen percent), 4) physician believed that the withdrawal of mechanical ventilation was or could be illegal in the state (fourteen percent), and 5) family opposed to the withdrawal or mechanical ventilation even though it was requested by a patient capable of making decisions (eleven percent)).

64. *Id.* at 291 tbl.5 (reporting that twenty-five percent of physicians had withheld life-sustaining treatment without the written or oral consent of the patient or family, fourteen percent had withheld life-sustaining treatment without the knowledge of the patient or family, and three percent had withheld life-sustaining treatment despite the objections of the patient or family).

65. *Id.*

66. *Id.*

67. *Id.* at 291 (citing assessments of prognosis and perceptions of other ethical, legal, and policy guidelines as additional factors for consideration).

and 1994, researchers examined the role of advance directives in the decision-making process, focusing their inquiry on the experience of patients and surrogates.<sup>68</sup> The study reports that advance directives played an important role in decision making in five of the fourteen cases.<sup>69</sup> In another five cases, the advance directives failed to play an important role in decision making, in part because of the failure to discuss the advance directive or clarify the patient's preferences in execution of the advance directive.<sup>70</sup> In four of the fourteen cases, the advance directive was limited or did not exist.<sup>71</sup> The qualitative data narratives identified three major themes that explained the limited role of advance directives.

[P]atients were not seen as "absolutely, hopelessly ill," and thus, it was never considered the time to invoke the [advance directive]; the contents of [advance directives] were vague and difficult to apply to current clinical situations; and family members or the surrogate designated in a [durable power of attorney] were not available, were ineffectual, or were overwhelmed with the their own concerns and did not effectively advocate for the patient.<sup>72</sup>

The investigators did not find "evidence in any of the cases that a physician unilaterally decided to ignore or disregard an [advance directive]."<sup>73</sup> Furthermore, the study found that even with the guidance of an advance directive, decisions to withhold or withdraw life-

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68. Joan M. Teno et al., *Role of Written Advance Directives in Decision-Making: Insights from Qualitative and Quantitative Data*, 13 J. GEN. INTERNAL MED. 439, 439-46 (1998). The unique aspect of this particular study was the use of quantitative data derived from existing patient records and interviews with the patient, surrogate, and responsible physician, as well as qualitative data consisting of narratives by specially trained nurses employed to facilitate the decision-making process. *Id.* For purposes of the qualitative data, interviews were conducted with the patients in the first and second weeks of hospitalization and, if still alive, two and six months after hospitalization. *Id.* The patients were questioned on whether they had talked to their physician about prognosis, resuscitation, preferred care, quality of life, and ability to function. *Id.* Likewise, the responsible physician was interviewed in the first and second weeks of the patient's hospitalization to determine the presence of an advance directive and whether the advance directive helped or hindered decision making. *Id.* The physicians were also asked to describe their perception of the patient's preferences for resuscitation, approach to care, and quality of life, as well as whether they discussed the patient's prognosis and desires with the patient or surrogate, if applicable. *Id.* The qualitative data consisted of narratives written by an intervention nurse shortly after the patient's death or discharge from the hospital. *Id.*

69. *Id.* at 441.

70. *Id.*

71. *Id.*

72. *Id.*

73. *Id.*



sustaining treatment were not finalized until the physician discussed the matter with the surrogate decision-maker.<sup>74</sup> In the presence of a duly executed advance directive for medical care and the circumstances giving rise to its applicability, no additional input from other decision-makers should be required before following the desires expressed in the advance directive. The practice of engaging in a collaborative decision-making process despite the presence of an advance directive evidences the inadequacy of the advance directive alone to effectuate patient desires. In fact, the study found that successfully implementing a patient's desires expressed in an advance directive required the opportunity to reconsider the patient's prognosis and the patient's advance directive with the surrogate decision-maker.<sup>75</sup> The researchers concluded that successful patient self-determination required that the process of executing advance directives move from a "formal, legal process . . . to . . . a process of communication and negotiation about the goals of care . . . called 'advance care planning.'"<sup>76</sup>

#### D. The UCLA Study

In addition to determining the medical profession's general attitudes toward advance directives and their practice in following end-of-life decisions made by patients or their surrogates, studies have identified the types of advance directives that are most successful in leading to medical decisions that conform to patient wishes. Since their inception, there have been three generations of advance directives. Initially, living wills stated "general desires in . . . general terms" that left tremendous discretion for physicians and surrogate decision-makers to determine the patient's intent and desires in very specific circumstances.<sup>77</sup> In response to criticism that general terms in advance directives left too much discretion in the surrogate decision-maker, second generation living will forms asked specific questions about the types of treatments and interventions desired in certain circumstances.<sup>78</sup> Such forms necessarily required discussions between doctors and patients in order to knowledgably select treatment op-

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74. *Id.*

75. *Id.*

76. *Id.* at 445 (footnote omitted).

77. Angela Fagerlin & Carl E. Schneider, *Enough: The Failure of the Living Will*, 34 HASTINGS CENTER REP. 30, 35 (2004).

78. *Id.*

tions.<sup>79</sup> These “questionnaire” type advance directives were overwhelming for patients to comprehend and a barrier to execution.<sup>80</sup> The third alternative approach was the “values history” assessment, which allowed patients to articulate “overarching beliefs” from which surrogates and physicians could deduce the patient’s likely response to specific treatment options.<sup>81</sup>

Concerned about the efficacy of advance directives and the degree to which physicians uniformly interpret their meaning, researchers at UCLA asked physicians about their willingness to withhold treatment based on their interpretation of three different advance directives: 1) a general statement advance directive modeled after the then-existing California Medical Association’s Durable Power of Attorney for Health Care Form Instructions and Checklist; 2) a therapy-specific advance directive delineating twelve specific therapies and four situations wherein an individual could elect which therapies she would “want,” “want tried,” “was undecided,” or “did not want”; and 3) the same therapy-specific advance directive described in the second above option combined with a patient narrative reporting previous discussions between the patient and physician about his advance directive and the appointment of a surrogate.<sup>82</sup>

Based on the results of the survey, the researchers concluded that physicians were “significantly more likely to withhold” treatment when presented with the therapy-specific advance directive as opposed to the general statement advance directive.<sup>83</sup> When the therapy-specific advance directive was combined with the patient narrative appointing an agent and discussing care options, the physician was most likely to withhold all treatment (except pain medication) that was consistent with the advance directive.<sup>84</sup>

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79. *Id.*

80. *Id.*

81. *Id.* (footnote omitted).

82. William R. Mower & Larry J. Baraff, *Advance Directives: Effect of Type of Directive on Physicians’ Therapeutic Decisions*, 153 ARCHIVES INTERNAL MED. 375, 376-77 (1993). Researchers surveyed 444 full-time faculty members of the Department of Medicine at a university medical center. *Id.* The survey confronted respondents with two different patient scenarios and twelve different therapies that could potentially be withheld. *Id.* Patient scenarios included a young adult in a coma from an accidental drowning and an older adult cancer patient. Respondents were asked which therapies they would withhold based on their interpretation of three different advance directives. *Id.*

83. *Id.* at 378.

84. *Id.* at 379.

The researchers further concluded that therapy-specific advance directives produced more uniform interpretation and application than the general statement advance directive and that neither advance directive could substitute for direct communication between physician and patient regarding care preferences.<sup>85</sup> On the issue of whether physicians are likely to ignore patient desires articulated in an advance directive, the study found that physicians were more likely to withhold life-sustaining therapies than non-life-saving treatments consistent with the provisions of an advance directive.<sup>86</sup> Furthermore, physicians were less likely to withhold less aggressive therapies and often initiated such treatments even in circumstances where the advance directive explicitly prohibited their use.<sup>87</sup>

Literature in the medical field confirms that while physicians are generally supportive of patient autonomy and self-determination at the time of end-of-life decision making, there is a gap between the theoretical support of such patient rights and actually effectuating such decisions in a clinical setting. This gap is due, in part, to the language of advance directives and the determination of when a patient has achieved the condition necessary to trigger application of an advance directive. Even when there is consensus among physician, patient, and surrogate that the patient's condition warrants application of their advance directive, the particular form of the advance directive also has an impact on the likelihood that the advance directive will be determinative of the care provided. Finally, the studies confirm that while the advance directive impacts the physician's treatment decisions, it is ultimately only one factor considered. It is imperative that studies arising out of the medical field inform the work of legislatures and drafting committees when drafting new advance directive laws.

#### IV. Enforcing Advance Directives

The effectiveness of advance directives is only as great as the court's willingness to enforce them over the objections of attending physicians, health care agents, or family members. Physicians cite fear of malpractice actions as the basis for refusing to comply with an advance directive despite specific language to the contrary in most

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85. *Id.*

86. *Id.* at 380.

87. *Id.*

statutes.<sup>88</sup> This concern is in stark contrast to the lack of concern expressed among physicians about being sued for *failure* to comply with an advance directive that results in continued life. This is in large part because courts have traditionally been unwilling to substitute its judgment for that of a physician when it comes to end-of-life care issues.<sup>89</sup>

When physicians refuse to comply with a patient's wishes, their refusal is based on one or more of the following objections: 1) the removal of life-sustaining treatment violates a physician's understanding of the Hippocratic Oath; 2) the removal of life-sustaining treatment violates a physician's or institution's moral objection to removal of life support; 3) the removal of life support exposes the physician to liability for medical malpractice; 4) the removal of life support is not, in the opinion of the physician, medically indicated; and 5) the removal of life support, while consistent with the patient's articulated desires, is not supported by attending family members.<sup>90</sup>

An early case, *Bartling v. Superior Court*, tested a patient's ability to enforce his living will over the objection of the physician and hospital when a patient executed a living will requesting that he be removed from a ventilator.<sup>91</sup> The patient was competent at the time of executing his living will and was competent at the time the request to remove the ventilator was made.<sup>92</sup> The hospital, a faith-based institution "devoted to the preservation of life," refused to comply with the request to remove the patient from the ventilator.<sup>93</sup> The trial court, relying heavily on *Quinlan*, acknowledged that life support could be removed from a patient in a comatose, vegetative state if the attending physician concluded that there was no reasonable possibility of recovery.<sup>94</sup> Because the patient, according to treating physicians, had a reasonable possibility of recovery if he could be successfully weaned from the ventilator, the trial court refused to grant the patient's re-

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88. Robert L. Fine & Thomas W. Mayo, *Resolution of Futility by Due Process: Early Experience with the Texas Advance Directives Act*, 138 ANNALS INTERNAL MED. 743, 744 (2003).

89. Renee H. Martin, *Liability for Failing to Follow Advance Directives*, PHYSICIAN'S NEWS DIG., Sept. 14, 1999, available at <http://www.physiciansnews.com/1999/09/14/liability-for-failing-to-follow-advance-directives/>.

90. See Asch et al., *supra* note 60, at 290; Perkins, *supra* note 11, at 53.

91. *Bartling v. Superior Court*, 163 Cal. App. 3d 186, 192 (Cal. Ct. App. 1984).

92. *Id.*

93. *Id.*

94. *Id.* (citing *In re Quinlan*, 355 A.2d 647, 656 (N.J. 1976)).

quest for injunctive relief.<sup>95</sup> The Court of Appeals reversed, holding that when a patient's condition is likely incurable though not terminal, the patient's right to refuse unwanted medical treatment is superior to competing interests by the state and institution;<sup>96</sup> thus, the patient could exercise that right over the objection of the physicians and the hospital.<sup>97</sup>

In *Scheible v. Joseph L. Morse Geriatric Center*, an elderly nursing home resident executed a living will requesting that no life-prolonging or resuscitative measures be employed if she was in the process of dying.<sup>98</sup> The living will was presented to the nursing home. Thereafter, the patient was found unresponsive and emergency personnel intubated her despite contrary language in her living will. The patient tried to remove the tubes and as a result her hands were placed in restraints. At the hospital and at the request of patient's granddaughter and health care agent, the patient was extubated and died four days later.<sup>99</sup> A complaint was filed against the nursing home by the personal representative of the patient's estate alleging willful disregard of an advance health care directive, willful disregard of the Federal Patient Self-Determination Act, common law intentional battery, violation of the Nursing Home Resident's Rights Act, and breach of contract.<sup>100</sup> The trial court awarded the estate monetary damages on the breach of contract claim based on the theory that the living will was incorporated into the contract between the patient and the nursing home.<sup>101</sup>

In *Cardoza v. USC University Hospital*, a daughter brought an action against her mother's treating physicians for harm arising out of her mother's death.<sup>102</sup> Plaintiff alleged that her mother's physicians, with the consent of her brother and health care agent, continued in a course of rehabilitation inconsistent with her mother's advance health

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95. *Id.*

96. *Id.* at 193 (noting that competing interests include "the preservation of life, the need to protect innocent third parties, the prevention of suicide, and maintaining of the ethics of the medical profession").

97. *Id.* at 194 (citing *Cobbs v. Grant*, 502 P.2d 1, 9-10 (Cal. 1972)).

98. *Scheible v. Joseph L. Morse Geriatric Ctr., Inc.*, 988 So. 2d 1130, 1131 (Fla. Dist. Ct. App. 2008).

99. *Id.* at 1131-32.

100. *Id.* at 1132.

101. *Id.*

102. *Cardoza v. USC Univ. Hosp.*, No. B195092, 2008 WL 3413312, at \*1 (Cal. Ct. App. Aug. 13, 2008).

care directive.<sup>103</sup> Plaintiff alleged in her complaint that her mother “suffered greatly, and lost her right to die with dignity.”<sup>104</sup> Plaintiff’s complaint raised the claims of wrongful death, professional negligence, elder abuse, and fraud.<sup>105</sup> Plaintiff’s mother had executed a health care power of attorney the day preceding her initial surgery, which provided that her son would serve as her agent for health care decisions and, in his absence, Plaintiff would serve. The health care power of attorney provided further that the agent would act in accordance with the wishes of the principal.<sup>106</sup> The instructions in the advanced health care directive provided that “she did not want life prolonged should she have an incurable condition . . . she was not expected to regain consciousness, or if the burdens of treatment would outweigh expected benefits.”<sup>107</sup> Plaintiff alleged that the defendants were reluctant in “letting [her] mother go” because her mother could be cured.<sup>108</sup> Subsequently, the defendants demurred, arguing statute of limitations and statutory immunization from liability for health care providers “who in good faith comply with a health care decision made by one whom they believe authorized to make it for the patient.”<sup>109</sup>

The court held that an intentional failure to comply with a patient’s health care instructions was a violation of a California Probate Code provision that provided for specific damages.<sup>110</sup> Particularly noteworthy is the court’s holding that the immunity granted to physicians for complying with the health care decisions of an appointed agent would not necessarily protect a physician who followed the health care decisions of an agent that were contrary to the patient’s

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103. *Id.* at \*3.

104. *Id.* at \*2.

105. *Id.* at \*1.

106. *Id.*

107. *Id.*

108. *Id.* at \*3.

109. *Id.*

110. *Id.* at \*5 (referencing CAL. PROB. CODE § 4623 (West 2000)). Plaintiff’s claims for wrongful death, professional negligence, and elder abuse were all dismissed for statute of limitations reasons; the fraud claim was likewise dismissed for causation and damages issues. *Id.* at \*4. Plaintiff was given leave to amend her complaint for violation of the California Probate Code, which was raised insufficiently in Plaintiff’s earlier complaints. *Id.* at \*5.

own specified directives.<sup>111</sup> This language provides compelling incentive for physicians who receive instructions from a patient's health care agent (or, to a lesser extent, a family member) that are contrary to the end-of-life decisions of the patient to follow the wishes of the patient or face potential liability. In addition to attacks by the patient's health care providers, a patient's living will may also be jeopardized by opposition of the health care agent or other family members.

In another case, the patient had a living will directing that life-prolonging measures should be withheld in the event he suffered a terminal condition with no chance of recovery.<sup>112</sup> The patient named his wife as his health care surrogate decision-maker. The patient was hospitalized for over eight months with complications resulting from congestive heart failure including failures of his renal, respiratory, and cardiovascular systems, all of which were maintained by artificial means.<sup>113</sup> The hospital petitioned the court to enforce his living will over the objections of his health care agent—his wife—who asserted that her husband was not terminally ill; therefore, the provisions mandating removal of life support were not triggered.<sup>114</sup> The circuit court ruled that the patient expressed his desires regarding his end-of-life care by the execution of a valid living will; additionally, the health care surrogate decision-maker cannot overrule the decision of the patient, regardless of the surrogate's personal feelings.<sup>115</sup> Having found by clear and convincing evidence that the patient would have confirmed the desires outlined in his living will, the court ordered the health care facility to remove him from life prolonging measures without recourse from the surrogate or any other interested parties.<sup>116</sup>

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111. *Id.* (holding that care provided at the request of a health care agent in opposition to the patient's living will would not be in "good faith" as required by the immunity statute).

112. 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*, ORLANDO SENTINEL, Nov. 18, 2004, at A1, available at 2004 WLNR 20130390.

113. *Id.*

114. *Id.*

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

116. *Id.*

In a recent New York case, *In re Livadas*,<sup>117</sup> the court again supported a health care facility's request to terminate care in accordance with a living will over the objection of the surrogate decision-maker.<sup>118</sup> The patient had a valid living will directing life-prolonging procedures to be withheld or withdrawn if the only purpose would be to prolong the dying process. The patient named her daughter as her surrogate decision-maker. Five months after admission to the hospital, the health care facility petitioned the court for the appointment of a guardian for the ninety-seven-year-old patient, alleging, in part, that the surrogate decision-maker was unwilling, or unable, to appreciate her mother's true condition and was not following the patient's expressed wishes and directives with respect to end-of-life care.<sup>119</sup> The court granted the hospital's relief, voided the patient's health care power of attorney that appointed her daughter, and appointed a guardian to act on behalf of the patient for purposes of removing the patient from acute care to custodial care and ultimately enforcing the terms of the patient's living will if appropriate.<sup>120</sup>

These cases show a trend towards enforcing a patient's living will over the objections of the health care provider, the surrogate decision-maker, or even family members. Such litigation, however, comes at an extreme expense to health care providers and families alike.

## V. Same Goal—Different Forms

### A. The MOST Movement.

In 1991, Oregon ethics committees voiced concern at a statewide meeting over the problems that arise when patients with do-not-resuscitate (DNR) orders are transferred from nursing homes to hospitals.<sup>121</sup> In response to this concern, a multidisciplinary task force was created to address the problem of unwanted transfers and medical interventions to those patients who did not want such interven-

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117. See *In re Livadas*, No. 08/03730 16-17 (N.Y. Sup. Ct. Apr. 28, 2008), available at <http://www.democratandchronicle.com/assets/pdf/A2115307811.pdf>.

118. *Id.* at 17.

119. *Id.* at 5.

120. *Id.* at 15.

121. *History of the POLST Paradigm Initiative*, OREGON HEALTH & SCI. U., <http://www.ohsu.edu/polst/developing/history.htm> (last visited Oct. 31, 2010).



tions.<sup>122</sup> One goal of the task force was to create a process that would shift the implementation of life-sustaining treatments from automatic application to one of “thoughtful advanced consideration.”<sup>123</sup>

The task force set about the work of creating a Medical Treatment Coversheet (MTC) with orders for four life-sustaining treatments and decisions about those treatments based on patient preferences and medical indications for treatments.<sup>124</sup> The preferences indicated on the MTC were medical orders and “not strictly a patient directive,” even though the patient actively engaged in the development of the preferences.<sup>125</sup> Once the MTC was reviewed and finalized, it was implemented and the impact of the MTC form on medical decision making was analyzed.<sup>126</sup> Investigators sought to determine whether medical decision making was more appropriate (based on what treatments were medically indicated and consistent with patient practices) before or after implementation of an MTC.<sup>127</sup> Based on this research, post-MTC decisions were more appropriate in almost all of the scenarios and treatments studied.<sup>128</sup> The authors concluded that, given the efficacy of the MTC in determining appropriate life-sustaining treatment, “a legally valid widely recognized form should be available for presentation to pre-hospital personnel” for patients otherwise eligible for life-sustaining treatments in a non-hospital setting.<sup>129</sup>

The authors further observed that while “a regulatory or legislative solution offers certain advantages, such as potential provider immunity, it did not seem politically feasible and may have hampered the refinement of the MTC necessary to optimize its effectiveness.”<sup>130</sup> Part VI of this Article identifies the challenges faced by state legislators attempting to create a more user-friendly and accessible advance directive.

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122. *The National POLST Paradigm Initiative Task Force*, OREGON HEALTH & SCI. U., <http://www.ohsu.edu/polst/about/task-force.htm> (last visited Oct. 31, 2010).

123. Patrick M. Dunn et al., *A Method to Communicate Patient Preferences About Medically Indicated Life-Sustaining Treatment in the Out-of-Hospital Setting*, 44 J. AM. GERIATRICS SOC'Y 785, 785-91 (1996).

124. *Id.* at 787 (identifying the four life-sustaining treatments as resuscitation, emergency medical services, antibiotics, and artificial fluids and nutrition).

125. *Id.* at 786.

126. *Id.*

127. *Id.* at 789.

128. *Id.*

129. *Id.*

130. *Id.*

Having concluded that the MTC is a safe and effective instrument that prevents unwarranted treatments, the use of the MTC was implemented throughout Oregon in its second generation Physician Orders for Life-Sustaining Treatment (POLST) form.<sup>131</sup> Other states have developed similar programs known by a variety of other names: MOST, MOLST, and POST. The term "POLST Paradigm" is used to describe these programs.<sup>132</sup> Even in states that do not yet have an endorsed POLST Paradigm program, many communities are testing pilot programs in nursing homes and other facilities where there is a high potential for life-sustaining treatment decisions.<sup>133</sup>

POLST Paradigm forms are recommended for use with seriously ill patients for whom life-sustaining treatment decisions may be necessary in the near future.<sup>134</sup> Although not recommended for patients who have stable medical problems with many years of life expectancy, there is nothing that prevents the POLST Paradigm form from being used with such patients.<sup>135</sup> Despite the limited pool of patients for whom a POLST Paradigm form is appropriate, within months of North Carolina's adoption of the MOST form in August 2007, it was reported that "many patients have used the MOST form to indicate their wishes well in advance of the end-of-life situation originally envisioned."<sup>136</sup> Absent a POLST Paradigm form or other state-specific DNR order, patients will receive advanced cardiac life support, including cardiopulmonary resuscitation (CPR), endotracheal intuba-

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131. *History of the Oregon POLST Registry*, OREGON HEALTH & SCI. U., <http://www.ohsu.edu/polst/programs/OrRegistryHistory.htm> (last visited Oct. 31, 2010). The POLST program directs EMTs, first responders, and their supervising physicians to respect patient wishes of life-sustaining treatment as evidenced by life-sustaining treatment orders executed by a physician and recorded on the POLST document. *Id.*

132. *Programs*, OREGON HEALTH & SCI. U., <http://www.ohsu.edu/polst/programs/> (last visited Oct. 31, 2010).

133. *POLST State Programs*, OREGON HEALTH & SCI. U., <http://www.ohsu.edu/polst/programs/state+programs.htm> (last visited Oct. 31, 2010).

134. Patrick Dunn et al., *The POLST Paradigm: Respecting the Wishes of Patients and Families*, 15 ANNALS LONG-TERM CARE, Sept. 2007, at 33, 37, available at <http://www.ohsu.edu/polst/news/the+polst+paradigm+respecting+wishes.pdf>.

135. *Id.*

136. Janelle A. Rhyne, *Medical Orders for Scope of Treatment*, 13 N.C. MED. BOARD F., Fall 2008, at 1, available at [http://www.ncmedboard.org/images/uploads/publications\\_uploads/no108.pdf](http://www.ncmedboard.org/images/uploads/publications_uploads/no108.pdf). One explanation for the use of the MOST form among non-terminal and otherwise healthy adults is the ability of individuals who are otherwise opposed to medical technology on religious grounds to use the MOST form to prohibit physicians from using such technology. *Id.*

tion, and defibrillation by medical personnel based on standard protocols.<sup>137</sup>

Unlike other advance directive documents, the POLST Paradigm form does not necessarily require the signature of the principal/patient or the patient's surrogate decision-maker.<sup>138</sup> However, of the eight endorsed POLST Paradigm programs,<sup>139</sup> each form has elected to require the principal's signature.<sup>140</sup>

Despite the widespread adoption of the POLST Paradigm in communities nationwide, medical professional and gerontology expert Joan M. Teno cautions against the reliance on the POLST Paradigm form as "the 'holy grail' of the advance directive movement."<sup>141</sup> She argues that the success of the POLST Program in Oregon was not based solely on the creation of a new form that attempts to articulate desires for life-sustaining treatment but also on a five-year review process of existing forms, institutional procedures, educational opportunities, and state policies. She suggests that it may have been this review process that led to the success of the POLST Program—not the form itself.<sup>142</sup> Teno emphasizes the need for ongoing advance care planning that she defines as a process of "communication over time in which clinicians, patients and their families . . . are partners in establishing goals of care."<sup>143</sup> Interestingly, the legal professional and advocate is glaringly absent from Teno's conversation. Finally, Teno warns against copying the Oregon program without engaging in the same political and cultural assessment that was at the foundation of Oregon's POLST Program.<sup>144</sup>

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137. *Id.*

138. Dunn et al., *supra* note 134, at 37.

139. *POLST State Programs*, *supra* note 133 (citing the endorsed programs in New York, West Virginia, North Carolina, Tennessee, Washington, Oregon, California, and Wisconsin as all requiring the patient's signature, or in the case of an incompetent patient, the signature of the surrogate decision-maker).

140. *Program Requirements*, OREGON HEALTH & SCI. U., <http://www.ohsu.edu/polst/developing/core-requirements.htm> (last visited Oct. 31, 2010).

141. Joan M. Teno, *Looking Beyond the "Form" to Complex Interventions Needed to Improve End-of-Life Care*, 46 J. AM. GERIATRICS SOC'Y 1170, 1170-71 (1998).

142. *Id.* at 1170.

143. *Id.*

144. *Id.* at 1171.

## B. Health Care Powers of Attorney

Every state allows an individual to dictate how his or her medical decisions will be made once that individual is unable to make such decisions on his or her own behalf.<sup>145</sup> In some states, one form is used to designate the health care agent appointed by the patient, as well as to document the patient's decisions regarding end-of-life care.<sup>146</sup> Other states have two distinct forms for the purposes of appointing a health care agent and declaring end-of-life decision choices.<sup>147</sup> All but ten states provide statutory forms, most of which are non-exclusive forms, for the purposes of making these appointments and elections.<sup>148</sup> A health care power of attorney allows the agent to make health care decisions on behalf of the patient within the scope of the power or applicable statute.<sup>149</sup>

## C. Living Wills

While a health care power of attorney appoints a surrogate decision-maker to make decisions for the patient under circumstances when the patient cannot make them for him or herself, the living will seeks to provide a mechanism for the patient to make decisions about the type of care desired at end of life that will be binding despite the patient's subsequent incapacity or inability to communicate end-of-life decisions at the appropriate time.<sup>150</sup> Each state has passed a living will statute that articulates the requirements for a valid living will and, in most cases, provides a statutory form to effectuate such desires.<sup>151</sup>

In a scathing condemnation of living wills, a 2004 Hastings Center Report declared that living wills have "failed" and that living wills

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145. *Health Care Power of Attorney and Combined Advance Directive Legislation*, AM. BAR ASS'N (Jan. 2008), <http://www.abanet.org/aging/legislativeupdates/docs/HCPA-CHT08-Final.pdf> (providing a table of state statutes authorizing creation of health care powers of attorney or living wills).

146. *Id.*

147. *Id.*

148. *Id.* (reporting that no statutory forms are provided in Arkansas, Colorado, Indiana, Massachusetts, Missouri, New Jersey, South Dakota, Tennessee, Utah, or Washington).

149. *Health Care Forms – Choice of Medical Care*, FINDLAW, <http://www.uslegalforms.com/findlaw/healthcare> (last visited Oct. 31, 2010).

150. *Id.*

151. *State Living Wills Laws*, FINDLAW, <http://law.findlaw.com/state-laws/living-wills/> (last visited Oct. 31, 2010).

cannot—and do not—achieve the goal of patient autonomy.<sup>152</sup> The report argues that in order for living wills to serve the purpose for which they were created they must meet five criteria: 1) “people must have living wills,” 2) individuals “must decide what treatment they would want if incompetent,” 3) the treatment preferences must be stated accurately, 4) the living wills must be available to people making end-of-life care decisions, and 5) surrogate decision-makers and caregivers must comply with the decisions articulated in the living will.<sup>153</sup> The authors of the report found that living wills fail with respect to every criterion and that their failure does not result from “want of effort, or education, or intelligence, or good will, but because of stubborn traits of human psychology and persistent failures of social organization.”<sup>154</sup> Among the criticisms leveled at living wills, the report argues that not only is it impossible for humans to really know their “preferences for an unspecifiable future confronted with unidentifiable maladies with unpredictable treatments,” but also that those preferences can and do change with time and circumstances.<sup>155</sup> Acknowledging the limitations of a written form to articulate the shifting sands of patient desires supports the movement to an open “process of communication and negotiation” and the dilution of the advance directive as a determinative factor in advance care planning.<sup>156</sup>

## VI. The Legislative Labyrinth of Self-Determination

On May 21, 2009, Senator Jay Rockefeller [D-WV], introduced Senate Bill 1150 (“SB 1150”) entitled “The Advance Planning and Compassionate Care Act of 2009.”<sup>157</sup> The bill is substantially similar to other bills introduced in 1997, 1999, 2002, and 2007—all of which died in committee.<sup>158</sup> In addition to community and provider education

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152. See Fagerlin & Schneider, *supra* note 77, at 30–42.

153. *Id.* at 32.

154. *Id.* at 38.

155. *Id.* at 33.

156. Teno et al., *supra* note 68, at 446.

157. Advance Planning and Compassionate Care Act of 2009, S. 1150, 111th Cong. (2009).

158. See *Overview, S. 1345: Advance Planning and Compassionate Care Act of 1997*, GOVTRACK.US, <http://www.govtrack.us/congress/bill.xpd?bill=s105-1345> (last visited Aug. 30, 2010) (noting the bill was not passed and such bills are cleared from the Congressional docket); see also *Overview, S. 628: Advance Planning and Compassionate Care Act of 1999*, GOVTRACK.US, <http://www.govtrack.us/congress/bill.xpd?bill=s106-628> (last visited Oct. 31, 2010); *Overview, S. 2857: Advance Planning and Com-*

provisions,<sup>159</sup> the bill would fund legal services to low-income individuals for advance end-of-life care planning<sup>160</sup> and would make grants available to establish programs within the POLST paradigm.<sup>161</sup> While the bill does not promote a national form for articulating end-of-life decisions, it does provide for portability of validly executed advance directives, the creation of state registries, and driver's license notifications of advance directives.<sup>162</sup> During presentation of the bill on the Senate floor, Senator Rockefeller recognized that "end-of-life planning and care for most Americans is perplexing, disjointed, and lacking an active dialogue."<sup>163</sup> The bill was read twice and referred to the Senate Committee on Finance.

Proponents of SB 1150 should take counsel from jurisdictions that have enacted legislation to promote patient self-determination. Following the *Quinlan* decision, North Carolina enacted its first patient self-determination legislation in 1979 with the passage of Article 23 of the North Carolina General Statutes Chapter 90, authorizing "patients to submit advance directives for natural death."<sup>164</sup> The approved statutory form allowed individuals to indicate their desire for end-of-life care, and in the absence of such a form, the statutes outlined the decision-making process for making such decisions on behalf of incompetent individuals.<sup>165</sup> The statutory living will form identified the conditions under which the individual's preferences might be applied and included 1) a terminal and incurable condition, and 2) a persistent vegetative state.<sup>166</sup> The living will allowed an indi-

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*passionate Care Act of 2002*, GOVTRACK.US, <http://www.govtrack.us/congress/bill.xpd?bill=s107-2857> (last visited Oct. 31, 2010); *Overview, S. 464: Advance Planning and Compassionate Care Act of 2007*, GOVTRACK.US, <http://www.govtrack.us/congress/bill.xpd?bill=s110-464> (last visited Oct. 31, 2010). See generally *Advance Planning and Compassionate Care Act of 1997*, S. 1345, 105th Cong. (1997); *Advance Planning and Compassionate Care Act of 1999*, S. 628, 106th Cong. (1999); *Advance Planning and Compassionate Care Act of 2002*, S. 2857, 107th Cong. (2002); *Advance Planning and Compassionate Care Act of 2007*, S. 464, 110th Cong. (2007).

159. S. 1150 §§ 104, 122.

160. *Id.* § 111.

161. *Id.* § 112.

162. *Id.* §§ 131-32.

163. Blaine, *Posting of Sen. Rockefeller Repeats Call for Advance Care Planning Legislation*, COMPASSION & CHOICES (Oct. 20, 2009), <http://compassionandchoices.org/blog/?m=200910> (quoting Sen. Rockefeller's report of "Additional Views"); 155 CONG. REC. S5862 (daily ed. May 21, 2009) (statement of Sen. Jay Rockefeller).

164. N.C. GEN. STAT. §§ 90-320-21 (2009).

165. N.C. GEN. STAT. §§ 90-321-22 (2009).

166. N.C. GEN. STAT. § 90-321(d) (2009).

vidual to elect the withholding or discontinuation of 1) extraordinary means only *or* 2) extraordinary means *and* artificial food and hydration.<sup>167</sup> In the absence of a declaration, the statute further provided a procedure for end-of-life care decision making. When an individual was determined to either 1) have a terminal and incurable condition, or 2) be in a persistent vegetative state, a physician was allowed to remove or withhold extraordinary means or artificial nutrition and hydration upon agreement by 1) a duly appointed health care agent, 2) a guardian of the person, 3) a person's spouse, or 4) a majority of relatives of the first degree, in that order.<sup>168</sup>

Likewise, in response to the decision in the *Cruzan* case, in 1991, the North Carolina legislature enacted Article 3 of Chapter 32A of the North Carolina General Statutes, which authorized the appointment of a health care agent in a health care power of attorney, recognizing that "as a matter of public policy the fundamental right of an individual to control the decisions relating to his or her medical care, and that this right may be exercised on behalf of the individual by an agent chosen by the individual."<sup>169</sup> In addition to having authority to make health care decisions on behalf of the principal, the agent could be authorized to withhold or discontinue life-sustaining procedures when the principal was determined to be "terminally ill, permanently in a coma, suffering severe dementia, or . . . in a persistent vegetative state."<sup>170</sup> It is interesting to note that when making declarations about one's own end-of-life care, the statute identifies terminal and incurable illnesses and persistent vegetative states as those conditions that would trigger the end-of-life care desired; when decisions are authorized by proxy, however, those decisions could apply in situations of terminal conditions and persistent vegetative states, *as well as* permanent comas and severe dementia.<sup>171</sup>

Along with inconsistencies in application, there was also ambiguity between the forms and statutes about whether the living will or the health care power of attorney would control in the event of a conflict.<sup>172</sup> A conflict could occur if the principal has a living will that di-

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167. N.C. GEN. STAT. § 90-321(d) (2009).

168. N.C. GEN. STAT. § 90-322(b) (2009).

169. N.C. GEN. STAT. § 32A-15(a) (2009).

170. N.C. GEN. STAT. § 32A-25(3)(G) (repealed 2007).

171. Compare N.C. GEN. STAT. § 90-321(d), with N.C. GEN. STAT. § 32A-25(3)(G) (repealed 2007).

172. See N.C. GEN. STAT. § 32A-15(c) (2009).

rects the withdrawal *only* of extraordinary means in the event of a terminal and incurable condition but has a health care power of attorney directing the agent to withhold extraordinary means *and* artificial food and hydration in the event of a terminal and incurable condition. When the principal's condition becomes terminal and incurable and the principal is no longer capable of decision making, which document controls? In addition to conflicts between documents, add in family members that are not in agreement about the proper course of action, and the attending physician may likely refuse to proceed either way pending authority from the courts, usually by way of a guardianship proceeding.

Prior to recent amendment, the North Carolina health care power of attorney statute provided that, in the event of a conflict between the living will and the health care power of attorney, the living will controlled.<sup>173</sup> The contrary position favoring the supremacy of the health care power of attorney rested in the assertion that a patient could make decisions about his or her medical care even when those decisions were contrary to his or her living will. If a principal may make decisions contrary to his or her living will, should not the duly appointed agent be authorized to act contrary to a living will? Might not many individuals prefer to use the living will as a method of declaring their preferences for end-of-life decisions in order to alleviate the burden of such decision making on their agents but likewise desire that their agent exercise their independent judgment given the circumstances at the time a decision is required? A common practitioner response to this conflict in North Carolina was to encourage clients to execute only a health care power of attorney or execute a health care power of attorney along with a "springing" living will.<sup>174</sup>

Consistent with the reactionary manner in which the legislature had adopted amendments to statutes governing patient self-determination, the North Carolina statutes remained largely unmodi-

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173. *Id.*

174. See Larry H. Rocamora, *Drafting Considerations After Enactment of House Bill 634*, in END-OF-LIFE PLANNING: NEW LIVING WILL, HEALTH CARE POWER OF ATTORNEY AND ORGAN DONATION STATUTES III-2 (North Carolina Bar Association-Continuing Legal Education (2007)) ("Because medical treatments continue to evolve, most . . . clients preferred to give an agent the ability to make future health care decisions in light of the treatments available at the time, rather than mandate a result which may not be preferable in the future when additional treatments may have been developed.").



fied until the Terry Schiavo case arose in Florida in 1998.<sup>175</sup> Given the inconsistencies and ambiguities in the North Carolina laws, a drafting committee was formed to make recommendations to the legislature about updating and clarifying the health care decision-making statutes.<sup>176</sup> The result of the drafting committee's work was House Bill 634 (HB 634), which was billed as "not a radical departure" from North Carolina's previous law, but rather a bill that "sought to clarify" the existing laws.<sup>177</sup> Drafters of the bill declared that the proposed law would provide a "more understandable means to exercise . . . self-determination rights and clearer ways to express . . . end-of-life wishes" and that the statutory forms would be more "user-friendly."<sup>178</sup> Despite such assertions, the bill's voyage through the congressional houses was treacherous.

In March 20, 2007, SB 1046 was filed in the North Carolina Legislature.<sup>179</sup> The bill's primary purpose was to resolve discrepancies in existing advance directive laws as well as bring North Carolina into the POLST Paradigm with the enactment of the MOST legislation. On March 21, 2007, SB 1046 was referred to the Senate Judiciary Commit-

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175. Since then, however, North Carolina's Living Will and Healthcare Power of Attorney statutes have been amended eight times. See N.C. GEN. STAT. §§ 90-320, 90-321, 90-322, 32A-15, 32A-25 (2009).

176. James E. Creamer, Jr. & E. Knox Proctor V, *Overview of House Bill 634, in END-OF-LIFE PLANNING: NEW LIVING WILL, HEALTH CARE POWER OF ATTORNEY AND ORGAN DONATION STATUTES I-1* (North Carolina Bar Association-Continuing Legal Education (2007)). The drafting group consisted of representatives from the North Carolina Bar Association: Elder Law, Estate Planning and Health Law sections, and members of the North Carolina Medical Society. *Id.* The group also consulted with the North Carolina Hospital Association, the Carolinas Center for Hospice and End-of-Life Care, and the North Carolina Health Care Facilities Association. *Id.* Prior to the creation of the drafting group, a Task Force was created to study these issues in North Carolina. *Id.* The Task Force included representatives from the North Carolina Bar Association, North Carolina Hospital Association, North Carolina Health Care Facilities Association, Carolinas Center for Hospice and End-of-Life Care, North Carolina Nurses Association, Office of Emergency Medical Services and the Division of Aging under Department of Health and Human Services, North Carolina Department of Justice, Old North State Medical Society, North Carolina Medical Directors Association, North Carolina Institute of Medicine, Family Policy Council, LifeTree, and Catholic Physicians of Raleigh. Melanie G. Phelps, N.C. Med. Soc'y, Address at the North Carolina Bar Association's Continuing Legal Education 29th Annual Estate Planning and Fiduciary Law Program: MOST: A New Portable Medicaid Order for North Carolina (July 26, 2008). Catholic Physicians of Raleigh declined to participate in the Task Force. *Id.*

177. Creamer & Proctor, *supra* note 176, at I-1.

178. *Id.*

179. H.B. 634, 2007 Gen. Assembly (N.C. 2008) (titled Advance Directives/Healthcare POA).

tee for review and discussion.<sup>180</sup> No radical amendments were proposed during the Senate process, and SB 1046 was sent to the House for what should have been an uncontroversial approval process.

On May 16, 2007, SB 1046 passed its first reading on the House floor and was referred to the House Committee on Health Affairs and Judiciary. The House Committee on Judiciary met to take up SB 1046 and a proposed committee substitute (PCS) to SB 1046 was offered for discussion. Members of the North Carolina Bar Association and representatives from the North Carolina Medical Society appeared before the committee to testify in support of SB 1046. Members of LifeTree, a pro-life Christian organization, were also present and testified in opposition to SB 1046.<sup>181</sup> LifeTree objected to the characterization of the proposed North Carolina advance directive bill as “not break[ing] new ground” inasmuch as the proposed law would, for the first time in North Carolina, allow advance directives to control end-of-life decisions in the case of “advanced dementia.”<sup>182</sup> LifeTree also objected to the change in statutory language from “life sustaining measures” to “life prolonging measures”<sup>183</sup> and to the adoption of the MOST form

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180. E. Knox Proctor V, Address at North Carolina Bar Center: New Organ Donation Law (Oct. 10, 2007). See *Legislative History of S.B. 1046/S.L. 2008-137*, NORTH CAROLINA GEN. ASSEMBLY, <http://www.ncga.state.nc.us/gascripts/BillLookUp/BillLookUp.pl?Session=2007&BillID=S1046&votestoView=all> (last visited Oct. 31, 2010) [hereinafter *History of S.B. 1046*]. Thereafter, on May 8, 2007, the Senate Judiciary Committee II adopted a committee substitute of S.B. 1046 and placed the modified bill on the Senate calendar for May 10, 2007. Between May 10 and May 14, 2007, S.B. 1046 passed its second and third readings in the North Carolina Senate and was engrossed on May 14, 2007. The second reading in the Senate passed by a vote of forty-seven to one (with one senator not voting and one senator absent). *Id.* The third reading passed by a vote of forty-seven to zero (with two senators not voting and one senator absent). *Id.*

181. *About LifeTree*, LIFE TREE, <http://www.lifetree.org/about/index.html> (last visited Oct. 31, 2010) (LifeTree is a self-described “pro-life Christian educational ministry” whose mission is “to raise awareness throughout North Carolina about the need to protect life, from its earliest beginnings to natural death”).

182. *Minutes, H. Comm. on Judiciary I, 2007-2008 Leg. Sess. 6* (N.C. July 19, 2007, at 10 AM). Despite this objection, the prior statutes allowed the withholding or withdrawing of end-of-life care in the cases of advanced dementia by direction of a health care agent. *Id.* It was only the living will that omitted language regarding advanced dementia. *Id.* This was one of the form discrepancies that drafters sought to remedy in the 2007 legislation. *Id.*

183. *Statement of LifeTree Concerning S1046 (Advance Directives) Before the NC House Health Committee*, LIFE TREE NEWSLETTER (LifeTree, Inc., Raleigh, N.C.), July 10, 2007, available at [http://www.lifetree.org/newsletter/07\\_07.html](http://www.lifetree.org/newsletter/07_07.html).

in North Carolina.<sup>184</sup> The House Judiciary Committee received numerous amendments to SB 1046,<sup>185</sup> the most significant of which were 1) ARN #14, which would have required inclusion in the language of the advance directive forms an election to affirmatively require physicians to provide life-prolonging treatments<sup>186</sup> and 2) ARN #17, which sought to remove the condition of “advanced dementia” as one of the triggering conditions for advance directives.<sup>187</sup> After discussion, both amendments failed.<sup>188</sup> Following a long and arduous journey, the House Judiciary Committee approved SB 1046 with the approved amendments, thus creating PCS #2. SB 1046, as amended, passed the House on July 25, 2007.<sup>189</sup>

Under the North Carolina Legislative Rules, when the second chamber has adopted a PCS for a bill originating in the first chamber, no further amendments may be made to the PCS in the originating chamber.<sup>190</sup> Using this process would have required that the House’s

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184. *Id.* See also *North Carolina Advance Directives Bill Is Not Pro-Life*, LIFETREE NEWSLETTER (LifeTree, Inc., Raleigh, N.C.), Apr. 29, 2007, available at [http://www.lifetree.org/newsletter/04\\_07.html](http://www.lifetree.org/newsletter/04_07.html).

185. *Minutes, H. Comm. on Judiciary I, 2007–2008 Leg. Sess.* (N.C. July 19, 2007 at 10 AM) (regarding the Proposed Committee Substitute (PCS1)), see also *H. Comm. on Judiciary I, 2007–2008 Leg. Sess.* (N.C. July 24, 2007, at 10 AM) (regarding ARN #18 (withdrawn in part and adopted in part) and ARN #14).

186. *Minutes, H. Comm. on Judiciary I, 2007–2008 Leg. Sess.* (N.C. July 24, 2007, at 10 AM). Representative Stam argued that individuals were not provided the full array of options by the “withholding” or “withdrawing” of care in the absence of a requirement that life-prolonging treatments be administered. *Id.*

187. *Minutes, H. Comm. on Judiciary I, 2007–2008 Leg. Sess.* (N.C. July 24, 2007, at 2 PM). Representatives from the North Carolina Medical Society testified that the presumption is “that you want to be treated” and that advance directives are necessary to withhold treatment that you would otherwise receive from a medical institution. *Minutes, H. Comm. on Judiciary I, 2007–2008 Leg. Sess.* (N.C., July 19, 2007, at 10 AM). Therefore, there is no need to include an affirmative direction to treat at end-of-life since that direction would be assumed absent other elections by the patient or the patient’s representative.

188. *Minutes, H. Comm. on Judiciary I, 2007–2008 Leg. Sess.* (N.C. July 24, 2007, at 2 PM). ARN #14 failed on a voice vote and ARN #17 failed for lack of a majority in a six-to-six vote. *Id.* Despite waning support for amendments to the bill, ARN #22 was proffered again attempting to modify the statutory forms in SB 1046 to require end-of-life care. *Id.* ARN #22 failed for lack of a majority with a vote of seven to seven by a show of hands. *Id.* ARN #19, which allowed a patient to be moved “to another health care provider when a health care provider refuses to follow a directive for treatment and such denial will cause or hasten the death of the patient,” was also proposed but failed for lack of a majority. *Minutes, H. Comm. on Judiciary I, 2007–2008 Leg. Sess.* 4 (N.C. July 24, 2007, at 2 PM).

189. *Legislative History of S.B. 1046*, *supra* note 180.

190. Gerry F. Cohen, *Legislative Reform in North Carolina, Case Study 1971–2004 of Actions on the Recommendations in the Sometime Governments: A Critical Study of the 50 American Legislatures* (2004) (unpublished M.A. thesis, Uni-

PCS #2 be put before the Senate on an “up or down” vote. Although PCS #2 had avoided many of the attempted modifications in the House Judiciary Committee, as passed in the House, it still represented a significant departure from the underlying philosophy of the originally introduced Senate bill.<sup>191</sup>

Consistent with North Carolina Legislative Rules, PCS #2 to SB 1046 was received in the Senate for a vote of concurrence. Absent concurrence, SB 1046 would have been returned to committee or died. Feeling the pressure of the approaching end of the legislative term but unwilling to concur with PCS #2, the Senate used the post-1979 legislative rules to force the House to concur with a Senate Committee Substitute. The Senate took HB 634, an unrelated bill that had already passed in the original chamber and was awaiting Senate action and stripped HB 634 of its original language, replacing it with the original language of SB 1046, effectively creating a Senate Committee Substitute to HB 634. Once the Senate Committee Substitute to HB 634 passed the Senate it was only subject to a vote of concurrence in the House. Upon receiving the Senate Committee Substitute to HB 634, the House voted to concur with the Senate Committee Substitute by a vote of 68 to 48.<sup>192</sup> The new advance directive law finally passed in a form substantially similar to that originally proposed in SB 1046. The Governor signed the finalized bill on August 30, 2007.<sup>193</sup>

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. The new law’s incorpora-

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versity of North Carolina at Chapel Hill), available at <http://ncbilldrafting.wordpress.com/files/2007/07/2004mathesis.doc>.

191. *Legislative History of S.B. 1046*, *supra* note 180. Specifically, PCS #2 provided an election in the statutory living will form that permitted a patient to designate that a health care provider “may provide life prolonging measures” or “shall provide life prolonging measures.” *Id.* PCS #2, thus deviated from the underlying premise of advance directives that, absent consent to the contrary (medical futility excepting), physicians are under a professional obligation to provide such care. Similarly, PCS #2 provided an election for the affirmative imposition of artificial food and hydration which likewise was inconsistent with a physician’s implied duty to act.

192. *Legislative History of House Bill 634*, NORTH CAROLINA GEN. ASSEMBLY, <http://www.ncga.state.nc.us/gasscripts/BillLookUp/BillLookUp.pl?Session=2007&BillID=s1046> (last visited Oct. 31, 2010).

193. *Id.*

tion of MOST, as well as the Portable DNR Order,<sup>194</sup> only adds to the complexity, creating a model for self-determination analogous to an old-fashioned game of Rock-Paper-Scissors.

On the positive side, the new law successfully eliminated the ambiguity about which document controls when a conflict exists between the living will and the health care power of attorney by retaining the original statutory language providing that the living will controls. The new law, however, adds a caveat for circumstances in which the “health care power of attorney or a declaration provides that the declaration is subject to decisions of a health care agent.”<sup>195</sup> As further support for the statutory default rule that, absent indication to the contrary, the living will prevails over the health care power of attorney, the new statutory living will form specifically provides for this outcome.<sup>196</sup>

Likewise, as to the conditions under which the decision-making authority of the agent or the effectiveness of the living will may be triggered, the new law clarified inconsistencies in the previous law by allowing an individual to designate in his or her living will the withholding or withdrawal of care in the following conditions: 1) an incurable or irreversible condition that will result in death in a relatively short period of time; 2) unconsciousness combined with a medical determination that, to a high degree of medical certainty, consciousness will never be regained; or 3) advanced dementia or any other condition resulting in substantial loss of cognitive ability combined with a medical determination that, to a high degree of certainty, the dementia or loss is not reversible.<sup>197</sup>

Before the ink dried on the session laws and new statutory forms, practitioners were already discussing alternate forms and the relationships among the various methods of making end-of-life deci-

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194. N.C. GEN. STAT. § 90-21.17 (2009).

195. N.C. GEN. STAT. § 32A-15(c) (2009). Even though the statute provides that either the living will or the health care power of attorney may specify which instrument shall prevail in the event of an inconsistency, the statutory forms amended by HB 634 provide for this election only in the living will form and not the statutory health care power of attorney. The drafters were concerned that an individual “using both forms would get confused and insert inconsistent directives about which document prevailed.” See Rocamora, *supra* note 174, at I-4.

196. N.C. GEN. STAT. § 90-321(d)(1) (2009).

197. N.C. GEN. STAT. § 90-321-1 (2009).

sions.<sup>198</sup> Likewise, the relationships proved to be a complicated scheme: if a patient has both a health care power of attorney and a living will, the patient may designate in the living will form whether the living will or the direction of the agent under a health care power of attorney will control.<sup>199</sup> In the absence of such an election, the statutory default will be that the patient's elections in the living will control.<sup>200</sup> If the patient has executed a health care power of attorney and *no* living will, the health care agent will have the authority to make decisions regarding the principal's health care.<sup>201</sup> If, however, the patient has a health care power of attorney and a living will and is subsequently declared incompetent, necessitating the appointment of a *guardian ad litem*, the guardian has the authority to petition for the suspension of the health care agent's authority.<sup>202</sup> The guardian may not, however, revoke a living will.<sup>203</sup> If a patient has no health care power of attorney, living will, or guardian, life-prolonging measures may be withheld upon the direction and supervision of the attending physician with the concurrence of someone with a statutorily enumerated relationship to the patient.<sup>204</sup>

If the patient has a health care power of attorney, a living will, and a MOST form and a conflict exists among the patient's elections in these documents, the elections in the MOST form will control, suspending any conflicts between the health care power of attorney and living will.<sup>205</sup> The rationale for the superiority of the MOST form over the health care power of attorney and living will is due to the fact that the MOST form is a doctor's order as opposed to a patient executed legal instrument. A patient's health care power of attorney or living will authorizes certain actions or inactions by the physician on the patient's behalf, but these forms, without more, do not effectuate those actions—only a subsequent doctor's order for treatment can result in

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198. See generally Graham D. Holding & Larry H. Rocamora, *Uses of and Variations on Statutory Forms*, in END-OF-LIFE PLANNING: NEW LIVING WILL, HEALTH CARE POWER OF ATTORNEY AND ORGAN DONATION STATUTES III (North Carolina Bar Association-Continuing Legal Education Manual (2007)).

199. N.C. GEN. STAT. § 90-321(d1) (2009).

200. N.C. GEN. STAT. § 32A-15(c), § 90-321(d1) (2009).

201. N.C. GEN. STAT. § 32A-25.1(a) (2009).

202. N.C. GEN. STAT. § 32A-22(a) (2009).

203. N.C. GEN. STAT. § 35A-1208(b) (2009).

204. N.C. GEN. STAT. § 90-322(b) (2009) (listing the order of preference for individuals providing the concurrence for the physician's decision regarding the withholding or withdrawing of end-of-life care).

205. N.C. GEN. STAT. § 90-21.17(c) (2009).

the withholding or withdrawal of care.<sup>206</sup> The MOST form, as a medical order, can, without more, bring about the resulting treatment or cessation of treatment.<sup>207</sup> The advance directives “inform physicians about the level of care desired . . . [while] physician orders instruct . . . what level of care to provide.”<sup>208</sup> Thus, in the presence of all three documents, the MOST form—a medical order—will trump the other legal instruments.

Even though a guardian cannot revoke a living will previously executed by the principal prior to an adjudication of incompetence, a guardian can effectuate a de facto revocation of a living will by authorizing the execution of a MOST form. If a patient is not capable of giving informed consent for the MOST form, a MOST form may still be entered on behalf of the patient with the consent of the patient’s representative.<sup>209</sup> The first such authorized representative is the patient’s appointed guardian.<sup>210</sup> Thus, in the battle of the forms, it would appear that there would be no impediment to the guardian who, unable to revoke the patient’s living will, could authorize the execution of a MOST form, which could contain contrary provisions regarding most life-sustaining treatments.

Finally, North Carolina’s new statute continued its authorization of the use of Portable DNR Orders.<sup>211</sup> The Portable DNR and MOST forms are identical inasmuch as both of them are medical orders and thus carry the same weight in terms of trumping the health care power of attorney and the living will. The difference between the Portable DNR and the MOST form is the type of end-of-life care treatments that each form addresses. The Portable DNR deals *only* with the withholding of CPR while the MOST form allows the withholding or withdrawal of a range of medical interventions, including CPR.<sup>212</sup> In the event that there is a discrepancy regarding the use of CPR between the Portable DNR and the MOST form, one must presume that

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206. North Carolina Bar Association-Continuing Legal Education Manual at II-3, Oct. 10, 2007.

207. *Id.*

208. *Id.*

209. N.C. GEN. STAT. § 90-21.27(b)(2) (2009).

210. N.C. GEN. STAT. § 90-21.17(c) (2009) (referring to the order of preference of representatives in N.C. Gen. Stat. § 90-322, the first of whom is the guardian).

211. N.C. GEN. STAT. § 90-21.17(a) (2009).

212. N.C. GEN. STAT. § 90-21.17(c) (2009).

the most recent valid medical order would control despite failure of the statute to resolve this issue.

## VII. Alternative Forms

In response to the challenges and limitations of the living will, alternative forms have been proposed that allow a patient to articulate his or her desires at end of life.

### A. Five Wishes Document

The *Five Wishes* document, created by Aging with Dignity, a national nonprofit organization, is dubbed “the living will with a heart and soul.”<sup>213</sup> The *Five Wishes* document attempts to combine the goals of a legally binding medical document with the additional benefits of allowing patients to direct their comfort levels, spiritual beliefs, and desires at end of life. The “five wishes” contained in the document articulate:<sup>214</sup>

The Person I Want to Make Care Decisions for Me When I Can't  
The Kind of Medical Treatment I Want or Don't Want  
How Comfortable I Want to Be  
How I Want People to Treat Me  
What I Want My Loved Ones to Know

Within each wish, there are options for inclusion or exclusion at the election of the patient. Although the *Five Wishes* may be used in any state, it meets the legal requirements of a living will in forty-two states and may be attached to a legal living will in the other eight states.<sup>215</sup> The *Five Wishes* document has been translated into twenty-three languages and more than fourteen million copies are in circula-

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213. *About Us*, AGING WITH DIGNITY, <http://www.agingwithdignity.org/about.php> (last visited Oct. 31, 2010).

214. *Five Wishes*, AGING WITH DIGNITY, 4-9, <http://www.agingwithdignity.org/forms/5wishes.pdf> (last visited Oct. 31, 2010).

215. *Five Wishes States*, AGING WITH DIGNITY, <http://www.agingwithdignity.org/five-wishes-states.php> (last visited Oct. 31, 2010) (identifying Alabama, Indiana, Kansas, New Hampshire, Ohio, Oregon, Texas, and Utah as “non-Five Wish” states). In these states, the statutory form living will is the exclusive means of executing a living will; thus, the *Five Wishes* document may supplement but may not supplant the statutory form. *Id.* (follow respective hyperlinks to view state-specific information).



tion across the United States;<sup>216</sup> however, the number of *Five Wishes* documents in use and the demographics of those individuals are unknown.

In a study conducted by the National Institute of Health and the National Cancer Institute, the *Five Wishes* document was tested among a small group of adolescents and young adults, all of whom had cancer or HIV.<sup>217</sup> The researchers were particularly interested in whether these young patients would find it helpful to have a document to express their end-of-life decisions and to facilitate the discussion of end-of-life decisions with their families and loved ones.<sup>218</sup> The *Five Wishes* document was the only advance directive form provided for their consideration.<sup>219</sup> The study population was asked to describe the "wishes" and their associated options as appropriate, helpful, or stressful.<sup>220</sup> Ninety-five percent of participants reported that the overall document could be "helpful" or "very helpful" in their own end-of-life situation.<sup>221</sup> None of the participants reported that reviewing the concepts in the document was "stressful" or "very stressful," although thirty-five percent reported it as "somewhat stressful" and twenty percent reported it as a "little stressful."<sup>222</sup> Specific treatment options identified as "stressful" or "very stressful" often were associated with conditions close to death, coma, or severe brain damage.<sup>223</sup>

Not surprisingly, given the age of the study cohort and the prominence of parental involvement in the decision making, the researchers found that patients were more concerned with how they would be treated and remembered by those they left behind more than with legal issues, medical decision making, and life-support treatments.<sup>224</sup>

Primary concerns about the *Five Wishes* document include: 1) whether the document's ambiguous language meets a state's specific

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216. *Accomplishments*, AGING WITH DIGNITY, <http://www.agingwithdignity.org/accomplishments.php> (last visited Oct. 31, 2010).

217. Lori Wiener et al., *How I Wish to Be Remembered: The Use of an Advance Care Planning Document in Adolescent and Young Adult Populations*, 11 J. PALLIATIVE MED. 1309, 1309 (2008).

218. *Id.* at 1310.

219. *Id.*

220. *Id.* at 1309-10.

221. *Id.* at 1311.

222. *Id.*

223. *Id.* at 1312.

224. *Id.*

legal requirements for advance directives, and 2) whether the document can be appropriately integrated without conflict between a state's living will, health care power of attorney, and durable power of attorney.<sup>225</sup> Despite these limitations, even wary practitioners acknowledge that the *Five Wishes* document is an "excellent tool to foster conversation."<sup>226</sup>

## B. Will to Live Form

In response to rising concerns that the patient self-determination movement had crossed the line into a territory where a culture of death prevailed, the National Right to Life Committee (NRLC) began the Will to Live Project and also introduced "The Pro-Life Living Will."<sup>227</sup> The "Pro-Life Living Will" seeks to reestablish a decision-making process in favor of life, contrary to the perception that many doctors now base medical decision making in the foundation of a "quality of life" ethic.<sup>228</sup> The NRLC provides state specific *Will to Live* forms that include a statement in favor of the "General Presumption For Life."<sup>229</sup> Under the presumption, food and water are defined as basic necessities and not medical treatment, and their provision is mandatory "to the full extent necessary both to preserve my life and to assure me the optimal health possible."<sup>230</sup> The *Will to Live* form also directs that medical care and treatment be provided "to preserve . . . life" without regard to age, physical condition, or "quality of life."<sup>231</sup> In addition, the *Will to Live* form does allow for care and treatment to be withheld by election when "death is imminent" – defined as likelihood of death within a week or less even with lifesaving treatment – and in the case of "terminal illness" – defined as likely to result in

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225. Koenig & Hyde, *supra* note 10, at 243.

226. *Id.* at 245.

227. *Statement of Bob Schindler, Jr.*, NAT'L RIGHT TO LIFE COMMITTEE, <http://www.nrlc.org/MedEthics/WilltoLiveProject.html> (last visited Oct. 31, 2010).

228. *National Right to Life*, NAT'L RIGHT TO LIFE COMMITTEE, <http://www.nrlc.org/euthanasia/willtolive/QAWTL.html> (last visited Oct. 31, 2010).

229. *See Suggestions for Preparing Will to Live Durable Power of Attorney*, NAT'L RIGHT TO LIFE COMMITTEE, 4, <http://www.nrlc.org/euthanasia/willtolive/docs/northcarolina.rev0209.pdf> (last visited Oct. 31, 2010).

230. *Id.* The form further prohibits the use of any tissue or organ of an unborn or newborn child who has been subject to an induced abortion (except ectopic pregnancies). *Id.*

231. *Id.* at 5.

death in three months or less despite the imposition of lifesaving treatment.<sup>232</sup> Patients are instructed to fill in these special circumstances sections with precision and specificity in light of the “pro-euthanasia views widespread in society and particularly among many (not all) health care providers.”<sup>233</sup>

### **VIII. Ensuring Adherence to a Patient’s End-of-Life Wishes**

A review of the medical literature illustrates that physicians generally have a positive attitude toward the use of advance directives. When the advance directive is combined with treatments that the physician has determined to be medically futile, physicians are willing to withhold treatment in surprisingly high numbers. In contrast, where medical futility is not at issue, a patient’s preferences for end-of-life care set out in a living will are only one factor in determining the imposition or removal of treatments. In these cases, the consent of the surrogate decision-maker plays an equally important role in determining the outcome of patient care at end of life. When these factors are combined with the dismally low rate at which living wills are exercised, living wills are not having the intended impact on patient self-determination. The legal forms that currently exist to encourage discussions among family members and health care professionals fail to do so effectively.

While the use of alternative forms such as the *Five Wishes* document raises concerns among legal professionals, such documents are more successful in achieving open communication between patients and their families about end-of-life care. It also appears that patients are more willing to execute a form written in common, accessible language about end-of-life decisions than the more legalistic statutory forms adopted in most states. Given the ease with which adolescents and young adults used the alternative forms, they are a good start to ensuring conversation between patients and their families. Combining active dialogue with the appointment of a trusted health care decision-maker on whom physicians can rely to make end-of-life decisions will do more to ensure that a patient’s desires are followed at end of life than the existing methods. Even in the presence of living wills,

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232. *Id.*

233. *Id.* at i (referencing instructions to the North Carolina Will to Live Form).

physicians frequently look to the surrogate decision-maker prior to withholding end-of-life care; the presence of a strong personal advocate will be more effective at enforcing a patient's wishes than the existence of a legally executed living will. We have used legal forms too long as a barrier to, and substitution for, real conversation about the things that matter most at end of life; it is time for this substitution to end. Physicians, patients, and their surrogate decision-makers should engage the conversation.

As a means to encourage the conversation between patients and their surrogate decision-makers that is the foundation for successful care at end of life, states should modify their living will and health care power of attorney statutes to require that the surrogate decision-maker accept their responsibilities under the living will or power of attorney as follows: 1) that the surrogate has been in dialogue with the patient-principal and understands the desires of the patient at end of life and 2) that the surrogate is prepared to make decisions consistent with the patient's preferences. In most statutory forms, there is no place for the agent to acknowledge the desires of the patient or to articulate a willingness to perform his duties.<sup>234</sup> While patients may be encouraged to speak with their agents about their desires, more often, the patient's appointment of a health care surrogate is done with little or no conversation with the appointed agent prior to his election.<sup>235</sup> If the surrogate decision-maker has acknowledged the appointment and made a commitment to act in conformity with the patient's desires, it would help ensure the appointment of a confident and compassionate surrogate decision-maker. Dismally few states require the principal to acknowledge having spoken with their agent prior to appointment, require the agent to accept the appointment, or require the agent to agree to serve in accordance with the patient's desires.<sup>236</sup> In order to

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234. See, e.g., ALA. CODE § 22-8A-4 (2009); IOWA CODE § 144B.5 (2009).

235. Michael D. Cantor, Michele J. Karel & Jean Powell, *Using a Values Discussion Guide to Facilitate Communication in Advance Care Planning*, 55 PATIENT EDUC. & COUNSELING 22, 22 (2004).

236. See ALA. CODE § 22-8A-4 (2009) (requiring the principal to acknowledge that he or she has "talked with [the agent] about [his or her] wishes" and requiring the agent to sign the health care proxy evidencing his or her willingness to serve). See also IOWA CODE § 144B.5 (2009) (authorizing an optional provision in the health care power of attorney acknowledging that the agent has been "notified" of his or her appointment and has "consented to the designation"); MICH. COMP. LAWS § 700.5507 (2009); N.D. CENT. CODE § 23-06.5-17 (2009); OR. REV. STAT. § 127.525 (2009). The Michigan, North Dakota, and Oregon Statutes require the health care agent to sign an acceptance before serving as the medical decision-maker under an

facilitate the conversations between the principal and his agent prior to the appointment, alternate forms such as the *Five Wishes* document should be used and retained by the surrogate as evidence of the patient's desires that the surrogate can rely on when making decisions on behalf of his or her principal.

The remaining challenge is responding to a decision-maker who has deviated from the known desires of the patient. This can be accomplished by the appointment of an alternate decision-maker to serve in such event, provided that the alternate surrogate decision-maker has the standing to petition the removal of the first-appointed agent in the event the agent cannot—or will not—act in accordance with the known desires of the principal. This additional provision will provide a safeguard for the spouse, child, or surrogate who is unable to make such critical decisions.

## IX. Conclusion

Communication is the underlying key to dying a good death and we should strive for national legislation that will focus on the importance of the conversation. Funding should be made available to encourage hospital staff, chaplains, physicians, and nurses to encourage the dialogue. Legislative bodies should focus on drafting forms that seek to articulate a broad range of patient desires at end of life with a goal of encouraging a discussion between patient and decision-maker. Caregivers and surrogate decision-makers should be counseled on the challenges of responding to end-of-life decisions. Lawyers should advocate patient wishes with the surrogate decision-maker and, when necessary, the health care provider. Forms that are ineffective for lack of use or failure to adequately inform end-of-life care should be abandoned. While adopting these steps will not prevent death, they will bring our society one step closer to becoming a society whose belief in self-determination is manifested in the creation of opportunities for dying well that are supported by our medical and legal institutions.

