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## *Schiavo* and Contemporary Myths About Dying

Rebecca Dresser

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# *Schiavo* and Contemporary Myths About Dying

REBECCA DRESSER\*

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## I. INTRODUCTION

When the *Schiavo* case burst onto the national scene most people assumed that everyone would see the case as they did. This proved incorrect, however; what had seemed settled was in fact unsettled. *Schiavo* showed everyone that American pluralism is alive and well regarding life-sustaining treatment decisions. *Schiavo* also demonstrated that at least some of this pluralism reflects misguided myths about human life and death. Although different beliefs and values underlie the myths, each myth supplies comforting but false notions about death and dying.

*Schiavo* also revealed how poorly prepared we are for the imminent aging of the Baby Boom generation. As a nation, we are about to experience a significant demographic event. We can expect a large rise in the number of older individuals facing physically and mentally debilitating conditions. Many will depend on medical interventions for survival. Decisions about extending life will be more common than ever, but neither our culture nor our legal system is ready to cope. And, as long we hold fast to our myths, we will remain unready.

In this Article, I examine three myths that *Schiavo* exposed. The first myth is that death with dignity is easily attainable in modern America, so long as people make living wills. The second myth is that only patients themselves are permitted to take quality of life into account when making life-sustaining intervention decisions. The third myth is that research advances are bringing an end to the difficulties of aging.

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According to this myth, medicine will soon offer ways for us to live longer and better, and then to die quick, comfortable deaths. *Schiavo* was a harsh reminder that none of these myths reflect reality.

To examine the myths, I draw on the *Schiavo* public commentary that has emerged from various individuals and groups. I also draw extensively from four texts published in 2005, the year the *Schiavo* case made headlines. Two of the texts are memoirs. Joan Didion's *The Year of Magical Thinking*<sup>1</sup> recounts her experiences as the wife of someone who died suddenly and as the mother of someone with an unexpected and prolonged life-threatening illness. Marjorie Williams' *Hit by Lightning: A Cancer Memoir*<sup>2</sup> describes facing terminal illness as a mother of young children and as a writer at the height of her career. The third book is Ray Kurzweil's *The Singularity Is Near: When Humans Transcend Biology*,<sup>3</sup> which belongs to a genre offering utopian visions of a scientifically-enhanced future. Kurzweil predicts that humans will soon triumph over biology in ways that will reverse aging and defeat disease, allowing people to live as long as they desire. Fourth is a report from the President's Council on Bioethics, *Taking Care: Ethical Caregiving in Our Aging Society*.<sup>4</sup> I am part of the group that prepared this report; not surprisingly, I think it offers a realistic, although unsettling, picture of what we face.

Together with the *Schiavo* commentary, these texts illuminate contemporary American thinking about death and dying. In Part I of this Article, I describe how myths about dying influenced perceptions of Terri Schiavo's situation. In Part II, I discuss how the four texts cited above both express and challenge the myths. Part III argues for replacing the myths with a medical system more responsive to the needs of patients and society. This system would place less emphasis upon advancing the frontiers of medicine and more emphasis upon delivering humane and decent care to all patients. In a system setting high-quality care as a first priority, doctors and other clinicians would have more time to speak with patients and families and to provide people the care that they need.

## II. MYTHS SCHIAVO EXPOSED

Public scrutiny of the *Schiavo* case brought to the forefront certain

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1. JOAN DIDION, *THE YEAR OF MAGICAL THINKING* (2005).

2. MARJORIE WILLIAMS, *Hit by Lightning: A Cancer Memoir*, in *THE WOMAN AT THE WASHINGTON ZOO* 307-39 (Timothy Noah ed., 2005).

3. RAY KURZWEIL, *THE SINGULARITY IS NEAR: WHEN HUMANS TRANSCEND BIOLOGY* (2005).

4. PRESIDENT'S COUNCIL ON BIOETHICS, *TAKING CARE: ETHICAL CAREGIVING IN OUR AGING SOCIETY* (2005) [hereinafter *TAKING CARE*].

cultural themes about death and dying. As the controversy played itself out, previously unrecognized background beliefs became explicit features of the *Schiavo* narrative. Although not everyone embraced each one of these beliefs, each belief was defended by a vocal constituency.

### A. *The Living Will Myth*

The absence of a living will was at the heart of the *Schiavo* dispute. The Florida courts relied on testimony about the patient's former conversational remarks because there was no formal written or oral advance directive.<sup>5</sup> Terri Schiavo had been raised a Roman Catholic.<sup>6</sup> But, it was unclear whether she agreed with church teachings on forgoing medical nutrition and hydration.<sup>7</sup> This ambiguity about her beliefs left room for her husband and parents to make contradictory claims about her treatment preferences.

At the national level, *Schiavo* became a cautionary tale about what can happen when patients neglect to make living wills. Commentators urged members of the public to complete the necessary documents to prevent similar personal disasters.<sup>8</sup> In turn, news accounts reported increased interest in living wills from individuals "acting to avoid the type of situation that has torn apart the family of Terri Schiavo."<sup>9</sup> Many referred to *Schiavo*'s "beneficial side effect," which was that "[p]eople across the . . . nation are talking about, and, more important, writing in living wills instructions for their own final days."<sup>10</sup> *USA Today* reported on an emerging entertainment venue – the living will party – and offered tips on hosting one.<sup>11</sup>

More conversation among family and friends about end-of-life care is a welcome development, but a narrow focus on living wills as the means to achieve a "good death" may be counterproductive.<sup>12</sup> Crusades

5. See *In re Guardianship of Schiavo*, 780 So. 2d 176, 178-80 (Fla. 2d Dist. Ct. App. 2001).

6. *Id.* at 180.

7. See *id.* In a 2004 statement, Pope John Paul II asserted that medical nutrition and hydration are morally obligatory for patients in a persistent vegetative state ("PVS"). See Thomas A. Shannon & James J. Walter, *Implications of the Papal Allocution on Feeding Tubes*, HASTINGS CTR. REP., July-Aug. 2004, at 18.

8. See, e.g., Christopher J. Gearon, *A Matter of Life and Death: Schiavo Case Spurs More Americans to Weigh Living Wills*, AARP BULL., Dec. 2003, available at <http://www.aarp.org/bulletin/yourhealth/Articles/a2003-12-09-livingwill.html>.

9. *Id.*

10. Connie Prater, *Schiavo Case Increases Interest in Living Wills*, MIAMI HERALD, Oct. 27, 2003, at 1A.

11. Janet Kornblum, *Living Wills Make the Scene*, USA TODAY, Apr. 28, 2005, at 8D, available at 2005 WLNR 6652811.

12. It is not even clear that a living will would have prevented the *Schiavo* dispute. Disagreement between Michael Schiavo and the Schindlers about other dimensions of Terri Schiavo's situation, such as her level of awareness and prognosis, could have made this a

to promote living wills ignore an impressive body of empirical research demonstrating this device's practical shortcomings.<sup>13</sup> Despite numerous campaigns and other promotional efforts, relatively few people issue specific instructions about their life-sustaining treatment preferences.<sup>14</sup> Those who do express their preferences tend to make general statements that often fail to resolve the actual treatment questions that later arise.<sup>15</sup> Unless someone is facing a life-threatening illness with a predictable future course, advance choices are made without the information and understanding that characterize informed medical decisionmaking. Finally, data suggest that relatives and clinicians disregard preferences expressed in a patient's living will if they perceive a conflict with the patient's current welfare.<sup>16</sup> Indeed, in one study a majority of participants said they wanted their living wills overridden in certain circumstances.<sup>17</sup>

An emphasis on living wills also neglects other elements of good end-of-life care. Public messages seem to imply that living wills are the primary vehicle for individuals to achieve a "death with dignity."<sup>18</sup> But, whether one receives high-quality care at the end of one's life depends on the services and facilities one uses. In a medical system that emphasizes acute care, "rescue" measures, and cutting-edge science, the palliative care, support for caregivers, and other forms of low-tech assistance that help dying patients and their families are not always available. A living will cannot furnish a good death when care is inadequate.

In sum, living wills can be useful in helping families and clinicians address treatment decisions. Given the complexities of medical care,

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contentious case even if she had made a living will. Although living wills might reduce the chance of a later family dispute, it is misleading to suggest that they can guarantee family harmony about an incapacitated relative's end-of-life care. See Rebecca Dresser, Schiavo: *A Hard Case Makes Questionable Law*, HASTINGS CTR. REP., May-June 2004, at 9.

13. See James Q. Wilson, *Killing Terri*, WALL ST. J., Mar. 21, 2005, at A16 ("[S]cholars have shown that we have greatly exaggerated the benefits of living wills. Studies by University of Michigan professor Carl Schneider and others have shown that living wills rarely make any difference. People with them are likely to get exactly the same treatment as people without them, possibly because doctors and family members ignore the wills. And ignoring them is often the right thing to do, because it is virtually impossible to write a living will that anticipates and makes decisions about all of the many, complicated, and hard to foresee illnesses you may face.").

14. TAKING CARE, *supra* note 4, at 71.

15. Wilson, *supra* note 13.

16. *Id.*

17. TAKING CARE, *supra* note 4, at 72. For extensive discussion of the issues touched on in this paragraph, see *id.* at 53-93, and Angela Fagerlin & Carl Schneider, *Enough: The Failure of the Living Will*, HASTINGS CTR. REP., Mar.-Apr. 2004, at 30-42. There are ethical questions, too, about whether a person's partially informed preferences as a healthy individual should control future treatment as an incapacitated patient. See Rebecca Dresser, *Precommitment: A Misguided Strategy for Securing Death with Dignity*, 81 TEX. L. REV. 1823, 1837-41 (2003).

18. Wilson, *supra* note 13.

however, advance instructions are seldom the sole basis for such decisions. Living wills are only one component of end-of-life planning, and planning is just one component of good end-of-life care. Thus, a narrow focus on promoting living wills is an inadequate response to improving end-of-life decisionmaking. To be responsive to patients and families, state and national policies must address treatment situations' multifaceted elements without narrowly focusing on living wills.

### B. *The Quality-of-Life Myth*

People who endorsed continuing Terri Schiavo's life-sustaining treatment focused on the quality-of-life judgment implicit in the decision. Most physicians examining her said that she was permanently unconscious but could live for many years if nutrition and hydration were continued.<sup>19</sup> Because she had no progressive terminal illness, the choice to forgo treatment depended on the judgment that life in her condition was not worth living. These treatment proponents found it particularly problematic that the courts would permit withdrawal of nutrition and hydration.<sup>20</sup> The proponents felt that if a patient could be deprived of these basic measures on grounds that her life was of insufficient value, there was little to distinguish American medicine from Nazi Germany's euthanasia program for people with mental disabilities.<sup>21</sup>

Conservative publisher and commentator William Federer defended this position. Writing on the organization Priests for Life's Web site, he described how Nazi mass killings first targeted people the state characterized as having a poor quality of life.<sup>22</sup> Although Nazi doctors and government officials claimed that the euthanasia program would relieve patients' suffering, their actual motivations were economic and

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19. See *In re Guardianship of Schiavo*, No. 90-2908-GB-003, 2002 WL 31817960, at \*2-5 (Fla. 6th Cir. Ct. Nov. 22, 2002) (three of five physicians testifying at the evidentiary hearing said Terri Schiavo was in a PVS); JAY WOLFSON, A REPORT TO GOVERNOR JEB BUSH AND THE SIXTH JUDICIAL CIRCUIT IN THE MATTER OF THERESA MARIE SCHIAVO (2003), available at <http://abstract.appeal.com/schiavo/WolfsonReport.pdf>.

20. See, e.g., Wilson, *supra* note 13.

21. *Id.* ("What is lacking in this matter is not the correct set of jurisdictional rules but a decent set of moral imperatives. That moral imperative should be that medical care cannot be withheld from a person who is not brain dead and who is not at risk for dying from an untreatable disease in the near future. To do otherwise makes us recall Nazi Germany where retarded people and those with serious disabilities were 'euthanized' (that is, killed).").

22. William Federer, *The Court-Ordered Death of Terri Schiavo*, PRIESTS FOR LIFE, Oct. 17, 2003, <http://priestsforlife.org/euthanasia/townhall.htm> ("The Nuremberg trials, exposing the horrible Nazi war crimes, revealed that Germany's trend toward atrocity began with their progressive embrace of the Hegelian doctrine of 'rational utility,' where an individual's worth is in relation to their contribution to the state, rather than determined in light of traditional moral, ethical and religious values.").

eugenic.<sup>23</sup> According to Federer, the court decisions permitting withdrawal of Terri Schiavo's feeding tube reflected a similar philosophy.<sup>24</sup>

Writing in the *Wall Street Journal*, political scientist James Q. Wilson also saw a parallel to Nazi practices.<sup>25</sup> Wilson said that the United States should adopt a rule "that medical care cannot be withheld from a person who is not brain dead and who is not at risk for dying from an untreatable disease in the near future."<sup>26</sup> Without such a rule, this nation would too closely resemble "Nazi Germany where retarded people and those with serious disabilities were 'euthanized' (that is, killed)."<sup>27</sup>

Some critics portrayed the decision to withdraw Terri Schiavo's treatment as cold-blooded and cruel. For example, Wisconsin Congressman James Sensenbrenner said that forgoing nutritional support would be "nothing short of inhumane."<sup>28</sup> In a similar vein, an Operation Rescue spokesman explained the group's protest as follows: "We're not going to stand idly by while she is starved to death. . . . This wouldn't happen to a dog; you wouldn't do it to your pet."<sup>29</sup>

Other critics emphasized that Terri Schiavo's own views on quality of life were unclear. One such critic, former Congressman Tom DeLay, stated, "[i]t's not for any one of us to decide what her quality of life should be. It's not for any one of us to decide whether she should live or die."<sup>30</sup> DeLay was also skeptical of Michael Schiavo's claims about Terri Schiavo's former preferences: "[U]nless she had specifically written instructions in her hand and with her signature, I don't care what her husband says."<sup>31</sup>

Commentator John Leo took a similar position, arguing that *Schiavo* represented a departure from previous end-of-life policies:

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23. *Id.*

24. *Id.* ("Will America chose [sic] the 'sanctity of life' concept, as demonstrated by Mother Teresa, or will America chose [sic] the 'quality of life' concept, championed by self-proclaimed doctors of death court decisions – such as in the case of Terri Schiavo – and continue its slide toward Auschwitz? What kind of subtle anesthetic has been allowed to deaden our national conscience? What horrors await us? The question is not whether the suffering and dying person's life should be terminated, the question is what kind of nation will we become if they are? Their physical death is preceded only by our moral death!").

25. See Wilson, *supra* note 13.

26. *Id.*

27. *Id.*

28. Alisa Ulferts, Anita Kumar & William R. Levesque, *U.S. House Acts to Save Schiavo*, ST. PETERSBURG TIMES, Mar. 17, 2005, at 1A, available at [http://www.sptimes.com/2005/03/17/Tampabay/US\\_House\\_acts\\_to\\_save.shtml](http://www.sptimes.com/2005/03/17/Tampabay/US_House_acts_to_save.shtml).

29. Manuel Roig-Franzia, *Another Hearing Set in Right-to-Die Case*, WASH. POST, Feb. 23, 2005, at A2, available at <http://www.washingtonpost.com/wp-dyn/articles/A45357-2005Feb22.html>.

30. William Saletan, *Deathbed Conversion: The Lesson of Tom DeLay's Mortal Hypocrisy*, SLATE, Mar. 28, 2005, <http://www.slate.com/id/2115879/>.

31. *Id.*

Once we had a bright line between pulling the plug on patients being kept alive by life support systems and killing people like Terri Schiavo, who are not on life support but merely being fed through a tube. Requiring clear evidence of consent is no longer required. In the *Schiavo* case, we have vaguely remembered consent from a party with a vested interest (the husband) some eight years after the patient was stricken.<sup>32</sup>

These speakers and writers raised legitimate moral questions about decisions to forgo treatment regarding incapacitated patients, but they were disingenuous in acting as though the *Schiavo* case broke new substantive ground. For many years, courts and legislatures have authorized surrogates to make just these sorts of decisions.<sup>33</sup> Terri Schiavo was simply the latest in a series of incapacitated patients whose diminished quality of life was a factor in the decision to forgo life support.

Seventeen years ago, the U.S. Supreme Court explicitly addressed the question of nutrition and hydration for another permanently unconscious woman, Nancy Cruzan.<sup>34</sup> In *Cruzan*, a five-justice majority of the Court held that the federal Constitution allows states to mandate continued life-sustaining treatment for incapacitated patients unless there is clear and convincing evidence that the patient would refuse such treatment.<sup>35</sup> At the same time, Justice O'Connor stated in a concurrence that the Constitution allows states to devise more lenient rules to govern this difficult area.<sup>36</sup> According to Justice O'Connor, states may permit non-treatment when less than clear and convincing evidence exists about a patient's previous beliefs and preferences.<sup>37</sup> Indeed, a Missouri trial court allowed withdrawal of Cruzan's feeding tube based on evidence that fell short of an explicit and formal treatment refusal.<sup>38</sup>

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32. John Leo, *Schiavo Scandal Indicates Low State of Bioethics*, UEXPRESS.COM, Mar. 27, 2005, [http://www.uepress.com/johnleo/index.html?uc\\_full\\_date=20050327](http://www.uepress.com/johnleo/index.html?uc_full_date=20050327) (emphasis supplied).

33. See generally Alan Meisel, *Suppose the Schindlers Had Won the Schiavo Case*, 61 U. MIAMI L. REV. 733 (2007).

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

35. *Id.* at 282.

36. *Id.* at 292 (O'Connor, J., concurring).

37. See *id.* ("the more challenging task of crafting appropriate procedures for safeguarding incompetents' liberty interests is entrusted to the 'laboratory' of the States").

38. In his book about the case, the Cruzans' attorney describes conversations between Nancy Cruzan and coworkers during the 1970s. Because these coworkers did not contact the family until after the initial trial, this testimony became available only after the U.S. Supreme Court's ruling. At the time the conversations occurred, Ms. Cruzan was working as an aide in a school for severely disabled children. One of her duties was to care for a profoundly impaired child. According to the coworkers, Nancy Cruzan referred to the child as a "vegetable" and said that she would not want to be tube-fed in such a condition. On remand, the trial judge found that these remarks constituted clear and convincing evidence that Nancy Cruzan would have chosen to forgo nutritional support in her then-current state. See WILLIAM H. COLBY, *LONG GOODBYE: THE DEATHS OF NANCY CRUZAN* 333-36 (2002).



*Cruzan* and *Schiavo* involved patients diagnosed as completely unaware, patients who would never be able to participate in any form of human interaction. Legal authorities have recognized a legitimate role for quality-of-life judgments in treatment decisionmaking for conscious incompetent patients as well. If treatment interventions would impose severe burdens and offer little benefit to patients, courts and legislatures permit non-treatment.<sup>39</sup> Implicit in this approach is the judgment that a painful or distressing intervention may sustain life, but may also make that life too burdensome for the impaired individual. Rulings like this contradict claims that the court decisions in *Schiavo* were deviant in allowing quality of life to influence the treatment outcome.

At the same time, however, proponents of continuing Terri Schiavo's life-sustaining treatment were not the only group making questionable assertions about quality-of-life decisions' proper place regarding incapacitated patients. Few people defending the Florida courts' *Schiavo* rulings acknowledged the troubling aspects of allowing such judgments to support end-of-life choices. This feature of the debate disturbed both disabled persons and their families.

Disabled persons raised concerns about remarks healthy individuals were making regarding Terri Schiavo's quality of life.<sup>40</sup> Disability advocates said their experiences had helped them appreciate the value of life with physical and mental limitations.<sup>41</sup> Some said they identified with Terri Schiavo, in that they shared what outsiders viewed as a low quality of life.<sup>42</sup> Their personal knowledge led them to question whether Terri Schiavo was as impaired as most of the doctors said she was and whether she would have actually supported the decision to withdraw treatment.<sup>43</sup> A societal judgment that Terri Schiavo's life was not worth living made other disabled people fear that they were more vulnerable to care and treatment denials.<sup>44</sup> As one advocate put it, "[a]mong the disability rights community, it is a generally heard belief that in society at

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39. See, e.g., *In re Conroy*, 486 A.2d 1209 (N.J. 1985). In this case, the New Jersey Supreme Court articulated a rule allowing life-sustaining treatment to be withheld or withdrawn if there is some indication that the patient would refuse, and "it is clear that the burdens of the patient's continued life with the treatment outweigh the benefits of that life for him." *Id.* at 1232. If there is no evidence that the patient would refuse, treatment may still be forgone if "the recurring, unavoidable and severe pain of the patient's life with the treatment [is] such that the effect of administering life-sustaining treatment would be inhumane." *Id.*

40. Ceci Connolly, *Schiavo Raised Profile of Disabled*, WASH. POST, Apr. 2, 2005, at A9, available at <http://www.washingtonpost.com/wp-dyn/articles/A19752-2005Apr1.html>.

41. *Id.*

42. *Id.*

43. *Id.*

44. *Id.*

large the view is 'better dead than disabled.'"<sup>45</sup>

Disability rights attorney Harriet McBryde Johnson presented an especially compelling account of these concerns.<sup>46</sup> Johnson has a neuromuscular disease that will at some point require her to use a feeding tube.<sup>47</sup> This condition might also deprive her of the ability to speak.<sup>48</sup> In contrast to many commentators, Johnson supported Congress' decision to intervene in *Schiavo*.<sup>49</sup> In her view, federal court review of state court decisions was justified.<sup>50</sup> She argued that strong safeguards are needed when disabled persons are unable to make their own medical choices.<sup>51</sup> Federal court review could help ensure that "state courts are not tainted by prejudices, myths, and unfounded fears – like the unthinking horror in mainstream society that transforms feeding tubes into fetish objects, emblematic of broader, deeper fears of disability that sometimes slide from fear to disgust and from disgust to hatred."<sup>52</sup>

Relatives of people with disabilities also spoke out about the quality-of-life issues. For example, law professor Marjorie Shultz commented on *Schiavo* in light of her own experience as the mother of a patient who recovered consciousness after three months in a vegetative state.<sup>53</sup> As a parent, she was dismayed at hearing her son described as "vegetative" and disturbed by what she believed were "inappropriate levels of certainty" exhibited by "designated experts" making the diag-

45. *Id.* (quoting William G. Stothers, Deputy Director of the Center for an Accessible Society).

46. Harriet McBryde Johnson, *Not Dead at All: Why Congress Was Right to Stick Up for Terri Schiavo*, SLATE, Mar. 23, 2005, <http://www.slate.com/id/2115208>.

47. *Id.*

48. *Id.*

49. *Id.*; see An Act for the Relief of the Parents of Theresa Marie Schiavo, Pub. L. No. 109-3, 119 Stat. 15 (2005).

50. Johnson, *supra* note 46.

51. *Id.*

52. *Id.* Some liberal members of Congress, such as Senator Tom Harkin, agreed with the need for a federal review proceeding. See Sheryl Gay Stolberg, *Lawmakers Ready to Again Debate End-of-Life Issues*, N.Y. TIMES, Mar. 28, 2005, at A1, available at 2005 WLNR 4818185 ("In the Senate, Tom Harkin, Democrat of Iowa, has also been consulting with advocates for disability rights and is preparing to introduce legislation along the lines of the bill that the House passed, a spokeswoman said. Senator Harkin, an author of the Americans With Disabilities Act, was one of the few Democrats in the Senate who spoke in favor of the so-called private relief measure that allowed a federal court to review Ms. Schiavo's case.").

53. Barry Bergman, *An Ethical Postmortem on the Schiavo Case*, BERKELEYAN, May 4, 2005, available at [http://www.berkeley.edu/news/berkeleyan/2005/05/04\\_schiavo.shtml](http://www.berkeley.edu/news/berkeleyan/2005/05/04_schiavo.shtml) ("To me, the import of *Schiavo* has to do with the difference between expert opinion about abstracted rules on the one hand, and a more lay, intuitive, experiential, feeling-oriented sense of what is going on in relation to a case like [Terri Schiavo's], said [Boalt Hall Professor of Law Marjorie] Schulz, observing that 'the public at large did not much participate' in the conversations that supposedly 'settled' key bioethical questions.'").

nosis.<sup>54</sup> She also questioned claims that there was a clear consensus on ethical approaches to treating vegetative patients.<sup>55</sup> Shultz called for more humility among clinicians evaluating brain-injured patients and more public participation in bioethics discussions about acceptable treatment decisions for patients like Terri Schiavo.<sup>56</sup>

Much of the public commentary surrounding *Schiavo* fell into one of two extremes: either (1) condemning or (2) endorsing the role of quality-of-life judgments in end-of-life decisions. A few writers, however, expressed reservations about each extreme. For example, columnist William Raspberry wrote:

We might agree as a matter of law that the recorded wishes of the person whose death is at issue ought to be determinative. But it doesn't really carry us through the deeper moral questions. . . . [W]hat of the guy who doesn't wish to go on living without the girlfriend who left him? Does he have a right to die? To call on others to help him die? . . . The quality of life standard, I am saying, is not as reliable as some of us would like to believe. The question of ending life – of which life is not worth prolonging – is never easy, nor should it ever become easy.<sup>57</sup>

David Brooks of the *New York Times* also found fault with each extreme. He rejected the position that quality-of-life judgments are always inappropriate, noting that with today's technology "there are people living forms of existence that upon direct contact do seem even worse than death."<sup>58</sup> Yet he also rejected the moral relativism implicit in the view that individuals and families should have complete discretion to decide when life is worth living: "Once you say that it is up to individuals or families to draw their own lines separating life from existence, and reasonable people will differ, then you are taking a fundamental issue out of the realm of morality and into the realm of relativism and mere taste."<sup>59</sup>

Legal authorities, too, are divided on how quality of life should affect treatment decisions. Some courts have agreed with Tom DeLay and John Leo that decisions to forgo treatment involving patients with severe brain damage implicate quality-of-life judgments that must come from the patients themselves. This was the Missouri Supreme Court's

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54. *Id.*

55. *Id.*

56. *Id.*

57. William Raspberry, Editorial, *Whose Life Are We Supporting?*, WASH. POST, Mar. 28, 2005, at A17, available at <http://www.washingtonpost.com/wp-dyn/articles/A5758-2005Mar27.html>.

58. David Brooks, Editorial, *Morality and Reality*, N.Y. TIMES, Mar. 26, 2005, at A13, available at 2005 WLNR 4743835.

59. *Id.*

decision in *Cruzan*,<sup>60</sup> although the U.S. Supreme Court said Missouri was constitutionally free to choose between either deferring to the patient's wishes or allowing close family members to decide.<sup>61</sup> When a patient's previous wishes are unclear, Chief Justice Rehnquist wrote, "we think a State may properly decline to make judgments about the 'quality' of life that a particular individual may enjoy, and simply assert an unqualified interest in the preservation of human life to be weighed against the constitutionally protected interests of the individual."<sup>62</sup> And, when patients are conscious, but afflicted by Alzheimer's disease, stroke, or brain injury, several state supreme courts have demanded clear and convincing evidence of an individual's prior wishes before allowing non-treatment.<sup>63</sup>

The mixed rulings in these cases express our nation's ambivalence and uncertainty about quality-of-life judgments' proper place in treatment decisions concerning patients incapable of independent choice. Although clinicians and officials commonly acknowledge that quality of life plays a role in decisions to forgo life-sustaining treatment, the acceptable boundaries of this role remain uncertain. To develop adequate policies on end-of-life care for incapacitated patients, more national debate about where to place these boundaries is necessary.

### C. *The Life Extension Myth*

One major point of contention in *Schiavo* was whether medical interventions could improve the patient's brain function. Early on, "following months of therapy and testing," Michael Schiavo took his wife to California to try "an experimental thalamic stimulator implant in her brain."<sup>64</sup> Afterwards, they returned to Florida where clinicians continued "regular and aggressive physical, occupational, and speech therapy."<sup>65</sup> Apparently, all of these measures were ineffective, and Terri Schiavo's failure to improve contributed to her husband's conclusion that continued life was of no value to her.

Terri Schiavo's parents, on the other hand, wanted to continue the search for an effective treatment, and certain physician-entrepreneurs reinforced the wisdom of this search. At a 2002 hearing, two physicians

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60. *Cruzan v. Harmon*, 760 S.W.2d 408, 426 (Mo. 1988), *aff'd sub nom. Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261 (1990).

61. *Cruzan*, 497 U.S. at 286-287.

62. *Id.* at 282.

63. See generally Rebecca Dresser, *The Conscious Incompetent Patient*, HASTINGS CTR. REP., May-June 2002.

64. WOLFSON, *supra* note 19, at 9.

65. *Id.*

testified that further treatment interventions could help this patient.<sup>66</sup> Each physician claimed he could provide Terri Schiavo with therapy that would “significantly improve her quality of life.”<sup>67</sup> One doctor said that Terri Schiavo could benefit from hyperbaric therapy.<sup>68</sup> But, three other physicians said they had never referred brain-injured patients in Terri Schiavo’s condition for this treatment and predicted it would have no effect.<sup>69</sup> Another physician-witness described an intervention called vasodilatation therapy that he offered on a fee-for-service basis at a clinic he operated.<sup>70</sup> However, as the judge noted, that form of intervention “is not recognized in the medical community.”<sup>71</sup> No witness could produce case studies or other published reports suggesting that hyperbaric or vasodilatation therapy would benefit a patient with Terri Schiavo’s medical problems.

Like Terri Schiavo’s parents, others opposed to withdrawing treatment seized on claims that additional intervention could improve her condition. For example, John Kilner, President of the Center for Bioethics and Human Dignity, argued, “[i]f life truly is precious, then therapies that might make a significant difference ought to be tried . . . .”<sup>72</sup> Jay Wolfson, the guardian *ad litem* charged with reporting on the *Schiavo* litigation to Florida Governor Jeb Bush, observed:

In recent months, individuals have come forward indicating that there are therapies and treatments and interventions that can literally regrow Theresa’s functional, cerebral cortex brain tissue, restoring part or all of her functions. There is no scientifically valid, medically recognized evidence that this has been done or is possible, even in rats . . . . It is imaginable that some day such things may be possible; but holding out such promises to families of severely brain injured persons today may be a profound disservice.<sup>73</sup>

Sensationalism about both alternative therapies and early-stage laboratory discoveries makes some people reluctant to rule out the possibility that patients will recover despite a dismal prognosis. Faith in medical miracles is nothing new, but today’s journalists and scientists do

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66. *In re Guardianship of Schiavo*, No. 90-2908-GB-003, 2002 WL 31817960, at \*2 (Fla. 6th Cir. Ct. Nov. 22, 2002).

67. *Id.* at \*3.

68. *Id.* For a description and discussion of hyperbaric therapy, see Michael Neumeister, *Hyperbaric Oxygen Therapy*, eMEDICINE.COM, July 21, 2005, <http://www.emedicine.com/plastic/topic526.htm>.

69. *In re Guardianship of Schiavo*, 2002 WL 31817960, at \*4.

70. *Id.*

71. *Id.*

72. John Kilner, *The Schiavo Controversy: First Things First*, CTR. FOR BIOETHICS & HUMAN DIGNITY, Mar. 24, 2005, [http://www.cbhd.org/resources/endoflife/kilner\\_advanceddirective\\_2005-03-24\\_print.htm](http://www.cbhd.org/resources/endoflife/kilner_advanceddirective_2005-03-24_print.htm).

73. WOLFSON, *supra* note 19, at 31.

a lot to foment such faith. Vulnerable patients and families hear reports of lifesaving cures on the horizon, and this only adds to their preexisting hopes for an escape from death.<sup>74</sup> Media and Internet-based claims about unproven interventions involving stem cells, gene therapy, and the emerging field of “regenerative medicine” create a fertile environment for beliefs akin to those the Schindlers entertained regarding their daughter, Terri Schiavo.<sup>75</sup>

The myths about living wills, quality of life, and miracle cures shaped public perceptions of the *Schiavo* case. Writers and speakers brought their preexisting views to bear in their *Schiavo* commentary. Unfortunately, much of the commentary perpetuated misconceptions about end-of-life care in contemporary America. In this sense, the *Schiavo* public debate had a detrimental impact on the nation’s attitudes toward death and dying.

### III. OTHER PORTRAITS OF DEATH, PRESENT AND FUTURE

Commentary on the *Schiavo* case was just one piece of a larger body of American literature on death and dying. In 2005, other writers offered their thinking on these topics, including some who were contemplating human mortality from widely different vantage points. These writers were influenced by the same myths that influenced the *Schiavo* debate, but for the most part, they also displayed a deep and rich understanding of medicine and the meaning of death.

#### A. *Joan Didion’s The Year of Magical Thinking*

Joan Didion delivered a searing account of what it was like to lose her husband, John Gregory Dunne, to heart disease. At the beginning of her book, she implied that her husband’s death was unexpected, “a sudden massive coronary event.”<sup>76</sup> Didion described with breathtaking immediacy the shock of the sudden death: “Life changes fast. Life changes in the instant. You sit down to dinner and life as you know it ends.”<sup>77</sup>

Gradually, however, Didion revealed that she had many warnings of her husband’s impending death. The heart disease was not new and her husband had a pacemaker implanted the previous year. Later, she

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74. See generally REBECCA DRESSER, *WHEN SCIENCE OFFERS SALVATION: PATIENT ADVOCACY AND RESEARCH ETHICS* 129-50 (2001).

75. Indeed, stem cells were “discussed at great length” at the 2002 *Schiavo* hearing, although the judge noted that “one of the few agreements between these experts is that stem cell research is currently at the experimental stage and is years away from being accepted either medically or politically.” *In re Guardianship of Schiavo*, 2002 WL 31817960, at \*3.

76. DIDION, *supra* note 1, at 7.

77. *Id.* at 3.

recalled that as long ago as the 1980s,<sup>78</sup> his doctor told him that he “was a candidate for a catastrophic cardiac event.”<sup>79</sup> Indeed, his condition was labeled “the widow-maker.”<sup>80</sup> Although he underwent angioplasty, he predicted that the condition would eventually kill him.<sup>81</sup> But, until his death, Didion had “[e]ither . . . not remembered this or . . . had determinedly chosen not to remember this.”<sup>82</sup>

Her husband also tried to prepare her for his death. “He believed he was dying. He told [her] so, repeatedly. [Didion] dismissed this.”<sup>83</sup> In short, the threat of her loved one’s death was there all along – as it is for everyone to some degree. But, like many of us, Didion found that threat impossible to accept.

Didion also helps us to understand why she – and we – avoid facing death. The grief is unbearable. Without sugarcoating or resorting to euphemism, she described real grief.<sup>84</sup> Real grief is paralyzing; it has intense physical effects.<sup>85</sup> It is so overpowering that “magical thinking” occurs.<sup>86</sup> Didion found herself “thinking as small children think, as if [her] thoughts or wishes had the power to reverse the narrative, change the outcome.”<sup>87</sup> For example, on the night of her husband’s death, she “needed to be alone so that he could come back.”<sup>88</sup>

Grief imposed another burden on Didion, the belief that she should have done something to prevent this catastrophic event. After her husband’s death, she was “increasingly fixed on locating the anomaly that could have allowed this to happen.”<sup>89</sup> Later, she realized, “[she] was not however operating from [her] rational mind.”<sup>90</sup> During this time, Didion was coping with a second family tragedy, her only child’s serious and ultimately fatal illness.<sup>91</sup> She felt somehow responsible for this disaster as well. In this case, she had failed to act as a parent should. Didion eventually realized that her “basic promise” to her daughter was in fact “a promise [she] could not keep. [She] could not always take care of her [daughter].”<sup>92</sup>

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78. *Id.* at 147-48.

79. *Id.* at 155.

80. *Id.* at 157.

81. *Id.*

82. *Id.* at 155.

83. *Id.* at 78.

84. *Id.* at 26-28.

85. *Id.* at 27-28.

86. *Id.* at 33.

87. *Id.* at 35.

88. *Id.* at 33.

89. *Id.* at 204.

90. *Id.* at 205.

91. *See id.* at 83-88.

92. *Id.* at 96.

Didion also portrayed the social separation that comes with grief. After her husband died, she felt “invisible” to most of the world: “[She] seemed to have crossed one of those legendary rivers that divide the living from the dead, entered a place in which [she] could be seen only by those who were themselves recently bereaved.”<sup>93</sup>

Didion did not have the luxury of disappearing, however, for she still had to watch over her severely ill daughter. Rather than attempting to cross into Didion’s world of grief, many of the people she knew offered her their “management skills.”<sup>94</sup> These people, she wrote, “believed absolutely in the power of the telephone numbers they had at their fingertips, the right doctor, the major donor.”<sup>95</sup> Yet Didion herself saw that managing this crisis was impossible; that what she was enduring was largely out of her hands. Because she was “born fearful,” she knew intuitively that “some events in life would remain beyond [her] ability to control or manage them. Some events would just happen. This was one of those events.”<sup>96</sup>

Didion’s story is full of raw pain, but it offers wit and irony as well. These emerge most often in her criticism of the medical system. For example, she noted that her daughter, Quintana, received a new drug called Xigris for septic shock.<sup>97</sup> A nurse told Didion that the Eli Lilly drug cost \$20,000.<sup>98</sup> Curious about the medication, Didion went to the Internet. There she found a reported survival rate of 69% for sepsis patients given Xigris and a 56% survival rate for patients given other interventions.<sup>99</sup> Didion also found a business report on Xigris, which “said that Eli Lilly’s ‘sleeping giant’ was ‘struggling to overcome its problems in the sepsis market.’”<sup>100</sup> To Didion,

[t]his seemed in some ways a positive prism through which to view the situation: Quintana was not the child who had been a deliriously happy bride five months before and whose chance of surviving the next day or two could now be calibrated at a point between 56 and 69 percent, she was “the sepsis market,” suggesting that there was still a

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93. *Id.* at 75. In this discussion, Didion referenced a classic work by historian PHILIPPE ARIÈS, *WESTERN ATTITUDES TOWARD DEATH: FROM THE MIDDLE AGES TO THE PRESENT* (Patricia M. Ranum trans., Johns Hopkins Univ. Press 1974). Ariès examined a shift that occurred during the 1930s; before that time, death was accepted as part of ordinary experience. Didion writes, quoting Ariès, that after that period death was transformed into an unusual, “shameful and forbidden” event. DIDION, *supra* note 1, at 60. In turn, grief was increasingly seen as a private matter, not to be imposed on others. *Id.*

94. DIDION, *supra* note 1, at 98.

95. *Id.*

96. *Id.*

97. *Id.* at 65.

98. *Id.*

99. *Id.*

100. *Id.*



consumer choice to be made.<sup>101</sup>

Didion also noticed odd gaps between everyday language and the way clinicians talk. One day, for example, a physician's assistant told her that he was encouraged about Quintana's condition.<sup>102</sup> When the worried mother, eager for good news, asked why, he explained that he had not expected Quintana to be alive when he came in that day.<sup>103</sup> In the midst of Quintana's surgery, a doctor emerged to deliver the good news that the team expected her to "leave the [operating] table."<sup>104</sup> But, this confused Didion: did they mean that Quintana would be alive when she left the table?<sup>105</sup>

*The Year of Magical Thinking* touches on many dimensions of the *Schiavo* controversy, but in a separate 2005 piece, Didion directly addressed the case. Of course, she saw the case through the lens of her own ordeal. Two of her comments are noteworthy. First, Didion wondered about the significance of Terri Schiavo's former statements about life-sustaining treatment, some reportedly made while watching a television movie. Didion wrote:

Imagine it. You are in your early twenties. You are watching a movie, say on Lifetime, in which someone has a feeding tube. You pick up the empty chip bowl. "No tubes for me," you say as you get up to fill it. What are the chances you have given this even a passing thought?<sup>106</sup>

Second, Didion called for more openness about the quality-of-life questions underlying the *Schiavo* controversy. In her view, the central moral argument in the case, "whether, when it comes to life and death, any of us can justifiably claim the ability or the right to judge the value of any other being's life[,] remained largely unexpressed."<sup>107</sup> Didion criticized the opposing sides for engaging in name-calling and other forms of intolerance, instead of confronting the core question, which "had ultimately to do with whether . . . there could be occasions when the broad economic and ethical interests of the society at large should outweigh any individual claim to either the most advanced medical attention . . . or indefinite care."<sup>108</sup>

In sum, Didion's position was that remarks about a future state of

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101. *Id.*

102. *Id.* at 66.

103. *Id.*

104. *Id.* at 92.

105. *Id.*

106. Joan Didion, *The Case of Theresa Schiavo*, N.Y. REV. OF BOOKS, June 9, 2005, available at <http://www.nybooks.com/articles/18050>.

107. *Id.*

108. *Id.*

illness constitute a limited and, in some cases, an uninformed attempt to gain power over events that are often unmanageable. More broadly, nature imposes severe limits on our ability to control how and when we die. Didion refused to turn a blind eye to the quality-of-life judgments others inevitably make in decisions about how to care for incapacitated patients. Didion also demonstrated that while extended life spans may be fun to dream about, people today cannot avoid the painful reality that their loved ones will die, that they may die in horrible, unpredictable ways, and that there is no escape from this almost unbearable fact. And she beautifully expressed how difficult it can be for a parent to experience and accept losing a child.

### B. *Marjorie Williams' Hit by Lightning: A Cancer Memoir*

Marjorie Williams was a well-respected journalist who died of liver cancer in 2005. After her death, her husband edited a collection of her essays, including a previously unpublished piece on her four-year experience with terminal illness. Williams used down-to-earth terms to describe what it was like to confront mortality. At first, she “felt weirdly like an actor in a melodrama.”<sup>109</sup> There were highs and lows in this melodrama. After her diagnosis, she enjoyed thinking of the upsides: no taxes to pay, no Department of Motor Vehicle hassles, no coping with teenaged children. She wrote, “I won’t have to be human, in fact, with all the error and loss and love and inadequacy that come with the job. I won’t have to get old.”<sup>110</sup> Williams also had a few surprisingly practical reactions. She purchased a new car, but registered it in her husband’s name so that any future sale would be easier for him.<sup>111</sup> She requested a cheaper version of some recommended dental work because “it would be foolish to sink four thousand dollars into . . . infrastructure at this point.”<sup>112</sup>

But, most of her thoughts were about the basics of human existence. She spent her time doing the “lonely work” of “facing my death and loving my life.”<sup>113</sup> She was thankful for “the chance to rise and rise to life’s generosity.”<sup>114</sup> And yet she also felt bitter toward the people around her who were blissfully unaware of how and when they would die. “I resent you,” she wrote, “for the fact that you may never even

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109. WILLIAMS, *Hit by Lightning: A Cancer Memoir*, in *THE WOMAN AT THE WASHINGTON ZOO*, *supra* note 2, at 320.

110. *Id.* at 323.

111. *Id.* at 321-22.

112. *Id.* at 322.

113. *Id.* at 323.

114. *Id.* at 322.

catch sight of the blade assigned to you.”<sup>115</sup> Sometimes, she was simply gripped by “horror, that most elementary thing.”<sup>116</sup>

Williams’ discussion of hope is complicated and full of apparent contradictions. She reported “nurturing a garden of eleven or twelve different varieties of hope.”<sup>117</sup> One hope was unrealistic: to attain the cure that the medical evidence ruled out. Because of that hope, she “never thought of refusing treatment.”<sup>118</sup> That hope also impelled her to criticize certain physicians for being so insistent about her dismal prognosis and to praise the one doctor who was willing to talk about prognostic error.<sup>119</sup>

Her hope to beat the odds also drove her to use personal connections to secure appointments with top physicians. She felt guilty about this for she knew that other people would not have these options. At the same time, she asserted, “when your own time comes you will pull pretty much every string available to get what you need.”<sup>120</sup> She also noted that her contacts were not always effective because a lot of other cancer patients were attempting to pull the same strings. When her husband asked one doctor whether she could access a promising experimental drug, the doctor responded that there was no chance. “This is Washington. Everyone thinks they can be the exception,” the doctor said. “But the lists for the kind of treatment you’re talking about are ten thousand long.”<sup>121</sup>

Williams refused to relinquish her “right to hope for the best,”<sup>122</sup> but she also refused to count on a miracle. She turned down an academic physician who tried to “sell me on a phase I clinical trial from which I couldn’t possibly profit.”<sup>123</sup> She declined because her optimism had to have some basis in reality: “I don’t want to end my life in some hospital barfing in the name of science. I mean it: I want to be realistic about what’s happening to me.”<sup>124</sup> She was furious at people who suggested that she would live, feeling that they were dismissing her hard-won progress in accepting her death. Williams admitted to harboring unrealistic hope, but she also wrote, “[f]orced into a corner, I’ll choose truth over hope any day.”<sup>125</sup>

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115. *Id.*

116. *Id.*

117. *Id.* at 323.

118. *Id.* at 335.

119. *Id.* at 337.

120. *Id.* at 324-25.

121. *Id.* at 332.

122. *Id.* at 337.

123. *Id.* at 326.

124. *Id.*

125. *Id.* at 338.

Williams had high praise for some of her doctors, especially the ones who became her advocates:

There is nothing like having a doctor who really cares about you – who can cut through the inhuman pace of medical time, which usually leaves patients begging to hear their test results, waiting too many days for an appointment, at a loss until the conveyor belt brings along the next hurried intervention.<sup>126</sup>

Yet like Didion, Williams was confused and enraged by the actions of other clinicians. Williams relayed a chilling account of her missed cancer diagnosis, due to a mix-up in laboratory test results.<sup>127</sup> She also pointed out that there are many improper things to say to a seriously ill person and that for her, some of the most appalling remarks came from healthcare professionals.<sup>128</sup>

These encounters made Williams skeptical of doctors, and her feelings even affected her political views. She noted that she did not trust 2004 presidential candidate Dr. Howard Dean because of his profession. “Where else but in medicine,” she asked, “do you find men and women who never admit a mistake? Who talk more than they listen, and feel entitled to withhold crucial information? Whose lack of tact in matters of life and death might disqualify them for any other field?”<sup>129</sup>

Williams also wrote about her mother’s death, and in another essay, she wondered about the wisdom of seeking complete control over dying. She recognized that her mother had an “easy” death, but wrote that “even this short, kind end was excruciating to be a part of.”<sup>130</sup> The pain came because this “crucial passage . . . was so entirely beyond our control.”<sup>131</sup>

Though the lack of control was agonizing, Williams doubted whether more control would make things better. In contemplating the legalization of physician-assisted suicide, she began to wonder if human beings can really be trusted with the suggestion that there are ways to make the process manageable, to combat the losses of autonomy and control that are the essence of death. “You bear the unbearable, in the orbit of a loved one’s death, because you have to. If we come to believe that we and our families can sometimes be spared that, how many of us will be willing to endure it at all, under any circumstances?”<sup>132</sup> Williams refused to condemn individuals desperate enough to resort to

126. *Id.* at 317.

127. *Id.* at 324.

128. *Id.* at 336.

129. *Id.* at 346-47.

130. *Id.* at 248.

131. *Id.* at 249.

132. *Id.*

active measures, but she also opposed laws that permitted such measures: “[O]fficially, publicly, in the open realm where our norms develop, I hope we continue to honor the assumption that death is the one matter that is out of our hands.”<sup>133</sup>

Williams told a brave and brutally honest story about seeking a good and dignified end to her life. She mentioned her mother’s living will, but said nothing about having one herself. Instead, her death plans focused on practical concerns, such as “whether, with children so young, I was entitled to die at home.”<sup>134</sup> She was realistic and practical, but at some level she also hoped for a miracle in the face of impossible odds. For her, death and dying were bearable because she took on the tough psychological work of facing her mortality and because she had the care and support of loved ones and some good doctors. And, though she did benefit from modern medicine, living more than three years longer than the doctors first predicted, much of it was “wasted by the boredom and exhaustion and enforced stillness of treatment.”<sup>135</sup>

### C. *Ray Kurzweil’s The Singularity Is Near: When Humans Transcend Biology*

In his book, Ray Kurzweil presented quite a different vision of human mortality. Kurzweil is one of a collection of futurists who have recently announced that we are on the verge of enjoying a vastly extended life span.<sup>136</sup> Some of the progress will come from the new field of “regenerative medicine,” which enthusiasts say will allow people to obtain replacement tissue when aging impairs proper human functioning.<sup>137</sup> But Kurzweil predicted more spectacular achievements than do many of his colleagues. According to Kurzweil, we are on the verge of the “Singularity,” when “the pace of technological change will be so

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133. *Id.*

134. *Id.* at 334.

135. *Id.* at 331.

136. Stephen Hall describes people holding similar views in his work *MERCHANTS OF IMMORTALITY: CHASING THE DREAM OF HUMAN LIFE EXTENSION* (2003). *But see* S. JAY OLSHANSKY & BRUCE A. CARNES, *THE QUEST FOR IMMORTALITY: SCIENCE AT THE FRONTIERS OF AGING* 212 (2001) (“Futurists and prolongevity advocates claim that it is only a matter of time before aging and all of its accompanying diseases, disorders, and infirmities will be a thing of the past. They maintain that every person is born to be healthy; disease is a product of modern civilization and decadent lifestyles; and aging is just another disease waiting to be conquered. Have the prolongevists of today, with their vitamin supplements, hormones, and spirituality, really discovered the Fountain of Youth? Both history and science suggest that they have simply rediscovered the same old false claims and misleading promises used throughout history to exploit the desire of people to find youth in a bottle.”).

137. For a discussion of these predictions, see PRESIDENT’S COUNCIL ON BIOETHICS, *HUMAN CLONING AND HUMAN DIGNITY* 65-70 (2002), available at <http://www.bioethics.gov/reports/cloningreport/index.html>.

rapid, its impact so deep, that human life will be irreversibly transformed."<sup>138</sup>

This transformation will usher in incredible changes for humankind. Kurzweil wrote that the "Singularity will allow us to transcend . . . limitations of our biological bodies and brains. We will gain power over our fates. Our mortality will be in our own hands. We will be able to live as long as we want . . ."<sup>139</sup> According to Kurzweil, revolutionary advances in three fields will produce the changes.<sup>140</sup> First, discoveries in genetics are already enabling scientists to both understand and manipulate human biological processes.<sup>141</sup> As a result, Kurzweil claimed, "we are starting to learn to reprogram our biology to achieve the virtual elimination of disease, dramatic expansion of human potential, and radical life extension."<sup>142</sup> Kurzweil predicted that successes in gene therapy, therapeutic cloning, and drug and vaccine development will offer many opportunities to reverse aging.<sup>143</sup>

The second source of progress will involve medical applications of nanotechnology. In a few decades, Kurzweil predicted, physicians will be able to use nanobots, "small robots . . . that can travel inside the bloodstream," to "perform a broad variety of diagnostic and therapeutic functions."<sup>144</sup> The third major advance will involve both nanotechnology and artificial intelligence.<sup>145</sup> Kurzweil expressed a belief that these combined technologies will enable us to preserve the information that constitutes our identity and transfer it to a new home, one that could be either biological or non-biological.<sup>146</sup> He believed that "we will [eventually] gain the means of 'backing ourselves up' (storing the key patterns underlying our knowledge, skills, and personality), thereby eliminating most causes of death as we know it."<sup>147</sup>

Kurzweil thought that the benefits of these revolutions were within reach of people like him: "Sufficient information already exists today to slow down disease and aging processes to the point that Baby Boomers like myself can remain in good health until the full blossoming of the biotechnology revolution, which will itself be a bridge to the nanotechnology revolution."<sup>148</sup> Because he saw "disease and death at

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138. KURZWEIL, *supra* note 3, at 7.

139. *Id.* at 9.

140. *Id.* at 205-59.

141. *Id.* at 206-26.

142. *Id.* at 205.

143. *See id.* at 214-21.

144. *Id.* at 253-54.

145. *Id.* at 226-59.

146. *Id.* at 198-204, 323-26.

147. *Id.* at 323.

148. *Id.* at 210.

any age as a calamity, as problems to be overcome," he was doing everything he could to battle the aging process.<sup>149</sup> This included taking 250 pills and supplements daily and six intravenous nutritional supplements weekly.<sup>150</sup>

Kurzweil entertained no serious concerns about the future he foresaw. He had ample faith in technology to solve any problems, such as overpopulation, limited natural resources, and social inequalities in access to life-extending measures.<sup>151</sup> Kurzweil saw only the upside of the new world of human immortality; he expected that the "technology of the Singularity will provide practical and accessible means for humans to evolve into something greater, so we will no longer need to rationalize death as a primary means of giving life."<sup>152</sup>

In the world Kurzweil envisioned, no one will face the struggles that Didion and Williams described. The conflicts surrounding patients like Terri Schiavo will cease to exist because such patients' neural information will be available for downloading, thus enabling their restoration to the people they were before their brain injuries. Such a world is undeniably attractive, but it is so speculative that it would be unwise to buy into Kurzweil's vision. Moreover, Kurzweil's ideas offer no answers to the many short-term problems facing those who must decide how and when their incapacitated loved ones should die.

#### D. *The President's Council on Bioethics' Taking Care: Ethical Caregiving in Our Aging Society*

Rather than one person's conception of contemporary death and dying, this report contains the views of a group of people, primarily academic and medical professionals.<sup>153</sup> *Taking Care* begins by describing the coming demographic and social conditions that will make health and other supportive care a societal preoccupation.<sup>154</sup> Baby Boomers are living longer than previous generations did due to modern medicine's successes.<sup>155</sup> As they age, Baby Boomers will suffer from diseases that limit physical and mental functioning.<sup>156</sup> Many will face Alzheimer's disease, stroke, and other conditions that impair cogni-

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149. *Id.* at 210 (internal citation and quotations omitted).

150. *Id.* at 211.

151. *See id.* at 391-426.

152. *Id.* at 326.

153. For a list of Council members, see <http://www.bioethics.gov/about/members.html> (last visited Jan. 16, 2007).

154. *TAKING CARE*, *supra* note 4, at xvii-xix.

155. *Id.*

156. *Id.*

tion.<sup>157</sup> The number of frail elderly Americans unable to participate in medical choices will increase.

In *Taking Care*, the bioethics council joined other voices warning of a social and healthcare crisis that has yet to receive adequate attention.<sup>158</sup> Countless individuals will need long-term care, and they will need surrogates to make medical choices on their behalf. But our nation lacks the healthcare facilities and programs needed to serve this population.<sup>159</sup> Because families are small and dispersed, fewer patients will have close relatives to serve as surrogates.<sup>160</sup>

*Taking Care* offers a detailed analysis of the medical decisionmaking challenges we face. First, the report examines advance directives as a means of resolving treatment for incapacitated patients.<sup>161</sup> It summarizes the justifications for living wills and then describes their practical and ethical shortcomings.<sup>162</sup> A major problem is that living wills are often too crude to supply real guidance. For most older, debilitated patients, factually complicated treatment questions arise and those at the bedside face a series of medical choices that cannot be resolved ahead of time. *Taking Care* concludes that future care instructions can only and should only play a partial role in decisions concerning incapacitated patients. Instructions may be helpful in some cases, but appointing a healthcare proxy is much more useful given the realities of illness.<sup>163</sup> The remainder of the report's analysis addresses the bedside decisionmaking that is crucial to resolving most end-of-life dilemmas involving incapacitated patients like Terri Schiavo. The report sets forth general moral guidelines for such decisions and endorses a standard of "best care for the person now here."<sup>164</sup> This standard does not demand life-sustaining measures in every case, but it does demand that the patient's interests, rather than the interests of others, shape the course of care.

"Best care" is a formulation of the traditional best interest standard.<sup>165</sup> This standard is exquisitely fact-sensitive and depends on the individual patient's situation. To illustrate how the best care standard works, *Taking Care* applies it to seven cases involving patients with

157. *Id.*

158. See generally JOANNE LYNN, *SICK TO DEATH AND NOT GOING TO TAKE IT ANYMORE!* (2004).

159. See *TAKING CARE*, *supra* note 4, at xvii-xix.

160. *Id.* at 1-51.

161. *Id.* at 53-93.

162. *Id.*

163. See *id.* at 53-93. Through a proxy directive, people may designate a trusted friend or relative to make medical decisions on their behalf in the event that they become incapacitated. *Id.* at 58.

164. *Id.* at 128.

165. See *id.* at 64-67; Dresser, *supra* note 17, at 1842-44.



dementia.<sup>166</sup> In most cases, the best care standard does not point to one answer, but rather to a group of resolutions that appear more defensible than others. The report's major contribution is that it attends to the moral and practical details of appropriate end-of-life care. Rather than the individual patient's prior choices, treatment is usually determined by other considerations, including the ethical duty to protect vulnerable patients, the limits of medicine, and the realization that every human life must end at some point.<sup>167</sup>

### E. *Learning from the Texts*

Each of these rich accounts offers much insight regarding health-care and life-sustaining treatment. Didion and Williams showed us how hard it can be to let go of one's own life or the life of a loved one. They also confronted us with their terrible isolation and the shock and pain death imposes. As these gifted writers demonstrated, our cultural denial of death makes it difficult for sick and grieving people to find a home among the living. The constant effort to exclude death from ordinary life leaves many of us inexperienced, awkward, and inadvertently cruel when we encounter people facing mortality.<sup>168</sup>

Kurzweil engaged in a popular form of death denial – the belief that science will rescue us from nature's limits. In his view, nature once forced us to accept those limits, but with advances in science this will soon change. We will only have to face debilitation or death when we are very old, and even then we will have the option of downloading ourselves into new and healthy physical containers. *Taking Care* pours cold water on these ideas, pointing to the dire situation we will face in the coming decades. It will soon be impossible to ignore this situation. Our failure to prepare now could have serious consequences for Baby Boomers, their families, and those who supply their care and financial support.

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166. See *TAKING CARE*, *supra* note 4, at 151-202.

167. See *id.* at 103-18; *id.* at 226 (personal statement of Rebecca Dresser).

168. One journalist described the situation as follows:

Has there ever been a time when we were less equipped to acknowledge illness and loss? For a culture that is largely in denial about such things, the book makes clear that "I know how you feel" is not a helpful consolation. You don't know how the other person feels. The conversation isn't about you. And a sick or dying person should not have to deal with lies, competitiveness or an exaggerated sense of catastrophe. Yet the speaker unaccustomed to empathy will have no better idea of what to say.

Janet Maslin, *Open Mouth, Remove Boorishness: A Guide*, N.Y. TIMES, Dec. 19, 2005, at E6, available at 2005 WLNR 20453985 (reviewing MARGARET SHEPHERD WITH SHARON HOGAN, *THE ART OF CIVILIZED CONVERSATION* (2005)).

#### IV. GIVING UP OUR MYTHS

What is wrong with the myths that shaped the national perceptions of *Schiavo*? What is wrong with believing that: (1) living wills will “solve” the death with dignity problem; (2) only patients themselves may consider quality of life in life-sustaining treatment decisions; and (3) medical advances in the coming decades will eliminate the end-of-life challenges that human frailties now generate?

The problem with these myths is that they produce a variety of harms. They mislead people about the value of living wills and other forms of advance planning. Planning strategies can be useful, but their benefits are limited. As Didion, Williams, and the President’s Council revealed, access to high-quality healthcare – including life-extending therapies, palliative care programs, and skilled and sensitive clinicians – is adequate end-of-life care’s key component. By focusing on the individual’s right or duty to express future treatment preferences, the American debate neglects the wider medical and social investments necessary to enable patients and families to cope with the inevitable burdens that accompany serious illness and dying. Without such services, there will be limited opportunities to respect the wishes expressed by patients and by their surrogate decisionmakers. In the absence of a decent care system, living wills offer empty promises about the individual’s ability to obtain a personally acceptable death.

Didion and Williams also demonstrated how the three myths foster a cultural denial of death and isolate people who have no choice but to confront their own, or a loved one’s, mortality. Again, the emphasis on advance planning implies that those at the bedside can avoid hard choices about which interventions an incapacitated patient should receive. Yet those choices must always take into account the patient’s existing situation, including pain, distress, and ability to benefit from continued life. These are quality-of-life considerations that can rarely be avoided. Public debates must acknowledge this element of bedside decisionmaking. Prospective patients and their loved ones must be aware that quality of life will play a role and that quality-of-life choices are often quite difficult. All too often this component of end-of-life care remains hidden, and families are unprepared and overwhelmed by the burdens it imposes.

The myths contribute to a third harm as well. The belief that human mortality can somehow be mastered and fully controlled promotes inattention to serious policy issues facing this nation. As long as Kurzweil’s attractive philosophy maintains its stronghold on the American psyche, there will be a tendency to focus on advancing medical frontiers rather than improving the current care system for existing and soon-

to-be patients. Instead of making the policy and cultural changes that are needed to develop adequate end-of-life services, American resources will be disproportionately devoted to cutting-edge cures and pie-in-the-sky anti-aging endeavors. To continue this trend would be a mistake.

Legal and policy officials can and should do more to reduce the harm that comes from these myths. First, legal authorities should stop suggesting that living wills and other individual planning can do most of the hard work in resolving end-of-life dilemmas. Second, the *Schiavo* controversy revealed a lack of consensus on the proper boundaries of quality-of-life judgments. To fill this gap, courts, legislatures, and policymakers should attempt to articulate proper boundaries for the quality-of-life judgments that are acceptable in end-of-life care. As *Taking Care* and other scholarship suggests, this will require further development of the best interest approach to decisions about life-sustaining treatment for incapacitated patients. Third, policymakers should promote more realistic public discussion of the potential for future cures and treatment improvements. They should urge journalists, scientists, and clinicians to make clear distinctions between preliminary research findings and proven medical therapies.

The debate over *Schiavo* created an opportunity for members of the public, as well as medical and legal professionals, to reexamine common American attitudes toward death and dying. Although the case has generated some perceptive scholarship, much of the initial *Schiavo* commentary reinforced damaging myths about end-of-life decisionmaking. Didion, Williams, Kurzweil, and the President's Council on Bioethics offer a deeper understanding of the human meaning of life-threatening illness. It is my hope that the second wave of *Schiavo* commentary will focus less on the detrimental myths and more on the neglected elements of good end-of-life care.