

---

---

Critical Essay:  
Musings on the Need to Convince Some People With  
Disabilities That End-of-Life Decision-Making  
Advocates Are Not Out to Get Them

*Kathy L. Cerminara\**

*I felt a real connection to Kristen when I met her outside Woodside Hospice . . . .*

*I liked Kristen.*

*Sure didn't want her to be afraid of me.*

*"I am not a cabbage, an onion, nor[sic] a cob of corn. I am a child of God, sister of Jesus, with purpose just like Terri. Just like you," read a sign in front of where Kristen lay.*

*Her sister, Tracey, said she wrote the message because Kristen's hands are curled tight and she's practically immobile. But it's what Kristen wanted to write down. Just as it was Kristen who told Tracey to head to Woodside Hospice. . . .*

*The [Theresa Marie] Schiavo case, as the sign showed, had Kristen worried.*

*Which is a shame. Because Kristen has nothing to worry about. She suffered residual brain damage as a result of viral encephalitis in 1976 . . . . She's alert. And although I can't make out her words, Kristen's clearly communicating.*

*Wish I could make her understand that she has nothing to worry about. That the people who fought legislative intrusion denying Schiavo the right to die would fight just as hard to make sure some politician didn't deny Kristen her right to live – if that was her choice.<sup>1</sup>*

---

\* Professor, Nova Southeastern University Shepard Broad Law Center. Thanks to Todd Cole and Russell Dombrow for exemplary research assistance, and to Elizabeth Pendo for thoughtful comments. Errors remain mine.

1. Ralph de la Cruz, *A Battle for the Right to Choose*, S. FLA. SUN-SENTINEL, Mar. 29, 2005, at 1E.

## I. INTRODUCTION

South Florida columnist Ralph de la Cruz wrote that passage shortly after a visit to the protest scene outside the hospice in which Theresa Marie Schiavo was a patient.<sup>2</sup> At that time, Ms. Schiavo was two days from death.<sup>3</sup> Now that she has died, it seems an appropriate time to reflect upon the situation de la Cruz described. As noted legal scholar John Robertson has recognized,<sup>4</sup> the importance of *Schiavo* is not legal. In fact, the various *Schiavo* opinions broke no new legal ground other than the constitutional questions raised after both legislatures and courts attempted to direct the Schiavo family's end-of-life decision making.<sup>5</sup> Rather, it was activism by certain disability rights and vitalist groups<sup>6</sup> that caught the attention of the public, the politicians, and the media.<sup>7</sup>

Kristen's fear is the type that helps such activism flourish. Although she remained capable of interacting with others and making competent decisions, Kristen nevertheless feared that someone would deny her

---

2. *Id.*

3. Abby Goodnough, *Schiavo Dies, Ending Bitter Case Over Feeding Tube*, N.Y. TIMES, Apr. 1, 2005, at A1.

4. John Robertson, *Schiavo and Its (In)significance*, 34 STETSON L. REV. (forthcoming 2005) (manuscript at 2, on file with the author) ("In the end the case of Theresa Schiavo will have contributed little to end-of-life law. . ."). Attorney and author William Colby made a similar point in his keynote speech at this Symposium, when he noted that much of the controversy in this area of law is not about the law.

5. Courts faced separation of powers issues when the Florida Legislature passed a law directed at overturning court rulings authorizing removal of the tube providing Ms. Schiavo with artificial nutrition and hydration. *Bush v. Schiavo (Schiavo V)*, 885 So. 2d 321 (Fla. 2004), *aff'g* 871 So. 2d 1012 (Fla. Dist. Ct. App.), *cert. denied*, 125 S. Ct. 1086 (2005). Similarly, courts encountered jurisdictional and constitutional questions, although they ignored them in the short term, when the United States Congress later passed a law granting Ms. Schiavo's parents the ability to file a lawsuit in federal court to protest the removal of that same tube. *Schiavo ex rel. Schindler v. Schiavo*, 404 F.3d 1270, 1272–77 (11th Cir. 2005) (Birch, J., specially concurring), *stay denied*, 125 S. Ct. 1722 (2005). All *Schiavo* opinions cited in this Essay, published and unpublished, may be accessed at an Internet-based, interactive timeline. University of Miami Ethics Program, [http://www.miami.edu/ethics2/schiavo\\_project.htm](http://www.miami.edu/ethics2/schiavo_project.htm) (last visited Nov. 1, 2005).

6. The term "vitalist" here is used to describe those pro-life groups whose work Lois Shepard has described in *Schiavo* as being "substantially about other causes that such groups wished to advance, such as the protection of fetuses and embryos." Lois Shepherd, *In Respect of People Living in a Vegetative State—And Allowing Them to Die* 50 (Fla. State Univ. Coll. of Law Pub. Law & Legal Theory, Working Paper No. 153), available at <http://ssrn.com/abstract=700245>. The terms "disability rights and vitalist groups," "disability rights and vitalist activists," and "activists" are used here to denote the disability rights groups who have adopted vitalist positions and chosen to work in concert with pro-life groups in cases such as *Schiavo*. Clearly, this does not include all disability rights groups. See *infra* Part IV (discussing the strange pairing of the disability rights movement and vitalist activists).

7. See, e.g., Arian Campo-Flores, *The Legacy of Terri Schiavo*, NEWSWEEK, Apr. 4, 2005, at 22, 24 (describing, in retrospect, the "unprecedented mobilization of powerful actors—including the Florida governor and Legislature, the Congress, the president, the Vatican and scores of activist groups").

medical care if the law permitted the withdrawal of Ms. Schiavo's medically supplied nutrition and hydration.<sup>8</sup> Focused upon the imagery and framing utilized by vitalist activists, Kristen saw herself reflected in Ms. Schiavo's position, despite the fact that Ms. Schiavo, unlike Kristen, lay in a persistent vegetative state (PVS).<sup>9</sup> In this way, Kristen's fears reflect those shared by many persons with disabilities: despite their ability to communicate and make medical care decisions, they fear either that they will be coerced into giving up on life because others devalue their lives or that others who devalue their lives will intervene to remove treatment and leave them to die without food or water.<sup>10</sup> As a result, Kristen's fear—and the fears of all those with disabilities—must be addressed by those who believe in the right to self-determination in end-of-life medical decision-making in order to avoid retreat from the principles eloquently explained in the landmark case of *In re Quinlan*.<sup>11</sup>

Since *Quinlan*, those who keep abreast of end-of-life decision-making law have noted the increasing frequency with which disability rights activists pair with vitalist activists to oppose certain end-of-life choices.<sup>12</sup> In the 1980s, for example, protesters expressed concerns about disability discrimination when Elizabeth Bouvia, a young woman with cerebral palsy, petitioned the California courts for the right to

8. See *infra* Part II.A.2 (discussing the use of medically supplied nutrition and hydration).

9. See *infra* Part II.A.1 (discussing the differences between those in persistent vegetative states and those who are minimally conscious).

10. See Stanley S. Herr, *No Place to Go: Refusal of Life-Sustaining Treatment by Competent Persons With Physical Disabilities*, 8 ISSUES L. & MED. 3 (1992) (examining the factors that affect a person's decision to refuse life-sustaining care and treatment); Joseph P. Shapiro, *No Less Worthy A Life*, in NO PITY: PEOPLE WITH DISABILITIES FORGING A NEW CIVIL RIGHTS MOVEMENT 260 (1993) (citing the story behind *State v. McAfee*, 385 S.E.2d 651 (Ga. 1989), as a "another chilling reminder of how a disabled life was dismissed . . . as a devalued life"); 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/> (characterizing Ms. Schiavo's case as being "not about end-of-life decision-making" but about "whether she should be killed by starvation and dehydration").

11. *In re Quinlan*, 355 A.2d 647 (N.J.), cert. denied sub nom. Garger v. New Jersey, 429 U.S. 922 (1976). *Quinlan* was the first reported end-of-life decision-making case. ALAN MEISEL & KATHY L. CERMINARA, THE RIGHT TO DIE: THE LAW OF END-OF-LIFE DECISIONMAKING § 1.04, at 1-10 (3d ed. 2004) [hereinafter THE RIGHT TO DIE]. As such, it "set the pattern for succeeding death and dying jurisprudence." 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).

12. E.g., *Issues Surrounding Terri Schindler-Schiavo Are Disability Rights Issues*, Say National Disability Organizations, [www.ragged-edge-mag.com/schiavostatement.html](http://www.ragged-edge-mag.com/schiavostatement.html), Oct. 27, 2003 (noting that "[t]he 'right to life' movement has embraced [Ms. Schiavo's] cause to prove 'sanctity of life'" but that "the life-and-death issues surrounding Terri Schindler-Schiavo are first and foremost disability rights issues").

refuse medically supplied nutrition and hydration.<sup>13</sup> In the late 1980s and early 1990s, disability rights activists and vitalist activists paired not only to articulate legal arguments in the case of Nancy Beth Cruzan, who lay in a PVS, but also to storm her hospital when her family finally won the right to withdraw her medically supplied nutrition and hydration in accordance with her wishes.<sup>14</sup> Most recently in 2005, the nation saw the same story unfold in Florida even more dramatically in the *Schiavo* case.<sup>15</sup> Activists not only articulated legal arguments and protested outside of Ms. Schiavo's hospice, they also joined in the efforts of Ms. Schiavo's parents to pressure the President of the United States, the Governor of Florida, and state and federal legislators to overturn court rulings that permitted Ms. Schiavo's husband to authorize the withdrawal of her medically supplied nutrition and hydration.<sup>16</sup>

Ralph de la Cruz's story about Kristen helps those of us who are not disabled comprehend how activists heightened the fears of some persons with disabilities through the *Schiavo* case. In that sense, de la Cruz's column is reminiscent of the position of one disability rights activist (a personal friend of this author) who generally supports individual autonomy and the right to live one's life as one chooses. This person, however, opposes many developments in end-of-life decision-making law. Such a position seems inconsistent until one hears the story behind her beliefs. Once, this activist had been a fervent supporter of many important developments in end-of-life decision-making, such as advance directives and "Do Not Resuscitate" (DNR)

---

13. See Judith Cummins, *Judge Prepares to Rule on Death Plea*, N.Y. TIMES, Dec. 13, 1983, at A22 (noting, at time of trial, view of same advocacy group as being that Ms. Bouvia's wish to refuse her nasogastric tube feeding "poses a threat to all handicapped people by seeming to cheapen the value of their lives"); Murray Dubin, *Young Quadriplegic Hopes to Win One Last Battle: the Right to Die*, MIA. HERALD, Dec. 16, 1983, at 1A (quoting a lawyer for a disability rights advocacy group intervening in the case as saying, "[t]he message that Elizabeth Bouvia and other disabled in this country must hear is that she shall live"). See generally *Bouvia v. Superior Court*, 225 Cal. Rptr. 297 (Cal. Ct. App. 1986) (holding that the state's interest in preserving life did not outweigh a patient's right to refuse treatment).

14. WILLIAM H. COLBY, *THE LONG GOODBYE: THE DEATHS OF NANCY CRUZAN* 369-72 (2002); see generally *Cruzan v. Dir.*, Mo. Dept. of Health, 497 U.S. 261 (1990) (holding that a state could require clear and convincing evidence of an incompetent's wishes to refuse treatment).

15. See generally Campo-Flores, *supra* note 7 (describing the various individuals involved in the *Schiavo* case).

16. See Abby Goodnough, *Protesters Hold Vigil for Schiavo at Hospice*, N.Y. TIMES, Mar. 20, 2005, at A29 (reporting actions of protesters prior to the passage of the Act for the Relief of the Parents of Theresa Marie Schiavo, Pub. L. No. 109-3, 119 Stat. 15 (2005)); *Comatose Woman's Parents Ask Governor to Forestall Her Death*, S. FLA. SUN-SENTINEL, Oct. 14, 2003, at 1A (describing vigil and email pleas to the governor prior to eventual passage of 2003 Fla. Laws 418 (*held unconstitutional in Bush v. Schiavo*, 885 So. 2d 321 (Fla. 2004))).

orders. Then, years ago, while representing mentally ill patients in a facility, she discovered that every mentally ill patient in that facility had a charted DNR order, often without the patient's family's knowledge. Seeing that, she began to believe that the risks of abuse of people with disabilities were too great to justify supporting the extension of the principle of self-determination beyond those competent to assert their wishes at the time of medical decision-making.<sup>17</sup>

Those with legal training may respond on multiple levels to this story and this activist's position. The particular facility described in that story entered DNR orders on the charts of patients without appropriately consulting surrogate decision-makers and apparently in the absence of adequate reason. This alleged act raises serious concerns about violations of patients' rights.<sup>18</sup> However, this alleged act alone does not mean that the law is flawed; it may simply point to the necessity of policing and punishing violations of the law. Further, that anecdote could have been exaggerated or may not tell the entire story, so basing a legal response upon that story may be unwise.<sup>19</sup> Finally, even assuming complete accuracy and lack of exaggeration in that account, this single story does not demonstrate that such events were widespread, and it certainly does not negate the presence of some good-faith mistakes about the meaning of the law at that time. In fact, according to the person telling the story, the situation was corrected the minute it was discovered, thus arguably demonstrating the presence of a good-faith mistake.<sup>20</sup>

---

17. See also Johnson, *supra* note 10 (characterizing the Schiavo case as about starvation rather than end-of-life decisions).

18. Informed consent may not always be legally required for entry of a DNR order on a patient's chart. THE RIGHT TO DIE, *supra* note 11, § 6.02, at 6-6. Entry of a DNR, however, would not be appropriate except in cases of futile (or medically inappropriate) care, and, even then "respect for patients and their families, not to mention ordinary prudence, strongly suggests that physicians should at least inform patients or families that if a cardiopulmonary arrest occurs, no efforts will be made to resuscitate because the treatment offers little benefit in comparison with the burden it imposes." *Id.* at 6-17. On futility generally, see COUNCIL FOR ETHICAL AND JUDICIAL AFFAIRS, AMERICAN MEDICAL ASSOCIATION, CURRENT OPINIONS WITH ANNOTATIONS, § 2.035, at 11 (2002) ("Physicians are not ethically obligated to deliver care that, in their best professional judgment, will not have a reasonable chance of benefiting their patients.").

19. Many scholars note in other contexts that basing policy decisions upon anecdote rather than evidence may not lead to appropriate results. See, e.g., David Hyman, *Do Good Stories Make For Good Policy?*, 25 J. HEALTH POL. POL'Y & L. 1149 (2000) ("Stories may be effective in mobilizing support for a policy, but it is quite a different question whether sound policies will result.").

20. Certainly one can find individual instances of discrimination against persons with disabilities in the medical setting just as in other setting. E.g., W. Richard Boyte, *Pizza Ship: Language Counts*, 23 HEALTH AFFAIRS 240 (2004) (illustrating erroneous assumptions made by physician about capability of ten-year-old patient with cerebral palsy). In allocating medical

Persons with disabilities, however, may have different but similarly strong reactions to my colleague's story that activists could use for political ends.<sup>21</sup> Activists may easily capture the attention of some people with disabilities by framing end-of-life dramas in the ways most likely to incite fear.<sup>22</sup> For this reason, more time must be spent eliciting the full range of views on the subject from people with disabilities. Surely there are as many people with disabilities who wish to secure for themselves the right to make end-of-life decisions as those who are galvanized by the fear stirred up by activist groups such as Not Dead Yet.<sup>23</sup> Policy makers must acknowledge the fears activists have incited among people with disabilities, resist the urge to brush those concerns off as unfounded, and assure full airing of the views of both those people with disabilities who wish to exercise self-determination near the ends of their lives and those who are afraid.<sup>24</sup> Doing so ultimately will

---

resources, however, physicians who adhere to the American Medical Association's Code of Ethics are admonished that "[n]on-medical criteria, such as ability to pay, age, social worth, perceived obstacles to treatment, patient contribution to illness or past use of resources should not be considered." COUNCIL FOR ETHICAL AND JUDICIAL AFFAIRS, *supra* note 18, § 2.03, at 8. With respect to DNR orders in particular, the AMA CEJA opines:

Efforts should be made to resuscitate patients who suffer cardiac or respiratory arrest except when circumstances indicate that cardiopulmonary resuscitation (CPR) would be inappropriate or not in accord with the desired or best interests of the patient. . . .

Physicians should not permit their personal value judgments about quality of life to obstruct the implementation of a patient's preferences regarding the use of CPR.

*Id.* § 2.22, at 93. *See also id.* § 2.17, at 60–61 ("In the making of decisions for . . . persons who are severely disabled by injury or illness, the primary consideration should be what is best for the individual patient and not the avoidance of a burden to the family or to society.").

21. *E.g.*, Johnson, *supra* note 10 (arguing that the *Schiavo* case is not about end-of-life decisions); *The Elephant in the Living Room: End-of-Life Care Should Not Be About Ending the Lives of People With Disabilities* (unpublished literature distributed by disability rights organization Not Dead Yet) (on file with the author) (advocating for the rights of people with disabilities and against withdrawal of life support); *see generally* Not Dead Yet Homepage, <http://www.notdeadyet.org> (visited Nov. 1, 2005) (expounding the beliefs of the organization, Not Dead Yet); International Task Force on Euthanasia and Assisted Suicide, <http://www.iaetf.org/> (visited Nov. 1, 2005) (explaining the beliefs of the organization and providing news and recommendations).

22. The websites of certain activist organizations use terminology such as "non-voluntary euthanasia based on the decisions of statutory guardians or health care providers" to describe cases such as *Schiavo*, *see for example*, Not Dead Yet, <http://www.notdeadyet.org/docs/drmwants0305.html> (visited Nov. 1, 2005); or use the terms "food and water" rather than "nutrition and hydration" to create imagery of starvation and dehydration surrounding withdrawal, *see* International Task Force on Euthanasia and Assisted Suicide, <http://www.iaetf.org/> (at link to questions and answers about "artificial feeding") (visited Nov. 1, 2005).

23. *See infra* Part II.A (discussing the different terminology used and explaining how that terminology results in misperceptions); *see also supra* notes 21–22 (citing Not Dead Yet's website).

24. *See generally* Carl E. Schneider, *Hard Cases and the Politics of Righteousness*, 35

strengthen the right to self-determination of all citizens, as described so well by the New Jersey Supreme Court in *Quinlan*.<sup>25</sup>

This Essay will examine how and why the concerns of some people with disabilities so strongly emerged in *Schiavo*. First, it establishes a framework for this examination by providing an overview of the relevant end-of-life medical issues and key cases involved in these controversies.<sup>26</sup> It will then examine why *Schiavo* struck such a chord among activists and enabled them to inspire fear among others, drawing the entire country into a highly publicized drama.<sup>27</sup> Next, it will explore *Schiavo*'s pairing of a portion of the disability community with vitalist forces and will place that pairing in historical perspective.<sup>28</sup> Following, the Essay will demonstrate that the fears incited by vitalist activists are in fact extreme and unfounded.<sup>29</sup> Nevertheless, because the power of imagery and framing is strong, this Essay will conclude that a better attempt must be made to assure people with disabilities, like Kristen, that advocates of the right to refuse treatment are not "out to get them."<sup>30</sup>

## II. BACKGROUND

To best understand the concerns of persons with disabilities and the ways in which those concerns emerged in the *Schiavo* case, it is important first to understand the backdrop against which those fears developed. This Part therefore provides a brief explanation of key terminology and cases as they relate to end-of-life issues.

### A. End-of-Life and Medical Care Terminology

Terminological precision is important in the end-of-life decision-making setting, particularly with regard to certain medical conditions and types of treatments. Patients in persistent vegetative states differ in important ways from those who are minimally conscious,<sup>31</sup> yet the

---

HASTINGS CENTER REP. 24 (2005) (encouraging readers to hear the Schindler's supporters with "generosity").

25. *In re Quinlan*, 355 A.2d 647 (N.J. 1975), *cert. denied sub nom. Garger v. New Jersey*, 429 U.S. 922 (1976). *See also infra* Part II.B.1 (discussing the *Quinlan* decision).

26. *See infra* Part II (examining key cases relating to end-of-life medical issues).

27. *See infra* Part III (examining *Schiavo*'s effect on activists).

28. *See infra* Part IV.A (exploring the pairing of a segment of the disabled community with the vitalist movement).

29. *See infra* Part IV.B (deconstructing the fears the vitalist activists have created).

30. *See infra* Part V (concluding that there is a need for reasoned discussions about the right of autonomy of both disabled and non-disabled people alike).

31. *See generally* Editorial, *Raising Consciousness*, 115 J. CLINICAL INVESTIGATION 1102, 1102 (2005) (distinguishing between the two and describing *Schiavo* as "expos[ing] a critical gap

terms are easily confused.<sup>32</sup> Similarly, persons receiving medically supplied artificial nutrition and hydration are not receiving “food and water” in the sense that one envisions when hearing those words.<sup>33</sup> The distinctions are important.

### 1. Patients in Persistent Vegetative States As Contrasted With Those Who Are Minimally Conscious

A patient in a PVS exists in a condition providing fertile ground for activists’ warnings of slippery slopes.<sup>34</sup> For the most part, these patients do not appear to lack cognitive function, despite the long-standing neurological position that they do. The term “persistent vegetative state” has been around since 1972, when neurologists first used it to label “patients who had, after trauma to the brain, entered a continuing state of unconsciousness marked by periods of wakefulness.”<sup>35</sup> A person in a PVS actually can look as if he or she is

---

between emotional fervor about brain-injured patients and the medical science that informs the standard of care for them”).

32. Patients in either condition might be considered, and described as, “brain-damaged,” for example. Newspaper coverage of Ms. Schiavo’s case often referred to her using that broader descriptor, which does not accurately distinguish between a person in the uncommunicative, unaware state of a PVS and a person with diminished mental capacity due to brain injury. *See., e.g.,* Abby Goodnough, *U.S. Judge Denies Feeding-Tube Bid in Schiavo’s Case*, N.Y. TIMES, Mar. 23, 2005, at A1 (using the broad term “brain damaged” to describe Ms. Schiavo’s mental state); Samantha Gross, *Florida Effort to Keep Terri Schiavo Alive Hits Roadblock*, ORLANDO SENTINEL, Mar. 17, 2005, at 1 (referring to Ms. Schiavo as “the severely brain-damaged woman”); Carl Hulse & David D. Kirkpatrick, *Congress Passes and Bush Signs Legislation in Schiavo Case*, N.Y. TIMES, Mar. 21, 2005, at A1 (explaining that Ms. Schiavo suffered brain damage and was in a “persistent vegetative state”). Even court opinions can lead to similar confusion. Karen Ann Quinlan was diagnosed as being in a PVS, but the court and at least one physician witness, perhaps reflecting the level of medical knowledge at that time, also referred to her as being “in a state of coma,” or “comatose.” *In re Quinlan*, 355 A.2d 647, 654, 671–72 (N.J. 1975), *cert. denied sub nom. Garger v. New Jersey*, 429 U.S. 922 (1976). Comas and PVSs are different conditions, although they are both forms of unconsciousness. Eelco F.M. Wijdicks & Ronald E. Cranford, *Clinical Diagnosis of Prolonged States of Impaired Consciousness in Adults*, 80 MAYO CLINIC PROCEEDINGS 1037, 1037 (2005); The Multi-Society Task Force on PVS, *Medical Aspects of the Persistent Vegetative State (First of Two Parts)*, 330 NEW ENG. J. MED. 1499, 1499 (1994) [hereinafter Multi-Society Task Force].

33. *See infra* Part II.A.2 (discussing medically supplied nutrition and hydration).

34. A “slippery-slope” argument is an argument intended to say “that if we take the first step there will be no stopping.” BRYAN A. GARNER, A DICTIONARY OF MODERN LEGAL USAGE 812 (2d ed. 1987). In *Washington v. Glucksberg*, 521 U.S. 702 (1997), for example, Justice Souter, saying “the case for the slippery slope is fairly made out here,” expressed concern about eventual approval of euthanasia if a constitutional right to physician-assisted suicide were recognized. 521 U.S. at 784–85 (Souter, J., concurring).

35. Shepherd, *supra* note 6, at 8 (citing B. Jennett & F. Plum, *Persistent Vegetative State After Brain Damage: A Syndrome in Search of a Name*, 1 LANCET 734 (1972)). Jennett and Plum’s definition still applies, although it has been expanded upon over the years. In 1994, the Multi-Society Task Force on PVS said, “The vegetative state is a clinical condition of complete

aware, even though the label describing him or her incorporates the word “vegetative,” thus giving rise to the popular, if offensive, reference to persons in this condition existing as “vegetables.”<sup>36</sup> In reality, and as the public was made well-aware in *Schiavo*, a patient in a PVS moans, appears to react, and has sleep-wake cycles.<sup>37</sup> Most end-of-life decision-making cases in the United States have involved patients in a PVS,<sup>38</sup> at least in part because those patients may appear to be functioning although they are not.

In sharp contrast to a patient in a PVS, a person who is “minimally conscious” has brain damage but “demonstrate[s] unequivocal, but intermittent, behavioral evidence of awareness of self or . . . environment.”<sup>39</sup> Such patients exhibit “[e]vidence of limited but clearly discernible self or environmental awareness on a reproducible or sustained basis.”<sup>40</sup> The term “vegetative” does not apply to these patients.<sup>41</sup> Sadly, however, the misleading outward characteristics of PVS patients can cause the general public and loving family members to believe that those patients are instead minimally conscious.<sup>42</sup> These misconceptions are compounded when reports surface of patients who

---

unawareness of the self and the environment, accompanied by sleep-wake cycles with either complete or partial preservation of hypothalamic and brain-stem autonomic functions.” Multi-Society Task Force, *supra* note 32, at 1499. “In general, though not without exception, the courts use the term to describe a body which is functioning entirely in terms of its internal controls but which exhibits no behavioral evidence of either self-awareness or awareness of the surroundings in a learned manner.” THE RIGHT TO DIE, *supra* note 11, § 6.04[I][1][a], at 6-125 (quoting *In re Jobes*, 529 A.2d 434, 438 (N.J. 1987) (internal quotations omitted)).

36. Shepherd, *supra* note 6, at 9.

37. Kathy L. Cerminara, *Tracking the Storm: The Far-Reaching Power of the Forces Propelling the Schiavo Cases*, 34 STETSON L. REV. (forthcoming 2005) (manuscript at 3, 28–29, on file with author); Shepherd, *supra* note 6, at 14. See also *Cruzan v. Dir.*, Mo. Dept. of Health, 497 U.S. 261, 266 (1990) (describing Ms. Cruzan’s PVS condition); *Quinlan*, 355 A.2d at 654 (describing Ms. Quinlan’s sleep-wake cycles and noting that “[i]n the awake cycle she blinks, cries out and does things of that sort but is still totally unaware of anyone or anything around her”).

38. THE RIGHT TO DIE, *supra* note 11, § 6.04[I][1], at 6-123.

39. N.D. Schiff, et al., *MRI Reveals Large-Scale Network Activation in Minimally Conscious Patients*, 64 NEUROLOGY 514, 514 (2005).

40. Shepherd, *supra* note 6, at 15 n.36 (citing BRYAN JENNETT, THE VEGETATIVE STATE: MEDICAL FACTS, ETHICAL AND LEGAL DILEMMAS (2002)).

41. It is difficult to find accurate estimates of the numbers of patients in either PVS or minimally conscious state, but about 15 years ago the American Medical Association estimated that at least 100,00 patients existed in PVSs. THE RIGHT TO DIE, *supra* note 11, § 6.04[I][1], at 6-124. The *New York Times* stated in 2005 that “an estimated 100,000 to 300,000” persons are in a minimally conscious state. Benedict Carey, *New Signs of Awareness Seen in Some Brain-Injured Patients*, N.Y. TIMES, Feb. 8, 2005, at A1.

42. See *infra* Part III.A (discussing the PVS condition in the context of the *Schiavo* case).

emerge after many years from comas or other states of unconsciousness.<sup>43</sup>

In fact, however, the instances of such recovery are exceedingly rare.<sup>44</sup> After some period of time, the chances of recovery are practically nonexistent, a fact that has led neurologists to advocate use of the term “permanent vegetative state” rather than “persistent vegetative state” when such a condition has existed for longer than the period of time during which emergence back to consciousness is not at all likely.<sup>45</sup>

Both the condition of PVS and the way that people treat and view it are complex. A person with a disability with some level of brain damage, such as Kristen, might be led to the misconception that a patient in a PVS is in fact minimally conscious.<sup>46</sup> It would not be a great leap thereafter to mistakenly believe that the law might not protect persons with less brain damage, such as her.

## 2. Medically Supplied Nutrition and Hydration

Cases involving withholding or withdrawal of medically supplied nutrition and hydration occupy a great deal of court and attorney time in this country.<sup>47</sup> This hot-button issue has occupied the attention of

---

43. See, e.g., Miranda Hitti & Michael Smith, *Progress For Man Who Spoke After 10-Year Coma*, May 4, 2005, <http://mywebmd.com/content/article/105/107841.html> (describing case of firefighter regaining consciousness after 10 years); Nancy L. Childs & Walt N. Mercer, *Late Improvement in Consciousness After Post-Traumatic Vegetative State*, 334 NEW ENG. J. MED. 24 (1996) (describing case of recovery after 15 months). See *In re Schiavo*, No. 90-2908GD-003, at 6 (Fla. Cir. Ct. Pinellas County, Feb. 11, 2000), available at University of Miami Ethics Program, <http://www.miami.edu/ethics/schiavo/timeline.htm> (follow February 11, 2000 “Trial Court Ruling” hyperlink) (last visited Nov. 1, 2005) (noting that evidence had been presented at trial of a woman “who awakened from a coma . . . after sixteen years”).

44. Wijdicks & Cranford, *supra* note 32, at 1044 (describing the media as being “replete with so-called miracle awakenings, some of which are only temporary” and noting that the “press coverage of these cases is hyperbolic”). See also THE RIGHT TO DIE, *supra* note 11, § 6.04[I][1][b], at 6-129 (examining the “clear and convincing” evidence standard in right-to-die context).

45. Childs & Mercer, *supra* note 43, at 24–25. See also Wijdicks & Cranford, *supra* note 32, at 1038 (terming the word “permanent” a “prognostic rather than diagnostic qualifier”).

46. For example, in an article describing a study on minimally conscious patients, a professor of neurology at Dartmouth College was described as saying that “findings from studies like these would be relevant to cases like that of Terri Schiavo, a Florida woman with brain damage who has been kept alive for years against her husband’s wishes.” Carey, *supra* note 41. Reading further into the article reveals that this professor meant that the study’s conclusions could help neurologists in the future better determine the difference between patients in PVSs and those in minimally conscious states, not that the study’s findings about minimally conscious patients applied to Ms. Schiavo, who was in a PVS. *Id.* A casual reader, stopping after this professor’s statement, however, could develop a very different impression.

47. THE RIGHT TO DIE, *supra* note 11, § 6.03[G][5], at 6-79.

religious leaders<sup>48</sup> and has invoked use of terminology such as “starvation” in describing the actions of those seeking to withdraw treatment.<sup>49</sup> It is not a new concept, however, that medically supplied artificial nutrition and hydration is considered medical treatment capable of being refused like other medical treatments. The California Appellate Court held to that effect when it permitted a competent, twenty-eight year old woman with cerebral palsy to refuse administration of artificial nutrition and hydration through a nasogastric tube despite the absence of any physical medical condition that would lead to imminent death.<sup>50</sup> The vast majority of American state courts have similarly held,<sup>51</sup> and the United States Supreme Court has ruled that medically supplied nutrition and hydration constitutes medical treatment that can be refused.<sup>52</sup> In Florida, the state statute governing advance directives specifically provides that the term “life-prolonging treatment” includes “artificially provided sustenance and hydration.”<sup>53</sup> Indeed, the provision of nutrition and hydration through a percutaneous endoscopic gastrostomy (PEG) tube involves the surgical insertion of a tube into a patient’s stomach to permit the injection of liquefied nutrients directly into the stomach.<sup>54</sup> The patient’s medical condition has rendered his or her body unable to ingest and process food and water in the usual way.<sup>55</sup> Before nasogastric and PEG tubes were

48. See generally Cerminara, *supra* note 37, at 23 (examining the Catholic Church’s position on the issue of withholding or withdrawing nutrition and hydration).

49. E.g., Not Dead Yet, *Disability Activists Call for Moratorium on Starvation and Dehydration*, Feb. 14, 2005, <http://www.notdeadyet.org/docs/moratoriumPR021405.html> (stating “thousands of people around this country with labels of both MCS and PVS are being starved and dehydrated”). Attorneys also use such inflammatory terminology. See Emergency Application for Stay of Enforcement of the Judgment Below Pending the Filing and Disposition of a Petition for a Writ of Certiorari to the District Court of Appeal of the State of Florida, Second District, Schindler *ex rel.* Schiavo v. Schiavo, No. 04A844, at 8 (U.S. Mar. 17, 2005) (on file with the author) (“With less process than would be necessary to seize a refrigerator, a Florida court has ordered the death of an innocent, disabled woman through one of the most cruel and unusual means imaginable: starvation and dehydration.”) (internal citations and quotation omitted).

50. *Bouvia v. Superior Court*, 225 Cal. Rptr. 297, 299 (Cal. Ct. App. 1986).

51. THE RIGHT TO DIE, *supra* note 11, § 6.03[G][4], at 6-74.

52. *Cruzan v. Dir., Mo. Dept. of Health*, 497 U.S. 261, 287 (1990) (O’Connor, J., concurring) (joining four dissenters to comprise a majority on this issue). See generally THE RIGHT TO DIE, *supra* note 11, § 6.03[G][4][a], at 6-77 (discussing Justice O’Connor’s concurrence, along with four dissenting justices, constituting a majority on the issue of whether medical nutrition could be refused).

53. Fla. Stat. Ann. § 765.101(10) (2005).

54. Cerminara, *supra* note 37, at 4 n.6.

55. See, e.g., Floyd Angus & Robert Burakoff, *The Percutaneous Endoscopic Gastrostomy Tube: Medical and Ethical Issues in Placement*, 98 AM J. GASTROENTEROLOGY 272, 274 (2003) (“The most common indication for PEG tube placement is neurological deficit causing impairment in ability to obtain sufficient oral nutritional intake.”).

invented through advances in technology, that patient's condition would have resulted in death.<sup>56</sup> Refraining from using these highly technical procedures to compensate for the body's malfunction is exactly analogous to refraining from maintaining a patient on a ventilator when his or her body is no longer able to breathe without assistance.<sup>57</sup>

The same court that decided *Quinlan*, the New Jersey Supreme Court, is one of several courts recognizing that the same rationale underlies the right to refuse both ventilator support and medically supplied artificial nutrition and hydration.<sup>58</sup> Such technologically advanced methods of life support differ greatly from bottle-feeding or spoon-feeding; "they are medical procedures with inherent risks and possible side effects, instituted by skilled healthcare providers to compensate for impaired physical functioning."<sup>59</sup> Not quite a decade after *Quinlan*, the New Jersey Supreme Court likened medically supplied artificial nutrition and hydration to breathing through use of a respirator.<sup>60</sup> As that same court elaborated two years thereafter:

Just as a patient does not die because of the withdrawal of a kidney dialysis machine, but because his underlying disease has destroyed the proper functioning of his kidney, so [the patient] Hilda Peter will not die from the withdrawal of the nasogastric tube, but because of her underlying medical problem, *i.e.*, her inability to swallow. Withdrawal of the nasogastric tube, like discontinuance of other kinds of artificial treatment, merely acquiesces in the natural cessation of a bodily function. The cessation is the cause of death, not the acquiescence.<sup>61</sup>

Unfortunately, the objections of religious leaders and continued use of terms such as "starvation" in connection with the withholding or withdrawal of such treatment fuels the fears of some persons with

---

56. *E.g.*, *In re Tavel*, 661 A.2d 1061, 1069 n.3 (Del. 1995) (stating that the physician testified that the death of the patient in PVS would result from "natural causes" if medically supplied artificial nutrition and hydration were removed).

57. *In re Conroy*, 486 A.2d 1209, 1235 (N.J. 1985); *THE RIGHT TO DIE*, *supra* note 11, § 6.03[G][3], at 6-72-6-73.

58. *Conroy*, 486 A.2d at 1235. *See also* *McConnell v. Beverly Enters.-Conn., Inc.*, 553 A.2d 596, 608 (Conn. 1989) (Healy, J., concurring) (affirming the similarity between removal of a respirator and gastrostomy tube); *In re Tavel*, 661 A.2d 1061, 1069 (Del. 1995) (holding that the "substitute judgment" of the guardian best accomplishes the ward's goal); *In re Estate of Greenspan*, 558 N.E.2d 1194, 1201 (Ill. 1990) (holding that a public guardian has standing to petition the court to discontinue artificial feeding and hydration of a ward); *In re Grant*, 747 P.2d 445 (Wash. 1987), *modified*, 757 P.2d 534 (Wash. 1988) (finding similarity between removing a feeding tube and removing a respirator).

59. *Conroy*, 486 A.2d at 1236.

60. *Id.*

61. *In re Peter*, 529 A.2d 419, 428 (N.J. 1985). This position accords with the positions of all the major medical associations. *Id.* *See also* *THE RIGHT TO DIE*, *supra* note 11, § 6.03[G][4], at 6-75 to 6-76 (examining the consensus on the right to forgo medical treatment).

disabilities. Pope John Paul II, of the Roman Catholic Church, entered the fray in 2004 when he gave an address in which he seemingly departed from the Roman Catholic tradition of determining on a case-by-case basis, based on a burden-benefit analysis,<sup>62</sup> whether to require administration of medically supplied nutrition and hydration.<sup>63</sup> In that address, the Pope first spoke of the importance of correctly diagnosing patients' conditions. Then he stated that "the administration of water and food, even when provided by artificial means, always represents a natural means of preserving life, not a medical act" and "should be considered, in principle, ordinary and proportionate, and as such morally obligatory."<sup>64</sup> In addition, religious leaders of other faiths, although generally supporting the right to withhold or withdraw life-sustaining treatment when a patient nears life's end,<sup>65</sup> sometimes describe (and certainly in *Schiavo* described) withdrawal of medically supplied nutrition and hydration as an immoral ending of life.<sup>66</sup> Activists are able to couple such moral criticism with use of inflammatory terminology such as "starvation" to refer to the process of withholding or withdrawing.<sup>67</sup> The result is that, even if they have capacity to express their own wishes, persons such as Kristen, assisted by the activists' rhetoric, may erroneously translate a willingness to withhold medically supplied nutrition and hydration into a willingness to rid the world of them by depriving them of food and water.

62. See Thomas A. Shannon & James J. Walter, *Implications of the Papal Allocation on Feeding Tubes*, 34 HASTINGS CENTER REP. 18 (2004) ("Historically, the method for making a determination about the use of a medical intervention was to consider the proportional benefits and its harms to the individual, family, and community."); but see Mark Repenshek & John Paul Slosar, *Medically Assisted Nutrition and Hydration: A Contribution to the Dialogue*, 34 HASTINGS CENTER REP. 13 (2004) (suggesting interpretation of the address in light of previous papal teaching and Catholic theology rather than viewing it as a turnaround). See generally *Death and Dying*, BIO-LAW UPDATE (LexisNexis Academic & Library Solutions), 2004, at 72-78 (describing various Catholic teachings on end-of-life issues).

63. Pope John Paul II, *On Life-Sustaining Treatments and the Vegetative State*, 4 NAT'L CATH. BIOETHICS Q. 573 (2004), available at [www.vatican.va/holy\\_father/john\\_paul\\_ii/speeches/2004/march/documents/hf\\_jp-ii\\_spe\\_20040420\\_congress-fiamc\\_en.html](http://www.vatican.va/holy_father/john_paul_ii/speeches/2004/march/documents/hf_jp-ii_spe_20040420_congress-fiamc_en.html).

64. *Id.* at 575 (emphasis omitted).

65. CAROL KROHN & SCOTT SUMMERS, *ADVANCE HEALTH CARE DIRECTIVES: A HANDBOOK FOR PROFESSIONALS* 120-29 (2002).

66. See Megan O'Matz, *Churches: Schiavo Must Live*, S. FLA. SUN-SENTINEL, Mar. 21, 2005, at 1B (naming a number of religious leaders of various churches constituting part of "a vocal and influential circle of fundamentalists waging a fierce political battle to keep [Ms.] Schiavo alive").

67. *E.g.*, Not Dead Yet, *Moratorium*, *supra*, note 49 (stating "thousands of people around this country with labels of both MCS and PVS are being starved and dehydrated").

### B. Important Cases Leading Up to Schiavo

Three cases of national notoriety have sparked interest in end-of-life decision-making: *In re Quinlan*;<sup>68</sup> *Cruzan v. Director, Missouri Department of Health*,<sup>69</sup> and the multiple opinions in *Schiavo*.<sup>70</sup> A review is instructive regarding the status of end-of-life issues in the court system.

#### 1. In re Quinlan

In *Quinlan*, the father of a 21-year-old woman in a PVS during the early 1970's petitioned to be appointed guardian of his daughter so that he could authorize the withdrawal of her ventilator support.<sup>71</sup> The New Jersey Supreme Court ruled that "[w]e have no doubt, in these unhappy circumstances, that if Karen were herself miraculously lucid for an interval (not altering the existing prognosis of the condition to which she would soon return) and perceptive of her irreversible condition, she could effectively decide upon the discontinuance of the life-sustaining apparatus."<sup>72</sup> Specifically, she could have exercised her constitutional right to privacy by making such a choice.<sup>73</sup> Moreover, "[t]he only practical way to prevent destruction of the right [was] to permit [her father] to render [his] best judgment as to whether she would exercise it in [the applicable] circumstances."<sup>74</sup>

---

68. 355 A.2d 647 (N.J.), *cert. denied sub nom.* Garger v. New Jersey, 429 U.S. 922 (1976).

69. 497 U.S. 261 (1990).

70. *In re Schiavo (Schiavo I)*, 780 So. 2d 176 (Fla. Dist. Ct. App.), *review denied*, 789 So. 2d 348 (Fla. 2001); *In re Schiavo (Schiavo II)*, 792 So. 2d 551 (Fla. Dist. Ct. App. 2001), *review denied*, 855 So. 2d 621 (Fla. 2003); *In re Schiavo (Schiavo III)*, 800 So. 2d 640 (Fla. Dist. Ct. App. 2001), *review denied*, 855 So. 2d 621 (Fla. 2003); Advocacy Ctr. for Pers. With Disabilities, Inc. v. Schiavo, 17 Fla. L. Weekly Fed. D 291 (M.D. Fla. 2003); Bush v. Schiavo (*Schiavo V*), 885 So. 2d 321 (Fla. 2004), *aff'g* 871 So. 2d 1012 (Fla. Dist. Ct. App. 2004), *cert. denied*, 125 S. Ct. 1086 (2005); Bush v. Schiavo, 861 So. 2d 506 (Fla. Dist. Ct. App. 2003); Bush v. Schiavo, 866 So. 2d 136 (Fla. Dist. Ct. App. 2004); Bush v. Schiavo, 871 So. 2d 1012 (Fla. Dist. Ct. App. 2004), *aff'd*, 885 So. 2d 321 (Fla. 2004), *cert. denied*, 125 S. Ct. 1086 (2005); *In re Schiavo (Schiavo IV)*, 851 So. 2d 182 (Fla. Dist. Ct. App. 2003), *aff'g*, No. 90-2908-GB-003, 2002 WL 31817960 (Fla. Cir. Ct. 2002), *review denied*, 855 So. 2d 621 (Fla. 2003); Schindler v. Schiavo, 866 So. 2d 140 (Fla. Dist. Ct. App. 2004); Schiavo *ex rel.* Schindler v. Schiavo, 403 F.3d 1223 (11th Cir.), *aff'g* 357 F. Supp. 2d 1378 (M.D. Fla.), *reh'g en banc denied*, 403 F.3d 1261 (11th Cir.) (en banc), *stay denied*, 125 S. Ct. 1692 (2005); Schiavo *ex rel.* Schindler v. Schiavo, 403 F.3d 1289 (11th Cir.), *aff'g* 358 F. Supp. 2d 1161 (M.D. Fla.), *reh'g en banc denied*, 404 F.3d 1270 (11th Cir.) (en banc), *reh'g denied*, 404 F.3d 1282 (11th Cir.), *stay denied*, 125 S. Ct. 1722 (2005); *In re Schiavo*, No. 90-2908-GB-003, 2005 WL 459634 (Fla. Cir. Ct. Mar. 28, 2005), *aff'd*, 30 Fla. L. Weekly D743 (Fla. Dist. Ct. App.), *stay denied*, 125 S. Ct. 1622 (2005).

71. *Quinlan*, 355 A.2d at 665.

72. *Id.* at 663.

73. *Id.* at 663-64.

74. *Id.* at 665.

The court in *Quinlan* spent some time discussing what it termed “the medical factor” in the case, referring as it did so to the “medical decision supporting the determination below.”<sup>75</sup> It distinguished the withdrawal of life support from suicide by recognizing “a real distinction between the self-infliction of deadly harm and a self-determination against artificial life support or radical surgery, for instance, in the face of irreversible, painful and certain imminent death.”<sup>76</sup> It noted that the medical profession was, at that time in 1976, debating definitions of death, and it acknowledged that “human decisions against resuscitation or maintenance therapy are frequently a recognized de facto response in the medical world to the irreversible, terminal, painridden patient, especially with familial consent.”<sup>77</sup> In an oft-quoted passage, the court stated:

We glean from the record here that physicians distinguish between curing the ill and comforting and easing the dying; that they refuse to treat the curable as if they were dying or ought to die, and that they have sometimes refused to treat the hopeless and dying as if they were curable. . . . [M]any of them have refused to inflict an undesired prolongation of the process of dying on a patient in irreversible condition when it is clear that such ‘therapy’ offers neither human nor humane benefit.<sup>78</sup>

The court named Mr. Quinlan as his daughter’s guardian and authorized disconnection of her ventilator support if, upon further review, her physicians and the hospital ethics committee concurred that there was “no reasonable possibility of Karen’s ever emerging from [her PVS] to a cognitive, sapient state and that the [ventilator] should be discontinued.”<sup>79</sup>

## 2. *Cruzan v. Director, Missouri Department of Health*

Fourteen years after the New Jersey Supreme Court’s decision in *Quinlan*, the United States Supreme Court issued its decision in the only case it has considered directly involving the asserted right to have medical treatment withheld or withdrawn.<sup>80</sup> In *Cruzan v. Director*,

75. *Id.* at 664.

76. *Id.* at 665.

77. *Id.* at 667.

78. *Id.*

79. *Id.* at 671–72.

80. *Cruzan v. Dir., Mo. Dept. of Health*, 497 U.S. 261 (1990). The Court has decided two other end-of-life decision-making cases, *Washington v. Glucksberg*, 521 U.S. 702 (1997), and *Vacco v. Quill*, 521 U.S. 793 (1997), but those cases considered whether a competent, terminally ill patient has a constitutional right to receive assistance in ending his or her own life. As such, while both they and *Cruzan* involved patients near the end of life and decisions that would result

*Missouri Department of Health*, the parents of a young woman in a PVS petitioned the Missouri courts for permission to authorize withdrawal of their daughter's PEG tube, which was providing her with medically supplied artificial nutrition and hydration. The Missouri State Court applied a clear and convincing evidentiary standard when deciding whether to authorize the withdrawal and concentrated on whether Nancy Beth Cruzan (the young woman) had indicated before the automobile accident that left her in a PVS that she wanted artificial nutrition and hydration withdrawn if she ever entered a PVS as a result of an auto accident.<sup>81</sup> The argument before the United States Supreme Court focused on whether the State of Missouri's application of a demanding standard of proof, requiring not only clear and convincing evidence but also that the evidence demonstrate Nancy's prior, actual, expressed wishes, violated Nancy's Fourteenth Amendment liberty interest in refusing treatment.<sup>82</sup> The United States Supreme Court held that the State of Missouri's imposition of such a high procedural, evidentiary barrier did not violate the Constitution.

*Cruzan* involved a patient in a PVS, like Karen Ann Quinlan, but differed from *Quinlan* because the patient's family wanted to withdraw

---

in the deaths of those patients, *Glucksberg* and *Vacco* differed from *Cruzan* in a number of respects. First, *Glucksberg* and *Vacco* concerned competent patients' rights whereas *Cruzan* addressed a situation involving an incompetent patient. Second, the patient-plaintiffs in *Glucksberg* and *Vacco* were seeking a right to assistance in suicide, a right to end their own lives by forces they set in motion other than the disease process; in *Cruzan*, withdrawal of the artificial nutrition and hydration would permit the patient's condition to proceed to its inevitable conclusion, without putting artificial barriers in the way of death. See *Quinlan*, 355 A.2d at 665 (noting the "real distinction between the self-infliction of deadly harm and a self-determination against artificial life support . . .").

81. The Missouri court thus searched for clear and convincing evidence of Nancy's subjective, actually expressed wishes. *Cruzan*, 497 U.S. at 316 (Brennan, J., dissenting). The subjective test is the most stringent test used in determining whether to permit the withholding or withdrawal of treatment, for it requires actual previous patient statements demonstrating consideration of the circumstances at hand to support withdrawal of treatment. *THE RIGHT TO DIE*, *supra* note 11, § 4.05, at 4-28 to 4-29. Most states instead use a "substituted judgment" test, which examines what the patient would have wanted had the patient considered the circumstances in question. See, e.g., *Quinlan*, 355 A.2d at 664-66 (applying the substitute judgment standard). The last available test, the best interests test, generally will be applied under two circumstances: (1) when the patient was never competent to make medical decisions (such as a child or a mentally retarded person), or (2) when no evidence is available to demonstrate either the patient's actual or the patient's inferred wishes. See, e.g., *Woods v. Commonwealth*, 142 S.W.3d 24, 34-35 (Ky. 2004) (applying the best interests test in the case of a disabled ward); *In re L.W.*, 482 N.W.2d 60, 67-68 n.8 (Wis. 1992) (citing statistics on individuals who had expressed their wishes concerning life-sustaining treatment to their families).

82. The Court noted that many state courts had "held that a right to refuse treatment is encompassed by a generalized constitutional right of privacy." The Court stated, however, "We believe this issue is more properly analyzed in terms of a Fourteenth Amendment liberty interest." *Cruzan*, 497 U.S. at 279 n.7.

medically supplied artificial nutrition and hydration rather than ventilator support. Although not explicitly stated in the Court's majority opinion, a majority of the Justices in *Cruzan* concluded that medically supplied artificial nutrition and hydration constitutes medical treatment that can be refused the same as any other treatment.<sup>83</sup> The majority opinion implied as much and even named "lifesaving nutrition and hydration" as the type of treatment it had in mind when assuming the constitutionally protected right to refuse.<sup>84</sup> More specifically, however, Justice O'Connor, writing in concurrence, made a point of stating, "[a]rtificial feeding cannot readily be distinguished from other forms of medical treatment."<sup>85</sup> Like other forms of medical treatment, artificial feeding involves intrusion and restraint, neither of which medical professionals can initiate without informed consent. She concluded: "Accordingly, the liberty guaranteed by the Due Process Clause must protect, if it protects anything, an individual's deeply personal decision to reject medical treatment, including the artificial delivery of food and water."<sup>86</sup>

The four dissenting Justices—Brennan, Marshall, Blackmun and Stevens—agreed. Justice Brennan, writing for himself and Justices Marshall and Blackmun, said bluntly that "[n]o material distinction can be drawn between . . . artificial nutrition and hydration . . . and any other medical treatment."<sup>87</sup> Justice Stevens, writing a separate dissent, did not expressly discuss whether artificial nutrition and hydration constitute medical treatment, but he did refer several times to Nancy Beth Cruzan's condition and her "medical treatment," while displaying a familiarity with the record implying that he could not have overlooked the fact that her "medical treatment" was artificial nutrition and hydration.<sup>88</sup> Clearly, in his view, the result of the case before him was an absolute bar to termination of something constituting "treatment."

### 3. The *Schiavo* Cases

In both *Quinlan* and *Cruzan*, family members were united. In contrast, "[t]he death of Theresa Marie Schiavo came about only after

---

83. *Id.* at 279.

84. *See id.* at 278–79 (listing injection of medication and transfer to a mental hospital coupled with mandatory behavior modification treatment as examples of treatment that may be refused).

85. *Id.* at 288 (O'Connor, J., concurring).

86. *Id.* at 289.

87. *Id.* at 307 (Brennan, J., dissenting).

88. When criticizing the majority's listing of cases it found precedential, for example, Justice Stevens noted "none of the decisions surveyed by the Court interposed an absolute bar to the termination of treatment for patient in a persistent vegetative state." *Id.* at 347 (Stevens, J., dissenting) (emphasis omitted).

almost seven years of argument among her family members.”<sup>89</sup> Her husband, Michael Schiavo, maintained, and succeeded in arguing to the court, that she would have refused medically supplied nutrition and hydration were she able to make decisions despite her PVS. Her remaining family members were sure that her condition was not so hopeless that she would have chosen to refuse treatment. “The result was a bitter battle reaching through state and federal court systems, legislatures and chief executives’ offices.”<sup>90</sup>

The courts in *Schiavo*, although expressing empathy for Ms. Schiavo’s parents, brother and sister, who disagreed with Michael Schiavo,<sup>91</sup> had no difficulty determining that Ms. Schiavo’s PEG tube should be withdrawn. Specifically, they ruled that clear and convincing evidence had demonstrated that Ms. Schiavo was in a PVS<sup>92</sup> and that she would want withdrawal of medically supplied artificial nutrition and hydration in her condition.<sup>93</sup> That decision became final and all appeals had been exhausted in August 2003, when the Florida Supreme Court denied review of the last ruling issued in the normal course of such a case.<sup>94</sup> Ms. Schiavo’s PEG tube was subsequently removed in October 2003.<sup>95</sup>

---

89. Kathy L. Cerminara, *Theresa Marie Schiavo’s Long Road to Peace*, 29 DEATH STUDIES (forthcoming 2005) (manuscript at 2, on file with the author). See generally Kathy Cerminara & Kenneth Goodman, *Key Events in the Case of Theresa Marie Schiavo*, <http://www.miami.edu/ethics/schiavo/timeline.htm> (visited Nov. 1, 2005) (providing a detailed timeline of the events of the Schiavo case).

90. Cerminara, *supra* note 89.

91. One appellate court, for example, said:

From our review of the videotapes of Ms. Schiavo, despite the irrefutable evidence that her cerebral cortex has sustained the most severe of irreparable injuries, we understand why a parent who had raised and nurtured a child from conception would hold out hope that some level of cognitive function remained. If Mrs. Schiavo were our own daughter, we could not but hold to such a faith.

But in the end, this case is not about the aspirations that loving parents have for their children. It is about Theresa Schiavo’s right to make her own decision, independent of her parents and independent of her husband.

*Schiavo IV*, 851 So. 2d 182, 186 (Fla. Dist. Ct. App. 2003), *aff’g*, No. 90-2908-GB-003, 2002 WL 31817960 (Fla. Cir. Ct. 2002), *review denied*, 855 So. 2d 621 (Fla. 2003). See also *Schiavo V*, 885 So. 2d 321, 336 (Fla. 2004), *aff’g* 871 So. 2d 1012 (Fla. Dist. Ct. App. 2004), *cert. denied*, 125 S. Ct. 1086 (2005) (determining the unconstitutionality of a law passed to reinsert Ms. Schiavo’s PEG tube, yet the court acknowledges “the grief so fully demonstrated by Theresa’s family members”).

92. *Schiavo V*, 885 So. 2d at 325–29.

93. *Id.* at 325–29.

94. *Schindler v. Schiavo*, 855 So. 2d 621 (Fla. 2003) (unpublished table decision); see *Schiavo V*, 885 So. 2d at 331 (reciting the history of that case that resulted in the review being denied by the Florida Supreme Court).

95. *Schiavo V*, 885 So. 2d at 331.

At that point, prompted by emails, call, letters and protests, the state legislature and governor intervened. In October 2003, the Florida Legislature passed, and the governor signed, a statute that would become known as “Terri’s Law.”<sup>96</sup> This statute, which was later held to be unconstitutional,<sup>97</sup> gave Florida Governor Jeb Bush power to issue an executive order requiring reinsertion of Ms. Schiavo’s PEG tube, and he so ordered.<sup>98</sup> The PEG tube then remained in place, pending the eventual ruling that Terri’s Law was unconstitutional and decisions on new motions filed by protesting family members,<sup>99</sup> until March 18, 2005, when it was again removed.<sup>100</sup>

Ms. Schiavo passed away on March 31, 2005, after the United States Congress had also gotten involved, again in response to emails, calls, letters and protests.<sup>101</sup> Congress passed, and President George W. Bush signed, the Act for the Relief of the Parents of Theresa Marie Schiavo.<sup>102</sup> This act granted to the federal courts power to hear federal claims Ms. Schiavo’s parents asserted in protesting the withdrawal of the PEG tube.<sup>103</sup> Efforts to reinsert the PEG tube failed, however, when the federal courts refused to order it because Ms. Schiavo’s parents were unlikely to eventually win their federal lawsuit.<sup>104</sup>

---

96. Terri’s Law, 2003 FLA. LAWS 418. See generally Barbara A. Noah, *Politicizing the End of Life: Lessons From The Schiavo Controversy*, 59 U. MIAMI L. REV. 107 (2004) (discussing the actions of politicians in the case of Terri Schiavo).

97. *Schiavo V*, 885 So. 2d at 328.

98. Terri’s Law, 2003 FLA. LAWS 418; Fla. Exec. Order No. 03-201, available at [http://sun6.dms.state.fl.us/eog\\_new/eog/orders/2003/october/eo2003-201-10-22-03.html](http://sun6.dms.state.fl.us/eog_new/eog/orders/2003/october/eo2003-201-10-22-03.html); *Schiavo V*, 885 So. 2d at 328.

99. *In re Schiavo*, No. 90-2908-GB-003, 2005 WL 459634 (Fla. Cir. Ct. Mar. 28, 2005), *aff’d*, 30 Fla. L. Weekly D743 (Fla. Dist. Ct. App.), *stay denied*, 125 S. Ct. 1622 (2005).

100. Abby Goodnough & Carl Hulse, *Despite Congress, Woman’s Feeding Tube Is Removed*, N.Y. TIMES, Mar. 19, 2005, at A1.

101. Goodnough, *supra* note 3. See also Robin Toner & Carl Hulse, *A Family’s Battle Brings Life’s End into Discussion*, N.Y. TIMES, Mar. 20, 2005, at A19 (reporting on the number of emails and calls to the U.S. Congress).

102. Act for the Relief of the Parents of Theresa Marie Schiavo, Pub. L. No. 109-3, 119 Stat. 15 (2005).

103. *Id.* See also *Schiavo ex rel. Schindler v. Schiavo*, 357 F. Supp. 2d 1378, 1382 (M.D. Fla.), *aff’d*, 403 F.3d 1223 (11th Cir.), *reh’g en banc denied*, 403 F.3d 1261 (11th Cir.) (en banc), *stay denied*, 125 S. Ct. 1692 (2005) (denying a motion for a temporary restraining order brought under the Congressional act).

104. *Schiavo ex rel. Schindler v. Schiavo*, 403 F.3d 1223, 1228–29 (11th Cir.), *aff’g* 357 F. Supp. 2d 1378 (M.D. Fla.), *reh’g en banc denied*, 403 F.3d 1261 (11th Cir.) (en banc), *stay denied*, 125 S. Ct. 1692 (2005); *Schiavo ex rel. Schindler v. Schiavo*, 403 F.3d 1289, 1295 (11th Cir.), *aff’g* 358 F. Supp. 2d 1161 (M.D. Fla.), *reh’g en banc denied*, 404 F.3d 1270 (11th Cir.) (en banc), *reh’g denied*, 404 F.3d 1282 (11th Cir.), *stay denied*, 125 S. Ct. 1722 (2005).

---

---

### III. A COMBUSTIBLE COMBINATION: WHY *SCHIAVO* STRUCK SUCH A CHORD

*Schiavo* differed in important ways from cases like *Quinlan*, and those differences combined to heighten the possibility that some people with disabilities would believe the “slippery-slope” arguments articulated by vitalist activists. Unsurprisingly, the process of common-law development outlined above<sup>105</sup> resulted in a progression of differences among end-of-life decision-making cases. As the law developed through *Quinlan* to *Cruzan* to *Schiavo*, increasing factual differences were accompanied by increasing pandemonium among activists.<sup>106</sup> *Schiavo* and *Cruzan* both resembled *Quinlan* in the sense that each involved a young woman in a PVS, yet they both differed from *Quinlan* because they addressed the withdrawal of medically supplied nutrition and hydration rather than ventilator support.<sup>107</sup> *Schiavo* later took the differences two steps further. In stark contrast to both *Quinlan* and *Cruzan*, it presented the courts and the public with a story in which family members disagreed.<sup>108</sup> Moreover, due to the passage of time and the increasing capability of telecommunications, activists were able to spread messages much more quickly and visually in *Schiavo* than in either *Quinlan* or *Cruzan*.<sup>109</sup> All of these differences

---

105. See *supra* Part II.B (discussing the *Quinlan* and *Cruzan* cases).

106. To the extent that right-to-life protests accompanied the *Quinlan* ruling, if at all, evidence of them is lost to time. In *Cruzan*, a small group of protesters picketed outside the facility in which Nancy Cruzan was a patient and made plans to storm in and either “rescue” her or re-insert a feeding tube into her nose and mouth. COLBY, *supra* note 14, at 368–69. In *Schiavo*, protesters gathered around Ms. Schiavo’s hospice by the hundreds, and thousands of others phoned, wrote to, and emailed their Congressmen. See generally Goodnough, *supra* note 16 (reporting about protesters at Schiavo’s hospice); Toner & Hulse, *supra* note 101, at A19 (noting “tens of thousands of calls and email messages in recent days”). See also Gary Schneeberger, *Linked Together for Impact*, 2005, <http://www.family.org/cforum/citizenmag/features/a0035297.cfm> (describing email pressure on state legislatures).

107. Compare *In re Quinlan*, 355 A.2d 647 (N.J. 1976) (allowing the removal of ventilator support), with *Cruzan v. Dir., Mo. Dept. of Health*, 497 U.S. 261 (1990) (allowing the removal of a nutrition and hydration tube), and *Schiavo I*, 780 So. 2d 176 (Fla. Dist. Ct. App.), review denied, 789 So. 2d 348 (Fla. 2001) (allowing the removal of a nutrition and hydration tube). See generally George J. Annas, “Culture of Life” Politics at the Bedside—The Case of Terri Schiavo, 352 NEW ENG. J. MED. 1710 (2005) (discussing all three cases).

108. See Jay Wolfson, *Erring on the Side of Theresa Schiavo: Reflections of the Special Guardian Ad Litem*, 35 HASTINGS CENTER REP. 16, 18–19 (2005) (describing points of family disagreement).

109. See Ronald E. Cranford, *Facts, Lies and Videotapes: The Permanent Vegetative State and the Sad Case of Teri Schiavo*, 33 J.L. MED. & ETHICS 363, 370 (2005) (noting the importance of videotaping, used both in the media by activists to visually portray Ms. Schiavo’s condition and at trial by those supporting withdrawal of treatment to show the depth of

led to the increased likelihood that activists could—and in fact did—galvanize some people with disabilities in *Schiavo*.

#### A. PVS as a Triggering Condition in Schiavo

The first appellate court to consider the *Schiavo* case noted that Ms. Schiavo had “cycles of apparent wakefulness and apparent sleep” and emitted “moaning sounds” when breathing.<sup>110</sup> Two years later, the same court noted, “[f]rom our review of the videotapes of [Ms.] Schiavo, despite the irrefutable evidence that her cerebral cortex has sustained the most severe of irreparable injuries, we understand why a parent who had raised and nurtured a child from conception would hold out hope that some level of cognitive function remained.”<sup>111</sup> In 2005, that same court stated, “the images of [Ms.] Schiavo’s face are haunting. But the images do not reveal the full extent of the devastation to her brain and her inability to engage in cognition.”<sup>112</sup> In response to last-ditch efforts in March 2005 to argue that Ms. Schiavo was not in a PVS, the trial court judge wrote that, as had been true throughout the court proceedings, consistent with the PVS diagnosis that had clearly and convincingly been proven, “from time to time, [Ms. Schiavo] responds to stimuli, . . . makes limited vocalizations, and . . . can move and change facial expressions.”<sup>113</sup>

It is the willingness and desire to attribute cognitive awareness and interactivity to a patient in a PVS based on such facts that cause cases like *Schiavo* to be so difficult. In *Schiavo*, it was precisely this misunderstanding that activists seized upon, perpetuated and magnified until television stations across the land were playing videotapes of Ms. Schiavo that misleadingly appeared to show a minimally conscious person.<sup>114</sup> At the least, these activists succeeded in misleading some federal legislators<sup>115</sup> and some persons with disabilities.<sup>116</sup>

---

neurological examinations performed).

110. *Schiavo I*, 780 So. 2d at 177.

111. *Schiavo IV*, 851 So. 2d 182, 196 (Fla. Dist. Ct. App. 2003), *aff’g*, No. 90-2908-GB-003, 2002 WL 31817960 (Fla. Cir. Ct. 2002), *review denied*, 855 So. 2d 621 (Fla. 2003).

112. *In re Schiavo*, No. 2D05-968, 30 Fla. L. Weekly D743 (Fla. Dist. Ct. App. 2005).

113. *In re Schiavo*, No. 90-2908-GD-003, 2005 WL 459634, at \*4 (Fla. Cir. Ct. Mar. 28, 2005), *aff’d*, 30 Fla. L. Weekly D743 (Fla. Dist. Ct. App.), *stay denied*, 125 S. Ct. 1622 (2005).

114. Cerminara, *supra* note 37, at 11–12 (saying that activists were portraying Schiavo as minimally conscious). While appearing to “show Terri consciously and emotionally interacting with her parents,” the videotapes and photographs of Ms. Schiavo, “to the trained eye of any doctor experienced in the diagnosis of the vegetative state and related conditions, . . . demonstrate rather conclusively that [she] was in a vegetative state.” Cranford, *supra* note 109, at 366.

115. See Anita Kumar, David Karp & Chris Tisch, *Congress Votes: Keep Schiavo Alive*, ST. PETERSBURG TIMES, Mar. 21, 2005, at 1A (quoting Rep. Jack Kingston (R-Ga.) as saying, based on seeing videotape clips of Ms. Schiavo, “Here is what we know . . . Terri is not in a persistent

*B. Medically Supplied Nutrition and Hydration in Schiavo*

Additionally, as noted, both *Cruzan* and *Schiavo* differed from *Quinlan* in that they required the courts to consider the propriety of withdrawing medically supplied nutrition and hydration rather than ventilator support, a treatment some more clearly see as “medical.” While the law has long seen no distinction,<sup>117</sup> some individuals, including policymakers and activists, in both *Quinlan* and *Cruzan* concentrated on inflaming the masses with judicious use of terminology.<sup>118</sup>

Demonstrations outside the patients’ health care facilities provided one prime opportunity to do so. In *Cruzan*, at least one protester “walked around the first floor of [Nancy Cruzan’s] hospital near the administrative offices for nearly an hour, carrying a cup of water.”<sup>119</sup> When questioned, he said he was trying to give a dying patient a cup of water.<sup>120</sup> Signs at a tent city included pleas to “feed Nancy.”<sup>121</sup> In *Schiavo*, protesters holding signs shaped like spoons that said, “Please feed Terri” stood outside her hospice.<sup>122</sup> Protesters were arrested for trying “to force their way past officers guarding the driveway of [the hospice] to take bread and water to Ms. Schiavo as a symbolic gesture.”<sup>123</sup> The Reverend Patrick Mahoney of the Christian Defense Coalition, a protester himself, described the scene: “People want to come with a cup of water and bread and say we’re not leaving until my sister Terri gets a chance to eat.”<sup>124</sup>

Another such opportunity arose during debate and demonstrations about Ms. Schiavo’s case in the capitals of both the United States and Florida regarding Ms. Schiavo’s treatment. Lobbying for a statute requiring reinsertion of Ms. Schiavo’s PEG tube in early 2005, Randall

---

vegetative state. Terri is able to laugh, able to cry and apparently able to hear.”).

116. See de la Cruz, *supra* note 1 (describing Kristen, a disabled woman who protested outside Schiavo’s hospice).

117. See *supra* Part II.A.2 (discussing the use of medically supplied nutrition and hydration).

118. Regarding the misleading effect of terminology on the public’s perceptions of the case, see Jean Heller, *An Image to Make Stomachs Tighten*, ST. PETERSBURG TIMES, Mar. 19, 2005, at 14A, and John Schwartz, *Experts Say Ending Feeding Can Lead to a Gentle Death*, N.Y. TIMES, Mar. 20, 2005, at A29.

119. COLBY, *supra* note 14, at 311.

120. *Id.*

121. *Id.* at 374.

122. Lesley Clark, Erika Bolstad & Martin Merzer, *Feeding Tube Could Be Reconnected Today*, S. FLA. SUN-SENTINEL, Mar. 21, 2005, at A2.

123. Goodnough, *supra* note 16.

124. Lauren Bayne Anderson, *Protesters Gather at Hospice*, ST. PETERSBURG TIMES, Mar. 17, 2005, at 4B.

Terry<sup>125</sup> said, “Terri does not deserve to be starved to death . . . . If we had a dog and put it in a cage here at the Capitol and said we were going to starve this dog to death, there’d be an outrage of public opinion—and rightly so. Why do we treat a human being in ways we wouldn’t treat a dog?”<sup>126</sup> U.S. Senator Mel Martinez (R-Fla.) said, “[a]nytime a mom wants to take a daughter home and love her and feed her, she ought to be able to do that.”<sup>127</sup> House Majority Leader Tom DeLay described Ms. Schiavo as “being dehydrated and starved to death,” adding that “[f]or 58 long hours, her mouth has been parched and her hunger pains have been throbbing.”<sup>128</sup>

Such language is effective. Anyone reading the references to “starvation” or seeing the images of people trying to take food and water into Ms. Cruzan’s or Ms. Schiavo’s room might wonder at the scope of what was happening. Persons with disabilities certainly might, and did.<sup>129</sup>

### C. Family Disagreement in Schiavo

Also as noted previously, *Schiavo* took us to a place neither *Quinlan* nor *Cruzan* did by exposing family divisions and bitter disagreement about the patient’s wishes.<sup>130</sup> Family disagreement is almost certain to lead to litigation unless alternative dispute resolution mechanisms such as ethics committees can avoid such an end.<sup>131</sup> If some loving family

125. See *supra* notes 168–69 (identifying Mr. Terry as the pro-life founder of Operation Rescue and an outspoken critic of withdrawing Ms. Schiavo’s PEG tube).

126. Bill Cotterell, *Judge Orders Schiavo Hearing*, TALLAHASSEE DEMOCRAT, Feb. 23, 2005, at A1.

127. Tamara Lytle & Sean Mussenden, *Stalemates Block Schiavo Legislation*, S. FLA. SUN-SENTINEL, Mar. 18, 2005, at 17A.

128. Kumar et al., *supra* note 115. In reality, death after withdrawal of artificial nutrition and hydration, even in patients that experience pain, does “not cause significant suffering. Physicians and particularly nurses have written many observational pieces describing peaceful and apparently comfortable deaths.” James L. Bernat, Bernard Gert & R. Peter Mogielnicki, *Patient Refusal of Hydration and Nutrition: An Alternative to Physician-Assisted Suicide or Voluntary Active Euthanasia*, 153 ARCH. INTERNAL MED. 2723, 2725–26 (1993) (proposing refusal of nutrition and hydration by competent patients as an alternative to seeking to commit suicide or asking someone to euthanize them). The process releases ketones in the body that can serve as anesthetic. *Id.* at 2726. Moreover, patients in PVS have, at most, “inconsistent” responses to pain stimuli. Wijdicks & Cranford, *supra* note 32, at 1038.

129. See de la Cruz, *supra* note 1 (describing Kristen’s reaction to what she saw about Ms. Schiavo’s situation).

130. See Timothy E. Quill, *Terri Schiavo—A Tragedy Compounded*, 352 NEW ENG. J. MED. 1630, 1631 (2005) (noting the breakdown of relationship between Ms. Schiavo’s husband and parents).

131. See generally THE RIGHT TO DIE, *supra* note 11, at § 3.24[B][1], at 3-93–3-94 (regarding family disagreement); *id.* at § 3.25[A], at 3-96 (regarding ethics committees); Rebecca Dresser, *Schiavo: A Hard Case Makes Questionable Law*, 34 HASTINGS CENTER REP., May–June 2004, at

members believe a patient is minimally conscious rather than in a PVS, then family disagreement is almost certain to be bitter and protracted.<sup>132</sup> For the general public, including some people with disabilities, the fact that some family members believe that treatment should continue may serve as a signal that family members objecting to treatment are acting negatively toward the patient because of prejudices against persons in states of diminished capacity.<sup>133</sup> In reality, family members who seek withholding or withdrawal of treatment can be, and often are, just as loving and focused on the patient's wishes as are those who seek continuation of treatment.<sup>134</sup> A family dispute over a desire to withdraw treatment does not equate to bad faith on the part of one side of that dispute, or to discrimination against people with disabilities.

The case of Hugh Finn provides an example of the way family dynamics can give rise to vitalist concerns articulated as being rooted in concern for people with disabilities.<sup>135</sup> Hugh Finn entered a PVS as a result of an automobile accident.<sup>136</sup> After about three and a half years of his existence in that state, his wife decided in 1998 that Mr. Finn would have chosen withdrawal of medically supplied nutrition and hydration.<sup>137</sup> The Governor of Virginia intervened "to protect the interests of the most vulnerable of the state's citizens,"<sup>138</sup> and 400 people gathered to protest at Mr. Finn's nursing home, after objections

---

8, 9 ("Schivo demonstrates the need for mediation and other dispute resolution procedures to address family disagreements over life-sustaining treatment.").

132. See, e.g., *In re Jobes*, 529 A.2d 434 (N.J. 1987) (ruling that a patient was in a PVS).

133. Cf. Lawrence O. Gostin, *Ethics, the Constitution, and the Dying Process: The Case of Theresa Marie Schiavo*, 293 J. AM. MED. ASS'N 2403, 2406 (2005) (discussing concerns of persons with disabilities).

134. This presumes, of course, that those seeking continuation of the treatment are not acting to serve their own needs by doing so, using the patient as an instrumentality. See Lois Shepherd, *Shattering the Neutral Surrogate Myth in End-of-Life Decisionmaking: Terri Schiavo and Her Family*, 35 CUM. L. REV. 575, 577 (2004) (acknowledging the possible existence of surrogates' self interests when making end-of-life decisions); JAY WOLFSON, A REPORT TO GOV. JEB BUSH IN THE MATTER OF THERESA MARIE SCHIAVO 14 (2003), <http://www.miami.edu/ethics/schiavo/wolfson%27s%20report.pdf> [hereinafter WOLFSON REPORT] (noting that Ms. Schiavo's parents, who wanted continuation of treatment, appeared to be acting in their own interests).

135. *Gilmore v. Finn*, 527 S.E.2d 426, 428 (Va. 2000).

136. *Id.*

137. *Id.*

138. John J. Paris, *Hugh Finn's 'Right to Die'*, AMERICA, Oct. 31, 1998, available at <http://www.americamagazine.org/articles/ParisFinn.htm>. Specifically, Virginia agencies conducted a series of investigative visits to the nursing home in which Mr. Finn was a patient, apparently in response to requests from one of Mr. Finn's relatives and a member of the state legislature. *Finn*, 527 S.E.2d at 430. The governor also filed a complaint against the nursing home, Mr. Finn's doctor and Mr. Finn's wife seeking an injunction to prohibit them from withdrawing Mr. Finn's artificial nutrition and hydration. *Id.*

to withdrawal of treatment were raised by Mr. Finn's parents and siblings.<sup>139</sup> In a preview of what would happen seven years later in *Schiavo*,<sup>140</sup> state social workers received anonymous calls that Mr. Finn was suffering abuse and neglect, and the media and protesters surrounded the nursing home until Mr. Finn died.<sup>141</sup> Family members who opposed Mrs. Finn's decision insisted "that Hugh was aware of his environment and that he did not want to die."<sup>142</sup>

It was family disagreement in the *Finn* case, just as it was family disagreement in *Schiavo*, that prompted concerns. Outside observers may question the motives prompting family members to take diametrically opposite positions on a patient's wishes, especially because the care of a patient in a PVS, like the care of some people with disabilities, often imposes financial costs and other burdens on family members.<sup>143</sup> People with disabilities observing disagreement among family members may be concerned about the natural tendency we all have to desire relief from costs and burdens.<sup>144</sup> Thus, they may become concerned about the extent to which society honors the statements of family members about incapacitated patients' wishes.<sup>145</sup>

Such views demonstrate a level of distrust that many who are not disabled find difficult to comprehend. Persons without disabilities often

---

139. See Janet Heald Forlini, *Hugh Finn Case is an Education for Advocates and the Public*, ABCD EXCHANGE, Nov. 1998, <http://mywhatever.com/cifwriter/content/19/abcd1664.html> (describing the "400-person protest" prompted by Mr. Finn's parents and siblings).

140. See Graham Brink, *DCF Found No Signs Terri Schiavo Abused*, ST. PETERSBURG TIMES, Apr. 16, 2005, at 3B (describing 89 complaints between 2001 and 2004); Chris Tisch & Curtis Krueger, *Schiavo Abuse Claims Were Old*, ST. PETERSBURG TIMES, June 4, 2005, at 1A (recounting release of "nearly 70 pages" of documents memorializing state agency's abuse investigations).

141. Forlini, *supra* note 139.

142. See Liz Townsend, *Court Upholds Virginia Governor's Right to Intervene in Hugh Finn Case*, NAT'L RIGHT TO LIFE NEWS, Apr. 2000, <http://www.nrlc.org/news/2000/NRL04/finn.html>.

143. One estimate of the costs of care provided to an elderly woman in a PVS receiving medically supplied nutrition and hydration for several months in the late 1980s was about \$700,000. Steven H. Miles, *Informed Demand for "Non-Beneficial" Medical Treatment*, 325 NEW ENG. J. MED. 512, 512 (1991). In 1991, shortly after *Cruzan* was decided, one general estimate of the cost of care of a patient in a PVS was "upwards of \$130,000 per year." John D. Arras, *Beyond Cruzan: Individual Rights, Family Autonomy and the Persistent Vegetative State*, 39 J. AM. GERIATRICS SOC'Y 1018, 1018 (1991), reprinted in CONTEMPORARY ISSUES IN BIOETHICS (Tom L. Beauchamp & LeRoy Walters eds., 1994). For a thoughtful discussion of such concerns with regard to providers (as opposed to surrogate decision-makers) who desire to withdraw care from "costly" patients, see Philip G. Peters, *When Physicians Balk at Futile Care: Implications of the Disability Rights Laws*, 91 NW. U. L. REV. 798, 857-62 (1997).

144. Gostin, *supra* note 133, at 2406.

145. Cf. Joan Didion, *The Case of Theresa Schiavo*, 52 N.Y. REV. BOOKS, June 9, 2005 (describing the social pressure to expressly choose to end one's life so as to not be a burden on family members).

are more ready than those with disabilities to put their faith in the courts, for they perceive the courts as being on guard for such concerns and ready to consider the parties' potential conflicts of interest when making decisions.<sup>146</sup> Against the background of discrimination that people with disabilities generally feel, those without disabilities should not discount such fears should people like Kristen experience them.<sup>147</sup>

#### D. Framing and Use of the Media in Schiavo

A final factor that differentiates *Schiavo* from *Quinlan* is the increased awareness and use of the power of imagery through framing and the media, including the Internet. All of the factors listed above were magnified in *Schiavo* when framed or described in carefully chosen terminology and when publicized through words, sounds and pictures on instantaneous media outlets.

"Framing is the use of visuals, slogans, and context use of words, images and context to manipulate or manage how people think about an issue."<sup>148</sup> A few examples from *Schiavo* illustrate just how well disability rights and vitalist activists have learned to use framing. Already discussed was the use of videotape clips to spread the inaccurate message that Ms. Schiavo was minimally conscious rather than in a PVS.<sup>149</sup> Television screens were filled with images of Ms. Schiavo apparently fixating on a balloon or gazing at her mother.<sup>150</sup> Selected clips and images such as these can indeed manipulate a viewer into believing that they truly depict the patient's condition.<sup>151</sup>

---

146. Cf. Jennifer Fitzgerald, *Bioethics, Disability and Death: Uncovering Cultural Bias in the Euthanasia Debate*, in *DISABILITY, DIVERS-ABILITY AND LEGAL CHANGE* 267, 277 (M. Jones & L.A. Basser Marks eds., 1999) (arguing that the views of persons with disabilities should be considered more explicitly, noting that the legal system's "understanding of the vulnerability of people with disabilit[ies] is . . . limited").

147. See Schneider, *supra* note 24, at 26–27 (arguing that society should "hear the Schindlers' supporters in [a] generous spirit").

148. Robin Fiore et al., *The Tragic and Strange Case of Terri Schiavo: How the "Framing" of This Case Has Misled the Public and Almost Destroyed Thirty Years of Progress in End-of-Life Policy* 3 (unpublished manuscript, on file with the author). This manuscript, possibly to appear soon as a book chapter, contains several examples of framing and media usage.

149. See *supra* Part III.A (describing how playing videotapes of Ms. Schiavo led to misunderstandings of her condition).

150. See Cranford, *supra* note 109, at 366 (discussing the brief videotapes of Ms. Schiavo appearing to interact with family and friends). See generally Eric J. Cassell, *The Schiavo Case: A Medical Perspective*, 35 *HASTINGS CENTER REP.* 22, 22 (2005) (discussing concerns about privacy, noting "[t]he shocking, clamoring, and very public intrusion into the life and death of Terri Schiavo").

151. Cranford, *supra* note 109, at 366 (describing a "strategy of misinformation").

Two other examples also relate to the previously discussed differences between *Schiavo* and *Quinlan*. Rather than explaining what a PEG tube is and how it works, and acknowledging that it had been fifteen years since Ms. Schiavo could eat as most people eat, activists discussed attempts to “starve” Ms. Schiavo and to deprive her of “food and water.”<sup>152</sup> Similarly, the case was presented not as a disagreement between loving, well-meaning family members, but as an example of one family member (Ms. Schiavo’s husband) seeking to benefit financially and to free himself from the burden of caring for a wife lying in a hospice bed in favor of continuing his life with another woman and the two children he had fathered with that other woman.<sup>153</sup>

Compounding the effects of such word choice and story construction was intelligent use of the media. Twenty-four-hour news broadcasts, unavailable at the time of *Quinlan* and in their infancy at the time of *Cruzan*, increased the opportunity for the previously mentioned videotape clips to reach the public.<sup>154</sup> Pictures of Ms. Schiavo appeared throughout the country, including on Internet sites devoted to “saving” her.<sup>155</sup> Whereas organizers had to rely on fax communications and

---

152. See *supra* Part III.B (describing activists’ demonstrations and media references to “starvation”).

153. Both money and Mr. Schiavo’s relationship with another woman were sources of antagonism. First, Ms. Schiavo’s parents accused her husband of denying his wife treatment because he wanted to inherit the money won in a malpractice case over the cause of the cardiac arrest that resulted in her PVS. Melanie Ave & David Karp, *After Jury Award, Battle Lines Drawn*, ST. PETERSBURG TIMES, Mar. 23, 2005, at 1A (noting that Mr. Schiavo in turn accused them of greed in wanting a share of the money). The trial court also mentioned that Ms. Schiavo’s parents had argued that Michael should be disqualified as his wife’s guardian because he stood to benefit by inheritance upon her death. See *In re Schiavo*, No. 90-2908GD-003, at 2 (Fla. Cir. Ct. Pinellas County, Feb. 11, 2000), available at <http://www.miami.edu/ethics/schiavo/timeline.htm> (follow February 11, 2000 “Trial Court Ruling” hyperlink) (last visited Nov. 1, 2005) (“Regrettably, money overshadows this entire case and creates potential of conflict of interest for both sides.”).

Second, by the time Ms. Schiavo’s death drew near, protesters picketed the home Michael shared with the mother of his children with signs saying, “Michael don’t plan the wedding yet, [sic] we still have hope!” and “Arrest Mike for Bigamy.” Jamie Thompson, *She’s the Other Woman in Michael Schiavo’s Heart*, ST. PETERSBURG TIMES, Mar. 26, 2005, at 1A (describing the mother of Michael Schiavo’s two children as having been “anathematized, her name invoked as a key reason why Schiavo . . . should not control his wife’s fate”). See also Chris Tisch, *A Fate Unclear, A Legacy Assured*, ST. PETERSBURG TIMES, Feb. 27, 2005, at 1A (describing Michael Schiavo as having “at times been cast as a money-hungry villain only after the money his wife received in a settlement and who has a new life with a girlfriend”).

154. See Cranford, *supra* note 109, at 363 (describing “a war waged in the media and over the internet”); see also Brad Smith, *Schiavo Videotapes Offer Powerful But Misleading Evidence*, TAMPA TRIB., Mar. 20, 2005, at 12 (describing the powerful influence that the video clips of Terri Schiavo had on the public).

155. E.g., The Terri Schindler-Schiavo Foundation, [www.terrisfight.org](http://www.terrisfight.org) (last visited Nov. 1, 2005).

word of mouth at the time of *Cruzan*, they could use email at the time of *Schiavo*, thus allowing for much larger demonstrations.<sup>156</sup> Email even provided an efficient means of pressuring legislators; the Florida Legislature received emails by the thousands in 2003, when the *Schiavo* case initially reached the final judgment stage.<sup>157</sup>

Bombarded with the effects of such framing and media usage, it is easy for members of the general public, let alone some people with disabilities, to believe that the facts are quite different from those revealed in an actual courtroom.<sup>158</sup> Increased appreciation of the ability to manipulate using words and images coupled with the remarkable ease of publicity over the Internet makes it extremely easy to incite fear, agitation, and anger.<sup>159</sup> Those who believe that the end result of *Schiavo* was absolutely correct may find it difficult to, but should nonetheless, empathize with those with disabilities who were hearing these messages. Kristen and others like her saw many powerful images and heard many touching descriptions designed to foster a misplaced feeling of comradeship with Ms. Schiavo.<sup>160</sup>

#### IV. THE PROBLEM WITH PAIRING THE DISABILITY RIGHTS MOVEMENT AND VITALIST ACTIVISTS

At the time the New Jersey Supreme Court decided *Quinlan* in 1976, the disability rights movement was in its infancy.<sup>161</sup> By the time of the events leading to *Cruzan* in 1990, the rights of people with disabilities had nearly garnered comprehensive recognition through major federal legislation, the Americans with Disabilities Act.<sup>162</sup> *Schiavo* brought to

---

156. Maya Bell, *Sophisticated Tactics Aid Schiavo's Parents*, ORLANDO SENTINEL, Mar. 13, 2005, at A1.

157. See Schneeburger, *supra* note 106 (stating that "legislators received more than 100,000 emails . . . that day from concerned citizens from coast to coast"). See also Toner & Hulse, *supra* note 101 (describing email pressure on federal legislators).

158. Wisconsin Republican Representative James Sensenbrenner, Jr., provides an example. The St. Petersburg Times quoted him as saying, "What's going on in Florida regarding Terri Schiavo is nothing short of inhumane. . . . What Terri Schiavo and all disabled people deserve, in contested cases, is for justice to tilt toward life." Alisa Ulferts, Anita Kumar & William R. Levesque, *U.S. House Acts to Save Schiavo*, ST. PETERSBURG TIMES, Mar. 17, 2005, at 1A. The law in fact already affords such a presumption toward preservation of life. See *supra* Part II.B.2 (describing the high standard of proof in withdrawal of treatment cases).

159. See *supra* notes 101, 106, 109, 114, 157 and accompanying text (describing the use of pictures, videos, and emails in the *Schiavo* case).

160. Cf. Cranford, *supra* note 109 (discussing the use of videotaped images in Terri Schiavo's case).

161. See Richard K. Scotch, *Politics and Policy in the History of the Disability Rights Movement*, 67 MILBANK Q. (supp. 2, pt. 2) 380, 387 (1989) (dating the beginning of a "broadly based cross-disability movement advocating rights for disabled people" to the late 1960s).

162. The Americans With Disabilities Act, 42 U.S.C. §§ 12,101–12,213, was passed in 1990.

a head a phenomenon that had been foreshadowed since shortly after *Quinlan*: the pairing of the disability rights and the vitalist activist movements.<sup>163</sup> Unfortunately, individual persons with disabilities who have joined the pairing of disability rights and vitalist activists that we saw in *Schiavo* are in fact not being served by that pairing. They are being used by it, in an effort by the vitalist community to bolster other political agendas.

#### A. *The Unfortunate Pairing*

An early, if not the earliest, organized pairing of the disability rights community and vitalist activists is an organization called Not Dead Yet.<sup>164</sup> Self-described as a group opposed to legalization of assisted suicide and euthanasia, it was formed in response to the 1996 acquittal of Dr. Jack Kevoorkian when he assisted two women in ending their lives in Michigan.<sup>165</sup> Its founder, Diane Coleman, argues that many forms of what she terms legalized “assisted suicide and euthanasia”—including instances of withholding and withdrawal of life-sustaining treatment at the express request of patients such as Elizabeth Bouvia—do not present issues of “individual autonomy and rights” but instead present issues of “disability discrimination, a profit-oriented health care system, and a legal system that does not guarantee the equal protection of the law.”<sup>166</sup>

Not Dead Yet was among the disability rights and vitalist activist groups who joined in various aspects of the *Schiavo* case.<sup>167</sup> That the

---

The ADA prohibits discrimination “on the basis of disability in the full and equal enjoyment of the . . . services . . . of any place of public accommodation.” 42 U.S.C. § 12,182 (2000). Its importance in this context, however, is not its prohibition of discrimination against persons with disabilities, see *infra* Part IV.B.2, but in the symbolism of its passage as a sign of increased political power on the part of persons with disabilities. See Scotch, *supra* note 161, at 398 (noting, before passage of the ADA, “[t]he most significant legislative goal for the disability rights movement and a test of its ability to enter coalitions has become enactment of” the ADA).

163. See *supra* Part I (discussing the pairing from *Bouvia* in the 1980s through *Cruzan* and *Schiavo*).

164. See *supra* notes 21–22 (citing to the Not Dead Yet homepage and related websites and describing the organization’s purpose and goals).

165. *Id.*

166. Diane Coleman, *Assisted Suicide and Disability: Another Perspective*, 27 HUMAN RIGHTS 6, 7 (Winter 2000). See also Press Release, Issues Surrounding Terri Schindler-Schiavo Are Disability Rights Issues, Say National Disability Organizations, Oct. 27, 2003, <http://www.ragged-edge-mag.com/schiavostatement.html> (stating the position that *Schiavo* presents disability rights issues).

167. See *Schiavo IV*, 851 So. 2d 182 (Fla. Dist. Ct. App. 2003), *aff’g*, No. 90-2908-GB-003, 2002 WL 31817960 (Fla. Cir. Ct. 2002), *review denied*, 855 So. 2d 621 (Fla. 2003) (listing as *amici curiae* Not Dead Yet and 18 other groups, including the American Catholic Lawyers Association).

activists are not motivated solely by concern for the rights of people with disabilities is evident when one considers the presence and intense involvement of Randall Terry in the *Schiavo* cases.<sup>168</sup> Mr. Terry, described on a pro-life website as a “powerful and eloquent pro[-]life spokesman,”<sup>169</sup> is not an officer of Not Dead Yet; rather, he founded the now-defunct pro-life organization Operation Rescue, which made headlines in the 1990s by protesting at facilities providing abortions. He now heads the Society for Truth and Justice, a similar group.<sup>170</sup> During the political struggles of the final days of Ms. Schiavo’s life, Mr. Terry lobbied for federal or state legislative or state gubernatorial action that would result in reinsertion of the PEG tube.<sup>171</sup> After Ms. Schiavo died, he urged his followers to “ensure that Terri’s struggle was not in vain.”<sup>172</sup>

It is important to note that not all people with disabilities buy into this pairing. Only some disability rights groups, like some individual persons with disabilities, have adopted vitalist positions and chosen to work in concert with pro-life groups.<sup>173</sup> Adrienne Asch, a noted authority on reproductive and other socio-ethical issues, has noted that “[t]he disability perspective on treatment of disabled newborns, physician-assisted suicide, and prenatal diagnosis and selective abortion shares nothing with the right-to-life analysis, with which it is often linked in bioethics discussion.”<sup>174</sup> Noting the pairing of disability rights and vitalist activists at the time that the United States Supreme Court

---

168. Mr. Terry was also involved in protests at the time of *Cruzan*. COLBY, *supra* note 14, at 376.

169. Welcome to RandallTerry.com, <http://www.randallterry.com/home/index.cfm> (last visited Nov. 1, 2005).

170. History of Operation Rescue West, <http://www.operationrescue.org/?p=64> (last visited Nov. 1, 2005); The Society for Truth and Justice Home Page, <http://www.societyfortruthandjustice.com> (last visited Nov. 1, 2005).

171. See Goodnough, *supra* note 16 (describing Mr. Terry as saying that he would continue lobbying both the United States Congress and the state legislature for legal action); Tamara Lytle & Maya Bell, *Schiavo Decision Sent Back to Court; Congress Rushes Through Legislation to Keep Her Alive*, S. FLA. SUN-SENTINEL, Mar. 21, 2005, at 1A (describing Mr. Terry’s travel to the Florida state capital “to begin escalating the pressure on legislators and Gov. Jeb Bush”); see also Erika Bolstad, Phil Long & Cara Buckley, *Schiavo Receives Sacred Rites*, MIAMI HERALD, Mar. 28, 2005, at 1A (quoting Mr. Terry as saying of Ms. Schiavo, “she’s responsive[;] she is still communicating and this girl is fighting for her life”).

172. *The Death of Terri Schindler Must Not be in Vain*, May 19, 2005, [http://www.societyfortruthandjustice.com/terri\\_followup.htm](http://www.societyfortruthandjustice.com/terri_followup.htm).

173. See Andrew I. Batavia, *Disability and Physician-Assisted Suicide*, 336 NEW ENG. J. MED. 1671, 1671 (1997) (noting that the disabled community’s position on physician-assisted suicide is not unanimous).

174. Adrienne Asch, *Disability: Attitudes and Psychological Perspective*, in 2 ENCYC. BIOETHICS 602, 606 (1995).

was considering the constitutionality of laws prohibiting physician-assisted suicide, Andrew Batavia, a quadriplegic attorney and professor of some note, decried statements that Not Dead Yet was “just a mouthpiece of the right-to-life movement and religious conservatives generally.”<sup>175</sup> Offering his “general impression” that members of Not Dead Yet were “primarily on the other end of the political spectrum – liberals and radicals,” he termed the disability rights-vitalist pairing “a case of some very strange political bedfellows.”<sup>176</sup>

Yet it is clear that the pairing was strong in *Schiavo*. The listing of *amicus* briefs on the legal opinions reveals both disability rights and vitalist activist groups.<sup>177</sup> Attorneys for Ms. Schiavo’s parents were paid by groups as diverse as the anti-abortion Life Legal Defense Foundation; the anti-gay-rights Alliance Defense Fund; and the Discovery Institute, which advocates the “teaching of creationist ‘intelligent design’ theory in public schools.”<sup>178</sup> Some politicians citing a “culture of death” joined in the effort to overrule judicial decisions in *Schiavo* not out of concern for people with disabilities but based upon vitalist convictions.<sup>179</sup>

### B. Why the Pairing Is Unfortunate

Strange or not, a pairing between disability rights and vitalist activists would not necessarily be unfortunate if each party in the pairing were equally and fully committed to assisting the other party, without making misrepresentations or preying on ill-founded fears to achieve support. It also would not be unfortunate if the result were equally beneficial to both sides. In this setting, however, the disability rights activists who pair with vitalist activists, as well as people with disabilities like Kristen who buy into the pairing, will be negatively affected in the long term if

---

175. Andrew I. Batavia, *Disability and Physician-Assisted Dying*, in *PHYSICIAN-ASSISTED DYING: THE CASE FOR PALLIATIVE CARE AND PATIENT CHOICE* 57 (Timothy E. Quill & Margaret P. Battin eds., 2004). Mr. Batavia founded a group called AUTONOMY, Inc. to counter the efforts of groups such as Not Dead Yet at that time. *Id.* at 58–59.

176. *Id.* at 57. See also Scotch, *supra* note 161, at 396 (describing first pairing of these “two movements with substantially divergent ideologies”); Fiore et al., *supra* note 148, at 7 (describing *Schiavo* as involving “a disability community that has rarely enjoyed the help or support of social conservatives [that] has been convinced by those conservatives that it has an interest in the outcome of Ms. Schiavo’s case”).

177. See, e.g., *supra* note 167 (noting the involvement of Not Dead Yet and the American Catholic Lawyers Association, among others).

178. Jon B. Eisenberg, *The Terri Schiavo Case: Following the Money*, *THE RECORDER*, Mar. 4, 2005, at 4.

179. E.g., Steve Bousquet, *A Crusade Against a ‘Culture of Death’: For Dennis Baxley, Terri’s Schiavo’s Case is a Personal Fight*, *ST. PETERSBURG TIMES*, Mar. 17, 2005, at 1B (describing Republican House member Dennis Baxley’s involvement in the *Schiavo* case).

the advances in the law since *Quinlan* are permitted to be turned back.<sup>180</sup> Most sadly, they will suffer that ill effect because of misrepresentations and half-truths.<sup>181</sup>

Kristen revealed fears stemming from two major misconceptions regarding the *Schiavo* case. Going forward, perhaps reasoned discussion, removed from the fervor of activism, could enable people with disabilities such as Kristen to appreciate the position of those who supported the outcome in *Schiavo*.<sup>182</sup> In addition, perhaps those people with disabilities who agreed with the *Schiavo* decisions, for certainly there are some, will vocalize their positions as loudly as the disability rights-vitalist activists have. Without such discussion and vocalization, some people with disabilities, like Kristen, will buy into activists' pairing based on an incorrect perception that the law does not protect them. Should this occur, the unfortunate result would be that people with disabilities, along with the rest of society, would lose some of the most important gains of *Quinlan* and its progeny.

### 1. Two Misconceptions

Kristen's sign illustrated one of the most important underpinnings of the spread of fear among people with disabilities in *Schiavo*. Kristen made a point in her sign of saying that she was "not a cabbage, an onion, nor [sic] a cob of corn."<sup>183</sup> That young woman (who, though suffering brain damage, was perfectly alert) was worried about being considered a vegetable.<sup>184</sup> The very term "persistent vegetative state," describing the condition in which Karen Ann Quinlan, Nancy Beth Cruzan and Terri Schiavo existed before they died, can cause other persons with brain-related disabilities to think that they are being diminished.<sup>185</sup> Yet *Schiavo* involved not a person with a disability, but

---

180. See *infra* Part IV.B.2. (describing some ways laws proposed as a result of the pairing will impair autonomy for persons with disabilities).

181. E.g., Cranford, *supra* note 109, at 367, 369 (describing the "unbelievably false and misleading medical testimony" and describing the use of videotape clips in *Schiavo* as part of a "strategy of misinformation").

182. Schneider, *supra* note 24, at 27.

183. de la Cruz, *supra* note 1.

184. *Id.*

185. Use of the term "vegetative" inspires thoughts of vegetables, as illustrated by Kristen's reference to cabbages, onions, and corn. Referring to a human being as a vegetable reveals "a stigma that depicts [persons with disabilities] as 'not quite human.'" Harlan Hahn, *The Politics of Physical Differences: Disability and Discrimination*, 44 J. SOCIAL ISSUES 39, 41 (1988) (quoting E. GOFFMAN, *STIGMA: NOTES ON THE MANAGEMENT OF SPOILED IDENTITY* (1963) (describing generally the stigma facing "[p]ersons who fail to meet prescribed standards of physical attractiveness and functional independence")).

a “not abled” person,<sup>186</sup> indicating the presence of a clear dividing line between a person in a PVS and another person with brain damage or a physical disability. The task for supporters of the *Schiavo* rulings is to explain how a person in a PVS differs from a person with a disability. The person in a PVS has absolutely no awareness, even if appearances suggest otherwise.<sup>187</sup> He or she is in a totally different state from Kristen and the other people with disabilities who joined in the protests outside of Ms. Schiavo’s hospice room.

Moreover, even if a person is “disabled” rather than “not abled,” there are at least two reasons unrelated to disability discrimination why that person, and that person’s surrogate decision-makers, might wish to refuse the administration of medically supplied nutrition and hydration. First, the administration of such treatment can in some instances be physically harmful to the patient.<sup>188</sup> Second, even when it is not harmful in the sense of being painful or causing medical problems, it does constitute a bodily intrusion, and the ability to avoid such intrusions when not desired is at the heart of a person’s right to bodily integrity.<sup>189</sup>

The case of Sheila Pouliot in New York illustrates the point that the medical administration of nutrition and hydration actually may do more harm than good.<sup>190</sup> In 1999, at the age of 42, Sheila Pouliot was admitted to University Hospital at the State University of New York in Syracuse.<sup>191</sup> She was partially blind and profoundly mentally retarded; she could not speak, walk, or read; and she received nutrition and hydration through a gastrostomy tube (G tube) because she could not eat.<sup>192</sup> She was suffering from bleeding in her gastrointestinal tract and

186. Credit is due to Ken Goodman, Director of the University of Miami Ethics Programs, for conceiving this dichotomy and the use of the term “not abled” to describe a person in a PVS.

187. See Multi-Society Task Force on PVS, *supra* note 32, at 1499 (describing a lack of awareness in PVS patients); Cranford, *supra* note 109, at 369 (“[T]he patient in the vegetative state . . . is unconscious and thus incapable of any suffering.”). See also Shepherd, *supra* note 6, at 23 (describing PVS and its manifestations).

188. See *infra* text accompanying notes 190–97 (describing a case in which artificial nutrition and hydration caused greater pain than benefit to the patient). See, e.g., David Orentlicher & Christopher M. Callahan, *Feeding Tubes, Slippery Slopes, and Physician-Assisted Suicide*, 25 J. LEGAL MED. 389, 391–97 (2004) (summarizing studies “generally suggest[ing] that patients, families, and physicians misjudge the benefits derived from tube feeding”); Angus & Burakoff, *supra* note 55, at 273 (discussing the geriatric population and noting the burdens that artificial nutrition and hydration sometimes create without creating a significant benefit).

189. *Cruzan v. Dir., Mo. Dep’t of Health*, 497 U.S. 261, 288–90 (1990) (O’Connor, J., concurring).

190. *Blouin v. Spitzer*, 213 F. Supp. 2d 184, 186 (N.D.N.Y. 2002).

191. *Id.*

192. *Id.*

what appeared to be aspirational pneumonia.<sup>193</sup> Because of her gastrointestinal condition, the administration of nutrition through the G tube caused her pain, which she communicated by groaning.<sup>194</sup> Her family requested withholding of all nutrition, hydration and antibiotics, and a judge approved the termination of all medical treatment “except for nutrition, as tolerated, and palliative hydration care.”<sup>195</sup> Unfortunately, her body could tolerate no protein in the small amount of fluids she was able to take; of her approximately 300 calories a day, most consisted of sugar water.<sup>196</sup> The result was actually detrimental:

The long-term provision of calories in the absence of protein causes more problems than it solves. The nutrition contained in the fluids – consisting only of glucose – is sufficient to maintain life (heart and lung function). But it cannot prevent protein starvation. In fact, there is universal medical agreement that the prolonged provision of calories in the absence of the ability to provide protein is inappropriate medical care. . . .

During that time, Ms. Pouliot’s body began to catabolize her own tissue. The hydration provided through the IV tubes damaged her organs and caused her severe pain. Further, it caused her severe edema, which stretched her skin to the point where it fell off and left raw painful areas. She was in agony. She spent the next two months moaning and curled in the fetal position.

Despite aggressive efforts to control her symptoms, such control was not achieved, and the principle of safe and comfortable dying was violated.<sup>197</sup>

Ms. Pouliot’s life was prolonged in this condition because New York’s law at that time had been interpreted to bar the withholding or withdrawal of any life-sustaining treatment from a patient who had never had capacity to make her own decisions and thus had never had

---

193. *Blouin v. Spitzer*, 01-CV-0925 HGM/GJD, 2001 U.S. Dist. LEXIS 18243, at \*1 (N.D.N.Y. 2001). On the issue of whether she actually suffered from pneumonia, see Alicia R. Ouellette, *When Vitalism is Dead Wrong: The Discrimination Against and Torture of Incompetent Patients by Compulsory Life-Sustaining Treatment*, 79 IND. L.J. 1, 14 n.67 (2004).

194. Ouellette, *supra* note 193, at 14.

195. *Id.* at 15 (citing *Blouin v. Spitzer*, 213 F. Supp. 2d 184, 187 (N.D.N.Y. 2002)). To “palliate” is to “reduce the violence of a disease” or “ease without curing.” Medline Plus Online Medical Dictionary, <http://www2.merriam-webster.com/cgi-bin/mwmednlm?book=Medical&va=palliation> (last visited Nov. 1, 2005). “Hydration” is, in this context, the introduction of fluid into the body. Medline Plus Online Medical Dictionary <http://www2.merriam-webster.com/cgi-bin/mwmednlm> (last visited Nov. 1, 2005). Palliative hydration care thus consists of the administration of liquids for the comfort of the patient, not with an eye toward curing, or even treating, illness.

196. Ouellette, *supra* note 193, at 15–16.

197. *Id.* at 16 (quoting aff. of Kathleen Graff, M.D., J.A. on Appeal at 1647–48, *Blouin v. Spitzer*, No. 02-7997 (2d Cir. Mar. 5, 2003) (internal citations omitted)).

capacity to express her wishes regarding the administration or withdrawal of life-sustaining treatment.<sup>198</sup> State officials felt constrained to adopt a vitalist position even in that case, in which all parties agreed that the continued treatment was causing what one physician termed “grotesque harm” to Ms. Pouliot.<sup>199</sup>

Such harm is extreme; more common would be the risks to any persons existing on medically supplied nutrition and hydration, such as the risk of aspiration even though food is not traveling through the mouth and throat, and the risk of infection at the site of tube insertion.<sup>200</sup> Ms. Pouliot’s case serves to illustrate, however, that the provision of medically supplied nutrition and hydration is not an unadulterated good.<sup>201</sup> Termed in one law review article as an example of “vitalism run amuck,”<sup>202</sup> the *Pouliot* case provides a vivid example of a situation in which even persons who believe all life is worth preserving should balk at continuing treatment. Surely even members of the disability rights community who fear discrimination would agree that subjecting Ms. Pouliot to this treatment in fact diminished and even harmed her. Yet those familiar with *Schiavo* recognize such insistence to continue with treatment at all costs.<sup>203</sup>

---

198. That law has since changed. Health Care Decisions Act for Persons With Mental Retardation, N.Y. SURR. CT. PROC. ACT § 1750, 1750-b (McKinney 2003). See also *In re Baby Boy W.*, 773 N.Y.S.2d 255 (N.Y. Surrogate Ct. 2004) (explaining the history of cases involving end-of-life decisions that resulted in the adoption of the Health Care Decisions Act); *In re AB*, 768 N.Y.S.2d 256 (N.Y. Sup. Ct. 2003) (describing history of Health Care Decisions Act).

199. Ouellette, *supra* note 193, at 18 (quoting J.A. on Appeal at 960, *Blouin v. Spitzer*, No. 02-7997 (2d Cir. Mar. 5, 2003)).

200. Orentlicher & Callahan, *supra* note 188, at 397 (“[G]astrostomy tube placement may increase the risk that the stomach contents will reflux into the esophagus, and some studies have found that tube feeding increases the risk of aspiration pneumonia”; “[i]t also has not reduced the overall risk of infection.”).

201. For example, the data collected in an important study in the late 1990s indicated that while “artificial feeding was associated with increased survival in coma patients,” it was associated with “decreased survival in patients with acute kidney failure, multiple organ system failure, cirrhosis of the liver, of chronic obstructive pulmonary (or lung) disease.” *Id.* (citing Marie L. Borum et al., *The Effect of Nutritional Supplementation on Survival in Seriously Ill Hospitalized Adults: An Evaluation of the SUPPORT Data*, 48 J. AM. GERIATRICS SOC’Y S33 (2000)).

202. Ouellette, *supra* note 193, at 21.

203. Ms. Schiavo differed from Ms. Pouliot because Ms. Pouliot could experience pain while Ms. Schiavo could not, due to her existence in a PVS. Yet some similarities lie in what Jay Wolfson, the last *guardian ad litem* appointed for Ms. Schiavo, termed “[n]early gruesome examples” of Ms. Schiavo’s family’s “disturbing belief that they would keep Theresa alive at any and all costs . . . agreement by family members that in the event Theresa should contract diabetes and subsequent gangrene in each of her limbs, they would agree to amputate each limb, and would then, were she to be diagnosed with heart disease, perform heart surgery.” WOLFSON REPORT, *supra* note 134, at 14.

Moreover, even when doing good, the administration through medical means of artificial nutrition and hydration constitutes a bodily invasion that every person, with a disability or not, has the right to refuse. The United States Supreme Court itself recognized a right not to endure such bodily intrusion in *Cruzan*.<sup>204</sup> Both tort law and constitutional law long have honored a competent person's ability to refuse unwanted touching.<sup>205</sup> This is the absolute minimum of the right to refuse treatment, requiring no appreciation of constitutional dimensions.<sup>206</sup> The provision of artificial sustenance and hydration through a tube inserted into the stomach constitutes a physical touching.<sup>207</sup> A person may not wish to be poked, prodded, and continually handled, as one must be when subsisting on medically supplied nutrition.<sup>208</sup> If that person has no current ability to remind us of the way he or she once felt on that subject, then the testimony of that person's surrogate decision-maker, coupled with any other relevant evidence, may similarly convince a fact-finder that the intrusion is unwanted.<sup>209</sup> In either case, when an intrusion is unwanted, the person should not have to suffer that intrusion.<sup>210</sup> Even persons with disabilities may wish to prevent unwanted bodily intrusions such as the insertion and continuing presence of tubes in their stomachs.<sup>211</sup>

## 2. The Pairing Facilitated by These Misconceptions Could Actually Work to the Detriment of People With Disabilities

Disability rights groups that have joined with vitalist activists, as well as those individual people with disabilities who support the joiner, in fact seek to deprive people with disabilities of rights when they seek to diminish the ability to withdraw or withhold medical treatment. A vitalist position is not necessary to protect the interests of people with

---

204. *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 278 (1990) ("The principle that a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions.").

205. *Id.* at 269–70.

206. *See* THE RIGHT TO DIE, *supra* note 11, § 2.06[A], at 2-23 (recounting history of common-law source of right to refuse treatment).

207. *Cruzan*, 497 U.S. at 288–89 (O'Connor, J., concurring).

208. *See infra* note 233 (discussing a North Carolina poll relating to end-of-life issues); *infra* note 235 (discussing statistics regarding physician-assisted death in Oregon). *See also In re Peter*, 529 A.2d 419, 424 (N.J. 1987) (reiterating its recognition in *Quinlan* that "most people would consider an artificially-prolonged vegetative existence 'unendurable[']").

209. *See, e.g., In re Peter*, 529 A.2d at 426–27 (reviewing the types of evidence a court may find helpful).

210. *Id.* at 423 ("Medical choices are private, regardless of whether a patient is able to make them personally or must rely on a surrogate.").

211. *E.g., Bouvia v. Superior Court*, 225 Cal. Rptr. 297 (Cal. Ct. App. 1986).

disabilities because the law already incorporates safeguards to prevent inappropriate withholding or withdrawal of life-sustaining treatment.<sup>212</sup> Those people with disabilities who wish to have the same rights of self-determination as people without disabilities with respect to the administration or withdrawal of life-sustaining treatment should recognize that the pairing of the disability rights community with vitalist activists is detrimental to their interests.

In fact, the law already incorporates several features that protect people with disabilities, as well as any other person whose end-of-life decisions medical professionals and loved ones debate. First, as Lois Shepherd has noted, surrogate decision-makers who choose continuation of treatment rarely face challenge.<sup>213</sup> Other than in the relatively rare and extreme situations in which physicians or other caregivers argue that treatment should be discontinued as futile,<sup>214</sup> treatment will continue when surrogate decision-makers state that the patient would have wished continuation.

Second, regardless of the condition of the patient or the type of treatment at issue, the “clearly dominant” standard of proof for end-of-life decision-making cases is the clear and convincing standard of proof applicable when a surrogate decision-maker seeks authorization to withhold or withdraw treatment.<sup>215</sup> “Clear and convincing evidence,” while not necessarily uncontroverted,<sup>216</sup> has been described as

produc[ing] in the mind of the trier of fact a firm belief or conviction as to the truth of the allegations sought to be established, evidence so clear, direct and weighty and convincing as to enable [the factfinder] to come to a clear conviction, without hesitancy, of the truth of the precise facts at issue.<sup>217</sup>

This constitutes a presumption, requiring a surrogate decision-maker favoring withholding or withdrawal of treatment to prove more clearly than in a regular civil lawsuit either (1) that the patient actually had stated that he or she wished withholding or withdrawal in the circumstances at hand,<sup>218</sup> (2) that the patient would have wished

---

212. See *infra* notes 213–226 and accompanying text (discussing the three features of the law regarding the administration or withdrawal of life-sustaining treatment).

213. Shepherd, *supra* note 6, at 42.

214. See THE RIGHT TO DIE, *supra* note 11, at § 13 (examining the issues and problems of “futile” medical treatment).

215. *Id.* at § 3.27[A], at 3-126.

216. *Id.*

217. *In re Jobes*, 529 A.2d 434, 441 (N.J. 1987).

218. That would be evidence satisfying the subjective standard. THE RIGHT TO DIE, *supra* note 11, at § 4.05, at 4-28 to 4-33. In *Cruzan*, the Missouri Supreme Court searched for clear and convincing evidence of Nancy’s subjective, actually expressed wishes. *Cruzan v. Dir. Mo. Dep’t*

withholding or withdrawal in the circumstances at hand, based on evidence including that patient's statements values, beliefs and attitudes,<sup>219</sup> or (3) in certain limited circumstances, that withholding or withdrawal would be in the patient's best interests.<sup>220</sup> In certain cases, courts have been even more cautious, requiring evidence of actual statements that withholding or withdrawal was desired rather than evidence of values, beliefs and attitudes, even though their states' laws otherwise would have permitted withholding or withdrawal on the basis of the latter sort of evidence.<sup>221</sup>

Finally, of course, although not applying to most end-of-life treatment situations, it must be remembered that laws specifically prohibiting disability discrimination exist to protect the interests of those people with disabilities.<sup>222</sup> Section 504 of the Rehabilitation Act of 1973<sup>223</sup> prohibits discrimination by hospitals participating in the Medicare and Medicaid programs against "otherwise qualified," "handicapped" individuals.<sup>224</sup> Section 302 of the Americans With

---

of Health, 497 U.S. 261, 316 (1990) (Brennan, J., dissenting).

219. That would be evidence satisfying the substituted judgment standard. *THE RIGHT TO DIE*, *supra* note 11, at §§ 4.02, 4.03, at 4-11-4-25. *E.g.*, *In re Quinlan*, 355 A.2d 647, 664-666 (N.J. 1976) (discussing the substituted judgment standard).

220. That would be evidence satisfying the best interests standard, which is usually a burden-benefit analysis. *THE RIGHT TO DIE*, *supra* note 11, at § 4.07, at 4-41-4-79. The best interests test generally only will be applied under two circumstances: (1) when the patient was never competent to make medical decisions (such as a child or a mentally retarded person), or (2) when no evidence is available to demonstrate either the patient's actual or the patient's inferred wishes. *See, e.g.*, *Woods v. Ky. Cabinet of Human Resources*, 142 S.W.3d 24, 34-35 (Ky. 2004) (describing the best interest test and its application); *In re L.W.*, 482 N.W.2d 60, 67-68 n.8 (Wis. 1992) (detailing the infrequency with which written instructions are available).

221. *See In re Wendland*, 28 P.3d 151 (Cal. 2001) (requiring clear and convincing evidence, in the form of actual statements, when the individual is conscious but several physically and mentally impaired); *In re Martin*, 538 N.W.2d 399 (Mich. 1995) (refusing to authorize the removal of life support without clear and convincing evidence of the conscious incapacitated individual's pre-injury statement expressing his decision to refuse life-sustaining medical treatment under the present circumstances); *In re Edna M.F.*, 563 N.W.2d 485 (Wis. 1997) (refusing to allow a guardian to withdraw life support when there were no actual statements from patient of her desires).

222. *See THE RIGHT TO DIE*, *supra* note 11, at §§ 11.09[B], [C], at 11-68-11-71 (discussing the Americans With Disabilities Act, 42 U.S.C. §§ 12,101-12,213 (2000), and § 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794 (2000)). Claims based on these laws were raised and ruled unlikely to succeed in *Schiavo*. *Schindler v. Schiavo*, No. 8:05-CV-530-T-27-BM (M.D. Fla. Mar. 22, 2005), *aff'd* No. 05-11556 (11th Cir. Mar. 23, 2005) (en banc), available at University of Miami Ethics Program, <http://www.miami.edu/ethics/schiavo/timeline.htm> (follow March 22, 2005 "Federal Court Order" hyperlink) (last visited Nov. 1, 2005).

223. 29 U.S.C. § 794(a) (2000).

224. *In re Baby K*, 832 F. Supp. 1022, 1027 (E.D. Va. 1993), *aff'd*, 16 F.3d 590 (4th Cir. 1994).

Disabilities Act (ADA)<sup>225</sup> prohibits all public accommodations (including hospitals and other health care providers) from discriminating against disabled individuals, without regard to whether those individuals are otherwise qualified to receive the services at issue.<sup>226</sup>

In addition to recognizing these protections already built into the law, one must also remember that evidence does not exist to support fears of discrimination against people with disabilities in end-of-life decision-making.<sup>227</sup> It is difficult to find empirical research addressing these matters, but empirical research about Oregon's law permitting physician assistance in ending lives may serve as an imperfect analogy for present purposes.<sup>228</sup> Despite fears articulated at the time of its passage, Oregon's law in fact has not resulted in discrimination against and has not been overly utilized by vulnerable persons.<sup>229</sup>

It is paternalistic to believe that no person with a disability wishes to refuse life-sustaining treatment. Persons with disabilities should no more be subjected to unwanted medical treatment than non-disabled persons are.<sup>230</sup> Yet the pairing of disability rights and vitalist activists during and since *Schiavo* has resulted in the introduction of bills in federal and state legislatures that would infringe upon (or, at a minimum, severely burden) the rights of both people with and without disabilities in the name of protecting the vulnerable.<sup>231</sup>

225. 42 U.S.C. §12,182(b)(2)(A)(i) (2000).

226. *Id.* See also *Baby K*, 832 F. Supp. at 1028 (describing Congress' legislative intent).

227. Cf. Norman L. Cantor, *On Kamisar, Killing and Physician-Assisted Death*, 102 MICH. L. REV. 1793, 1813 (2004) (noting that refusal of life-sustaining medical treatment "poses hazards," but that "despite thousands of deaths per day associated with medical management of the dying process, medical services for dying patients have been remarkably free of widespread abuse in the sense of premature terminations of human lives").

228. Oregon's law has endured several legal and political challenges since its inception. See, e.g., *Lee v. Oregon*, 891 F. Supp. 1429 (D. Or. 1995) (enjoining implementation), *vacated and remanded*, 107 F.3d 1382 (9th Cir. 1997) (finding a lack of federal jurisdiction), *cert. denied sub nom. Lee v. Harclerod*, 522 U.S. 927 (1997) (denying the petition for certiorari). The most recent challenge came from the federal government, when the United States Department of Justice notified physicians and pharmacists that it would revoke the Drug Enforcement Administration registrations of those writing or filling prescriptions in accordance with the Oregon law. (DEA registration is necessary to prescribe and fill prescriptions for federally controlled substances.) See generally *Oregon v. Ashcroft*, 192 F. Supp. 2d 1077 (D. Or. 2002); *aff'd*, 368 F.3d 1118 (9th Cir. 2004), *cert. granted*, 125 S. Ct. 1299 (2005) (challenging the federal revocation of registration).

229. See DEATH WITH DIGNITY ANNUAL REPORTS, <http://egov.oregon.gov/DHS/ph/pas/ar-index.shtml> (last visited Nov. 1, 2005) (listing statistics on persons requesting and using lethal prescriptions pursuant to Oregon's Death With Dignity Act since its inception).

230. Cf. *Bouvia v. Superior Court*, 225 Cal. Rptr. 297 (Ct. App. 1986) (holding the state's interest in preserving life did not outweigh patient's right to refuse treatment).

231. As of August 2005, research revealed at least 30 such legislative proposals.

A key feature of such bills is often an attempt to require a written advance directive to authorize withholding or withdrawal of medically supplied nutrition and hydration from a patient in a PVS or who is otherwise incapable of making medical decisions.<sup>232</sup> This is proposed although most people say they wish to have medically supplied nutrition and hydration withheld or withdrawn when they enter a PVS or otherwise reach a point at which they believe continued medical intervention is inappropriate.<sup>233</sup> The proposed bills would require the continuation of treatment for that majority of people, however, because most people, for whatever reason, do not write their wishes down.<sup>234</sup> While it would be interesting to see some studies indicating whether

---

Incapacitated Persons Legal Protection Act of 2005, H.R. 1151, 109th Cong. (2005); Alabama Starvation and Dehydration of Persons With Disabilities Prevention Act, H.B. 592, 2005 Reg. Sess. (Ala. 2005); Florida Starvation and Dehydration of Persons With Disabilities Prevention Act, H.B. 701 & S.B. 2128, 107th Reg. Sess. (Fla. 2005); H.B. 1345 & S.B. 2308, 107th Reg. Sess. (Fla. 2005); Hawaii Starvation and Dehydration of Persons With Disabilities Prevention Act, H. B. 1332, 1577 & S.B. 1809, 23d State Leg. (Haw. 2005); Iowa Starvation and Dehydration of Persons With Disabilities Prevention Act, H. Study B. 302, 81st Gen. Assem., 1st Sess. (Iowa 2005); H.B. 2287, 81st Leg., Reg. Sess. (Kan. 2005); H.B. 501, 2005 Reg. Sess. (Ky. 2005); Human Dignity Act, S.B. 40, 31st Reg. Sess. (La. 2005); H.B. 4743, 93d Leg. Reg. Sess. (Mich. 2005); Presumption of Nutrition and Hydration Sufficient to Sustain Life Act, S. File 2008, H. File 2369, & 2450; H.B. 905, 93d Gen. Assem., 1st Reg. Sess. (Mo. 2005); An Act Authorizing the Use of a Declaration, Also Known as a Living Will, To Require the Provision of Life-Sustaining Treatment as well as the Withholding or Withdrawal of Life-Sustaining Treatment, H.B. 526, 59th Reg. Sess. (Mont. 2005); Assem. B. 7009, 7912 & S.B. 4083, 228th Ann. Leg. Sess. (N.Y. 2005); North Carolina Disabled Persons Protection Act, H.B. 1175, Gen. Assem., Sess. 2005 (N.C. 2005); H.B. 201, 216 & S.B. 130, 126th Gen. Assem., Reg. Sess. (Ohio 2005); H.B. 1567 & H.B. 2054, 50th Leg., 1st Sess. (Okla. 2005); South Carolina Starvation and Dehydration of Persons With Disabilities Prevention Act, H.B. 4013, Gen. Assem., 116th Sess. (S.C. 2005). One bill, in Louisiana, was passed and signed into law. Human Dignity Act, H.B. 675, 31st Reg. Sess., 2005 La. Acts 447.

232. *E.g.*, Florida Starvation and Dehydration of Persons With Disabilities Prevention Act, H.B. 701, 107th Reg. Sess. (Fla. 2005) (listing presence of a specific written advance directive as one of three limited ways incompetent patients would have medically supplied nutrition and hydration withdrawn). *Cf.* H.B. 201, 126th Gen. Assem., Reg. Sess. (Ohio 2005) (giving priority among possible surrogate decision-makers to individuals agreeing not to withhold life-sustaining treatment); H.B. 216, 126th Gen. Assem., Reg. Sess. (Ohio 2005) (erecting barriers to withholding or withdrawal of life-sustaining treatment when a person has not designated a surrogate decision-maker). *See generally* Michael Allen, *The Constitution at the Threshold of Life and Death: A Suggested Approach to Accommodate an Interest in Life and a Right to Die*, 53 AM. U. L. REV. 971, 1014 (2004) (describing a hypothetical state's requirement of a written advance directive and concluding that such a law would not impose an undue burden on those wishing to exercise a constitutional right to refuse treatment).

233. *See* AARP, NORTH CAROLINA END OF LIFE CARE SURVEY (2003), available at <http://www.aarp.org/research/reference/memberopinions/Articles/aresearch-import-68.html> (noting that seventy-nine percent of AARP members surveyed believe that it is important to be off machines that extend life).

234. *See* Angela Fagerlin & Carl E. Schneider, *Enough: The Failure of the Living Will*, 34 HASTINGS CENTER REP. 30, 32 (March-April 2004) ("People widely say they want a living will. . . . Despite this, and despite decades of urging, most Americans lack them.").

persons with disabilities differ from most Americans in these respects,<sup>235</sup> this Essay proceeds upon the assumption that, except perhaps to the extent that someone causes them to fear exploitation of a vulnerability, persons with disabilities do not differ greatly from people without disabilities with regard to end-of-life treatment wishes.<sup>236</sup> It is most likely that, as with so many issues, “like any politically, ethnically, and religiously diverse community . . . the community of people with disabilities is far from unanimous” on this issue.<sup>237</sup> For example, at least one important aspect of the disability rights movement, the independent living movement, has been rooted in a desire to “empower people with disabilities to control their lives and to live independently in their communities.”<sup>238</sup> Just as one foundation of the right to refuse treatment was the right to control one’s own body, the foundation of the “independent living movement” was the right of persons with disabilities “to make . . . independent choices about where and how [to] live.”<sup>239</sup> Persons who believe deeply in the right to independence in

---

235. The views of some persons with disabilities on a related, but distinct, issue may be instructive. At the time of passage of the Oregon law permitting physician-assisted suicide (in 1994), studies tended to show that the views of people with disabilities did not vary greatly from those of the general population. See, e.g., Andrew I. Batavia, *Disability and Physician Assisted Suicide*, 336 NEW ENG. J. MED. 1671, 1671 (1995) (describing a Harris poll conducted in 1994 that found that 66 percent of people with disabilities who were surveyed support a right to assisted suicide, as compared with 70 percent of the general population).

236. This is not meant to diminish either the results of studies that indicate that people attempting to engage in advance medical decision-making often mis-predict what they actually will want or to refuse in terms of treatment once they are suffering from the condition they had been anticipating, or the statistics indicating that people are inaccurate in predicting their quality of life should they develop a disability. Fagerlin & Schneider, *supra* note 234, at 34. Cf. Elizabeth A. Pendo, *Substantially Limited Justice?: The Possibilities and Limits of a New Rawlsian Analysis of Disability-Based Discrimination*, 77 ST. JOHN’S L. REV. 225, 269–71 (2003) (noting people’s inability to accurately predict future perceptions regarding quality of life). See also Diane Coleman, *Not Dead Yet*, in *THE CASE AGAINST ASSISTED SUICIDE: FOR THE RIGHT TO END-OF-LIFE CARE* 225 (Kathleen Foley & Herbert Hendin eds., 2002) (citing studies that “show that medical professionals assess the quality of life of disabled people to be dramatically lower than disabled people themselves do”); Michelle Fine & Adrienne Asch, *Disability Beyond Stigma: Social Interaction, Discrimination, and Activism* 44 J. SOCIAL ISSUES 3, 8–15 (describing a range of discriminatory assumptions made about people with disabilities); Fitzgerald, *supra* note 146, at 271 (noting that “[t]he cultural stereotype of the ‘life not worth living’ is a very powerful one in relation to people with disability”). It merely is to say that there is no evidence that people with disabilities wish to have less right to refuse treatment than those without disabilities.

237. Batavia, *supra* note 235, at 1671.

238. Andrew I. Batavia, *The New Paternalism (Evaluating the Idea of Disabled Persons as Oppressed Minority)*, 12 J. DISABILITY POL’Y STUD. 107, 107 (2001) (considering “the negative implications of a disability rights strategy based in part on the characterization of people with disabilities as an oppressed minority” and concluding that “this approach is inconsistent with the antipaternalistic philosophical roots of the disability rights/independent living movement”).

239. Andrew I. Batavia, *Disability Rights in the Third Stage of the Independent Living*

choices in how to live will support other rights, such as the right to refuse treatment, based on autonomy and self-determination.<sup>240</sup>

Indeed, “[t]he contention that all people with disabilities are so oppressed, simply by virtue of their disability status, as to be presumed incapable of making end-of-life decisions reflects the same paternalism that the independent living movement was established to abolish.”<sup>241</sup> Given that assumption, the problem with such bills is that, rather than protecting the people with disabilities and other vulnerable persons from abuse, they actually make it more difficult for both people with and without disabilities to exercise important rights to avoid unwanted bodily intrusion and exercise self-determination.

#### V. CONCLUSION

In sum, one lesson to be learned from tracing the development of the law and politics from *Quinlan* to *Cruzan* to *Schiavo* is that people with disabilities like Kristen should be drawn into reasoned conversation to a greater extent. Rather than indulging what one commentator has termed “reflexive scorn” for the people demonstrating against the withdrawal of Ms. Schiavo’s PEG tube,<sup>242</sup> those who believe in self-determination should listen more carefully to the fears motivating some of the persons with disabilities participating in such demonstrations. Interest among the disability rights community in end-of-life decision-making matters is not new, but it has been powered, most recently in *Schiavo*, by imagery and an unfortunate alliance of disability rights and vitalist activists. The result actually diminishes and devalues persons with disabilities, by attempting to protect them rather than permitting them to make their own decisions. In contrast, decisions like *Schiavo*, far from endangering persons with disabilities, serve all persons who value control over their own bodies, including persons with disabilities.

---

*Movement: Disability Community Consensus, Dissention, and the Future of Disability Policy*, 14 STAN. L. & POL’Y REV. 347, 347 (2003) (published in draft form after Mr. Batavia’s death).

240. Cf. Batavia, *supra* note 239, at 350 (describing the reasons some persons with disabilities support the right to physician-assisted suicide).

241. Andrew I. Batavia, *Disability and Physician-Assisted Dying*, in PHYSICIAN-ASSISTED DYING: THE CASE FOR PALLIATIVE CARE AND PATIENT CHOICE 67 (Timothy E. Quill & Margaret P. Battin eds., 2004).

242. Schneider, *supra* note 24, at 24, 25.