TRACKING THE STORM: THE FAR-REACHING POWER OF THE FORCES PROPELLING THE SCHIAVO CASES

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More than fifteen years elapsed between the date Theresa Marie Schiavo suffered a cardiac arrest, leaving her in a persistent vegetative state because of brain damage, and the date she took her last breath.\(^1\) The conflict between her parents and her husband regarding her medical care lasted for more than twelve of those fifteen years.\(^2\) The litigation over her care lasted for more than six.\(^3\) It is difficult to keep track of the multiple court cases filed, let alone to pinpoint the highlights of their many twists and turns.\(^4\) It may be possible, however, to predict how the after-effects of the Schiavo maelstrom will impact the law of end-of-life decisionmaking in Florida. It appears as if those lingering effects will be bitter and may leave important rights of self-determination and privacy in a battered state, much as hurricanes ripping through Florida leave her shores.

In this Essay, I will dissect the history of the Schiavo cases to determine their implications for the law of end-of-life decision-making in Florida. Relying on others who have preceded me to set

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\(^1\) Kathy L. Cerminara & Kenneth Goodman, Key Events in the Case of Theresa Marie Schiavo, http://www.miami.edu/ethics2/schiavo/timeline.htm (last updated Nov. 15, 2005).

\(^2\) Id.

\(^3\) Id.

\(^4\) For links to additional relevant resources as well as an interactive timeline tracking developments from the date of Terri’s birth to the most recent legislative and judicial activity, see Kathy L. Cerminara & Kenneth Goodman, Schiavo Case Resources, http://www.miami.edu/ethics2/schiavo_project.htm (accessed Feb. 19, 2005).
the stage, I will presume that the reader knows the identities and positions of Theresa Marie (Terri) Schiavo; her husband, Michael; and her parents, Robert and Mary Schindler. Against that background, I first will explain that about three years into the Schiavo litigation, the Schindlers significantly changed their focus. A relatively straightforward dispute about proxy decision-making then metamorphosed into a political furor, and a debate strikingly similar to those undertaken in hospitals every day thrust an intensely personal family crisis into the national spotlight. The history of the Schiavo cases and the transformation that took place within them provide direct links to the second portion of this Essay, for the long-lasting effects of these cases stem almost exclusively from arguments advanced and actions taken after that transformation. Because of the forces pushing the cases along since that time, Floridians will see lingering effects in their state law of end-of-life decisionmaking.

I. TRANSFORMATIVE FORCES

One of the most striking characteristics of the Schiavo cases was the shift in argumentative focus over the years. Between 1998 and 2001, the Schindlers professed a belief that their son-in-

6. Infra nn. 10–40 and accompanying text.
7. In Florida, a person who may make medical decisions for an incapacitated person without having been appointed to do so by the patient (one who has acquired his or her decisionmaking authority by operation of law) is termed a proxy decision-maker. Fla. Stat. § 765.401 (2004). This terminology contrasts with that used in other states, in which persons making medical decisions for incapacitated persons without patient appointment to such a position (again, those who derive their authority from operation of law) are called surrogates. See Alan Meisel & Kathy L. Cerminara, The Right to Die: The Law of End-of-Life Decisionmaking § 7.01[B][4], [6] (3d ed., Aspen L. & Bus. 2004 & Supp. 2005). In Florida, the term “surrogate” is used to identify a person the patient has appointed to make medical decisions on that patient’s behalf. Fla. Stat. § 765.202, Terri Schiavo had appointed no surrogate decision-maker. In re Schiavo, 780 So. 2d 176, 177 (Fla. 2d Dist. App. 2001), rev. denied 789 So. 2d 348 (Fla. 2001) (“Schiavo I”). Michael Schiavo was Terri’s judicially appointed guardian and, as such, was first on the list of proxy decision-makers for her. Fla. Stat. § 765.401. He was also second on the proxy list because of his status as her husband. Id.
8. Infra nn. 12–40 and accompanying text.
law was misrepresenting their daughter’s wishes. Thereafter, however, in addition to voicing this belief, they also became vanguards of the disability-rights movement, in part by arguing that Terri was not in a persistent vegetative state. This transformation resulted in the Schiavo cases playing a different role in the development of the law of end-of-life decisionmaking than they would have played had the Schindlers’ focus remained consistent throughout.

A. Schiavo I and II

In 2001, when Florida’s Second District Court of Appeal first considered the Schiavo case, the court ruled that “[t]he evidence is overwhelming that Theresa is in a permanent or persistent vegetative state.” The parties involved in the case beginning in 1998, when Michael Schiavo sought a determination of whether Terri’s medically supplied nutrition and hydration should be withdrawn, were Michael Schiavo and the Schindlers, no one else. The court made a point of stating that persons such as Terri, in persistent vegetative states (PVS), had “cycles of apparent wakefulness and apparent sleep without any cognition or awareness, . . . [and] often [made] moaning sounds,” and that she was “in an unconscious, reflexive state.” Yet there was no indication in the judicial opinion that the Schindlers contended on appeal that Terri was in a state other than a PVS. Rather, the court noted three arguments the Schindlers advanced against the removal of Terri’s PEG tube. First, they argued “that the trial

10. See e.g. Schiavo I, 780 So. 2d at 178.
11. See e.g. In re Schiavo, 800 So. 2d 640 (Fla. 2d Dist. App. 2001) (“Schiavo III”).
12. Schiavo I, 780 So. 2d at 177.
14. Schiavo I, 780 So. 2d at 177.
15. Id.
16. Id.
court was required to appoint a guardian ad litem for [the] proceeding because Michael [stood] to inherit under the laws of intestacy.\textsuperscript{19} The court discarded that argument because Michael was not in fact serving as decision-maker; he had asked the trial court to make the decision because of the controversy between himself and the Schindlers about withdrawing the PEG tube.\textsuperscript{20}

The court characterized the Schindlers’ second argument as revolving around the admissibility of evidence in the form of testimony about the results of certain social science surveys targeting people’s wishes regarding end-of-life decisionmaking.\textsuperscript{21} The thrust of the Schindlers’ argument on this point seemed to have been that the trial judge, having heard this sort of evidence, had made a decision with Terri’s best interests, rather than her wishes, in mind.\textsuperscript{22} The court ruled that it was “convinced that the stomach.” \textit{Stedman’s Medical Dictionary} 1345, 733 (Maureen B. Pugh ed., 27th ed., Lippincott Williams & Wilkins 2000). Physicians use an endoscope to facilitate placement of a tube through the skin using a technique that “requires only two small incisions into the abdominal wall.” David Orentlicher & Christopher M. Callahan, \textit{Feeding Tubes, Slippery Slopes, and Physician-Assisted Suicide}, 25 J. Leg. Med. 389, 391 (2004). A physician implanting a PEG tube may be guided in proper placement by either a light shining through the patient’s skin from the inside of the patient’s stomach or the directions of an observer viewing the inside of the patient’s stomach walls through a camera. Brigham & Women’s Hosp., \textit{Health Information: Percutaneous Endoscopic Gastrostomy (PEG)}, http://healthgate.partners.org/browsing/browseContent.asp?fileName=14852.xml&title=Percutaneous%20Endoscopic%20Gastrostomy%20(PEG) (accessed Feb. 25, 2005). The camera or light is located on the end of an endoscope, a flexible tube inserted through the patient’s mouth, down the esophagus, and into the patient’s stomach. \textit{Id.} The endoscope is removed after the PEG procedure, and the PEG tube remains protruding from the patient’s stomach to be used for direct introduction of nutrition and hydration. \textit{What You Need to Know, supra} n. 18. In contrast, when an NG (nasogastric) tube is used, nutrition and hydration are introduced through a flexible hose inserted through the nose and down the esophagus into the stomach. Orentlicher & Callahan, \textit{supra} n. 18, at 390. At one time, all tube feedings were provided through NG tubes, but gastrostomy tubes have supplanted them for long-term feeding. \textit{Id.}

\textsuperscript{19.} \textit{Schiavo I}, 780 So. 2d at 178. A guardian ad litem had earlier found no problem with Michael Schiavo’s service as guardian. Wolfson, \textit{supra} n. 17, at 11. A second guardian ad litem had suggested an investigation of a possible conflict of interest, but the court thereafter decided to retain Michael Schiavo as guardian, thus presumptively determining that there was no cause for removal. \textit{Id.} at 11–13; Cerminara & Goodman, \textit{supra} n. 1. The guardian ad litem appointed by Governor Jeb Bush in 2003 similarly considered “the incorrect perception that [Michael Schiavo] [had] refused to relinquish his guardianship because of financial interests, and . . . allegations that he actually abused Theresa,” and concluded, “[t]here [was] no evidence in the record to substantiate any of these perceptions or allegations.” Wolfson, \textit{supra} n. 17, at 34 n. 1.

\textsuperscript{20.} \textit{Schiavo I}, 780 So. 2d at 178.

\textsuperscript{21.} \textit{Id.} at 179.

\textsuperscript{22.} \textit{Id.}
trial judge did not give undue weight to this evidence and that the court made a proper surrogate decision rather than a best-interests decision."\textsuperscript{23} This evidence had nothing to do with whether Terri Schiavo was in a PVS.

The court described the Schindlers’ final argument as being that the evidence considered by the trial court, “which was conflicting, was insufficient to support the trial court’s decision by clear and convincing evidence.”\textsuperscript{24} The court ruled, “We have reviewed that testimony and conclude that the trial court had sufficient evidence to make this decision. The clear and convincing standard of proof, while very high, permits a decision in the face of inconsistent or conflicting evidence.”\textsuperscript{25} The appellate court then discussed Terri’s background, upbringing, and prior statements in determining that the trial court had not erred in deciding that she would have wished to refuse the PEG tube.\textsuperscript{26} The overall impression from \textit{Schiavo I} is not of parents arguing that their daughter was a disabled person who should be protected, but rather is of parents who, while perhaps wishing their daughter were in a different condition, distrusted her husband and asserted that their daughter would in fact have wanted treatment to continue.

That was early 2001.\textsuperscript{27} After the Florida Supreme Court denied review of the case, Terri’s PEG tube was removed on April 24, 2001.\textsuperscript{28} The Schindlers, however, had Terri’s PEG tube reinserted by filing emergency motions contesting the propriety of Michael Schiavo’s assertion of Terri’s wishes.\textsuperscript{29} The Second District Court noted that “the Schindlers have not seriously con-

\begin{itemize}
  \item \textsuperscript{23} \textit{Schiavo I}, 780 So. 2d at 179.
  \item \textsuperscript{24} \textit{Id}.
  \item \textsuperscript{25} \textit{Id}.
  \item \textsuperscript{26} \textit{Id}. at 180. The court described the question that faced the trial court as being whether Theresa Marie Schindler Schiavo, not after a few weeks in a coma, but after ten years in a persistent vegetative state that has robbed her of most of her cerebrum and all but the most instinctive of neurological functions, with no hope of a medical cure, but with sufficient money and strength of body to live indefinitely, would choose to continue the constant nursing care and the supporting tubes in hopes that a miracle would somehow recreate her missing brain tissue, or whether she would wish to permit a natural death process to take its course and for her family members and loved ones to be free to continue their lives. \textit{Id}.
  \item \textsuperscript{27} \textit{Id}. at 176.
  \item \textsuperscript{28} \textit{Schiavo II}, 792 So. 2d at 555.
  \item \textsuperscript{29} \textit{Id}. at 556.
\end{itemize}
tested the fact that Mrs. Schiavo’s brain has suffered major, permanent damage.” It also noted that, at trial,

A board-certified neurologist who had reviewed a CAT scan of Mrs. Schiavo’s brain and an EEG testified that most, if not all, of Mrs. Schiavo’s cerebral cortex—the portion of her brain that allows for human cognition and memory—is either totally destroyed or damaged beyond repair. . . . Although it is conceivable that extraordinary treatment might improve some of the motor functions of her brain stem or cerebellum, the Schindlers have presented no medical evidence suggesting that any new treatment could restore to Mrs. Schiavo a level of function within the cerebral cortex that would allow her to understand her perceptions of sight and sound or to communicate or respond cognitively to those perceptions.

It was still true at this stage of the litigation, in mid-2001, that the case involved only the Schindlers and Michael Schiavo disputing what Terri would have wanted.

B. Schiavo III

The year 2001, however, would prove to be a turning point. By late that year, the Schindlers had changed their arguments considerably. Through a motion for relief from judgment, the Schindlers first argued again that Michael Schiavo was untrustworthy and that Terri would not have chosen to have the PEG tube withdrawn. Second, however, they argued the following to the Second District Court of Appeal:

Mrs. Schiavo’s medical condition in February 2000 was misrepresented to the trial court and to this court throughout the[ ] proceedings. They claim[ed] that she [was] not in a persistent vegetative state. What [was] more important, they maintain[ed] that current accepted medical treatment exist[ed] to restore her ability to eat and speak. The initial
trial focused on what Mrs. Schiavo would have decided given her current medical condition and not on whether any available medical treatment could improve her condition. The Schindlers argue[d] that in light of this new evidence of additional medical procedures intended to improve her condition, Mrs. Schiavo would now elect to undergo new treatment and would reverse the prior decision to withdraw life-prolonging procedures.\textsuperscript{35}

For the first time on appeal, the Schindlers had articulated the argument that would generate a great deal of media attention over the coming years.

While noting “skepticism” about the affidavit submitted indicating that Terri might have shown some improvement, the court reminded the parties that the issue was “whether there was clear and convincing evidence to support the determination that Mrs. Schiavo would choose to withdraw the life-prolonging procedures.”\textsuperscript{36} In that regard, the appellate court stated that the Schindlers’ motion indicated that there might exist “a new treatment that could dramatically improve Mrs. Schiavo’s condition and allow her to have cognitive function to the level of speech,” which might affect what Terri would choose.\textsuperscript{37} The court determined that further evidence should be taken on that issue.\textsuperscript{38} It precisely described the process to undergo on remand, when the trial court was to hear evidence on the issue of whether “the initial judgment [authorizing the withdrawal of the PEG tube was] no longer equitable.”\textsuperscript{39} The court cautioned that, on remand, the Schindlers had to establish that new treatment offer[ed] sufficient promise of increased cognitive function in Mrs. Schiavo’s cerebral cortex—significantly improving the quality of Mrs. Schiavo’s life—so that she herself would elect to undergo this treat-

\textsuperscript{35} Id. at 643–644.
\textsuperscript{36} Id. at 644–645.
\textsuperscript{37} Id. at 645. The court here acknowledged that it might, in effect, have invited the Schindlers to make this argument by statements it made in \textit{Schiavo II}. Id. In \textit{Schiavo II}, the court had noted that the Schindlers had provided no evidence suggesting this sort of new treatment and that such evidence might merit a new hearing. Id. (citing \textit{Schiavo II}, 792 So. 2d at 560).
\textsuperscript{38} Id.
\textsuperscript{39} Id.
ment and would reverse the prior decision to withdraw life-prolonging procedures.  

Although the law had required Michael Schiavo to support the initial judgment authorizing withdrawal of the PEG tube by clear and convincing evidence, the Schindlers, on remand, only had to carry their burden by a preponderance of the evidence to succeed in having the judgment lifted.  

C. Post-Schiavo III  

That remand order unleashed the floodgates. At the time of the Schiavo III opinion, in the autumn of 2001, those involved in the litigation numbered three: Michael Schiavo and Mr. and Mrs. Schindler. While only the attorneys for those parties participated in the hearing on remand in late 2002, amici curiae abounded by the time the appeal was decided in mid-2003. Taking part in the appeal that resulted in the Schiavo IV opinion  

40. Id.  
41. Id.  
42. Id. at 640.  
44. In re Schiavo, 851 So. 2d 182, 183 (Fla. 2d Dist. App. 2003) ("Schiavo IV").  

The terms “disability rights and other vitalist causes” and “disability rights and vitalist groups,” as used hereafter in this Essay, denote the disability-rights groups who have adopted vitalist positions and chosen to work in concert with pro-life groups in these cases. Not all disability-rights groups are vitalist. Andrew I. Batavia, Disability and Physician-Assisted Suicide, 336 New Eng. J. Med. 1671 (1997). Certainly, disability-rights groups and pro-life groups generally find themselves on opposite sides of the political spectrum. See Adrienne Asch, Disability: Attitudes and Sociological Perspectives, in 2 Ency. Bioethics 602, 606 (rev. ed. 1996). In the Schiavo cases, they united to form a powerful alliance. See
were the parties plus representatives of many special-interest groups, several of which focused on disability rights and other vitalist causes.\footnote{46}

Moreover, not only had many outside groups become interested in the litigation, but the Schindlers themselves also had changed course in argument. As the Second District Court later noted, the issue with which the trial court actually dealt on remand differed vastly from the issue the appellate court had anticipated the hearing would involve when it remanded the case.\footnote{47} The appellate court noted that it had believed that the trial court would be considering "whether new treatment exists which offers such promise of increased cognitive function in Mrs. Schiavo's cerebral cortex that she herself would elect to undergo this treatment and would reverse the prior decision to withdraw life-prolonging procedures."\footnote{48} On that issue, however, the Schindlers "presented little testimony."\footnote{49} Instead, the Schindlers contended that Terri was not in a PVS.\footnote{50} The trial court ruled, and the appellate court affirmed, that the Schindlers had failed to prove by a preponderance of the evidence that the original trial court's order,

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This is not the first time disability-rights and other vitalist activists have become embroiled in end-of-life decisionmaking issues. See Carol J. Gill, *Health Professionals, Disability, and Assisted Suicide: An Examination of Relevant Empirical Evidence and Reply to Batavia*, 6 Psychol. Pub. Policy & L. 526, 540 (2000) (stating that “[f]rom the Elizabeth Bouvia . . . case in the mid-1980s to the recent Bill White . . . story, many disability-rights activists have protested society’s and the medical system’s willingness to let people with disabilities die before they have been offered adequate supports to live as they wish” (citations omitted)); William R. Macklin, *Disability-Rights Activists Answer Right-to-Die Comment with Protest; Members Fighting to Show They Aren’t a Drain on Society*, Dallas Morn. News 4A (Sept. 26, 1999) (describing the disability rights efforts of Not Dead Yet, a grassroots group of disability-rights advocates). Concern about treatment of the disabled also surfaced in attempts to block the decision of family members of Sheila Pouliot, a forty-two-year-old, mentally retarded woman with cerebral palsy, to refuse medically supplied nutrition and hydration. *Blouin v. Spitzer*, 356 F.3d 348 (2d Cir. 2004); 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, 21, 42–43 (2004) (noting that “Sheila Pouliot was a victim of vitalism run amuck,” and describing “disability advocates who argue vociferously that all ‘right-to-die’ cases hurt rather than help the disabled community”).

\footnote{46} Schiavo IV, 851 So. 2d at 185.
\footnote{47} Id.
\footnote{48} Id.
\footnote{49} Id.
\footnote{50} Id.
authorizing removal of the PEG tube, was no longer equitable. Terri’s PEG tube was again removed.

Thus, between Schiavo III and Schiavo IV, the vision of their daughter in which the Schindlers acquiesced transformed from that of a person lying in a PVS to that of a person in some other extreme state. Two of the five testifying physicians (the two chosen by the Schindlers) opined that, based on observation of what appeared to be reactions to verbal or physical contact with her mother, Terri was not in fact in a PVS. The appellate court, however, affirmed the trial court’s opinion, in which the trial court judge had recounted the testimony presented by all five physicians and concluded that “the credible evidence overwhelmingly support[ed] the view that Terri Schiavo remain[ed] in a persistent vegetative state.”

This is the point at which gale-force winds built in the Schiavo storm. Video clips and still photographs purporting to show Terri’s reactions to stimuli appeared on the Terri Schindler-Schiavo Foundation’s website. Newspapers, radio, and television outlets turned their focus on the case and ran stories. Supporters asked the Governor of Florida to intervene. Florida legislators received emails and telephone calls by the thousands. Public perception was of a disabled person who needed care and was

51. Id.
52. Id. at 187.
53. In re Schiavo, 2002 WL 31817960 at **2–3 (commenting at page three that “[e]ven Dr. Maxfield [who was testifying for the Schindlers] acknowledge[d] that vegetative patients can track on occasion and that smiling can be a reflex”).
55. See e.g. William R. Levesque, Judge Delays Removal of Schiavo’s Feeding Tube, St. Petersburg Times 3B (Dec. 14, 2002); Cary McMullen, A No-Win Situation in Matter of Schiavo, Lakeland Ledger (Lakeland, Fla.) D1 (Dec. 7, 2002); David Sommer, Schiavo’s Husband Files Request to Block Trial, Tampa Trib. Metro 7 (Feb. 14, 2002).
57. Gary Schneeberger, Linked Together for Impact, http://www.family.org/cforum/citizenmag/features/a0035297.cfm (accessed Nov. 12, 2005) (stating that “legislators received more than 100,000 e-mails and 50,000 phone calls that day from concerned citizens from coast to coast”); see also Leslie Clark & Phil Long, Bush Orders Feeding Tube to be Reinserted, Miami Herald 1A (Oct. 22, 2003) (describing Gov. Bush’s intervention in reinserting Terri’s feeding tube).
being denied it—a person who simply could not stand up for herself to obtain the care she needed.\textsuperscript{58}

In response to the pressure, Florida Governor Jeb Bush, who had already called the Legislature into special session to address medical malpractice issues, asked the Legislature to consider the Schiavo matter; the result was “Terri’s Law,” a bill literally introduced one day and passed into law the next.\textsuperscript{59} Examination of the discussion on the floor of the legislature about Terri’s Law reveals that the letters, emails, telephone calls, and media images caused at least some legislators to believe that the bill would protect a “brain-damaged individual” rather than an individual in a PVS.\textsuperscript{60}

Terri’s Law thus authorized Governor Bush to issue an executive order requiring reinsertion of the PEG tube and appointing a guardian ad litem to report back to him on Terri’s condition.\textsuperscript{61} Later, in the next two regular sessions, a subsequent, less-famous result of the political pressure from Schiavo was the introduction in the Florida Legislature of a bill titled the “Starvation and Dehydration of Persons With Disabilities Prevention Act.”\textsuperscript{62}

This public relations transformation of the Schiavo case from a matter involving a patient in an acknowledged PVS to one involving a patient in a questionable state, which happened at about the time at which various disability-rights and other vitalist groups became involved, had two distinct effects. First, as will be explored below, it focused the Florida Legislature on the fact


\textsuperscript{60} Fla. H. Sound Recording, \textit{supra} n. 58. While it is not incorrect to term an individual in a PVS a “brain-damaged individual,” use of that sort of language raises a different image than does use of the term PVS. \textit{Id.}

\textsuperscript{61} Wolfson, \textit{supra} n. 17, at 36.

\textsuperscript{62} Senate Bill 692 was introduced in 2004 in the Florida Senate but was later withdrawn from committee consideration. Fla. Sen. 692, 2004 Reg. Sess. (Mar. 2, 2004). The same bill was re-submitted in the next legislative session, as House Bill 701. Fla. H. 701, 2005 Reg. Sess. (Mar. 8, 2005).
that patients in PVSs sometimes appear to be functioning; patients in PVSs do not lie passively without opening their eyes or appearing to react. Second, the transformation provided a vehicle for opportunistic use by the disability-rights community, wrenching away a private, sorrowful dispute for public exploitation in the name of a larger political purpose.

Disability-rights and vitalist activists attempted to fit this case into a narrow category of cases (those involving minimally conscious patients)\(^{63}\) in which courts have been willing to impose heavy burdens of proof upon surrogate decision-makers attempting to refuse treatment on behalf of patients. Had an argument that Terri was minimally conscious been supported by the facts and proven before the trier of fact, then perhaps the Florida courts similarly could have been influenced to impose a more strict standard of decisionmaking than that which was employed. Instead, however, before and after the involvement of those activists, multiple factfinders consistently concluded not only that Terri was in a PVS, but also that she would have decided to refuse medically supplied nutrition and hydration if capable of making healthcare decisions in the condition in which she existed. As a consequence, the activists involved in Schiavo were forced to rely on the Legislature to accept the spectre of discrimination against a minimally conscious disabled person in a case not actually involving a minimally conscious person.

**II. LINGERING EFFECTS**

The Schiavo cases and related legislation thus illustrate a progression. The situation began as a relatively commonplace

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63. See *In re Wendland*, 110 Cal. Rptr. 2d 412 (Cal. 2001) (holding that conservator failed to prove that a conscious patient who was severely disabled both mentally and physically wished to refuse life-sustaining treatment, or that it was in his best interest to end such treatment); *In re Martin*, 538 N.W.2d 399 (Mich. 1995) (holding that conservator failed to prove that an incompetent but conscious patient wanted to end life-sustaining treatment because of patient’s prior statements); *cf. In re Conroy*, 486 A.2d 1209 (N.J. 1985) (holding that incompetent nursing home patient did not meet any of the tests for termination of life-sustaining treatment); *In re Edna M.F.*, 563 N.W.2d 485 (Wis. 1997) (holding that it was not in the best interest of an incompetent ward afflicted with dementia to withdraw life-sustaining support without a statement clearly indicating ward’s desire to end treatment); see generally Meisel & Cerminara, *supra* n. 7, at §§ 4.08[B], 6.04[I][2][b] (noting the differential treatment courts afford patients with varying degrees of consciousness).
end-of-life dispute between family members of a patient in a PVS who had not left written evidence of her wishes regarding continuation or withdrawal of life-sustaining treatment. Even those arguing that she should continue to receive nutrition and hydration through a PEG tube—her parents—proceeded from acquiescence in the judicial and medical conclusion that she was in a PVS. Over the next six years, however, that portrait of Terri Schiavo morphed into a portrait of a disabled person suffering discrimination because of her disability—an incapacitated person who was being put to death because of that status. The resulting images linger, and Floridians are likely to see several manifestations, both procedural and substantive, of the effects of that change in imagery in the law. Undeniably forceful, those images have caused the Florida Legislature to question some of the most fundamental principles of the law of end-of-life decisionmaking.

A. Procedural Issues

Two issues that may loom in the future are procedural points that drew the attention of the Florida Legislature during the debates about Terri’s Law. These issues are procedural in the sense that they deal with questions of who should make decisions regarding withholding and withdrawal of life-sustaining treatment, not which standard for decisionmaking should be used or what factors should be considered when making such decisions. The first relates to the identity of the person who may serve as decision-maker when a patient has not designated a surrogate decision-maker. The second relates to the duties a court may assume in end-of-life cases.

1. Identity of Proxy Decision-Makers

One issue that the Schindlers raised throughout the proceedings was whether Michael Schiavo should be disqualified from serving as Terri’s guardian, with the power to make decisions regarding withholding or withdrawal of life-sustaining treatment, because he, as her husband, would benefit financially when she passed away.64 During the Legislature’s discussions of Terri’s

Law, more than one legislator discussed whether Florida law should categorically prevent persons who might inherit from a patient upon that patient’s death from making decisions regarding withholding or withdrawal of life-sustaining treatment. 65

Florida law does not, as a blanket matter, prevent persons who would inherit from serving either as judicially appointed guardians, 66 patient-designated healthcare surrogate decision-makers, 67 proxies authorized by law to make healthcare decisions for incapacitated persons, 68 or attorneys-in-fact designated to make healthcare decisions through durable powers of attorney. 69 Rather, if a financial conflict of interest is alleged and proven in a particular case, then an individual guardian, proxy, or surrogate decision-maker will be disqualified from serving. 70 Indeed, that is usually the case in state statutory law, for “[c]onflicts of interest will almost always exist in decisionmaking about life-sustaining treatment.” 71 Those persons most likely to “benefit” financially or otherwise from a person’s death in fact are also the persons most likely to know the patient well enough to know what that patient would have wanted with regard to administration, withholding, maintenance, or withdrawal of life-sustaining treatment. 72 Therefore, “the fact that a surrogate [decision-maker] may ultimately


66. Fla. Stat. § 744.309 (providing for disqualification for conflict of interest only if a conflict of interest actually surfaces); Fla. Stat. § 744.312 (2004) (specifying as preferred guardians those who would fall into the categories of people who would inherit in the event of death, such as persons “related by blood or marriage to the ward”).


69. See generally Fla. Stat. § 709.08 (2004); cf. Fla. Stat. § 765.204(2) (recognizing that a healthcare decision-maker may be given attorney-in-fact status through a durable power of attorney specifically granting authority to make healthcare decisions even though Florida Statutes Chapter 765 includes a specific form for designation of a healthcare surrogate decision-maker).

70. See Fla. Stat. § 744.446 (2004) (providing for removal of guardian when prohibited conflicts of interest arise); Schiavo I, 780 So. 2d at 178 (recognizing that a surrogate’s decisionmaking ability could be questioned based on his or her likelihood of inheriting from the ward).

71. See Meisel & Cerminara, supra n. 7, § 3.24(C) at 3-96 (citing Cruzan v. Dir., Mo. Dept. of Health, 497 U.S. 261, 286 (1990)).

72. See generally Meisel & Cerminara, supra n. 7, § 3.24(C) (discussing the varying conflicts of interest that can arise with end-of-life situations).
inherit from the patient should not automatically compel the appointment of a guardian [ad litem].” 73

In Schiavo, in fact, both the courts and at least two guardians ad litem considered allegations that Michael Schiavo had a financial conflict of interest, 74 but no court ever found that such a conflict of interest existed. Nonetheless, the spectres raised during the political battles over Terri’s Law blew through Florida’s capitol with enough force to prompt legislators, unwisely, to consider categorically denying those who would be best informed the ability to make decisions in accordance with patients’ wishes. The lingering effects could cause the issue to resurface.

2. The Browning “Court as Guardian” Procedure

Florida, like most states, does not require that the courts approve decisions regarding withholding or withdrawal of life-sustaining treatment before they are implemented. To require judicial scrutiny of all such private, sorrowful moments in people’s lives would be both intrusive and unnecessary, as both Florida courts and other courts have ruled. 75 Requiring such scrutiny, in fact, might well overwhelm the judicial system, given the “hundreds, if not thousands,” of critically ill patients dying each day in situations in which decisions must be made about the necessity for and propriety of life-sustaining treatment. 76 Again like courts in most states, however, Florida courts have been careful to assure potential litigants that they are “always open to adjudicate legitimate questions” regarding end-of-life decisionmaking. 77 The Florida Supreme Court has identified two ways such a case could reach a court: “First, the surrogate or proxy may choose to

73. Schiavo I, 780 So. 2d at 178.
74. Id. at 173.
75. E.g. In re Tavel, 661 A.2d 1061, 1068–1069 (Del. 1995); In re Browning, 568 So. 2d 4, 15 (Fla. 1990) (stating that “we are loath to impose a cumbersome legal proceeding at such a delicate time in those many cases where the patient neither needs nor desires additional protection”); see generally Meisel & Cerminara, supra n. 7, §§ 3.18[E] at 3-73–3-74; 3.19 at 3-75.
77. In re Browning, 568 So. 2d at 16.
present the question to the court for resolution. Second, interested parties may challenge the decision of the proxy or surrogate.”

In Schiavo I, contrary to the impression given in the media, it was not the case that Michael Schiavo’s decision that Terri’s PEG tube should be removed prompted the Schindlers to ask a court to stop its removal. Rather, because Michael Schiavo recognized that he and the Schindlers would disagree on whether to remove her PEG tube, he asked the trial court to serve as decision-maker on the issue of removal. In other words, he approached the court under the first option outlined by the Florida Supreme Court in Browning. He and the Schindlers both presented their evidence to the trial court, and that court, “essentially serv[ing] as the ward’s guardian,” determined that discontinuance of life support was appropriate because it was what Terri would have wanted.

This procedure may come under fire in the Florida Legislature given that Governor Bush focused heavily on it when arguing in favor of Terri’s Law. In his unsuccessful petition for writ of certiorari in the United States Supreme Court in the litigation over Terri’s Law, Governor Bush alleged, among other things, that this procedure created a “judicial conflict of interest.” Attempting to portray Terri’s Law as an attempt to remedy this and other conflicts of interest allegedly inherent in the Schiavo proceedings, the Governor pointed to Florida law on guardianship appointments, which provides that “[n]o judge shall act as guardian . . . except when he or she is related to the ward by blood . . . or has maintained a close relationship with the ward or the ward’s family, and serves without compensation.” Attempting to draw an analogy, asserting a denial of due process and equal protection for incapacitated persons in Florida, the Governor maintained that a court could not “serve in the dual capacity of healthcare surrogate and judge.”

78. Id.
79. Schiavo I, 780 So. 2d at 178; see generally Meisel & Cerminara, supra n. 7, § 3.23[B] at 3-90 (noting the possibility that the court could take the surrogate’s role).
80. Schiavo I, 780 So. 2d at 179.
appointment of three guardians ad litem, as well as multiple appeals and petitions for review, however, it was difficult to argue that the proceedings failed to accord due process to anyone involved, especially Terri Schiavo.

Such an argument could resonate with the Florida Legislature, even though it has not resonated with the courts, due to the lingering power of the images of Terri Schiavo. With memories fresh from emails, phone calls, and video clips, and lacking a complete picture of the years of court cases and judicial factfinding, legislators could yet attempt to build on concerns expressed during the debates on Terri’s Law about Browning’s option one, the “court as guardian” procedure. Once again, however, were this to occur, it would be an example of the power of images and the force behind their creation overwhelming common sense and sensible legal principles.

The traditional power accorded to the courts in guardianship matters eliminates concerns that a court cannot act as surrogate. While the Governor cited, and the Florida Legislature may also focus upon, the statute providing that no judge shall be appointed a guardian, the existence of such a statute means absolutely nothing with respect to whether a court may engage in surrogate decisionmaking for a patient. Merely because the Legislature at one time recognized that it made no sense for a judge acting as guardian to submit required guardianship reports to him or herself as judge does not mean that a judge cannot sift through the evidence of a patient’s wishes and determine what the patient would have wanted in terms of end-of-life care.

In fact, the latter is the procedure engaged in by judges who are approached through Browning’s option two—a procedure no one claims is faulty. Under Browning’s option two, when someone disagrees with a surrogate’s or proxy’s determination of what a patient would have wanted near the end of life, that party challenges the surrogate’s or proxy’s decision before a judge, who then must determine what the patient would have wanted. To do that, the judge engages in precisely the same decisionmaking

84. Fla. H. Sound Recording, supra n. 58.
85. Clark & Long, supra n. 57, at 1A.
86. Fla. Stat. § 744.309(1) has been part of the law since at least 1975.
87. In re Browning, 568 So. 2d at 16.
process, hearing precisely the same arguments, as under *Browning’s* option one. The difference is that one party has already taken a step (for example, by instructing a doctor to withdraw a PEG tube) that detracts from the goal of achieving what the patient would have wanted by ensuring that the other party not only disagrees, but also becomes angry because of the step that was taken. *Browning’s* option two simply represents a more contentious way of commencing the same process as represented by *Browning’s* option one. Neither poses a conflict of interest for a court.

Should the Legislature consider proposals to revise Chapter 765 of the Florida Statutes either to require the appointment of guardians ad litem for all patients who are the subject of “option one” proceedings or to prohibit “option one” proceedings altogether, the law of end-of-life decisionmaking in Florida would be set back by decades. The law would shift away from encouraging families, when disagreeing about a patient’s wishes, to achieve what the patient would have wanted by asking a neutral decision-maker to decide. Instead, it would force such families, who are already facing gut-wrenching situations, to stake out contentious positions even more strongly than any of them may wish; these families should instead be focusing on what the patient would have wanted.

**B. Substantive Issues**

Additionally, the furor raised by *Schiavo* highlights three substantive issues that are quite likely to surface with increasing frequency in future legislative battles and judicial cases. Questions may arise regarding the substantive standard for decision-making that should apply to incapacitated persons who have not left written evidence of their wishes with respect to treatment near the end of life. Additionally, the subjects of withholding or withdrawal of medically supplied nutrition and hydration in general, and the withholding or withdrawal of life-sustaining treatment of any kind from patients in PVSs, perennially have raised difficult issues and will continue to do so.
1. Decisionmaking Standards

Schiavo highlights an interesting question that has surfaced periodically in the end-of-life decisionmaking literature for years. When a patient is incapacitated, his or her surrogate or proxy is charged with making healthcare decisions in accordance with certain decisionmaking standards. The most commonly utilized standard, and indeed the standard applicable in Florida to the vast majority of cases, is the substituted judgment standard. Decisionmaking in accordance with a substituted judgment standard requires the decision-maker to determine what the patient would have wanted to do had he or she considered the question at hand. Evidence of precisely what the patient would have wanted, in the form of written advance directives or oral statements effectively constituting advance directives, is useful, but it is not required. A decision made pursuant to a substituted judgment standard can be determined by asking what a patient would have wanted based on that patient’s values, beliefs, and attitudes.

When a patient is incapacitated, however, and has left no or virtually no evidence of precisely what he or she would have wanted, the question arises whether decision-makers are truly making decisions only in accordance with that patient’s presumed wishes. Norman Cantor has suggested that in these sorts of cases, decision-makers are actually determining a “constructive preference” for the patient—“imputing choices to a formerly competent patient based on what the vast majority of competent persons would want done for themselves in the circumstances at hand.” Indeed, there is evidence that although only a small

88. Id. at 15.
89. In re K.I., 735 A.2d 448, 455 (D.C. 1999); In re Browning, 568 So. 2d at 15; Meisel & Cerminara, supra n. 7, § 4.02[A] at 4-11. The substituted judgment standard thus stands in contrast to the subjective standard, which requires that a patient “actually have made the decision in question,” In re Browning, 568 So. 2d at 15, and the best interests standard, which generally constitutes a benefit/burden determination in which the patient’s wishes may play some role. Meisel & Cerminara, supra n. 7, at § 4.07[D].
90. See Fla. Stat. § 765.205(1)(b); Fla. Stat. § 765.401(1)(b) (outlining a surrogate’s charge).
91. Meisel & Cerminara, supra n. 7, § 4.03 at 4-17.
number of people execute advance directives, a significant percentage of people believe it would be intolerable to exist in a non-communicative state or a state in which they manifest little or no control over their surroundings or recognition or enjoyment of loved ones. Applying a constructive preference, one could determine that, even if it is difficult to ascertain the wishes of a particular patient, it is likely true that the patient’s beliefs will mirror the majority’s on the subject of withholding or withdrawal of life-sustaining treatment, at least as long as what is known generally about the patient’s values, beliefs, and attitudes would support that conclusion.

In *Schiavo I*, the court discussed some evidence that was introduced at trial about the beliefs of the majority of persons regarding Ms. Schiavo’s state. The Schindlers contended that it was error for the trial court to hear evidence about social science surveys indicating that “most people, even those who favor initial life-supporting medical treatment, indicate that they would not wish this treatment to continue indefinitely once their medical condition presented no reasonable basis for a cure.” The appellate court stated that it doubted that such testimony “provided much in the way of relevant evidence” in a substituted judgment case. The court also ruled that, although the evidence might have tempted the trial court to make a best-interests decision rather than a decision based on the patient’s wishes, the appel-
late court was satisfied from reviewing the record that the trial court had appropriately made a substituted judgment determination—a “proper surrogate decision”—in *Schiavo*.98

The concept of constructive preference is not unique to academic literature. Since the beginning of litigation over end-of-life decisionmaking, some courts have included in their substituted judgment determinations information about what most people would want to have done in the situation at hand.99 The substitution of judgment for an incapacitated person often involves consideration of all sorts of information about factors other than the patient's statements about his or her wishes.100 Indeed, it must, for most people shy away from talking about their wishes, just as they shy away from executing written advance directives.101 Given all this, considering information about what the majority of citizens would want in a similar situation does not necessarily detract from the ultimate inquiry and may, in fact, advance it.

*Schiavo* has obliquely raised the issue of whether decision-makers should be able to use constructive preferences as part of their substituted judgment determinations in deciding whether to authorize withholding or withdrawal of life-sustaining treatment. Absent legislative change, in Florida, decision-makers must use the substituted judgment standard if evidence of a patient’s wishes is available, rather than discarding it entirely for a constructive preference standard.102 Judicially, however, evidence

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98. *Schiavo I*, 780 So. 2d at 179.
100. Meisel & Cerminara, *supra* n. 7, at 4–25 (listing a wide variety of factors courts and legislatures in various states have approved for consideration in making substituted judgment decisions).
102. See *Fla. Stat.* §§ 765.105(1), 765.205(1)(b), 765.401(2) (collectively providing that if a patient has left a written advance directive, the surrogate or proxy must abide by that patient’s “known desires or the provisions of this chapter,” which includes deciding what the surrogate “believes the principal would have [done] under the circumstances if the principal [was] capable”; if a patient has not left a written advance directive, the proxy must make decisions “the proxy reasonably believes the patient would have made under the circumstances” or, “[i]f there is no indication of what the patient would have chosen,” the surrogate must act in the “patient’s best interest”); *but cf.* Rebecca Dresser, *Schiavo: A Hard Case Makes Questionable Law*, 34 Hastings Ctr. Rpt. 8, 9 (May–June 2004) (discussing cases like *Schiavo* and concluding that “ethicists and policymakers must develop an enriched approach to evaluating the patient’s interests, one that improves on the relatively
regarding the majority’s preferences can be and ought to be con-
sidered as part of the decisionmaking process when determining
what a patient’s wishes would have been. The Florida Supreme
Court did not rule on the issue in Schiavo, and it could resurface,
especially as the Legislature recalls being buffeted by the force of
the disability-rights and vitalist movements and remembers the
images of Terri Schiavo.

2. Medically Supplied Nutrition and Hydration

Withholding or withdrawal of medically supplied nutrition
and hydration always has been a sensitive issue. The only United
States Supreme Court case addressing a withholding and with-
drawal of treatment issue involved requested withdrawal of medi-
cally supplied nutrition and hydration.103 As of the beginning of
2005, courts and state attorneys general had issued more than
sixty reported opinions concerning withholding or withdrawal of
medically supplied nutrition and hydration.104 The issue is more
difficult than issues regarding other forms of medical treatment
because a person suggesting to family members that withdrawal
of medically supplied nutrition and hydration is appropriate may
sound as if he or she is saying, “Don’t feed this person or give her
water.”

At least in the minds of some people of Roman Catholic faith,
the issue of withholding or withdrawal of medically supplied nu-
trition and hydration has become stickier during the past year
than it may have been previously. There always has been some
level of discomfort with withholding or withdrawal of medically
supplied nutrition and hydration among some Roman Catho-
lies.105 Until a 2004 statement by Pope John Paul II, however, it
had been clear that the Church’s position was that it was appro-

unsophisticated best interest standard that exists today”).
103. Cruzan, 497 U.S. at 261.
104. Meisel & Cerminara, supra n. 7, at § 6.03[G] tbl. 6-2 (providing a state-by-state list
of medically supplied nutrition and hydration cases and attorney general opinions).
105. E.g. Bishop James T. McHugh, Catholic Culture, Death and Dying Issues,
for providing PVS patients with artificial nutrition and hydration except in limited cir-
sumstances); see generally Krohm & Summers, supra n. 101, at 120–129 (describing the
views of many religions on advance directives and withholding or withdrawal of life-
sustaining treatment).
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appropriate to determine on a case-by-case basis, based on a burden-
benefit analysis, whether to require administration of medically
supplied nutrition and hydration to a patient. In other words, med-
ically supplied nutrition and hydration, under the Roman
Catholic tradition, constituted the sort of treatment that could be
withheld or withdrawn under much the same analysis as other
life-sustaining medical treatments. In 2004, however, addressing
the International Congress on “Life-Sustaining Treatments and
Vegetative State: Scientific Advances and Ethical Dilemmas,”
Pope John Paul II 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.”

Rather than immediately constituting a change of policy, at
least in the United States, the Pope’s statement has caused
Catholic healthcare institutions and commentators to re-examine,
but not necessarily to change, their positions. The Pope’s state-
ment does not constitute policy in and of itself; the United States
Conference of Catholic Bishops must offer further guidance before
Roman Catholic institutional policies in the United States must
change. The Conference is studying the statement and deter-
mining whether it mandates any change from the previously
stated official Roman Catholic position regarding medically sup-

106. Mark Repenshek & John Paul Slosar, Medically Assisted Nutrition and Hydration:

107. Pope John Paul II, Address of John Paul II to the Participants in the International
Congress on “Life-Sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas,”
(Mar. 20, 2004) (emphasis omitted); see generally Papal Address to the International Congress on “Life-Sustaining Treat-
Solutions Apr. 2004) [hereinafter Papal Address].

108. See Catholic Health Assn. of the U.S., News Releases, Statement on the Papal
(Apr. 1, 2004) (assuming that existing guidelines will remain in effect until the signifi-
cance and implications of the allocation have been examined); Papal Address, supra
n. 107, at U:76; Repenshek & Slosar, supra n. 106, at 16 (noting that interpretation of
the allocation by Catholic bishops will ultimately determine its impact); Thomas A.
Shannon & James J. Walter, National Catholic Reporter, Artificial Nutrition, Hydration: As-
(Apr. 16, 2004) (expressing concern that the allocation is at odds with existing Catho-
lic tradition and leaves many questions unanswered).
plied nutrition and hydration, which would permit withdrawal or withholding when the burdens of the treatment outweigh the benefits for patients and their families. Some have speculated that the Pope’s statement was intended to address the Schiavo case, but it remains unclear whether the Pope’s statement will in fact cause a change in the way the American Church or American Catholic institutions view instances of desired withholding or withdrawal of medically supplied nutrition and hydration in cases involving patients in PVSs.

Regardless of that ambiguity, the Pope’s statement ensures that withholding or withdrawal of medically supplied nutrition and hydration will remain a hot topic in the realm of end-of-life decisionmaking. Individual religious Roman Catholics are free to consider the Pope’s statement as instructive even if it is not binding on Roman Catholic institutions or the American Church. Religiously motivated voters are an important part of politicians’ constituencies, as demonstrated by the results of the 2004 presidential election. Many voters, religiously motivated or not, contact their legislators on issues that are important to them, as many did in the Schiavo case, and the Pope’s statement will cause many religiously motivated voters to believe the issue is important. If a legislature is already uneasy about withholding or withdrawal of medically supplied nutrition and hydration, as was the Florida Legislature when it heard about the Schiavo matter, constituent vocalization indeed could trigger special legislative treatment.

Some statutes in other states support this conclusion, as does the introduction of the Starvation and Dehydration of Persons with Disabilities Prevention Act in the Florida Legislature in the aftermath of its passage of Terri’s Law. At one time, many advance directive statutes prohibited the forgoing of medically supplied nutrition and hydration pursuant to statutory advance

109. Papal Address, supra n. 107, at U:77–78; see generally Fla. Catholic Conf., Florida Bishops Urge Safer Course for Terri Schiavo, http://www.flacathconf.org/Publications/BishopsStatements/Bst2000/TerriSchiavo.htm (Aug. 27, 2003) (stating that the removal of Schiavo’s feeding tube out of a belief that her life was without value or that removal would be in her best interests would violate the Church’s teachings).


In 2005, the Supreme Court has specifically held that medically supplied nutrition and hydration constitute a form of medical treatment, and most state statutes now permit its withholding or withdrawal. Some states, however, impose special requirements before medically supplied nutrition and hydration can be withheld or withdrawn in accordance with written advance directives. For example, in a handful of states, when a written advance directive is involved, “nutrition and hydration may be withheld only if the principal has specifically refused them, or the principal’s wishes regarding them are reasonably known or can . . . be ascertained” with reasonable diligence. Such statutes govern only a small percentage of actual instances of withholding and withdrawal, but they serve to illustrate the point that the emotional baggage accompanying the withholding or withdrawal of medically supplied nutrition and hydration sometimes causes it to be viewed differently from other forms of life-sustaining treatment.

The proposed Starvation and Dehydration of Persons with Disabilities Prevention Act (through its very name) clearly played on the emotions surrounding the withholding or withdrawal of medically supplied nutrition and hydration. The title of the proposed act was designed to arouse emotions and create an image of a healthy person wasting away in a condition that many people

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114. Meisel & Cerminara, *supra* n. 7, at § 7.07[B] (citing statutes) (footnote omitted). Even these do not, however, go so far as to require a written advance directive in order for a surrogate or proxy to refuse medically supplied nutrition and hydration on behalf of an incapacitated patient. For a discussion of the constitutional status of such a statute, see Allen, *supra* n. 59, at 1016.
associate with great pain, although research indicates that in fact unmanageable suffering is not involved and “lack of hydration and nutrition . . . may even have an analgesic effect.”

Moreover, even though, as a technical matter, a body deprived of artificial nutrition and hydration eventually will cease functioning because of lack of fuel, or more certainly lack of fluids, it is not the discontinuation of the medical procedure that causes the cessation of functioning. Instead, it is the condition of the patient that makes it impossible for that patient to receive nutrition or hydration through any means other than a medical procedure involving bodily invasion. Refraining from using highly technical medical procedures to take over when the body itself cannot perform functions on its own is the entire gist of the right to refuse treatment. It is the same as turning off a respirator when the body cannot breathe on its own; it constitutes removal of a mechanical way of taking over for a bodily function the body can no longer perform on its own.

More crucially, the proposed Starvation and Dehydration of Persons with Disabilities Prevention Act, most recently before the Florida Legislature as House Bill 701 (H. 701), would prevent the vast majority of Floridians from exercising their constitutional rights. H. 701 would establish an entire new section of Chapter 765 of the Florida Statutes, distinguishing medically supplied nutrition and hydration from all other types of medical treatment.

118. Bernat et al., supra n. 117, at 2725–2726.
119. See Cruzan, 497 U.S. at 288–289 (O’Connor, J., concurring) (noting that all feeding tubes involve bodily invasion); In re Tavel, 661 A.2d 1061, 1069 (Del. 1995) (stating that “[t]he majority of jurisdictions have held that removal of an artificial feeding tube is not a ‘death producing agent’”); In re Browning, 568 So. 2d at 11–12 (finding “no significant legal distinction” between respirators and feeding tubes); Orentlicher & Callahan, supra n. 18, at 390–391 (detailing, as a factual matter, bodily invasion of PEG, both through the initial procedure and through the continuing presence of the tube protruding through the stomach walls).
120. Entitled “Health Care Advance Directives,” this Chapter addresses advance directives and other end-of-life decisionmaking issues.
and making it practically impossible for a patient to refuse medically supplied nutrition and hydration.\(^{121}\) It would establish a presumption against the refusal of medically supplied nutrition and hydration\(^{122}\) contrary to established case law in both the Florida and the United States Supreme Courts that medically supplied nutrition and hydration does not stand in a class by itself, but rather is a form of medical treatment constituting exactly the sort of invasive procedure that all persons in this country, under both the common law and the state and federal constitutions, may refuse.\(^{123}\)

Moreover, in addition to establishing a presumption that infringes upon patients' constitutional rights in the first instance, H. 701 would permit that presumption to be overridden only in the most unlikely of circumstances. It would permit withholding or withdrawal of nutrition and hydration in only three instances,\(^{124}\) which, even collectively, could apply to such a small

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121. Fla. H. 701.
122. Id.
123. See e.g. Cruzan, 497 U.S. at 288–289 (O'Connor, J., concurring) (stating that the right to refuse medical treatment, including artificial hydration and nutrition, is undoubtedly protected by the Fourteenth Amendment); In re Browning, 568 So. 2d at 11 n. 6 (noting that a patient's right to refuse treatment is not based on the nature of the treatment refused).
124. First, H. 701 would not apply the presumption that medically supplied nutrition and hydration must be provided to incompetent persons when “[i]n reasonable medical judgment[,] (a) [t]he provision of nutrition or hydration is not medically possible; (b) [t]he provision of nutrition or hydration would hasten death; or (c) [t]he medical condition of the incompetent person is such that provision of nutrition or hydration would not contribute to sustaining the incompetent person's life or provide comfort to the incompetent person.” Fla. H. 701, 2005 Sess. § 765.604(1) (Mar. 8, 2005). The number of instances in which this exception would apply to safeguard a patient’s constitutional right to be free of invasive medical procedures would be vanishingly small, especially considering subsection (c).
Second, H. 701 would not require administration of medically supplied nutrition and hydration to incompetent persons who have executed written advance directives “specifically authoriz[ing] the withholding or withdrawal of nutrition or hydration, to the extent that the authorization applies.” Id. at § 765.604(2). The last phrase is unclear, so one wonders what, if anything, that phrase adds to the meaning of the bill. More important, however, was the unrealistic expectation that many patients would have executed advance directives. In the late 1980s and early 1990s, estimates of the percentage of the population that had executed advance directives varied between about nine percent and about twenty percent. Cruzan, 297 U.S. at 289–290 (O'Connor, J., concurring); 297 U.S. at 323 (Brennan, J., dissenting). Despite the passage of the Patient Self-Determination Act in 1990 and the implementation of advance directive statutes in every state in the Union, there is no indication that the number of patients executing advance directives has increased in any appreciable degree. See Kathy L. Cerminara, Eliciting Patient Preferences in Today's Health Care System, 4 J. Psychol. Pub. Policy & L. 688, 690 (1996) (noting that studies reveal only a slight increase in advance directives among seriously ill persons following
number of cases that the statute essentially would have established an irrebuttable presumption against the refusal of medically supplied nutrition and hydration.

The imagery accompanying the Schiavo cases and the strength of the forces propelling them combine powerfully with the emotional resonance of the nutrition and hydration issue. At the time of the passage of Terri’s Law, the Florida House and Senate floors were filled with legislators referring to “starvation” and to the common misconception that withdrawal of medically supplied nutrition and hydration causes pain or suffering. Medically supplied nutrition and hydration has always engendered passage of the Act. Moreover, not only is requiring execution of advance directives impracticable because so many people shy away from executing them, but it is also unfair to the most underprivileged segment of society. For the upper-class or higher middle-class person, failure to execute an advance directive is likely due to a general reluctance to deal with and to discuss death. Persons in those socio-economic classes, and with the amount of education usually enjoyed by those classes, likely have read about advance directives and their importance. They also likely have attorneys, and even may have engaged in some level of estate planning. In contrast, persons in lower socio-economic classes or with lesser amounts of education may not have attorneys, and they may or may not have read or heard about advance directives. If they have attorneys, it is not likely they are engaging in estate planning or other contemplation of what will happen near the end of their lives with those attorneys. While it is true that one need not have an attorney to execute an advance directive, if a person is aware of what advance directives are, he or she still does not necessarily understand how to go about preparing one or have access to the forms or to computers from which to print out the forms. See generally Allen, supra n. 59, at 1016. To require execution of an advance directive to authorize withholding or withdrawal of invasively supplied artificial nutrition and hydration in the cases of such persons unfairly impacts them based upon socio-economic reasons that should not matter in the realm of medical decisionmaking. Krohm & Summers, supra n. 101, at 56–59.

Finally, House Bill 701 would exempt from the presumption of administration of medically supplied nutrition and hydration persons who, as shown by clear and convincing evidence, “when competent, gave express and informed consent to withdrawing or withholding nutrition or hydration in the applicable circumstances.” Fla. H. 701, 2005 Sess. § 765.604(3) (Mar. 8, 2005). On the surface, this might seem like a reiteration of current caselaw providing that patients’ wishes be demonstrated by clear and convincing evidence. If that indeed had been the point of this provision, then proposed Section 765.604(3) of the Florida Statutes would have been unremarkable. In reality, however, because of the cramped definition provided for “express and informed consent” under proposed Section 765.602(1), this exception from the presumption would in fact have applied to no one. The definition of “express and informed consent” would have required that the patient, at the time of making the decision, have a “general understanding” of “[t]he proposed treatment or procedure for which consent is sought,” “[t]he medical condition of the person for whom consent for the proposed treatment or procedure is sought,” “[a]ny medically acceptable alternative treatment or procedure,” and “[t]he substantial risks and hazards inherent if the proposed treatment or procedure is carried out and if the proposed treatment or procedure is not carried out.” No one can know all these things in advance. Meisel & Cerminara, supra n. 7, at 7–22.
more emotional responses than other life-sustaining medical treatments; legislative efforts to distinguish between it and all the other life-sustaining medical treatments will continue to cloud the horizon.

3. Patients in PVSs

Terri Schiavo was in a PVS. So was Nancy Cruzan. So was Karen Ann Quinlan. So were the patients about whom most of the reported end-of-life decisionmaking appellate cases in the United States have been litigated. Patients in PVSs, like patients receiving medically supplied nutrition and hydration (and often they are the same), present emotionally difficult cases.

These cases are difficult because, as noted by the Schiavo courts, patients in PVSs do not always look as if they lack cognitive function. They do not necessarily appear to the casual observer to lack cognitive function, and they certainly do not appear that way to loving family members who wish that those patients were in better health than they are. The Florida Legislature was shocked to learn that a patient in a PVS occasionally can appear awake and can even seem to react to certain stimuli. It may not be a far stretch to imagine that the Florida Legislature may, in the aftermath of Schiavo, revisit the statutory definition describing patients in PVSs or, most dangerously, debate whether to permit persons to refuse treatment when in PVSs.

125. Schiavo I, 780 So. 2d at 179.
126. Cruzan, 497 U.S. at 261.
128. E.g. Rasmussen v. Fleming, 741 P.2d 674 (Ariz. 1987); In re Tavel, 661 A.2d at 1061; In re P.V.W., 424 So. 2d 1015 (La. 1982).
129. Schiavo IV, 851 So. 2d at 186; Schiavo I, 780 So. 2d at 177; In re Schiavo, 2002 WL 31817960 at **2–3 (Fla. Cir. Ct. 6th Dist. 2002); see generally Dorothy J. McNoble, The Cruzan Decision—A Surgeon’s Perspective, 20 Memphis St. U. L. Rev. 569, 569 n. 3 (1990) (quoting American Academy of Neurology definition of PVS).
130. Fla. H. Spec. Sess. E at 2:57; Fla. H. Sound Recording, supra n. 58 (stating that “this was not a PVS in terms of what we meant” at the time of a statutory revision in 1999). It bears noting, however, that the term “persistent vegetative state” was not added to Chapter 765 in 1999 but had already been part of the law. The 1999 amendments to Florida Statutes Chapter 765 merely moved the definition of “persistent vegetative state” from their position within the definition of “terminal illness” into a separate subsection of the definitions section of Chapter 765. 1999 Fla. Laws ch. 331, § 1. By definition, a PVS is not a “terminal illness.” See McNoble, supra n. 129, at 569 n. 3 (quoting American Academy of Neurology in defining PVS patients as “not ‘terminally ill’”).
Doing so would be unwise for a number of reasons. First, and most important, doing so would be unconstitutional under *Brown- ing*, in which the Florida Supreme Court held that a person in a PVS has a constitutional right to the withdrawal of medically supplied nutrition and hydration.\(^{131}\) It also would be unfortunate because PVS patients are cognitively unaware.\(^ {132}\) They have no higher brain function even though they moan, appear to react, and display other confusing indications.\(^ {133}\) They lack the awareness that most of us want right up until the time that we die. Most people do not want to exist in PVSs.\(^ {134}\) The law must permit them to refuse treatment, especially invasive treatment such as surgically implanted sources of artificial nutrition and hydration.

### III. CONCLUSION

The waves kicked up by the Schiavo storm will ebb and flow long after the gavel has struck for the final time in the courtroom. Images of Terri Schiavo as she was portrayed after the above-described transformation in litigation strategy will overshadow end-of-life decisionmaking in Florida for years. The *Schiavo* cases may increase the pressure on the Legislature and the courts to change laws currently on the books about guardianship qualifications, judicial procedures, decisionmaking standards, medically supplied nutrition and hydration, or patients in PVSs. While being buffeted by the forces behind the *Schiavo* cases, the Legislature and the courts must be careful not to destroy citizens’ rights of self-determination and liberty interests.

Practical effects accompany such potential legal effects. Politically, one must contemplate what Terri’s Law did to citizens’ feelings about the legislative process. The forces propelling *Schiavo* have capitalized on this opportunity to demonstrate that legislators and governors concerned about re-election cannot consider end-of-life decisionmaking an area of “settled consensus.”\(^ {135}\)

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131. *In re Browning*, 568 So. 2d at 13.
132. Far from advocating continuation of treatments for patients in PVSs, some even argue that, because they lack neocortical functioning, they should be considered legally dead. Meisel & Cerminara, *supra* n. 7, at § 6.04[A][5].
133. McNoble, *supra* n. 129, at 569 n. 3.
134. See AARP, *supra* n. 94, at 8 (noting that the majority of people would not want to live in a coma or other state in which they could not communicate with friends and family).
Citizens cannot be left with a good impression of the way that government works after hearing their legislators, in responding to politically powerful forces, state that they do not care whether a statute is constitutional if they believe that it represents an attempt to achieve a good result.\textsuperscript{136} Politics also inevitably reach into the judicial system when judges are elected, and another practical outcome of \textit{Schiavo} may be increased judicial reluctance to deal with end-of-life decisionmaking. It is difficult to imagine a judge wanting to be in the position of Pinellas Circuit Court Judge George Greer, who handled most of the trial-court proceedings and who also endured several motions to recuse and other allegations of bias during the years of the \textit{Schiavo} litigation.\textsuperscript{137} It similarly is difficult to imagine a judge who would want to face a retention election knowing that others are willing to run in opposition because of rulings in these types of cases.\textsuperscript{138}

More education in the law of end-of-life decisionmaking would help lessen some of these practical effects on judges, the legislature, and the citizenry. On the judicial front, more education would help judges feel prepared to hear cases and to produce considered results even in the face of heated reactions such as those Judge Greer faced. On the legislative front, education could help


\textsuperscript{137} See e.g. Maya Bell, \textit{Judge Ready to Rule on Woman Ill for 13 Years; He Refused to Recuse Himself in the Bitter Fight over the Fate of Brain-Damaged Terri Schiavo}, Orlando Sentinel B5 (Sept. 11, 2003); \textit{Jeb Bush Seeks Removal of Schiavo Case Judge}, The Bulletin’s Frontrunner (Nov. 24, 2003) (both discussing Gov. Bush’s and the Schindlers’ attempts to remove Judge Greer).

\textsuperscript{138} See e.g. Mahlburg & Bell, supra n. 136; David Sommer, \textit{Incumbent’s Decisions Disturb Judicial Challenger}, Tampa Trib. 1, Pinellas Sec. (Aug. 29, 2004) (discussing criticisms of Greer by an attorney campaigning against him in an election).
keep legislators from being engulfed in and carried along with the storm. Citizens would also benefit from and be better able to weather storms like this one with more education about advance directives and the law governing end-of-life decisionmaking. No matter what position they take on refusal of life-sustaining treatment, one message people have read or otherwise internalized from Schiavo is that they should memorialize their wishes regarding end-of-life decisionmaking.\footnote{See e.g. Martha Bellisle, Special Report: End of Life Planning, Reno Gaz.-J. 1A (Nov. 23, 2003) (discussing the renewed awareness of need for living wills after the Schiavo case); Pat Burson, Isn’t It Time for a Lively Conversation on Death? Orlando Sentinel E4 (Jan. 28, 2005) (discussing the need to talk to family members about wishes after death); Erin Marcus, Living with Court Limits on “Right to Die”; In Wake of Decision, Adults Are Advised to Set Down Wishes for Physicians, Wash. Post A8 (June 27, 1990) (discussing the increased awareness of the need for medical directives following the Cruzan decision); Mary Pickels, Advance Planning Lightens Burden on Survivors, Trib.-Rev. (Pitt.) (Feb. 20, 2005) (available at http://www.pittsburghlive.com/x/search/s_305602 .html) (discussing endeavors to increase awareness of living wills).} Although an increase in advance directives may present the medical and legal communities with additional challenging issues in the future,\footnote{For example, people who wish to ensure that treatment is administered to them might execute more advance directives requesting treatment, raising issues when physicians are opposed to continuing treatment because it is futile. See generally Meisel & Cerminara, supra n. 7, at ch. 13 (discussing physicians’ debates over ethics at continued treatment when such treatment is futile).} their execution would be a positive result indeed of this tragic commingling of strong political winds with two parents’ wishes for their daughter.