THE NEW IMPORTANCE OF ADVANCE DIRECTIVES

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I. INTRODUCTION

No right is held more sacred, or is more carefully guarded by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law.¹

Many developments have taken place in the arena of end of life decision-making since the New Jersey Supreme Court decided the case of Karen Ann Quinlan in 1976.² Medical breakthroughs and changes to the federal law led to requirements for health care providers to advise patients of the law and their rights to have advance directives.³ All fifty states and the District of Columbia have statutes that allow people to make advance directives.⁴ Politics have played a role in some cases.⁵ High profile cases

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^{1.} Union. Pac. Ry. Co. v. Botsford, 141 U.S. 250, 251 (1891).

^{2.} In re Quinlan, 355 A.2d 647, 651 (N.J. 1976).

^{3.} Pub. L. 101-508 § 4206, 104 Stat. 1388, 42 U.S.C. § 1395cc(f) (1990).

^{4.} See David M. English & Alan Meisel, *Uniform Health-Care Decisions Act Gives New Guidance*, 21 EST. PLAN. 355 (1994); see also ALAN MEISEL & KATHY L. CERMINARA, THE RIGHT TO DIE: THE LAW OF END-OF-LIFE DECISION MAKING, §§ 7.01, 7.13 (3d ed. 2009).

^{5.} See infra Part V.

fill the airways and grab the public's attention. Despite educational efforts, only about 25% of adults have made advance directives.

Medical advances, family disagreements, politics, and the lack of advance directives have changed the issues and the way decisions about dying are made.⁸ Whether fueled by the media or individual beliefs, now more than ever, matters that are intensely personal are debated in the court of public opinion, with every nuance analyzed and dissected. The 24-hour news channels, the internet, and the like promote every matter as newsworthy, perhaps at the cost of individual privacy.⁹

There may be various reasons why a person fails to make a directive or why families disagree on a course of action. The right to make choices about one's medical treatment, including end of life care, belongs to the patient. Without a directive, the decision-making process may become skewed and the focus diverted from the wishes of the patient. A surrogate directive becomes increasingly important for those individuals who want their wishes made known and followed; who want the family to honor their choices; who want to limit the type and amount of medical treatments; and who want to keep their dying from becoming a political moment. It is unlikely that a patient wants family members fighting over decisions regarding end of life treatment or wants special interests and government officials interceding in the determination and exercise of the patient's wishes.

- 8. See infra Part II.
- 9. Michael P. Allen, *Congress & Terri Schiavo: A Primer on the American Constitutional Order?*, 108 W. VA. L. REV. 309, 310 n.1 (2005). According to Professor Allen, there were thousands of stories about the case during the month of Mrs. Schiavo's death. *Id.*
 - 10. See infra Part III.
 - 11. See infra Part VII.
 - 12. See infra Part VII.

^{6.} See BILL COLBY, UNPLUGGED: RECLAIMING OUR RIGHT TO DIE IN AMERICA, 4 (2006) stating: From years of working on cases like Schiavo, I realize that at a very basic level it is impossible for us to understand—in any real way—what either the Schiavo or Schindler families have endured. Families I've talked with who can understand, like the Cruzans and Busalacchis, watched the news coverage of this fractured family and picked no side. Their hearts went out to parents and husband alike.

^{7.} Id. at 141, citing to The President's Council on Bioethics, Taking Care: Ethical Caregiving in Our Aging Society, 71, 75-76, U.S. Gov't Printing Off., Washington, D.C. (Sept. 2005), available at http://bioethics.gov/reports/taking_care/taking_care.pdf., citing to A. R. Eiser & M.D. Weiss, The Underachieving Advance Directive: Recommendations for Increasing Advance Directive Completion, AM. J. OF BIOETHICS 1 (2001).

^{13.} See infra Parts III-VII. The appropriate role in these cases is legislation that would apply to everyone, prospectively, rather than apparently legislation designed to change the outcome of a particular case perhaps because someone did not like the judge's decision. This article does not take the position that politics has no role in issues surrounding the "right to die." Politics may have some role, especially in the "normal" legislative process. Some individuals may want all treatment at any cost, and may not wish to state a preference regarding wishes, or may prefer a governor or other government official be involved. These individuals could leave appropriate instructions in writing as well. This article, however, takes the position that most people will not want their dying to follow that path, and therefore, an advance directive is critical as part of their planning.

This article examines four cases that illustrate family disagreements, medical advances, and political involvement in end of life cases in which the patient did not have a directive. ¹⁴ This article begins with a brief review of the history and development of right to die jurisprudence, statutes, and case law. ¹⁵ It then turns to a critical examination of select cases. ¹⁶ Additionally, this article discusses benefits, shortcomings, and the utility of surrogate advance directives in minimizing the impact of family disagreements, medical advances, and the potential of political involvement. ¹⁷ The article concludes with some observations about the importance of advance directives. ¹⁸

II. HISTORY OF THE "RIGHT TO DIE" IN THE UNITED STATES

Every human being of adult years and sound mind has a right to determine what shall be done with his own body \dots ¹⁹

Many articles have been written about what has become known in popular parlance as the right to die.²⁰ Perhaps the more precise phrase is the right to terminate treatment, including life-prolonging treatment.²¹ Although there are innumerable cases about terminating life-prolonging treatment, end of life decisions are made daily without disagreement and without the need for court involvement.²²

- 14. See infra Part II.
- 15. See infra Parts II-IV.
- 16. See infra Part II-IV.
- 17. See infra Parts V-VII.
- 18. See infra Part VII. Medical advances, family disagreements, and political agendas are not by any means the only matters that come into play in end of life cases. Societal values and religious views are factors that are, or may be, considered. See discussion infra Part IV (referencing the religious considerations for the Schiavo case).
 - 19. Schloendorff v. Soc'y of N.Y. Hosp., 105 N.E. 92, 93 (N.Y. 1914).
 - $20. \quad \textit{See Meisel \& Cerminara}, \textit{supra} \text{ note 4 (discussing various articles on the right to die)}.$
- 21. *Id.* (discussing the various labels given to this field and noting that each label has shortcomings). For example, the use of the word "right" in the phrase "right to die" has a different meaning to lawyers than it does to health care providers. *Id.* at § 1.01. Similarly, "physician-aided dying" may be more accurate than the phrase "physician-assisted suicide." Compassion in Dying v. Washington, 79 F.3d 790, 802 n.15 (9th Cir. 1996). Some may believe the distinction is merely semantics, but others have noted that there is a distinction. *Id.*

We use the terms "assisted suicide" and "physician-assisted suicide" interchangeably throughout this opinion, although as we have noted, we have serious doubts as to the correctness or propriety of the terms, as they are generally used. We should note, however, that there is another commonly used term—"physician-aid-in-dying"—that is also relevant to our discussion. That term includes not only the prescribing of drugs ("assisted suicide") but also the *administration* of drugs by the physician. The issue of the constitutionality of prohibiting physicians from administering life-ending drugs to terminally ill persons is not before us for decision.

Washington, 79 F.3d at 802 n.15; see also MEISEL & CERMINARA, supra note 4 (discussing the use of the phrase "right to die").

22. See Meisel & Cerminara, supra note 4, at §§ 1.04, 1.09.

The development of this area of the law began with the 1976 landmark case from New Jersey, *In re Quinlan*.²³ Karen Quinlan's father sought appointment as her guardian, with the express authority to consent to termination of "extraordinary medical procedures."²⁴ A number of parties were included or intervened in the suit, including the doctors, the hospital, the local prosecutor, and the state attorney general.²⁵

For unknown reasons, Karen Quinlan stopped breathing, and after being revived, failed to recover. A respirator and feeding tube sustained her vital functions. Her father sought guidance from his priest to "confirm the *moral rightness* of [his] decision" The New Jersey Supreme Court concluded,

After the *Quinlan* case, there was a succession of court opinions from various states.³⁰ The next significant case, *Saikewicz*, was decided in 1977.³¹ Although the *Quinlan* court outlined the applicable state interests, the *Saikewicz* court enumerated what has since become known as the "four state interests": preserving life, preventing suicide, protecting innocent

^{23.} In re Quinlan, 355 A.2d 647 (N.J. 1976).

^{24.} *Id.* at 651.

^{25.} *Id.* The state attorney general was included because of the state's interest in protecting life. *Id.* The New Jersey Supreme Court noted the state's interest in the preservation of life had a constitutional underpinning, citing to the Declaration of Independence and the New Jersey Constitution. *Id.* at 652 n.1. Not until the United States Supreme Court decided *Cruzan* was it clear that the basis for the right to refuse life-prolonging procedures was founded in liberty. *See infra* text accompanying notes 47-62 for a discussion of Cruzan v. Director, Mo. Dept. of Health, 497 U.S. 261 (1990).

^{26.} In re Quinlan, 355 A.2d at 653-54.

^{27.} *Id.* at 655-57. The New Jersey Supreme Court variously refers to her condition as coma and persistent vegetative state (PVS). *Id.*

^{28.} Id. at 658 (emphasis added).

^{29.} *Id.* at 671. Although the *Quinlan* court does not specifically mention politics in the opinion, the court makes various references to society, the "public discussion," and to the "moral judgment of the community at large." *Id.* at 652-67.

^{30.} See MEISEL & CERMINARA, supra note 4, § 1.09 and Table of Cases (noting a complete listing of cases).

^{31.} Superintendent of Belchertown State Sch. v. Saikewicz, 370 N.E.2d 417 (Mass. 1977).

third parties, and preserving the ethical integrity of the medical profession.³² Somewhat simultaneously, state legislatures passed legislation that specified how individuals could make health care advance directives.³³

Most of the cases during this time period focused on various types of treatments.³⁴ Some courts discussed the relevance of the patients' conditions.³⁵ Courts also discussed and determined what decision-making standards should be used in end of life cases.³⁶ Courts dealt with the issues on a case-by-case basis, with some opinions recognizing the use of a non-judicial framework for decision-making.³⁷ Court opinions often also called for legislative solutions to the issue.³⁸

While I agree with the Court's analysis today, and therefore join in its opinion, I would have preferred that we announce, clearly and promptly, that the federal courts have no business in this field; that American law has always accorded the State the power to prevent, by force if necessary, suicide—including suicide by refusing to take appropriate measures necessary to preserve one's life; that the point at which life becomes "worthless," and the point at which the means necessary to preserve it become "extraordinary" or "inappropriate," are neither set

^{32.} *In re* Quinlan, 355 A.2d at 663 (noting the state's interests in the "preservation and sanctity of human life and [the] defense of the right of the physician to administer medical treatment according to his best judgment."); *Saikewicz*, 370 N.E.2d at 417 (Mass. 1977).

^{33.} See English & Meisel, supra note 4; see also MEISEL & CERMINARA, supra note 4.

^{34.} In re Browning, 568 So. 2d 4, 11-12 (Fla. 1990) (rejecting any "distinction between . . . artificial means of life-support," holding that a "competent person has the constitutional right to choose or refuse medical treatment, and that right extends to all relevant decisions concerning one's health," and finding "no significant legal distinction between these artificial means of life-support.") (emphasis added). "We see no reason to qualify that right on the basis of the denomination of medical procedure as major or minor, ordinary or extraordinary, life-prolonging, life-maintaining, life-sustaining, or otherwise." Id. at 11 n.6; see also id. (citing Cruzan ex rel. Cruzan v. Director, Mo. Dep't of Health, 497 U.S. 261, 283 (1990)) (addressing the issue as the refusal of "life-sustaining medical treatment"); Corbett v. D'Alessandro, 487 So. 2d 368, 371 (Fla. Dist. Ct. App. 1986) ("We are unable to distinguish on a legal, scientific, or a moral basis between those artificial measures that sustain life-whether by means of 'forced' sustenance or 'forced' continuance of vital functions-of the vegetative, comatose patient who would soon expire without the use of those artificial means."), pet. denied, 492 So. 2d 1331 (Fla. 1986); Brophy v. New England Sinai Hosp., Inc., 398 Mass. 417, 437, 497 N.E.2d 626, 637 (1986) ("[w]hile we believe that the distinction between extraordinary and ordinary care is a factor to be considered, the use of such a distinction as the sole, or major, factor of decision tends, in a case such as this, [is] to create a distinction without meaning"); In re Hier, 18 Mass. App. Ct. 200, 207, 464 N.E.2d 959, 964, pet. denied, 392 Mass. 1102, 465 N.E.2d 261 (1984) (rejecting the distinction between nutrition and treatment); In re Gardner, 534 A.2d 947, 954 (Me. 1987) (noting that nutrition and hydration indistinguishable from other life-sustaining procedures); In re Conroy, 98 N.J. 321, 367-70, 486 A.2d 1209, 1233-34 (1985) "[W]e reject the distinction . . . between actively hastening death by terminating treatment and passively allowing a person to die of a disease . . . [and] also reject any distinction between withholding and withdrawing life-sustaining treatment."); In re Guardianship of Grant, 109 Wash. 2d 545, 563, 747 P.2d 445, 454 (1987) (noting the right to withhold life-sustaining procedures extends to "patient"); Gray ex rel. Gray v. Romeo, 697 F. Supp. 580, 588 n.4 (D.R.I.1988) (noting there's no analytical difference between withholding and withdrawing medical treatment).

^{35.} See, e.g., In re Conroy, 98 N.J. 321 (1985); In re Browning, 568 So. 2d 4 (Fla. 1990).

^{36.} See, e.g., Saikewicz, 370 N.E.2d at 427-32 (discussing the application of substituted judgment and best interest decision-making standards).

^{37.} See, e.g., In re Quinlan, 355 A.2d at 668-72 (discussing consultation and agreement amongst the involved parties and use of an ethics committee); see also In re Browning, 568 So. 2d at 16-18 (establishing a procedure for non-judicial decision-making and for challenges to the surrogate's decision).

^{38.} Consider Justice Scalia's concurrence in Cruzan:

By 1990, a number of cases had been decided by various states, and it appeared that the law regarding removal of life support had fallen into a pattern established by courts and legislation.³⁹ A competent individual has a right to refuse life-prolonging procedures.⁴⁰ That right was not lost by virtue of incompetency.⁴¹ Instead, a surrogate exercised the right for the patient, using an appropriate decision-making process.⁴² There also emerged a specified evidentiary standard.⁴³

forth in the Constitution nor known to the nine Justices of this Court any better than they are known to nine people picked at random from the Kansas City telephone directory; and hence, that even when it *is* demonstrated by clear and convincing evidence that a patient no longer wishes certain measures to be taken to preserve his or her life, it is up to the citizens of Missouri to decide, through their elected representatives, whether that wish will be honored. It is quite impossible (because the Constitution says nothing about the matter) that those citizens will decide upon a line less lawful than the one we would choose; and it is unlikely (because we know no more about "life and death" than they do) that they will decide upon a line less reasonable.

Cruzan, 497 U.S. at 294.

- 39. MEISEL & CERMINARA, *supra* note 4, at xvii and § 1.04; *see also* Kenneth Goodman, *Ethics Schmethics: The Schiavo Case and the Culture Wars*, 61 U. MIAMI L. REV. 863, 863 (2007) (noting "foundational issues" in end of life cases are "largely settled").
- 40. *Cruzan*, 497 U.S. at 279 (1990) ("assum[ing] that the United States Constitution would grant a competent person a constitutionally protected right to refuse lifesaving hydration and nutrition"); *see also In re* Browning, 568 So. 2d 4, 10 (Fla. 1990).
 - 41. In re Browning, 568 So. 2d at 17.
- 42. *Id.* at 10, 16. Starting with *Saikewicz*, courts were discussing the application of the substituted judgment standard, with the vast majority adopting it. Since, however, so many patients do not sign a directive or make a clear statement of their wishes, some began to move toward a "unified" substitute decision-making approach, that is, using the substituted judgment standard when there is evidence of the patient's wishes, and if not, then using the best interest standard. *Cruzan*, 497 U.S. at 261. *See* Uniform Health Care Decisions Act, § 5 (1993), *available at* http://www.law.upenn.edu/bll/archives/ulc/fnact99/1990s/uhcda93.pdf; *see also* Fl.A. STAT. § 765.401.
 - 43. Courts were requiring clear and convincing evidence. That became clear in *Cruzan*:

In our view, Missouri has permissibly sought to advance these interests through the adoption of a "clear and convincing" standard of proof to govern such proceedings "This Court has mandated an intermediate standard of proof—"clear and convincing evidence"—when the individual interests at stake in a state proceeding are both "particularly important" and "more substantial than mere loss of money." Further, this level of proof, or an even higher one, has traditionally been imposed in cases involving allegations of civil fraud, and in a variety of other kinds of civil cases involving such issues as . . . lost wills, oral contracts to make bequests, and the like.

We think it self-evident that the interests at stake in the instant proceedings are more substantial, both on an individual and societal level, than those involved in a run-of-the-mine [sic] civil dispute. But not only does the standard of proof reflect the importance of a particular adjudication, it also serves as a societal judgment about how the risk of error should be distributed between the litigants. (Citations omitted). We believe that Missouri may permissibly place an increased risk of an erroneous decision on those seeking to terminate an incompetent individual's life-sustaining treatment. An erroneous decision not to terminate results in a maintenance of the status quo; the possibility of subsequent developments such as advancements in medical science, the discovery of new evidence regarding the patient's intent, changes in the law, or simply the unexpected death of the patient despite the administration of life-sustaining treatment at least create the potential that a wrong decision will eventually be corrected or its impact mitigated. An erroneous decision to withdraw life-sustaining treatment, however, is not susceptible of correction. (Citations omitted).

The linchpin of a patient's right to make health care decisions is one of individual autonomy. 44 Although there were still some unresolved issues in the body of law, it appeared that there was a growing consensus in the laws and cases. 45

In 1990, two significant cases were decided, the first by the United States Supreme Court in Cruzan v. Director, Missouri Department of Health. 46 The second significant case was decided by the Florida Supreme Court, In re Browning. 47 Nancy Cruzan was in a car accident, and when paramedics arrived, had no cardiac or respiratory function. 48 It was later determined that she had not been breathing for somewhere between twelve and fourteen minutes before the first responders restored her heartbeat and breathing.⁴⁹ While her condition improved from a coma to being unconscious, she never recovered from a persistent vegetative state.⁵⁰ Once it became clear that she would not recover, her parents sought to instruct the health care providers to remove her feeding tube.⁵¹ The health care providers refused to do so without a court order.⁵² After the Cruzans worked through the state court system, the United States Supreme Court "granted certiorari to consider the question whether [Nancy] Cruzan has a right under the United States Constitution which would require the hospital to withdraw life-sustaining treatment from her under [the] circumstances" of this case.⁵³

Cruzan, 497 U.S. at 282-83.

^{44.} Black's Law Dictionary defines autonomy as "[t]he right of self-government . . . [a] self-governing state." Black's Law Dictionary (4th ed. 2004) (available on Westlaw). Courts also often make reference to a patient's "right of privacy" which Black's defines as "[t]he right to personal autonomy . . . The U.S. Constitution does not explicitly provide for a right of privacy or for a general right of personal autonomy, but the Supreme Court has repeatedly ruled that a right of personal autonomy is implied in the "zones of privacy" created by the specific constitutional guarantees." Id. (citations omitted).

^{45.} ALAN MEISEL & KATHY L. CERMINARA, THE RIGHT TO DIE: THE LAW OF END-OF-LIFE DECISIONMAKING, § 1.04 (3d ed. 2009); see also Kenneth Goodman, Ethics Schmethics: The Schiavo Case and the Culture Wars, 61 U. MIAMI L. REV. 863 (2007).

^{46.} Cruzan, 497 U.S. at 261.

^{47.} In re Browning, 568 So. 2d at 4.

^{48.} Cruzan, 497 U.S. at 266.

^{49.} Id. at 266-67.

^{50.} *Id.* at 261 (defining a "persistent vegetative state" as "generally, a condition in which a person exhibits motor reflexes but evinces no indications of significant cognitive function.").

^{51.} Id. at 266.

^{52.} *Id.* The trial court found her statements to a friend to be persuasive:

Nancy's expressed thoughts at age twenty-five in somewhat serious conversation with a housemate friend that if sick or injured she would not wish to continue her life unless she could live at least halfway normally suggests that given her present condition she would not wish to continue on with her nutrition and hydration.

Id. at 268 (citations omitted).

^{53.} *Id*.

Yet, the *Cruzan* case was not ultimately about Nancy Cruzan's right to have the life-prolonging procedures withdrawn, and instead focused on whether the State of Missouri's procedures were constitutional.⁵⁴

In this Court, the question is simply and starkly whether the United States Constitution prohibits Missouri from choosing the rule of decision which it did. This is the first case in which we have been squarely presented with the issue whether the United States Constitution grants what is in common parlance referred to as a "right to die"

Here, Missouri has in effect recognized that under certain circumstances a surrogate may act for the patient in electing to have hydration and nutrition withdrawn in such a way as to cause death, but it has established a procedural safeguard to assure that the action of the surrogate conforms as best it may to the wishes expressed by the patient while competent. Missouri requires that evidence of the incompetent's wishes as to the withdrawal of treatment be proved by clear and convincing evidence. The question, then, is whether the United States Constitution forbids the establishment of this procedural requirement by the State. We hold that it does not. ⁵⁵

Court opinions typically tend to be straightforward and unemotional. Oftentimes, the reader gets no sense of the whirlwind of activity surrounding a case.⁵⁶ So when reading the Supreme Court opinion in *Cruzan*, one does not get the sense that there was much, if any, political involvement in this case.

In his book about the case, the Cruzans' attorney, Bill Colby, provides some perspective beyond the Court's opinion.⁵⁷ After a Supreme Court

^{54.} Id. at 279-80.

^{55.} Id. at 277-80.

^{56.} One exception is one of the many opinions in *Schiavo* issued by the Second District Court of Appeals in Florida, where the judges made known their feelings:

The judges on this panel are called upon to make a collective, objective decision concerning a question of law. Each of us, however, has our own family, our own loved ones, our own children. From our review of the videotapes of Mrs. 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.

In re Schiavo, 916 So. 2d 814, 818 (Fla. Dist. Ct. App. 2005) (quoting In re Schiavo, 851 So. 2d at 186).

^{57.} WILLIAM H. COLBY, LONG GOODBYE: THE DEATHS OF NANCY CRUZAN 68, 72, 329-30 (Jill Kramer ed., 2002) (describing a conversation Colby had early in the case with the General Counsel for the Missouri Department of Health, during which the General Counsel told him that they want the matter to be a "friendly suit"). Although the Department would oppose the Cruzans at trial, and appeal if they lost the case, they didn't want it to be adversarial. In hindsight, it is visible that there were forces at work bigger than the issues in *Cruzan* case. The Governor of Missouri at the time was John Ashcroft, who would later become Attorney General for the United States, and while in office, challenged the Oregon assisted suicide statute. Furthermore, the Missouri Attorney General at the time was William Webster, who according to Mr. Colby, had courted the pro-life vote from the start of his political career. At the time, there was speculation that General Webster would subsequently run for Governor.

opinion, a new trial, and an order to remove the feeding tube, some things occurred in the *Cruzan* case that in comparison fifteen years later, are similar to those in the *Schiavo* case. A right to life organization asked the Governor of Missouri, John Ashcroft, to order the Missouri Attorney General to stop the judge's order from going into effect.⁵⁸ After the feeding tube was removed, Governor Ashcroft called the facility and requested that it be reinserted, but the doctor declined to do so.⁵⁹ Protestors gathered, vigils took place outside the facility, and even a rescue attempt appeared planned.⁶⁰

The second significant case in 1990 was the Florida Supreme Court decision in *In re Browning*. ⁶¹ *Browning* made some significant declarations about a patient's right to make health care decisions. ⁶² The Florida Supreme Court recognized that the state constitutional right of privacy could serve as a basis for a patient's right to refuse life-prolonging procedures. ⁶³ The Florida Supreme Court additionally determined that this right applied to all health care decisions, and that the patient's condition was not a determinant as far as the patient's right. ⁶⁴

All fifty states and the District of Columbia have statutes authorizing the creation and use of an advance health care directive. Despite the existence of the statutes, few people execute directives. One additional result of the *Cruzan* case was the adoption by Congress of the Patient Self-

Even though *Cruzan* was decided in 1990, things have not changed much as current numbers indicate that only about 25% of adults have made directives. *See* COLBY *supra* note 6, at 141 (2006), *citing* The President's Council on Bioethics, *Taking Care: Ethical Caregiving in Our Aging Society*, 71, 75-76, U.S. GOV'T PRINTING OFFICE (2005), *available at* http://bioethics.gov/reports/taking_care/taking_care.pdf., *citing* A. R. Eiser & M.D. *Weiss, The Underachieving Advance Directive: Recommendations for Increasing Advance Directive Completion*, AM. J. OF BIOETHICS 1 (2001).

^{58.} See COLBY supra note 57, at 363.

^{59.} Id. at 364.

^{60.} Id. at 368-77.

^{61.} In re Browning, 568 So. 2d 4 (Fla. 1990).

^{62.} Id. at 14.

^{63.} *Id*.

^{64.} *Id.* at 11-12.

^{65.} Cruzan v. Mo. Dep't of Health Dir., 497 U.S. 261, 312 n.11 (1990) (Brennan, J. dissenting) ("Since 1976, 40 States and the District of Columbia have enacted natural death Acts, expressly providing for self-determination under some or all of these situations" while "[t]hirteen States and the District of Columbia have enacted statutes authorizing the appointment of proxies for making health care decisions." *citing ante*, at 2857-58, n.2 (O'Connor, J., concurring)) (citations omitted); *see also* MEISEL & CERMINARA, *supra* note 4, at §§ 7.01, 7.13.

^{66.} See Cruzan, 497 U.S. at 323 n.21, (Brennan, J. dissenting) citing:

Emmanuel & Emmanuel, *The Medical Directive: A New Comprehensive Advance Care Document*, 261 JAMA 3288 (1989) (only 9% of Americans execute advance directives about how they would wish treatment decisions to be handled if they became incompetent); American Medical Association Surveys of Physician and Public Opinion on Health Care Issues 29-30 (1988) (only 15% of those surveyed had executed living wills); 2 President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Making Health Care Decisions 241-42 (1982) (23% of those surveyed said that they had put treatment instructions in writing).

Determination Act, which was designed to educate and encourage individuals to make advance directives.⁶⁷ At last, it appeared that this area of law had become "well-settled" and the decision-making process "routine," with other issues moving to the forefront. The Supreme Court and the states took up the issue of physician-aided dying.⁶⁸ Attention was paid to the provision of palliative care and pain management.⁶⁹ States legislatively addressed issues concerning out of hospital do not resuscitate

67. Patient Self-Determination Act, Pub. L. 101-508, 104 Stat. 1388, 42 U.S.C. § 1395cc(f). The American Bar Association describes the PSDA as requiring:

[T]hat most health care institutions (but not individual doctors) do the following:

- 1. Give you at the time of admission a written summary of:
- your health care decision-making rights (Each state has developed such a summary for hospitals, nursing homes, and home health agencies to use.)
- the facility's policies with respect to recognizing advance directives.
- 2. Ask you if you have an advance directive, and document that fact in your medical record if you do. (It is up to you to make sure they get a copy of it).
- 3. Educate their staff and community about advance directives.
- 4. Never discriminate against patients based on whether or not they have an advance directive. Thus, it is against the law for them to require either that you have or not have an advance directive.

American Bar Assoc., Division for Public Education, Law for Older Americans, Health Care Advance Directives, http://www.abanet.org/publiced/practical/patient_self_determination_act.html.

68. The United States Supreme Court considered the constitutionality of two statutes prohibiting aid in dying, In *Glucksberg* and *Vacco*, the Court upheld the specific state statutes, although on separate grounds. *Compare* Washington v. Glucksberg, 117 S. Ct. 2258, 2271 (1997) (determining that the Washington statute did not violate the Due Process Clause of the Fourteenth Amendment) *with* Vacco v. Quill, 117 S. Ct. 2293, 2302 (1997) (determining that the New York statute did not violate the Equal Protection Clause of the Fourteenth Amendment). The Court did not completely foreclose the idea of differing outcomes from a different set of facts:

Justice STEVENS states that "the Court does conceive of respondents' claim as a facial challenge-addressing not the application of the statute to a particular set of plaintiffs before it, but the constitutionality of the statute's categorical prohibition..." We emphasize that we today reject the Court of Appeals' specific holding that the statute is unconstitutional "as applied" to a particular class. Justice STEVENS agrees with this holding, but would not "foreclose the possibility that an individual plaintiff seeking to hasten her death, or a doctor whose assistance was sought, could prevail in a more particularized challenge," Our opinion does not absolutely foreclose such a claim. However, given our holding that the Due Process Clause of the Fourteenth Amendment does not provide heightened protection to the asserted liberty interest in ending one's life with a physician's assistance, such a claim would have to be quite different from the ones advanced by respondents here.

Glucksberg, 117 S. Ct. at 2275, n.24 (citations omitted).

In addition, the State of Oregon had approved the country's first physician-aided dying statute. Lee v. Oregon, 107 F.3d 1382 (9th Cir. 1997) (noting that the statute was challenged unsuccessfully and voted on by citizens twice before being implemented); *see also* State of Oregon, Dep't. of Human Servs., Death with Dignity Act History, http://oregon.gov/DHS/ph/pas/docs/History.pdf; Oregon Dept. of Human Services, http://oregon.gov/DHS/ph/pas/index.shtml.

Washington became the second state where voters approved physician-aided dying, voting 58% to 42% in favor of a measure on the November 2008 ballot. *See* Robert Steinbrook, M.D., *Physician-Assisted Death From Oregon to Washington State*, 359 NEW ENG. J. OF MED. 2513 (Dec. 11, 2008), *available at* http://content.nejm.org/cgi/content/full/359/24/2513. The Washington law, known as the "The Washington Death with Dignity Act: Initiative Measure 1000," The Washington Death with Dignity Act, http://wei.secstate.wa.gov/osos/en/Documents/I1000-Text%20for%20web.pdf, became effective on March 4, 2009.

69. MEISEL & CERMINARA, supra note 4, at § 6.03(I).

orders.⁷⁰ A discussion began regarding the issue of futility of treatment.⁷¹ Still, a significantly small number of Americans had signed advance directives.⁷²

III. A LACK OF AGREEMENT

It is the trial judge's duty not to make the decision that the judge would make for himself or herself or for a loved one. Instead, the trial judge must make a decision that the clear and convincing evidence shows the ward would have made for herself. It is a thankless task, and one to be undertaken with care, objectivity, and a cautious legal standard designed to promote *the value of life*. ⁷³

Medical technological advances are in many ways responsible for the development of the issues dealt with in these cases. He dicine can sustain life far longer than what was possible thirty years ago. As a result, courts face the difficult issues that arise in cases concerning termination of life-prolonging procedures. This section discusses four significant cases that

^{70.} *Id.* at § 6.02(C)-(D) (noting some states have statutes that provide specific requirements for a person to execute a pre-hospital or out of hospital do not resuscitate order).

^{71.} Id. at Chapter 13.

^{72.} See COLBY, supra note 6, at 14, citing to The President's Council on Bioethics, Taking Care: Ethical Caregiving in Our Aging Society, 71, 75-76; U.S. GOV'T PRINTING OFF., Washington, D.C. (Sept. 2005), available at http://bioethics.gov/reports/taking_care/taking_care.pdf., citing to EISER & WEISS, supra note 7; David John Doukas, "Family" in Advance Care Planning: The Family Covenant in the Wake of Terri Schiavo, 33 J. L. MED. & ETHICS 372, 372 (2005).

^{73.} In re Schiavo, 916 So. 2d 814, 818 (Fla. Dist. Ct. App. 2005) (citations omitted) (emphasis added).

^{74.} Cruzan v. Dir., Mo. Dep't of Health, 497 U.S. 261, 270 (1990) (citations omitted) ("[M]ore recently, however, with the advance of medical technology capable of sustaining life well past the point where natural forces would have brought certain death in earlier times, cases involving the right to refuse life-sustaining treatment have burgeoned."). "[M]edical technology has effectively created a twilight zone of suspended animation where death commences while life, in some form, continues. Some patients, however, want no part of a life sustained only by medical technology. Instead, they prefer a plan of medical treatment that allows nature to take its course and permits them to die with dignity." *Id.* at 301 (Brennan, J. dissenting) (quoting Rasmussen v. Fleming, 741 P. 2d 674, 678 (Az. 1987)).

^{75.} Id. at 328 (Brennan, J. dissenting).

Medical technology, developed over the past 20 or so years, is often capable of resuscitating people after they have stopped breathing or their hearts have stopped beating. Some of those people are brought fully back to life. Two decades ago, those who were not and could not swallow and digest food, died. Intravenous solutions could not provide sufficient calories to maintain people for more than a short time. Today, various forms of artificial feeding have been developed that are able to keep people metabolically alive for years, even decades.

Id., citing Spencer & Palmisano, Specialized Nutritional Support of Patients-A Hospital's Legal Duty?, 11 QUALITY REV. BULL. 160, 160-61 (1985); see also Cruzan, 497 U.S. at 329 (Brennan, J. dissenting), citing Anne Fadiman, The Liberation of Lolly and Gronky, LIFE MAGAZINE, Dec. 1986, at 72 (quoting medical ethicist Joseph Fletcher). "The 80% of Americans who die in hospitals are 'likely to meet their end . . . 'in a sedated or comatose state; be tubed nasally, abdominally and intravenously; and far more like manipulated objects than like moral subjects." Id.

^{76.} See, e.g., In re Martin, 538 N.W.2d 399, 415 (Mich. 1995). Mr. Martin suffered a closed head

illustrate the development of medical technology that created yet another set of issues for the courts.⁷⁷ Concomitantly, two of these cases underscore the potential for political involvement in end of life cases.⁷⁸

In 1995, the Michigan Supreme Court decided the case of *In re Martin*. The Michigan Supreme Court described its task as:

[T]o consider whether life-sustaining treatment in the form of a gastrostomy tube that provides nutritive support should be removed from a conscious patient who is not terminally ill or in a persistent vegetative state, but who suffers from a mixture of cognitive function and communication impairments that make it impossible to evaluate the extent of his cognitive deficits. 80

Noting the difficult choice before the court in deciding whether to order the cessation of life-supporting treatment, the court described its dilemma "[t]o end the life of a patient who still derives meaning and enjoyment from life or to condemn persons to lives from which they cry out for release is nothing short of barbaric. If we are to err, however, we must err in preserving life."81

Mr. Martin's mother and sister opposed the removal of his feeding tube, but there was no writing by Mr. Martin regarding his wishes. ⁸² Instead, testimony was introduced about prior conversations and what might be termed as "lifestyle evidence." ⁸³ There was a significant variation between the opinions of the experts. ⁸⁴ It did appear that Mr. Martin was able to interact and respond to some degree, although there was a question

injury that left him physically and cognitively impaired. *Id.* at 402. Although the experts disagreed in some respects regarding Mr. Martin's level of functioning, there appeared to be some consensus that Mr. Martin could respond to simple commands and all medical experts agreed that he was neither terminally ill nor PVS. *Id.* at 402-04.

^{77.} See Conservatorship of Wendland, 28 P.3d 151; In re Schiavo, 916 So. 2d 814; In re Martin, 538 N.W.2d at 399; Gilmore v. Finn, 527 S.E.2d 426 (Va. 2000).

^{78.} See Schiavo, 916 So. 2d 814; see also Gilmore, 527 S.E.2d at 426.

^{79.} In re Martin, 538 N.W.2d at 399. Mr. Martin's wife petitioned for termination of treatment. Id. at 402. They had been married for twenty-three years at the time of the Michigan Supreme Court decision, and had three children. Id. Mr. Martin was in a car accident in 1987 in which he was gravely injured. Id. Mr. Martin sustained a closed head injury that caused significant impairment of his cognitive and physical functioning. Id. He was unable to talk or walk and needed a feeding tube. Id. Mrs. Martin, his appointed guardian, began the process to stop life-prolonging procedures five years after the accident. Id.

^{80.} Id. at 401.

^{81.} Id. at 401-02.

^{82.} Id. at 402-03.

^{83.} *Id.* This includes information about an individual gained from the individual's philosophy, beliefs, etc. The court might consider the person's known views about health care—for example, whether the person assiduously avoided going to the doctor. *See, e.g.*, MEISEL & CERMINARA, *supra* note 4 at § 4.07(D); Norman L. Cantor, *Discarding Substituted Judgment & Best Interests: Toward a Constructive Preference Standard for Dying, Previously Competent Patients Without Advance Instructions*, 48 RUTGERS L. REV. 1193, 1209 (1996).

^{84.} In re Martin, 538 N.W.2d at 402-03.

regarding "the consistency and appropriateness of the perceived interaction and responses." The Michigan Court of Appeals remanded for additional testimony, in which additional experts indicated that Mr. Martin was able to understand "very short and very simple questions and cannot accurately comprehend [lengthy] questions . . . that require the retention of multiple thoughts" and was unable to understand his condition. His condition and cognition would not improve. Although the court's concern was with the sufficiency of the statements made by Mr. Martin prior to the accident as they related to his current condition, it is instructive to recognize the outcome of advances in medical technology. Despite the severities of his injuries, Mr. Martin retained some level of interaction. Although the family was in disagreement as to the appropriate course of action, the *Martin* case proceeded through the appellate system in a fairly typical fashion.

The same could not be said for the case of Hugh Finn. The *Finn* "case" is actually a series of four cases: first, an action in which his brother sought removal of Mr. Finn's guardian-wife and opposed the removal of life-prolonging procedures; second, the efforts by the Governor; third, an action in federal court by a state representative for an order that the feeding tube be reinserted; and fourth, an action by the wife-guardian against the medical examiner and others. Though *Finn* started as a "typical" case concerning the removal of a feeding tube from the patient; it ended up far from typical when Governor Gilmore of Virginia stepped into the litigation. Mr. Finn, a youngish man, and something of a local celebrity,

^{85.} Id.

^{86.} Id. at 403.

^{87.} Id. at 404.

^{88.} See id. at 411-13.

^{89.} See id. at 401. The court described his condition as "a conscious patient who is not terminally ill or in a persistent vegetative state, but who suffers from a mixture of cognitive function and communication impairments that make it impossible to evaluate the extent of his cognitive deficits." Id. Some patients may be diagnosed as being in a "minimally conscious state." See, e.g., J.T. Giancino, et. al., The Minimally Conscious State: Definition & Diagnostic Criteria, 58 NEUROLOGY 349 (2002), available at http://www.neurology.org/cgi/content/full/58/3/349 (discussing the types of behaviors needed for a diagnosis of MCS and noting that some of the characteristics of MCS include "intentional"—as opposed to "reflexive"—behavior, as illustrated by purposeful actions. However, the actions may not always be consistent (for example, a person in MCS may answer "yes" one time and "no" another time to the same question)); see also Joseph J. Fins, Brain Injury: The Vegetative and Minimally Conscious States, in FROM BIRTH TO DEATH AND BENCH TO CLINIC, THE HASTINGS CENTER BIOETHICS BRIEFING BOOK FOR JOURNALISTS, POLICYMAKERS AND CAMPAIGNS, Chs. 4, 15 (Mary Crowley, ed. 2008), available at http://www.thehastingscenter.org/uploadedFiles/Publications/Briefing_Book/brain%20injury%20chapter.pdf (discussing the types of behaviors needed for a diagnosis of MCS).

^{90.} See In re Martin, 538 N.W.2d 399 (Mich. 1995).

^{91.} See Gilmore v. Finn, 527 S.E.2d 426 (Va. 2000).

^{92.} See M. Garey Eakes, Michael Gilfix & William Colby, Planning Lessons Learned from End-of-Life Disputes, 17 NAELA Q. 21, 25 (Summer 2004).

^{93.} M. Garey Eakes & Alex Moschella, Two Cases That Never Should Have Happened: The

was in a car accident that left him severely brain damaged.⁹⁴ Finn resided in a nursing home and received nutrition and hydration through a feeding tube.⁹⁵ His wife, serving as his legal guardian, sought to have his feeding tube removed, which set off a cascade of legal battles between family members, leading to public scrutiny and ultimately, the involvement of the Governor of Virginia.⁹⁶

As noted above, numerous relatives of Mr. Finn opposed Mrs. Finn's decision. To start, one of his brothers sought an injunction prohibiting the removal of the feeding tube, as well as an order removing Mrs. Finn as Mr. Finn's guardian. During the hearing on the injunction, the medical testimony unanimously corroborated the diagnosis of Mr. Finn's PVS condition. In denying the injunction and granting the wife's petition, the court entered a twenty-one day stay. During the court-imposed stay, the brother filed a motion for reconsideration on newly discovered evidence

Misuse of Religious Doctrine in Cases Concerning the Withdrawal of Artificial Life Prolonging Medical Treatment, 12 NAELA Q. 4, 5 (Summer 1999). The attorney for Mrs. Finn co-authored an article about this case:

The authors faced insurmountable and deeply held family, clerical, political, and community religious beliefs in the different contexts of the two cases. In one case the misuse of the religious doctrine emanated from family members, local clergy, and the political community, while in the other case, religious doctrine was misused in yielding to the parents' personal beliefs over evidence of the patient's wishes.

Id. Eakes and Moschella also write that the politics actually started before the Governor stepped in:

Elaine Glazier, Michele Finn's sister, who opposed the removal of life support, found an ally in a Virginia State Delegate, Robert Marshall, who also opposed the withdrawal of artificial nutrition and hydration. Delegate Marshall galvanized the local Catholic parish and was instrumental in bringing the state into the case. Multiple investigations were initiated by various state and local agencies, either on their own initiative, or responding to a variety of allegations from confidential sources. The State Department of Health, Medical Assistance Services (Medicaid) and the local Adult Protective Services (APS) office conducted investigations of the nursing facility and the care of Hugh Finn for the duration of his life. The Department of Health conducted an investigation of the care of Hugh Finn, gave the nursing home administrator a favorable exit interview and never filed a report of their findings.

Id. (citations omitted).

94. *Gilmore*, 527 S.E.2d at 428; *see also* Bob Abernethy, *Prolonging Life*, http://www.pbs.org/wnet/religionandethics/week738/cover.html (noting that Mr. Finn was a newscaster on a local television network and thus well-known in his community).

- 95. Gilmore, 527 S.E.2d at 428.
- 96. *Id*.
- 97. *Id*.
- 98. *Id*

99. *Id.* at 428-29. Mr. Finn had not signed a directive, but shortly before the accident he asked his attorney to draft an advance directive. *Id.* at 428-29, n.2. Mrs. Finn and her attorney both gave reliable testimony about his statements regarding artificially prolonging his life. *Id.* at 428-29. According to Mrs. Finn's attorney, Mr. Finn covered a story about a case in Kentucky regarding life-prolonging procedures and directed his attorney to draft his directive so that would not happen to him. *See* interview with M. Garey Eakes, Chief Operating Officer, Partnership for Caring (May 29, 2008) (notes on file with author).

100. Gilmore, 527 S.E.2d at 429.

regarding Mr. Finn's diagnosis: an affidavit from a nurse who claimed Mr. Finn interacted with her. The nurse, a utilization review nurse working for the state's Department of Medical Assistance Services, repeatedly said "hi" to Mr. Finn as she reviewed Mr. Finn's medical records, and she believed he responded to her in a similar fashion. ¹⁰²

Additionally, during this time period, and continuing after the denial of the motion for reconsideration, various state agencies visited Mr. Finn as part of an investigation. These visits were in response to requests from family members and one member of the Virginia legislature. Then twenty members of the Virginia legislature released an "informal declaration" that nutrition and hydration should not be withheld from patients when it would be the "underlying cause of death." During a hearing on the motion to enjoin the state from further "visits," Mrs. Finn presented evidence that three of the state's doctors examined Mr. Finn and confirmed his condition as being PVS and discounted the nurse's report. Shortly thereafter, the family decided to not pursue any further legal action. The state of the state of the pursue any further legal action.

Although the short-lived family dispute ended, the legal battle continued. Two days after the family's decision not to pursue further legal action, Governor Gilmore, in his official capacity and in the name of the state, filed a complaint against the facility, Mr. Finn's wife, and Mr. Finn's attending physician, seeking an injunction prohibiting removal of Mr. Finn's feeding tube. One of the Governor's claims was that, in his official capacity as Governor, he had statutory authority to "protect or preserve the general welfare of the citizens of the [state]." The Governor also interpreted the applicable state health care decisions act as failing to

[W]hile reviewing Hugh Finn's medical records, she attempted to communicate with him. After repeatedly saying "Hi" to him, [she] believed she heard him respond in a similar fashion. [She] further stated that she then persisted in attempting to communicate with Hugh Finn for over an hour, but received no further response, although she observed Hugh Finn "[s]moothing" his hair. [She] also testified at the hearing, essentially reiterating the statements in her affidavit.

^{101.} *Id.* The newly discovered evidence consisted of an affidavit from a utilization review nurse who had "communicated" with Mr. Finn while reviewing his chart. *Id.* She believed she heard him say "hi" and observed him "smoothing" his hair. *Id.* The judge later amended the stay to thirty days. *Id.* at 429, n.3.

^{102.} Id. at 429. The nurse reported:

Id.

^{103.} Eakes' Interview, *supra* note 99 (noting that Mrs. Finn's attorney stated that state agency visits sometimes occurred daily).

^{104.} Gilmore, 527 S.E.2d at 430.

^{105.} Id.

^{106.} Id.

^{107.} Id.

^{108.} Id.

^{109.} Id.

^{110.} Id.

authorize the removal of the feeding tube. 111 The Governor argued that the law prohibits a deliberate act to end a patient's life. 112

After the lower court ruled against him, the Governor filed an emergency petition with the Virginia Supreme Court, arguing that the removal of the feeding tube would start the dying process, and since a person who is PVS is not in the "natural process of dying," it would be unlawful to remove the feeding tube. He also argued that failing to enter the restraining order would keep the parties from further investigating Mr. Finn's condition. The Virginia Supreme Court denied the emergency petition, and Mr. Finn later died after the withdrawal of the feeding tube.

After the main litigation ended, Mrs. Finn filed a motion for sanctions and fees against the Governor on the basis that his filings were frivolous, and that he had no standing to intervene in the case. The Governor claimed that he filed his suit in good faith and with a reasonable belief, raising for the first time a report on misdiagnosing PVS in patients. He also continued to offer his version of the interpretation of the statute—that Mr. Finn "was not in the natural process of dying." He argued that sanctions would inappropriately interfere with his executive powers and violate the separation of powers doctrine. The trial court ruled against the Governor and the State and awarded Mrs. Finn \$13,124.20 in costs and attorney fees; the court declined to award punitive sanctions. On appeal, the Virginia Supreme Court found that the Governor had a duty to protect Virginians' general welfare, and his argument was not completely without merit. The court reversed the award.

^{111.} Id. at 430-31.

^{112.} Id. at 431.

^{113.} Id. at 431-32.

^{114.} Id. at 432.

^{115.} Id.

^{116.} Id.

^{117.} *Id.* Additionally, the Governor raised issues about the quality of care Mr. Finn received and about the reports from the facility that Mr. Finn's condition improved. *Id.* The Governor also included an affidavit from a Catholic lay minister stating that Mr. Finn took his hand and cried. *Id.*

^{118.} *Id*

^{119.} *Id.* at 432-33. The Governor of Virginia raises the separation of powers doctrine as a shield from Mrs. Finn's claims. *Id.* A few years later in *Schiavo* another governor blurred the line of separation of powers in order to support his intervention in the case.

^{120.} Gilmore, 527 S.E.2d at 433.

^{121.} Id. at 436.

^{122.} *Id.* at 435-37. The court stated that:

This statute, for purposes of our present considerations, is more than a standing statute. It clearly acknowledges the Governor's duty, rather than a mere right, to protect the general welfare of all citizens of the Commonwealth. The trial court gave little significance to the duty of the Governor under this statute in exercising its discretion to impose sanctions in this case. We are of the opinion, however, that the duty placed upon the Governor is a highly significant factor to be considered in this and any case in which the appropriateness of sanctions against a Governor is at issue. No other litigant has the duty "to protect and preserve the general welfare of the citizens of the Commonwealth," including in this case the

Not all cases with family disagreements go the way of the *Finn* case. In 2001, the California Supreme Court decided a case of a patient who was conscious but with significant physical and mental disabilities. ¹²³ In this case, Mr. Wendland did not execute a directive prior to his automobile accident. ¹²⁴ As a result of the accident, Mr. Wendland suffered a brain injury, and was conscious but physically and mentally disabled. ¹²⁵ The court had to decide whether the conservator could withhold nutrition and hydration from a patient who was conscious and not terminally ill. ¹²⁶ Though initially comatose, Mr. Wendland regained consciousness and demonstrated a level of responsiveness. ¹²⁷ Two years after the accident, Mr. Wendland's wife declined to consent to a fourth surgery to replace a feeding tube. ¹²⁸ Mr. Wendland's mother and sister objected and obtained an order restraining the treating physician from removing the temporary naso-gastric feeding tube from Mr. Wendland. ¹²⁹ Mrs. Wendland petitioned the court to appoint her as her husband's conservator and to confirm her

legal rights and interests of Hugh Finn. With regard to the imposition of sanctions, we do not suggest that the Governor's action is clothed with a dispositive presumption of reasonableness or good faith. Rather, we are of the opinion that when, as here, the Governor asserts a legal contention in the context of fulfilling the duty to protect the welfare of one or all the citizens of this Commonwealth acting in the capacity as *parens patriae*, any doubts about the good faith of that action should be resolved in favor of the Governor's contention. It is only when the Governor's legal contention is totally without merit that his action is appropriately sanctioned.

Id. at 467-68.

123. Conservatorship of Wendland, 28 P.3d 151 (Cal. 2001). The case really concerned the evidentiary standard rather than political intervention, as illustrated in the *Finn* case. The California Supreme Court held that the conservator "may not withhold artificial nutrition and hydration from [the patient] absent clear and convincing evidence [that] the conservator's decision is in accordance with either the [patient's] own wishes or best interest." *Id.* at 154. Although Mr. Wendland died prior to the court issuing a decision, the California Supreme Court chose to decide the case rather than dismiss it as moot, because it was an issue that was "capable of repetition yet tend[s] to evade review." *Id.* at 151 n.1.

- 124. Id. at 154.
- 125. Id.
- 126. *Id.* Mr. Wendland was not PVS, terminally ill, or in a coma, but the court described him as "conscious yet severely disabled." *Id.*
- 127. *Id.* As described by the court from a detailed medical report, Mr. Wendland, at one point, "demonstrated clear, though inconsistent, interaction with his environment in response to simple commands." *Id.* "At his highest level of function . . . [he] was able to . . . throw and catch a ball, operate an electric wheelchair with assistance, turn pages, draw circles . . . and perform two-step commands." *Id.* Although able to communicate, there was no consistent method of communication. *Id.*
- 128. *Id.* The type of feeding tube used required surgery to implant it; Mrs. Wendland consented to surgery three times to replace dislodged tubes, but declined to consent the fourth time. *Id.* It appeared that their children and Mr. Wendland's brother all took the position that Mr. Wendland would not want the procedure. *Id.* at 155. The treating physician, other doctors, and the hospital ombudsman evidently supported Mrs. Wendland's decision. *Id.* The treating physician inserted another feeding tube (a nasogastric tube) to keep Mr. Wendland alive while the hospital ethics committee considered the case. *Id.* The hospital ethics committee ultimately unanimously approved Mrs. Wendland's decision, but without speaking to Mr. Wendland's mother or sister. *Id.*

129. *Id.* at 155. The treating physician inserted another feeding tube (a nano-gastric tube) to keep Mr. Wendland alive while the hospital ethics committee considered the case. *Id.*

authority to withhold life-sustaining medical treatment, including nutrition and hydration. Although the trial court appointed Mrs. Wendland as conservator, the court reserved judgment on her request for authority to consent to the removal of the feeding tube and ordered Mrs. Wendland to continue Mr. Wendland's therapy for sixty days. Upon completion of the sixty days, Mrs. Wendland renewed her request for power to remove the feeding tube. ¹³² Following her renewed request, orders were entered and appeals were taken. ¹³³ The trial court, and subsequently the California Supreme Court, held that there was insufficient evidence that Mr. Wendland wanted the feeding tube withheld under the circumstances of the case. ¹³⁴ Additionally, the conservator was unable to satisfy the best interest standard, and as a result, her request was denied. ¹³⁵

IV. THE SCHIAVO SAGA¹³⁶

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. In circumstances such as these, when families cannot agree, the law has opened the doors of the circuit courts to permit trial judges to serve as surrogates or proxies to make decisions about life-prolonging procedures. 137

It seems that the preceding parts of this article have built up to a discussion of the *Schiavo* case, and to some extent this is true. Even though much has been written about the case of Mrs. Schiavo, the case remains an important part of the discussion of politics in end of life cases.¹³⁸ This case

^{130.} Id.

^{131.} Id.

^{132.} *Id.* As part of the proceedings, the treating physician testified about Mr. Wendland's condition and ability to communicate. *Id.* at 156. Included in the opinion is a transcript of an interview that the doctor had with Mr. Wendland, using an assistive communications device ("a yes/no board"). *Id.* A series of the questions involved his physical condition and his wishes. *Id.* at 156-57. He answered all but one question: whether he wanted to die. *Id.* However, the doctor indicated there was no way to verify Mr. Wendland's understanding of the questions. *Id.* at 157. There was also some discussion about the consistency of the answers. *Id.*

^{133.} *Id*.

^{134.} Id.

^{135.} Id. at 156.

^{136.} See infra note 138 (noting that the Schiavo case has been the subject of many articles and several books. Although it may not have contributed too much to the body of law regarding removal of life-prolonging procedures, the amount of judicial scrutiny and political involvement makes the case remarkable if for no other reason.).

^{137.} In re Schiavo, 916 So. 2d 814, 818 (Fla. Dist. Ct. App. 2005).

^{138.} MICHAEL SCHIAVO & MICHAEL HIRSH, TERRI: THE TRUTH (2006); MARY & ROBERT SCHINDLER WITH SUZANNE SCHINDLER VITADAMO & BOBBY SCHINDLER, A LIFE THAT MATTERS: THE LEGACY OF TERRI SCHIAVO—A LESSON FOR US ALL (2006); see also DAVID GIBBS WITH BOB DEMOSS, FIGHTING FOR DEAR LIFE: THE UNTOLD STORY OF TERRI SCHIAVO AND WHAT IT MEANS

ranks among the top in this category of cases with the most scrutiny. ¹³⁹ A brief summary of the facts and procedural history of the case is necessary to appreciate the subsequent actions by the Governor of Florida, the Florida legislature, and the United States Congress. ¹⁴⁰

When the *Schiavo* case was first decided, it appeared for all intents and purposes to be as "routine" as an end of life case could be. Hrs. Schiavo collapsed in 1990 at the age of twenty-seven, in cardiac arrest, evidently from a potassium imbalance. Mrs. Schiavo called 911, and Mrs. Schiavo was transported to the hospital but never regained consciousness. According to the Florida appellate court's first opinion in this case, "[t]he evidence is overwhelming that [she was] in a . . . persistent vegetative state", although that would subsequently be litigated. Making reference to an earlier malpractice case, the appellate court succinctly observed that the parties no longer agreed on the appropriate course of care for Mrs. Schiavo:

Since the resolution of the malpractice lawsuit, both Michael and the Schindlers have become suspicious that the other party is assessing Theresa's wishes based upon their own monetary self-interest. The trial court discounted this concern, and we see no evidence in this record that either Michael or the Schindlers seek monetary gain from their actions. Michael and the Schindlers *simply cannot agree* on what decision Theresa would make today if she were able to assess her own condition and make her own decision. ¹⁴⁵

FOR ALL OF US (2006).

139. See Allen, supra note 9, at 310 n.1 (noting that there were thousands of stories about the case during the month of Ms. Schiavo's death).

140. See COLBY supra note 6, at 39, citing Anita Kumar, et al, House Scurries, ST. PETERSBURG TIMES, 1A (Mar. 21, 2005), available at http://www.sptimes.com/2005/03/21/State/House_scurries_on_Sch.shtml; see also Kathy Cerminara & Kenneth Goodman, Key Events in the Case of Theresa Marie Schiavo, http://www6.miami.edu/ethics/schiavo/timeline.htm.

141. *In re* Schiavo, 780 So. 2d 176 (Fla. Dist. Ct. App. 2001). For the purposes of this article, the first court opinion referred to is the first opinion on removal of the feeding tube, not the earlier opinions regarding the guardianship. *Id.* When reading the opinion, it followed a fairly consistent format for an end of life case. See Kathy L. Cerminara, *Collateral Damage: The Aftermath of the Political Culture Wars in Schiavo*, 29 W. NEW ENG. L. REV. 279, 281 (2007) (noting that the case was a "typical end-of-life decision-making case of no great import, presenting well-settled issues under Florida law.").

142. In re Schiavo, 780 So. 2d at 177; see also George Annas, "I Want To Live": Medicine Betrayed By Ideology In The Political Debate Over Terri Schiavo, 35 STET. L. REV. 49, 50 (2005).

143. See In re Schiavo, 780 So. 2d at 177.

144. *Id.*; see also In re Schiavo, 800 So. 2d 640 (Fla. Dist. Ct. App. 2001); In re Schiavo, 851 So. 2d 182 (Fla. Dist. Ct. App. 2003).

145. *In re Schiavo*, 780 So. 2d at 178 (emphasis added). Judge Greer had a certain amount of prescient on this, because the parties never again agreed:

On February 14, 1993, this amicable relationship between the parties was severed. While the testimony differs on what may or may not have been promised to whom and by whom, it is clear to this court that such severance was predicated upon money and the fact that Mr. Schiavo was unwilling to equally divide his loss of consortium award with Mr. and Mrs.

The appellate court, in affirming the trial court's order authorizing the removal of the feeding tube, summarized the evidence as:

[E]stablish[ing] that [she] was very young and very healthy when this tragedy struck. Like many young people without children, she had not prepared a will, much less a living will. She had been raised in the Catholic faith, but did not regularly attend mass or have a religious advisor who could assist the court in weighing her religious attitudes about life-support methods. Her statements to her friends and family about the dying process were few and they were oral. Nevertheless, those statements, along with other evidence about Theresa, gave the trial court a sufficient basis to make this decision for her.

In the final analysis, the difficult question that faced the trial court was 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. After due consideration, we conclude that the trial judge had clear and convincing evidence to answer this question as he did.¹⁴⁶

Schindler. The parties have literally not spoken since that date. Regrettably, money overshadows this entire case and creates potential of conflict of interest for both sides. The Guardian Ad Litem noted that Mr. Schiavo's conflict of interest was that if Terri Schiavo died while he is still her husband, he would inherit her estate. The record before this court discloses that should Mr. and Mrs. Schindler prevail, their stated hope is that Mr. Schiavo would divorce their daughter, get on with his life, they would be appointed guardians of Terri Schiavo and become her heirs at law. They have even encouraged him to "get on with his life." [sic] Therefore, neither side is exempt from finger pointing as to possible conflicts of interest in this case.

In re Schiavo, Case No. 90-2908GD-003, 2000 WL 34546715 (Fla. Cir. Ct. 2000); *see also* Lois Shepherd, *Terri Schiavo: Unsettling the Settled*, 37 Loy. U. Chi. L.J. 297, 303-04 n.32 (Winter 2006). The appellate court noted that the current case was affected by the earlier litigation:

In the early 1990s, Michael Schiavo, as Theresa's guardian, filed a medical malpractice lawsuit. That case resulted in a sizable award of money for Theresa. This fund remains sufficient to care for Theresa for many years. If she were to die today, her husband would inherit the money under the laws of intestacy. If Michael eventually divorced Theresa in order to have a more normal family life, the fund remaining at the end of Theresa's life would presumably go to her parents.

In re Schiavo, 780 So. 2d at 178 (noting that Mr. Schiavo and the Schindlers initially had a close relationship, working harmoniously to care for Mrs. Schiavo but had a falling out); Ronald Cranford, *Facts, Lies & Videotapes: The Permanent Vegetative State & The Sad Case of Terri Schiavo*, 33 J. L. MED. & ETHICS 363, 365 (Summer 2005).

146. In re Schiavo, 780 So. 2d, at 179-80.

There would be no finality in this case for years to come. 147 In fact, in many respects the process was just starting. 148 Various groups and activists supported the family during both appeals in what might be considered to be a public relations campaign. ¹⁴⁹ Among other things, Mrs. Schiavo's parents challenged the diagnosis of PVS, claiming that she responded to them. 150 The parties never again agreed on the course of action for Mrs. Schiavo, instead battling a private matter in a very public, and international, arena. The doctors removed Mrs. Schiavo's feeding tube an unprecedented three times. 151 The result was the same as that ordered by the trial court judge; it just took years of litigation for it to be implemented. 152

Other occurrences in the Schiavo case illustrate the political involvement similar to that in *Cruzan* and *Finn*. During the case, especially as the appellate options were diminishing, a number of calls were placed to the abuse hotline about Mrs. Schiavo. 154 The Florida Department

The case of Terri Schiavo was never about the law—the law was unchallenged and left unchanged by seven years of litigation, a Florida statute, and a federal statute. . . . But outside the judicial system, the case of Terri Schiavo was never really about her, her medical condition, her medical care, or her personal wishes. Her case, instead, was mostly about the screaming from the fundamentalist religious right into the ears of the Governor of Florida; his brother, the President of the United States; the Majority Leader of the United States Senate; and the leaders of the United States House of Representatives.

153. See, e.g., Annas, supra note 142, at 68. Remarks by minister and former Republican Senator John Danforth indicate the political agenda. Id. Professor Annas described Senator Danforth's remarks: Former Republican Senator and Episcopal minister John C. Danforth got it right when he observed that in pushing the Schiavo legislation, the Republican Party departed from its principles, especially those involving government intrusion into private decisions and federal courts overruling state courts, and "can rightfully be interpreted as yielding to the pressure of religious power blocs." Danforth went further, concluding that the Republican Party's "current fixation on a religious agenda has turned it in the wrong direction.

Id., quoting John Danforth, In the Name of Politics, N.Y. TIMES, Mar. 30, 2005, at A27. It is worth noting that Senator Danforth introduced the Patient Self-Determination Act as a result of the Cruzan case. See William H. Colby, From Quinlan to Cruzan to Schiavo: What Have We Learned?, 37 LOY. U. CHI. L.J. 279, 291 (2006); see also Eleanor Clift, Two Weeks of Life: A Memoir of Love, Death AND POLITICS 103-17 (2008).

154. See In re Schiavo, 932 So. 2d 264, 265 (Fla. Dist. Ct. App 2005.). Mr. Finn was visited almost daily in response to calls about him. Gilmore v. Finn, 527 S.E.2d 426, 430 (Va. 2000).

^{147.} See Shepherd, supra note 139, at 306-12.

^{148.}

See Cerminara, supra note 141, at 282, citing Kathy L. Cerminara, Tracking the Storm: The Far-Reaching Power of the Forces Propelling the Schiavo Cases, 35 STETSON L. REV. 147, 154-55 (2005) (noting that citizens bombarded the Florida Legislature and the U.S. Congress with e-mails and telephone calls). The citizens conducting the campaign "knew nothing about the case other than what they had heard on the radio or television, or had read on internet blogs or emails." Id.

^{150.} See Annas, supra note 142, at 66 (noting the edited video clip of Mrs. Schiavo in which she seemed to be interacting).

^{151.} See id.; see also Kathy Cerminara & Ken Goodman, University of Miami Ethics Programs, Key Events in the Case of Theresa Marie Schiavo, http://www6.miami.edu/ethics/schiavo/timeline.htm (last visited Sept. 13, 2009) (noting her feeding tube was clamped once and removed twice, with the second removal being the final one).

^{152.} See generally Schindler v. Schiavo, 544 U.S. 915 (2005) (last ruling before her death); see also Annas, supra note 142, at 49-50. George Annas describes this case as being about:

of Children and Families (DCF) tried unsuccessfully to intervene. ¹⁵⁵ Because of procedural mechanisms, during the final appeals of the case, the order entered by the trial court prohibiting DCF from taking Mrs. Schiavo was stayed automatically on appeal. ¹⁵⁶ Word spread that the Florida Governor intended to direct DCF, with the aid of the state law enforcement agency, to take custody of Mrs. Schiavo. ¹⁵⁷

Before this case ended, there was both a state and a federal law passed specifically to apply to Mrs. Schiavo. The first law came from Florida. Dubbed "Terri's Law," the legislation gave Governor Bush the power to override a judicial opinion by issuing a "stay to prevent the withholding of nutrition and hydration." The Florida Supreme Court subsequently ruled that the law was unconstitutional. The second, a federal law, Public Law 109-3, gave Mrs. Schiavo's parents a method by which to obtain federal court review of the orders entered by the Florida courts on removing the feeding tube from Mrs. Schiavo. This federal law seemed to be more carefully crafted than the Florida legislation. In addition, a statement

^{155.} See In re Schiavo, 932 So. 2d at 265. For a copy of the motion to intervene, see http://abstractappeal.com/schiavo/DCFpetition2.pdf.

^{156.} See In re Schiavo, 932 So. 2d at 264.

^{157.} See Cerminara, supra note 141, at 288, citing to Michael Schiavo with Michael Hirsch, TERRI: THE TRUTH 307 (2006); Dara Kam, Agents Readied in Case "Legal Window" Opened, Palm Beach Post, Mar. 26, 2005, at 8.

^{158. 2003} Fla. Laws 418; Pub. L. No. 109-3, 119 Stat. 15 (2005). The attorneys for then Governor Bush argued that Terri's Law, as the law became known, applied to anyone who met the specified criteria at that given time. Bush v. Schiavo, 885 So. 2d 321, 334 (Fla. 2004).

^{159. 2003} Fla. Laws 418.

^{160.} *Id.* Governor Bush overrode the court's order by issuing an executive order that resulted in the feeding tube being put back in. *Bush*, 885 So. 2d at 327. For a number of reasons, the law, and the Governor's actions, violated the separation of powers doctrine. *Id.* at 336-37. The Governor, and to some extent, the legislature, took the position that the law did not apply only to Mrs. Schiavo. *Id.* at 334. Although this might be technically true, it is unlikely that anyone else would fall within the provisions of the law during that time frame: no directive, PVS, removal of the feeding tube, and a family member who has challenged the removal of the feeding tube. *See* 2003 Fla. Laws 418. The law specifically provides:

Section 1. (1) The Governor shall have the authority to issue a one-time stay to prevent the withholding of nutrition and hydration from a patient if, as of October 15, 2003: (a) That patient has no written advance directive; (b) The court has found that patient to be in a persistent vegetative state; (c) That patient has had nutrition and hydration withheld; and (d) A member of that patient's family has challenged the withholding of nutrition and hydration. (2) The Governor's authority to issue the stay expires 15 days after the effective date of this act, and the expiration of the authority does not impact the validity or the effect of any stay issued pursuant to this act. The Governor may lift the stay authorized under this act at any time. A person may not be held civilly liable and is not subject to regulatory or disciplinary sanctions for taking any action to comply with a stay issued by the Governor pursuant to this act. (3) Upon issuance of a stay, the chief judge of the circuit court shall appoint a guardian ad litem for the patient to make recommendations to the Governor and the court.

^{161.} Bush, 885 So. 2d at 321 (noting a violation of separation of powers).

^{162.} See Relief of the Parent's of Theresa Marie Schiavo Pub. L. 109-3, 119 Stat. 15 (2005); see also Allen, supra note 9, at 313.

^{163.} See Pub. L. 109-3, 119 Stat. 15; see also Allen, supra note 9, at 313.

from the Pope regarding the removal Mrs. Schiavo's feeding tube created another round of filings to stop the removal of the feeding tube. 164

V. POLITICS IN THE LAW

As one of our most prominent jurists warned us decades ago: "Experience should teach us to be most on our guard to protect liberty when the government's purposes are beneficent.... The greatest dangers to liberty lurk in insidious encroachment by men of zeal, well meaning but without understanding." ¹⁶⁵

How could this happen? According to Professor Michael Allen, Public Law 109-3 brought up significant public policy questions. 166 State

164. See Pope John Paul II, Address of John Paul II To the Participants in The International Congress on Life-Sustaining Treatments & the Vegetative State: Scientific Advances & Ethical Dilemmas, http://www.vatican.va/holy_father/john_paul_ii/speeches/2004/march/documents/hf_jp-ii_spe_20040320_congress-fiamc_en.html; see also D. Dixon Sutherland, Theresa Schiavo & A Theology of Dying, in RESURRECTION & RESPONSIBILITY 225, 226 (Keith D. Dyer & David J. Neville, eds. 2009) (describing the timing of the Pope's comments as "more than coincidental."). Sutherland also describes the Schindlers' challenge to the diagnosis as important from a religious perspective, because by

[C]asting this picture of [Mrs. Schiavo] as if she was "just like us" heightened public awareness and allowed the heavy political hand of the "Christian right" to thrust the case into the U.S. Congress [sic]. Word was put out that political survival of anyone in Washington, including the President, was depending on taking action to reverse the court's decisions Astoundingly, on Palm Sunday, Congress met in an unprecedented, emergency session to pass a law aimed at one individual—

Id. at 227.

Professor Annas similarly notes,

The "culture of life" is, of course, a thinly coded reference to the anti-abortion movement (sometimes called the "pro-life movement"), but also can include opposition to physician-assisted suicide, capital punishment, opposition to embryonic stem cell research, and even opposition to war. In the United States, however, it is primarily anti-abortion, anti-embryo research, and anti-same-sex marriage.

Annas, supra note 142, at 54.

165. Cruzan v. Mo. Dep't of Health Dir., 497 U.S. 261, 330 (1990) (Brennan, J., dissenting), *quoting* Olmstead v. United States, 227 U.S. 438, 479 (1928) (Brandeis, J., dissenting).

166. See Allen supra note 9, at 314-15; see also Relief of the Parents of Theresa Marie Schiavo, Pub. L. No. 109-3.

SECTION 1. RELIEF OF THE PARENTS OF THERESA MARIE SCHIAVO.

The United States District Court for the Middle District of Florida shall have jurisdiction to hear, determine, and render judgment on a suit or claim by or on behalf of Theresa Marie Schiavo for the alleged violation of any right of Theresa Marie Schiavo under the Constitution or laws of the United States relating to the withholding or withdrawal of food, fluids, or medical treatment necessary to sustain her life.

SEC. 2. PROCEDURE.

Any parent of Theresa Marie Schiavo shall have standing to bring a suit under this Act. The suit may be brought against any other person who was a party to State court proceedings relating to the withholding or withdrawal of food, fluids, or medical treatment necessary to sustain the life of Theresa Marie Schiavo, or who may act pursuant to a State court order authorizing or directing the withholding or withdrawal of food, fluids, or medical treatment necessary to sustain her life. In such a suit, the District Court shall determine de novo any claim of a violation of any right of Theresa Marie Schiavo within the scope of this Act, notwithstanding any prior State court determination and regardless of whether such a claim has previously been raised, considered, or decided in State court proceedings. The District Court shall entertain and determine the suit without any delay or abstention in favor of State court proceedings, and regardless of whether remedies available in the State courts have been exhausted.

SEC. 3. RELIEF.

After a determination of the merits of a suit brought under this Act, the District Court shall issue such declaratory and injunctive relief as may be necessary to protect the rights of Theresa Marie Schiavo under the Constitution and laws of the United States relating to the withholding or withdrawal of food, fluids, or medical treatment necessary to sustain her life.

SEC. 4. TIME FOR FILING.

Notwithstanding any other time limitation, any suit or claim under this Act shall be timely if filed within 30 days after the date of enactment of this Act.

SEC. 5. NO CHANGE OF SUBSTANTIVE RIGHTS.

Nothing in this Act shall be construed to create substantive rights not otherwise secured by the Constitution and laws of the United States or of the several States.

SEC. 6. NO EFFECT ON ASSISTING SUICIDE.

Nothing in this Act shall be construed to confer additional jurisdiction on any court to consider any claim related—

- (1) to assisting suicide, or
- (2) a State law regarding assisting suicide.

SEC. 7. NO PRECEDENT FOR FUTURE LEGISLATION.

Nothing in this Act shall constitute a precedent with respect to future legislation, including the provision of private relief bills.

and federal courts had extensively reviewed *Schiavo*; it was inappropriate for Congress to interfere with the case. ¹⁶⁷ As Professor Allen observed,

One could be forgiven for believing that the national government had more pressing matters with which to deal in March 2005 than the end-of-life wishes of one person when there had already been such intense litigation. Moreover, the federal intervention appeared to be founded largely on a combination of political opportunism and political cowardice instead of rational policy determinations. The political opportunism came largely from those on the right of the political spectrum who seized on the issue as a means to divert attention from other unwelcome matters, such as grand jury investigations, or to advance broader political goals, such as restrictions on abortion rights or assent to higher office. Political cowardice came largely from the left. Very few people were willing to take a stand against the political grandstanding, apparently fearing reprisals at the polls. The ultimate result was federal interference in a basic, personal decision, something that seems quite difficult to justify. 168

Amazingly, during the legal debate, members of Congress were "diagnosing" Mrs. Schiavo's condition from the floor of both houses. 169

SEC. 8. NO AFFECT ON THE PATIENT SELF-DETERMINATION ACT OF 1990.

Nothing in this Act shall affect the rights of any person under the Patient Self-Determination Act of 1990.

SEC. 9. SENSE OF THE CONGRESS.

It is the Sense of Congress that the 109th Congress should consider policies regarding the status and legal rights of incapacitated individuals who are incapable of making decisions concerning the provision, withholding, or withdrawal of foods, fluid, or medical care

167. See Allen, supra note 9, at 314; see also Cerminara, supra note 141, at 286-87 (noting that Congress reconvened during Easter recess to pass the bill as emergency legislation).

168. See Allen, supra note 9, at 314-15 (citations omitted).

169. See Annas, supra note 142, at 58-59. Professor Annas describes Senator Frist's "diagnosis": On March 17, 2005, Frist, a former heart transplant surgeon (who insists on being called "Dr. Frist" even though his current occupation was Senate Majority Leader) said,

When I first heard about the situation facing Terri Schiavo, I immediately wanted to know more about the case from a medical standpoint. I asked myself, just looking at the newspaper reports, is Terri clearly in this diagnosis called a persistent vegetative state?

I was interested in it in part because it is a very difficult diagnosis to make and I've been in a situation such as this many, many times before as a transplant surgeon. . . . Persistent vegetative state, which is what the court has ruled—I question it. I question it based on a review of the video footage which I spent an hour or so looking at last night in my office here in the Capitol. And that footage, to me, depicts something very different than persistent vegetative state. . . . I mentioned that Terri's brother told me that Terri laughs, smiles, and tries to speak. Doesn't sound like a woman in a persistent vegetative state.

[T]here just seems to be insufficient information to conclude that Terri Schiavo is in a persistent vegetative state[.] [S]ecuring the facts I believe is the first and proper step at this juncture.

The United States House Committee on Oversight and Government Reform subpoenaed Mrs. Schiavo to appear before it for a hearing and an examination of her medical equipment. Senator Mel Martinez was criticized for circulating an unsigned memo describing the *Schiavo* case as a significant political opportunity for the Republican Party.

What of the aftermath of *Schiavo*? Some elected officials who voted in favor of the laws retreated from their positions. ¹⁷² Bills were introduced

Id. (emphasis omitted), quoting Sen. Frist, Speeches, Statement on Terri Schiavo Bill, Floor Statement, (Mar. 17, 2005).

Professor Annas also notes that Congressman Phil Gingrey, an OB-GYN, disagreed with the diagnosis of Mrs. Schiavo, saying,

I am not playing doctor, for indeed I am one . . . since Terri Schiavo's brain injury 15 years ago, she has been profoundly disabled. She is not, however, in a coma. She responds to people around her; she smiles and she can feel. Terri is very much alive. . . . Terri's condition can improve. Terri responds to verbal, auditory, and visual stimuli, normally breathes on her own and can move her limbs on command . . . to uphold a culture of life and compassion it is important we act today to save Terri Schiavo's life and uphold the moral and legal obligation of our nation, indeed this poor woman's Constitutional right to life.

Id. at 62 (emphasis omitted), quoting Congressman Gingrey at 151 Cong. Rec. at H1712-1713.

Florida Congressman Weldon, M.D., also "diagnosed" Mrs. Schiavo. Congressman Weldon, saying,

I practiced medicine for 15 years, internal medicine, before I came to the House of Representatives. I took care of a lot of these kinds of cases. . . . Number one, by my medical definition she was not in a vegetative state based on my review of the videos, my talking to the family, and my discussing the case with one of the neurologists who examined her. And, yes, I asked to get into the room and was unable to do so.

Id. at 62-63 (emphasis and citations omitted), quoting Congressman Weldon at 151 Cong. Rec. at H1715.

170. See COLBY, supra note 6, at 38; see also Cerminara, supra note 141, at 288. Mrs. Schiavo's feeding tube would have had to remain inserted in order to appear before the house committee. See Cerminara, supra note 141, at 288. The efforts of Congress, the Florida legislature, and the Governor, violated the separation of powers doctrine. Allen, supra note 9, at 309.

171. See Mike Allen, Counsel to GOP Senator Wrote Memo on Schiavo: Martinez Aide Who Cited Upside for Party Resigns, WASH. POST (Apr. 7, 2005) at A01, available at http://www.washingtonpost.com/wp-dyn/articles/A32554-2005Apr6.html. Senator Martinez, a Republican Senator for Florida, claimed to be unaware of the memo's origin. *Id.* Brian Darling, Senator Martinez's counsel, later admitted that he was the author of the "working draft." See id.

172. See Annas, supra note 142, at 71-72, quoting Janet Hook, Frist Plagued Again by Comments on Schiavo, L.A. TIMES, June 17, 2005, at A20. Senator Frist tried to deny that he had ever "diagnosed" Mrs. Schiavo. Id. As noted by Professor Annas: "Senator Frist, on the other hand, has been desperately trying, so far without much success, to distance himself from his original comments made as a physician-Senator, saying, 'I never made the diagnosis. . . . I wouldn't even attempt to make a diagnosis based on a videotape." Id. Senator Martinez backed away from his position in an interview in 2006, stating, among other things, "[p]erhaps this was not in the realm of federal concern. It may have been better left to state courts to deal with it." Adam C. Smith, Senator Changes Mind on Schiavo, ST. PETERSBURG TIMES, Feb. 12, 2006, at 1B, available at http://www.sptimes.com/2006/02/12/news_pf/Tampabay/Senator_changes_mind_shtml; see also Kenneth Goodman, Ethics Schmetics: The Schiavo Case and the Culture Wars, 61 U. MIAMI L. REV. 863, 869 (2007).

Congress's action on Public Law 109-3 even came up during the Democratic Presidential Candidate Debates in 2008. *Id.* In a debate between candidates Clinton and Obama, moderator Tim Russert asked then-Senator Obama if he had "any statements or vote [he'd] like to take back?" Then-Senator Obama responded regarding his inaction on Pub. L. 109-3:

Well, you know, when I first arrived in the Senate that first year, we had a situation surrounding Terri Schiavo. And I remember how we adjourned with a unanimous agreement

in various states to modify the existing right to die statutes.¹⁷³ Some may take the position that these proposals were actually part of a greater agenda to "change the culture surrounding end-of-life decision-making so that, while the law may allow people to direct that treatment be withheld or withdrawn in certain circumstances, more people will choose treatment, and thus life, than do now."¹⁷⁴ As the events such as those illustrated in the *Schiavo* case spin out, there is a resulting shift of focus from the patient's wishes and more on the politics and agendas of others.¹⁷⁵

VI. How DID WE GET HERE?

It may be unfortunate that when families cannot agree, the best forum we can offer for this private, personal decision is a public courtroom and the

that eventually allowed Congress to interject itself into that decisionmaking [sic] process of the families. It wasn't something I was comfortable with, but it was not something that I stood on the floor and stopped. And I think that was a mistake, and I think the American people understood that that was a mistake. And as a constitutional law professor, I knew better. And so that's an example I think of where inaction"

Democratic Presidential Debate for February 26, 2008, http://www.msnbc.msn.com/id/23394129/

173. Lois Shepherd, *State Legislative Proposals Following Schiavo: What Are They Thinking?*, 15 TEMP. POL. & CIV. RTS. L. R. 361, 363. According to Professor Shepherd, at least twelve states had proposals introduced based on a model act proposed by the National Right to Life Committee (NRLC). *Id.* According to their website, NRLC's mission statement is:

The ultimate goal of the National Right to Life Committee is to restore legal protection to innocent human life. The primary interest of the National Right to Life Committee and its members has been the abortion controversy; however, it is also concerned with related matters of medical ethics which relate to the right to life issues of euthanasia and infanticide. The Committee does not have a position on issues such as contraception, sex education, capital punishment, and national defense.

National Right to Life, http://www.nrlc.org/Missionstatement.htm (last visited Sept. 13, 2009). For more information about the "Will to Live" project, *see* http://www.nrlc.org/euthanasia/willtolive/index.html.

174. See Shepherd, supra note 173, at 363. Professor Shepherd takes the position that there is at least some dissembling about the true purpose for, and impact of, these legislative proposals. Id. Rather than promoting patient liberty, these bills would erode it. Id. The bills result in the promotion of a "culture of life" under "which life is preserved at nearly all cost . . . [if] the culture of life . . . pervades end-of-life decision-making, patient liberty will be eroded and patients and their families will suffer from more unwanted and nonbeneficial treatment." Id.; see also, Joshua E. Perry, Biopolitics at the Bedside: Proxy Wars & Feeding Tubes, 28 J. LEGAL MED. 171, 180 (Apr.-June 2007). See generally Cerminara, supra note 144, at 286-87 (discussing the bills introduced concerning end of life decisions); Corrine Parver, The Politics of Dying: How the Religious Right Has Come to Influence the Right-To-Die Debate, 15 TEMP. POL. & CIV. RTS. L. REV. 449, 466-68 (Spring 2006) (discussing the bills concerning the Schiavo case and end of life decision making).

175. See Annas, supra note 142, at 77. Professor Annas described the players as heroes and villains:

The primary villains are Senator Bill Frist and Representative Tom DeLay, both of whom attempted to use the plight of Terri Schiavo and her family for their personal political gain. Jeb and George Bush were, I think, more pawns than players in this saga. Neither ever claimed to be anything but fundamentalist Christian politicians; therefore, the fact that they succumbed to intense pressure from the religious right came as no surprise.

Id. See also Cerminara, supra note 141, at 307-08.

best decision-maker we can provide is a judge with no prior knowledge of the ward, but the law currently provides no better solution that adequately protects the interests of promoting the value of life. ¹⁷⁶

Perhaps at this point the question that needs to be asked is whether these developments come as a surprise? As noted earlier in this paper, prior to the *Finn* and *Schiavo* cases, it seemed that the law on terminating life-prolonging procedures had become settled and there were other, "newer" issues to decide. It should not come as a surprise how medical advances drove the evolution of the issues of terminating treatment for patients who have some degree of responsiveness, as illustrated in the *Wendland* and *Martin* cases. Medical advances are ongoing and medical treatments can now sustain lives that would have been lost years ago. When considering medical advances along with the small number of people making advance directives, it was inevitable that courts would be left to decide these issues. It is the same situation faced by the court in *Quinlan* thirty-plus years earlier.

Should the *Finn* and *Schiavo* cases surprise people? That answer is less clear, but probably is yes and no. Once again, medical advances and lack of directives lead to lack of evidence of what a patient wants. ¹⁸² Hope springs eternal, so family disagreements on the course of action should not be a surprise. ¹⁸³ But what about the political intervention? Those are harder questions but the signs were there. ¹⁸⁴

Consider the *Cruzan* case and the parallels it has to the *Schiavo* case: the protestors, the plan to "save" the patient, the constituents pressuring elected officials to act, and even the presence of some of the same prominent figures, though the cases occurred fifteen years apart. Consider the parallels in the *Finn* and *Schiavo* cases. In each case calls were made to the respective state agencies about the care, or lack thereof, provided to Mr. Finn and Mrs. Schiavo. Both cases involved witnesses claiming that the patients spoke. Finally, both cases included

^{176.} Bush v. Schiavo, 885 So. 2d 321, 327-28 (Fla. 2004).

^{177.} See supra notes 67-71 and accompanying text.

^{178.} See supra notes 89, 127 and accompanying text.

^{179.} See, e.g., Cruzan v. Director, Mo. Dep't. of Health, 497 U.S. 261, 329 (1990) (Brennan, J. dissenting) (noting that "[t]he new medical technology can reclaim those who would have been irretrievably lost a few decades ago and restore them to active lives.").

^{180.} See supra notes 66-67 and accompanying text.

^{181.} See supra notes 23-30 and accompanying text.

^{182.} See supra notes 10-13 and accompanying text.

^{183.} See supra Part III.

^{184.} See supra Part V.

^{185.} See supra notes 46-60 and accompanying text.

^{186.} See supra note 154 and accompanying text.

^{187.} See Gilmore v. Finn, 527 S.E.2d 426, 429 (Va. 2000) (noting the eye witness was a nurse); see also In re Schiavo, 916 So. 2d 814, 816 (2005) (noting the eye witness was an attorney).

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involvement of the states' governors and legislatures, and litigation at the state and federal levels. 188 When considering the parallels and connections, starting with Cruzan, this question comes to mind: In cases where the patient has not made a directive and the family disagrees on the course of action, is this a new paradigm for resolving such cases?

VII. THE "NEW" IMPORTANCE OF ADVANCE DIRECTIVES

Death is no longer something that just happens. Rather it is a process, planned in advance and monitored and controlled by lawyers, doctors, family members, legislatures, government officials, and the person who is dying. It is the concern, in short, of biopolitics. 189

What if a patient does not want the family fighting over the course of care or an elected official other than a judicial officer making decisions about the patient's end of life care? Will an advance directive serve as a shield to thwart political intervention in a person's end of life? Do these cases signal a shift away from a focus on the patient's wishes back to a paternalistic approach to decision-making?

It is unlikely, though not impossible, to believe that one would hope that the end of one's life would include the politics and publicity that accompanied the Schiavo case. 190 But our deaths may no longer be our own. 191 What then might be done to allow a patient to control the manner of dying? As long as families are in harmony with the patient's wishes, the chances of outsiders intervening are minimal. Even that, however, is no guarantee. 193 It would appear, then, that family harmony coupled with a surrogate appointment would be the most ideal course of action. 194 Since

See supra notes 109-22, 155-64 and accompanying text.

^{189.} Joshua E. Perry, Biopolitics at the Bedside: Proxy Wars & Feeding Tubes, 28 J. LEGAL MED. 171, 180 (April-June 2007), quoting John T. Parry, Society Must Be [Regulated]; Biopolitics & the Commerce Clause in Gonzalez v. Raich, 9 LEWIS & CLARK L. REV. 853, 873 (2005), stating:

[&]quot;We have become so good at keeping people alive that we've succeeded in keeping them alive when, in biological terms, they should have been dead long ago." Mrs. Schiavo was sustained for 15 years by a medico-juridico-political power that intervened to make her live for many years and, at the end, managed her death.

During those 15 years, her life was reduced to biological life—"anatomy in motion" or "death in motion"—a set of functions whose purpose was "no longer the life of an organism." Maintained only with the assistance of life-support technology, Mrs. Schiavo's life was sustained by virtue of legal decisions.

Id. at 181-82 (citations omitted).

^{190.} See Allen, supra note 171, at A10; see also Hook, supra note 172, at A20; Smith, supra note 172, at 1B.

^{191.} See infra note 207.

^{192.} In the Wendland, Martin, Finn, and Schiavo cases, at least one family member disagreed with the decision to remove life-prolonging procedures. See supra text accompanying notes 82, 92, 129, and 150.

^{193.} See infra notes 204-09 and accompanying text.

^{194.} See infra notes 202-03 and accompanying text.

family harmony is not always a given, a surrogate appointment would at least provide a decision-maker.

The individuals in the *Martin*, *Finn*, *Wendland*, and *Schiavo* cases were in rather similar situations. ¹⁹⁵ All were fairly young individuals with tragic events that cut their lives short. ¹⁹⁶ None had a directive, although Mr. Finn came close. ¹⁹⁷ All had a family disagreeing over what they wanted. ¹⁹⁸ All had debates about their conditions and wishes. ¹⁹⁹ Two had some level of responsiveness. ²⁰⁰ Two, *Finn* and *Schiavo*, had political intervention with the decision-making process. ²⁰¹

Had Mr. Finn or Mrs. Schiavo signed an advance directive, would these cases ever have occurred? While it is impossible to discern people's actions under another set of completed facts, it would seem that a directive would have greatly reduced, if not eliminated, outside involvement.²⁰² Arguably, the Florida legislature and United States Congressional representatives could not have justified their actions if Mrs. Schiavo had created a directive.²⁰³

^{195.} See supra notes 179-84 and accompanying text.

^{196.} *In re* Martin, 528 N.W. 2d 399, 402 (Mich. 1995); *see also In re* Schiavo, 916 So.2d 814, 815 (Fla. Dist. Ct. App. 2005); Conservatorship of Wendland, 26 Cal. 4th 519, 524 (2001); Gilmore v. Finn, 527 S.E.2d, 428 (Va. 2000).

^{197.} See In re Martin, 528 N.W.2d at 402; see also In re Schiavo, 916 So. 2d at 814; Wendland, 26 Cal. 4th at 519. Mr. Finn had not signed a directive, but shortly before the accident he asked his attorney to draft an advance directive. Gilmore, 527 S.E.2d at 428-29. There was reliable testimony from his wife and attorney about his statements regarding artificially prolonging his life. See id. at 429 n.2. According to Mrs. Finn's attorney, Mr. Finn covered a story about a case in Kentucky regarding life-prolonging procedures and directed his attorney to draft his directive so that couldn't happen to him. See Eakes' Interview, supra note 99.

^{198.} See In re Martin, 528 N.W. 2d at 402; see also Gilmore, 527 S.E.2d at 428; In re Schiavo, 916 So.2d at 815; Wendland, 26 Cal. 4th at 524.

^{199.} See In re Martin, 528 N.W. 2d at 402; see also Gilmore, 527 S.E.2d at 428-29; In re Schiavo, 916 So.2d at 815; Wendland, 26 Cal. 4th at 529.

^{200.} See In re Martin, 538 N.W.2d at 402-03; see also Wendland, 26 Cal. 4th at 524. Although Mrs. Schiavo's family claimed she was not PVS, but responsive, in the end the medical examiner confirmed that she was PVS. See In re Schiavo, 916 So.2d at 815; see generally, Jon R. Thogmartin, Sixth Circuit Medical Examiner, Autopsy Report, case 5050439, June 13, 2005, http://www6.miami.edu/ethics/schiavo/pdf_files/061505-autopsy.pdf (noting that "PVS is a clinical diagnosis arrived at through physical examination of living patients. Postmortem correlations to PVS with reported pathologic findings have been reported in the literature, but the findings vary with the etiology of the adverse neurological event.").

^{201.} See Gilmore, 527 S.E.2d at 430 (noting that Governor James S. Gilmore III, filed a bill of complaint seeking a permanent injunction prohibiting Finn's nursing home from withdrawing nourishment); see also Bush v. Schiavo, 885 So. 2d 321, 328 (Fla. 2008) (noting that after Schiavo's feeding tube was removed Governor Jeb Bush issued an executive order to stay the withholding of nourishment from Schiavo and the tube was reinserted).

^{202.} See, e.g., Fla. Stat. § 765.105 (noting that the Florida law does allow challenges to a surrogate's decision).

^{203.} See generally Annas, supra note 142, at 49 (arguing that the government overstepped bounds).

Advance directives are not without failings and have not lived up to their potential. Advance directives generally fall into one of two categories: an instruction directive or an appointment (or surrogate) directive. Regardless of type, these directives are not without shortcomings. An instruction directive could be challenged on several grounds, including ambiguity, vagueness, or inapplicability to the situation at hand. Living wills in particular have other failings, and their narrow application may be less effective than an appointment directive. The same may not necessarily be said of a surrogate directive.

Professor Annas wrote about the importance of a surrogate decision-maker:

No one should have his or her private life subjected to such intense and vicious public scrutiny for trying to do what his or her spouse would have wanted. There is no escaping the fact that when we are unable to make medical decisions for ourselves, someone else will have to make them for us. It will be easier on all our friends and family if we each designate a decision-maker ourselves. Decisionmaking at the end of life will never be easy and should never be formulaic; furthermore, families that were dysfunctional when one member was healthy are not usually healed when the member becomes incapacitated. But we should nonetheless maintain the presumption that close family members are the

^{204.} See Susan E. Hickman et al., Hope for the Future: Achieving the Original Intent of Advance Directives, Special Report/Improving End of Life Care: Why Has it Been So Difficult, Hastings CENTER REPORT S26 (Nov.-Dec. 2005).

^{205.} *Id.* An instruction directive is just that: a directive that gives instructions on what to do under certain circumstances. *Id.* An appointment directive appoints a surrogate to make health care decisions. *Id.* The two documents may be combined into one directive. *Id.* (discussing various types of directives).

^{206.} See, e.g., The President's Council on Bioethics, Taking Care: Ethical Caregiving in Our Aging Society, U.S. GOV'T PRINTING OFFICE, Washington, D.C. (Sept. 2005), http://bioethics.gov/reports/taking_care/taking_care.pdf (discussing common misconceptions of and serious problems with living wills); see also Angela Fagerlin & Carl E. Schneider, Enough: The Failure of the Living Will, HASTINGS CENTER REPORT 34, no. 2 at 30 (2004); COLBY, supra note 6, at 142 (noting that "[a] survey of doctors published in the summer of 2004 in the Archives of Internal Medicine found that 65[%] of doctors said they would not follow a living will if the instructions conflicted with the doctor's own views about the patient's prognosis or expected quality of life.") citing S.B. Hardin & Y.A. Yusufaly, Difficult End-of-Life Treatment Decisions: Do Other Factors Trump Advance Directives? 164 ARCH. OF INTERN. MED. 1531-33 (2004) (noting a study of physician's compliance with hypothetical advance directives); Hickman, supra note 204.

^{207.} Instruction directives, especially living wills, have triggers or "medical preconditions" that must be met before the document is effective. If the person does not end up in a condition covered by the directive, it would not become operative. *See, e.g.*, Fla. Stat. § 765.302 (discussing terminal conditions, end-stage conditions, and persistent vegetative states). It is virtually impossible to know what the future holds, and it is not possible to specify all conditions, injuries or illnesses which might befall someone; therefore, as a result the directive may be more of a general statement of directions rather than providing detailed guidance.

^{208.} See, e.g., Fagerlin & Schneider, supra note 206 and accompanying text; see also COLBY, supra note 6.

^{209.} See MEISEL & CERMINARA, supra note 4, § 7.01(B)(4).

best decision-makers and insist that end-of-life decisionmaking stay within the family, and out of the hands of politicians. Courts must remain available, but used only in cases, like the case of Terri Schiavo, where conflicts are not reconcilable. ²¹⁰

A surrogate appointment may have wider application than an instruction directive. By appointing a trusted surrogate and empowering that surrogate to have broad decision-making authority, the problem with gaps from medical preconditions that arise in an instruction directive may be avoided. That does not mean that family or others would never question a surrogate's decision. It would be harder, however, to support actions like those in *Finn* and *Schiavo*, in a situation in which the patient appointed someone to make the health care decisions. If the person left instructions and the person's condition fell squarely within those instructions, outside political intervention in the matter would be unlikely. There is no perfect solution, and there is always a chance of a repeat of litigation and legislative actions.

VIII. CONCLUSION

No one knows what the future holds. Some may prefer to be the center of a storm of controversy while others may prefer to go quietly and unnoticed by anyone other than an immediate circle of family, friends, and health care providers. Despite any shortcomings of advance directives, they appear to be the best chance to remove, or at least minimize, disagreements, court challenges, and politics from dying. Too few people execute any kind of advance directive to make them an effective deterrent; but the mere existence of an advance directive may minimize the intrusion into the dying process. Until a new paradigm for decision-making about dying is adopted, the use of advance directives takes on a new importance.

^{210.} See Annas, supra note 142, at 79.

^{211.} See MEISEL & CERMINARA, supra note 4, at § 7.01(B).

^{212.} See id. at § 7.01(B)(4).

^{213.} See ag., id. at § 7.01(C)(2).

^{214.} See, e.g., In re Schiavo, 916 So.2d 814 (Fla. App. 2nd Dist. 2005); Gilmore v. Finn, 527 S.E.2d 426 (Va. 2000).

^{215.} See Annas, supra note 142, at 79. Note that Florida's "Terri's Law" only applied to individuals without advance directives. See supra note 160.

^{216.} See id.

^{217.} See id.

^{218.} See Hickman et al., supra note 204, at S26.