Paradox and Pandora's Box: The Tragedy of Current Right-to-Die Jurisprudence

Cathaleen A. Roach
DePaul University College of Law

Follow this and additional works at: https://repository.law.umich.edu/mjlr
Part of the Constitutional Law Commons, Health Law and Policy Commons, and the Jurisprudence Commons

Recommended Citation
Available at: https://repository.law.umich.edu/mjlr/vol25/iss1/5
PARADOX AND PANDORA'S BOX:
THE TRAGEDY OF CURRENT
RIGHT-TO-DIE JURISPRUDENCE

Cathaleen A. Roach*

Sadly, private tragedy creates many an unwitting public figure, as demonstrated by the current "right-to-die" or "death-with-dignity" debate. Increasingly, this debate thrusts private grief into a public forum. Nancy Cruzan, for example, became an American household name after the national news media focused attention on her right-to-die case, which culminated in June 1990 with the United States Supreme Court decision in *Cruzan v. Director, Missouri Department of Health.*

The Court, however has not, nor could it have, resolved this national debate in a single right-to-die decision. Less than six months after *Cruzan,* the nation was once again riveted by two new cases: *In re Conservatorship of Wanglie* (heralded by some as a "reverse Cruzan" case because in *Wanglie* the hospital sought to terminate life support over the vociferous objections of the patient's family) and *In re Busalacchi,* a Missouri case which is hauntingly resonant of Justice Stevens's dissenting opinion in *Cruzan.*

---

* Instructor, DePaul University College of Law. A.B., Indiana University; J.D., University of Illinois. I gratefully acknowledge the tireless efforts of my research assistants Julie Sullivan and Kathy Mastoris.

2. The Court recognized that it may resolve only the issues and facts of the case or controversy before it and was thus precluded from addressing all of the issues involved in this complex debate. See *Cruzan,* 110 S. Ct. at 2851.
4. See Susan Tifft, *Life and Death After Cruzan,* TIME, Jan. 21, 1991, at 67 ("The Wanglie case is the reverse image of the controversy that surrounded Nancy Cruzan . . . ."); *At Odds with Family, Hospital Seeks to End Life,* CHI. TRIB., Jan. 10, 1991, § 1, at 4 ("This is the opposite of Cruzan,' said Arthur Caplan, director of the Center for Biomedical Ethics at the University of Minnesota . . . ."). The family members vigorously asserted that they and Helga Wanglie believed that only God should make such a determination and that Helga told them she would not want anything done to shorten her life in the event of her future incapacity. See Robert Steinbrook, *Hospital or Family: Who Decides the Right to Die?,* L.A. TIMES, Feb. 17, 1991, at A1; Tifft, supra, at 67.
6. See 110 S. Ct. at 290–91 (Stevens, J., dissenting) (discussing the problems of patients who have never been competent to express their wishes).
Christine Busalacchi became two new public figures, whose private tragedies were destined to play themselves out in public and judicial forums. Courts and legislatures across the country are confronting the legal parameters of an individual’s right to die with dignity, as well as the rights of an individual’s family members in that decision-making process.

It is apparent, therefore, that *Cruzan* has not settled the question of the right to die. Instead, according to some, it represents the opening of a “Pandora’s box,” filled with pernicious and troubling legal, medical, and moral issues, and further exposes the paradox and complexity of the debate. Christine Busalacchi’s father expresses that paradox with his lament that although those who know his daughter best know exactly what she would want, the ultimate decision will be made by those who never knew her. It is also paradoxical that Christine Busalacchi, through her father, seeks transfer to Minnesota so that she might be evaluated and possibly allowed to die, while Helga Wanglie’s family struggled in Minnesota in order that Helga Wanglie might live.

Following *Cruzan*, many individuals in this country remain unprotected from the tragedy that befell Nancy Cruzan and her family. In her concurring opinion, Justice O’Connor directs the nation back to “the ‘laboratory’ of the States.” As I discuss below, however, the majority opinion in *Cruzan* sends these cases back to the states without providing a constitutional floor for physically or mentally incompetent individuals below which all are protected and above which states may not interfere absent a compelling state interest.

---

9. Matchan, *supra* note 8, at 1. It is also ironic that Christine Busalacchi is cared for in the same hospital which housed Nancy Cruzan, *id.*, and that she seeks transfer to Helga Wanglie’s hospital in Minnesota. *See infra* note 113 and accompanying text.
10. *See infra* notes 74–94 and accompanying text.
11. 110 S. Ct. at 2859 (O’Connor, J., concurring).
12. The Supreme Court in *Cruzan* stated in dicta that there may be constitutional protection for the right to death with dignity for incompetent individuals who have created, during their previous competency, sufficient evidence of their personal wishes as to the removal of life-support systems. 110 S. Ct. at 2852, 2854–55; *see also infra* notes 40–42 and accompanying text. There is tremendous disparity between the states as to what types of advance health-care directives are recognized as legally sufficient. *See infra* notes 161–63. The majority opinion by Justice
Moreover, for patients who have not previously provided sufficient evidence of their own wishes regarding whether or not to continue life-prolonging treatment, *Cruzan* provides no constitutional protection. The Court thus leaves a large number of Americans virtually unprotected because these persons will not or cannot act preemptively to avoid a *Cruzan*-like tragedy.

In addition to leaving large numbers of persons unprotected, simply directing the nation to "the laboratory of the states" is inadequate because the existing state legislative piecemeal approach has resulted in a confusing smorgasbord of separate legislation for advance health-care directives, including living wills and proxy appointments for health care. This patchwork response creates inequity, confusion, and

Rehnquist provided that states may require the heightened evidentiary standard of clear and convincing evidence of a patient's wishes, and they may choose to defer only to the patient's expressed wishes and not repose substituted judgment with family members. 110 S. Ct. at 2855. Thus, individual states appear to be free to provide greater protection than that discussed in *Cruzan*, but they are not constitutionally compelled to do so.

13. Throughout this article the term "advance health-care directives" will refer to all current statutory provisions which allow an individual, while competent, to authorize in advance the course of her medical treatment in the event she later becomes ill and is incompetent to decide at that time. As such, advance health-care directives encompass living-will directives, proxy appointments for health care, and durable power of attorney appointments for health care.

14. A "living will" is a previously executed document which directs physicians to withhold or withdraw specific types of medical treatment in the event of a "terminal illness." States vary on when "terminal illness" ensues and what types of medical treatment may be withdrawn or withheld. See generally Marguerite A. Chapman, *The Uniform Rights of the Terminally Ill Act: Too Little, Too Late?*, 42 ARK. L. REV. 319, 374-84 (1989).

15. In the health-care context, proxy appointments and durable power of attorney directives identify an agent who is expressly authorized by the patient to make decisions on the patient's behalf regarding health care and the withdrawal of medical treatment in the event of his later incompetency. Generally, proxy appointment provisions may be found in a state's Living Will or Natural Death Act, and durable power of attorney statutes are listed elsewhere in a state's Probate Code. There is tremendous variation among the states as to whether such directives are recognized at all, and if so, under what conditions. See infra notes 166-86 and accompanying text.

16. Such a smorgasbord creates inequity because the 50 states and the District of Columbia vary tremendously in the type of protection they provide their citizens. See infra notes 166-86 and accompanying text. Moreover, only 12 states recognize the enforceability of advance health-care directives executed in a sister state. See infra note 174 and accompanying text. Thus, a citizen is not guaranteed that a lawfully executed advance health-care directive will be enforceable should she move to a new state. See Larry Tye, *Varying Laws on Life, Death Spur Quests for Best State*, BOSTON GLOBE, Jan. 6, 1991, at 1, 72 ("'Now, basic rights change when you move across state borders.'" (quoting Ronald Collins, visiting professor of law at Catholic University in Washington, D.C.).
forum shopping.\textsuperscript{17} In short, the "state laboratories" have failed to provide an effective or uniform framework for the American people. The Court's decision to simply return the problem to the states will only worsen the national crisis.

Part I of this Article examines the trilogy of recent right-to-die cases and contrasts the results of those cases with recent national opinion polls and statistical surveys of the issue. Part II examines federal and state legislative responses to the debate. It suggests that both the courts and legislatures are out of sync with an emerging national consensus on the death-with-dignity debate. In fact, the federal legislative response may only exacerbate the problem. Instead of creating new rights, it feeds individuals into the existing state network, which is a quagmire of confusing and inequitable statutory provisions. Part III examines some recent state legislation addressing the special problem of patients who have not created advance health-care directives. Finally, Part IV proposes a new legislative framework—the "Uniform Patient-Family Determination Rights Act"—which would coordinate the goals of the recently enacted federal initiative with a uniform state model framework. This new legislative framework advances three national objectives—"prevention," "uniformity," and "patient-family determination rights"—which must be advanced in order to deal more effectively with this national problem.

I. THE TRAGEDY AND THE TRILOGY

Three recent cases, \textit{Cruzan v. Director, Missouri Department of Health},\textsuperscript{18} \textit{In re Conservatorship of Wanglie},\textsuperscript{19} and \textit{In re Busalacchi},\textsuperscript{20} illustrate the overwhelmingly personal nature

\begin{itemize}
\item \textsuperscript{17} Tye, \textit{supra} note 16, at 1. For example, in \textit{In re Busalacchi}, No. 59582, 1991 Mo. App. LEXIS 315, 1991 WL 26851 (Mar. 5, 1991), the court stated:

The issue . . . is whether a guardian properly discharges his duties when he attempts to move his ward from the jurisdiction of the court for the ostensible reason of avoiding litigation in Missouri where the decision to remove the feeding tube from his ward may be subject to heightened legal scrutiny . . . . Specifically, we will not permit [a] guardian to forum shop in an effort to control whether Christine lives or dies.

\item \textsuperscript{18} 110 S. Ct. 2841 (1990).
\item \textsuperscript{19} No. PX-91-283 (Minn. Dist. Ct. June 28, 1991).
\end{itemize}
of the decision to withdraw or withhold medical treatment, for both the individual patient and her family. Questions no less imposing than "what is life" and "what is death" must be answered before a competent individual or his family can determine when life support should cease. In addition to the deeply personal nature of this inquiry, *Cruzan*, *Wanglie* and *Busalacchi* tangibly illustrate the need for a coordinated national prevention effort, as well as the need to create uniform rules in order to recognize individual and family rights. I will argue that the proposed legislative framework discussed in Part IV would likely have kept all three of these cases out of the courts. As I argue in Part I.D. below, national polls and statistics demonstrate a need for such a framework.

A. *Cruzan v. Director, Missouri Department of Health*

In June 1990, the United States Supreme Court for the first time squarely addressed the issue of the constitutional right to die in *Cruzan v. Director, Missouri Department of Health.*

At the age of thirty-three, after a tragic automobile accident, Nancy Cruzan became a patient in Missouri Rehabilitation Center, a state hospital in Missouri, where she was diagnosed as being in a persistent vegetative state. Before paramedics arrived at the scene of the accident, Cruzan's brain was deprived of oxygen for approximately twelve to fourteen minutes which resulted in severe and permanent brain damage requiring surgical implementation of a gastrostomy.

---

22. *Id.* at 2845. As defined in *Cruzan*, a persistent vegetative state:

"describes a body which is functioning entirely in terms of its internal controls. It maintains temperature. It maintains heart beat and pulmonary ventilation. It maintains digestive activity. It maintains reflex activity of muscles and nerves for low level conditioned responses. But there is no behavioral evidence of either self-awareness or awareness of the surroundings in a learned manner."

tube to provide her with food and hydration. Doctors did not expect her to regain cognitive awareness. Yet by some estimates, medical technology would have been able to keep her in this suspended state for as long as thirty years. According to her parents and close friends, Nancy Cruzan had indicated before her accident that she would not want to live on artificial life-support systems. Ultimately, her parents requested that her gastrostomy tube be removed; without it she was not expected to live. The hospital refused, and the parents initiated legal action.

The Missouri Supreme Court, sitting en banc, ultimately reversed the trial court's order granting the Cruzans' request. Thereafter, the United States Supreme Court granted certiorari "to consider the question of whether Cruzan has a right under the United States Constitution which would require the hospital to withdraw life-sustaining treatment from her under these circumstances."

The Court, in a 5-4 decision, held that the state of Missouri could require that there be clear and convincing evidence of an incompetent patient's previously expressed wishes before granting authority to terminate life support. In other words, a state is not constitutionally compelled to effectuate an individual's expressed wishes that medical treatment be withdrawn or withheld absent clear and convincing evidence

23. Cruzan, 110 S. Ct. at 2845.
24. Id. at 2846.
25. Id. at 2845 n.1; see also Norman L. Cantor, The Permanently Unconscious Patient, Non-Feeding and Euthanasia, 15 AM. J.L. & MED. 381, 398 (1989).
27. Id. at 2846.
29. Cruzan, 110 S. Ct. at 2846.
30. Throughout this article, the term "incompetent" refers exclusively to those patients who are in an extended coma-like or persistent vegetative state. See supra note 22.
32. It appears likely that, following Cruzan, "medical treatment" includes the removal of artificial feeding and hydration. The Rehnquist majority opinion in dicta included artificial feeding and hydration within the "medical treatment" which may be withdrawn or withheld. Id. at 2852 ("[F]or purposes of this case, we assume that the United States Constitution would grant a competent person a constitutionally protected right to refuse lifesaving hydration and nutrition."). Justice O'Connor, however, expressly included artificial feeding and hydration. Id. at 2857 (O'Connor, J., concurring) ("Accordingly, the liberty guaranteed by the Due Process Clause must protect, if it protects anything, an individual's deeply personal decision to reject medical treatment, including the artificial delivery of food and water.").
of the same. Although states are free to effectuate an individual's previously expressed wishes (oral or written) by imposing a lesser standard than Missouri's clear and convincing evidentiary standard, or even by recognizing the right of an individual to expressly appoint a proxy to make that health-care decision for her in the event of her incompetency, the states are not constitutionally required to do so.

The Court affirmed the Missouri Supreme Court's decision to remand the case to the trial court for a new evidentiary hearing which would comport with the clear and convincing evidentiary standard. Thereafter, at the trial court, Judge Teel received additional testimony from at least three new witnesses who were drawn out by the publicity of the case. These witnesses, all co-workers, testified as to Cruzan's earlier statements to them, while she was competent, that she would not want to be kept alive in a vegetable-like condition. Ultimately, Judge Teel ruled that the petitioners had met their evidentiary burden and granted the Cruzan family's petition to remove the gastrostomy tube. Twelve days later, Nancy Cruzan died. From the date of her automobile accident until her death in December 1990, her journey had taken seven years.

The Supreme Court's decision—the first right-to-die determination coming from the United States Supreme Court—is notable for several reasons, including what the majority opinion did not say. In his majority opinion, Justice Rehnquist "presumed" for the purposes of the opinion that a competent

33. *Id.* at 2854-56.
34. *Id.* at 2856. Following *Cruzan* it is unclear, but likely, that express health-care proxies may also be protected. The majority opinion expressly declined to address the issue of whether a state may be constitutionally required to recognize a decision made by a surrogate who was previously identified by the patient while competent. *Id.* at 2856 n.12. But Justice O'Connor noted that the decision "does not preclude a future determination that the Constitution requires the States to implement the decisions of a patient's duly appointed surrogate." *Id.* at 2858 (O'Connor, J., concurring). Thus, there may be a constitutionally protected right to expressly appoint a proxy for health-care decisions; however, the Court has not yet declared so.
35. *Id.* at 2856.
41. Justice Rehnquist wrote the majority opinion in which Justices White, O'Connor, Scalia, and Kennedy joined. *Id.* at 2844. Justices O'Connor and Scalia also wrote separate concurring opinions. *Id.* at 2856, 2859.
individual has a constitutional right to die. This right, he noted, is grounded in the Fourteenth Amendment’s Due Process Clause and liberty interests and not, as some state courts have held, in the constitutionally recognized right of privacy.\footnote{42} Nancy Cruzan, however, was no longer competent; thus, Justice Rehnquist’s “presumption” as to competent individuals did not apply strictly to her case. Justice Rehnquist also assumed “for purposes of this case” that a constitutionally protected right to withdraw medical treatment also includes the right to withdraw or withhold artificial feeding and hydration.\footnote{43} Thus, the majority did not expressly hold that a competent individual has a right to terminate medical treatment or that medical treatment includes artificial feeding and hydration. Justice O’Connor, however, in her concurring opinion, did expressly include artificial delivery of food and hydration within the constitutionally protected right to withdraw medical treatment.\footnote{44}

Finally, the majority opinion expressly declined to address the question of whether express proxy appointments for health-care decisions must be constitutionally recognized.\footnote{45} A health-care proxy appointment is broader than a living will because it provides authority for a previously selected party to act on behalf of the now-incompetent individual in all specified health-care decisions.\footnote{46} Strictly speaking, the Court did not have to reach the issue because Nancy Cruzan never executed an express advance proxy appointment for health-care decisions prior to her automobile accident. Justice O’Connor’s concurring opinion, however, expressly left the issue open and stated that an individual’s constitutionally protected right to refuse medical treatment may include the right to appoint a named proxy to make that decision in the event an individual becomes incompetent in the future.\footnote{47}

\footnote{42} Id. at 2851 n.7. 
\footnote{43} Id. at 2852. 
\footnote{44} Id. at 2857 (O’Connor, J., concurring). 
\footnote{45} Id. at 2856 n.12. But the majority did consider and expressly reject the Cruzan family’s argument that they had a constitutional right to step in on behalf of Nancy and make the decision on a substituted judgment basis without a previously executed written proxy directive. Id. at 2855. 
\footnote{46} See supra notes 14–15. 
\footnote{47} Cruzan, 110 S. Ct. at 2858–59 (O’Connor, J., concurring). Justice O’Connor also noted:

[Such a procedure] may be a valuable additional safeguard of the patient’s interest in directing his [own] medical care. Moreover, as patients are likely to
Because Nancy Cruzan left neither a written living will nor a health-care proxy appointment before her automobile accident left her incompetent, she left no written record of what her wishes would be in the event she became incompetent. Consequently, her parents, as her co-guardians, argued that they should be able to substitute their judgment for Nancy's judgment. Almost without discussion, the majority opinion rejected that argument. There is no constitutionally compelled requirement that a state recognize a family's right to substitute its judgment where there is no clear and convincing evidence that their views reflect the views of the patient. The majority opinion summarily declined to extend the protected and favored treatment of family relationships recognized in *Michael H. v. Gerald D.* and *Parham v. J.R.* to include a constitutionally protected right belonging to Nancy Cruzan or to her family to act on her behalf in the absence of an express proxy directive.

According to the majority opinion, because there can be no "automatic assurance" that the views of the family members will necessarily be the same as the patient's would have been, the state may choose to defer only to the patient's express wishes rather than repose the judgment with a spouse or other family member. The Due Process Clause does not require "the State to repose judgment on these matters with anyone but the patient herself."

In short, the *Cruzan* Court soundly, if summarily, rejected constitutional protection for "patient-family rights" where an individual leaves no express health-care proxy appointment. *Cruzan* implicates patient-family rights on two levels select a family member as a surrogate, giving effect to a proxy's decisions may also protect the "freedom of personal choice in matters of . . . family life."

*Id.* at 2858 (citation omitted).
48. *Id.* at 2855–56.
49. *Id.*
50. 491 U.S. 110, 130 (1989) (holding that each state may establish constitutionally favored treatment for traditional family relationships through its paternity laws).
51. 442 U.S. 584, 601–04 (1979) (upholding a state scheme in which parents make certain decisions for mentally ill minors).
52. *Cruzan*, 110 S. Ct. at 2855.
53. *Id.* at 2856.
54. *Id.* at 2855.
55. "Patient-family rights" refers to the right of an incompetent individual to have a family member or surrogate make a decision on her behalf, as well as the independent right that a family member may have to act on behalf of the incompetent patient.
and suggests that neither level of patient-family rights is constitutionally protected. First, even if he has left no previous directive, there is the right of the individual himself to have his own spouse or other family member step in and make this judgment for him when he becomes incompetent. Second, there is also the family's right to make that judgment on the incompetent's behalf, much like the recognized right of a parent to act on behalf of a minor.\textsuperscript{56} For the incompetent patient who has left no express proxy appointment, however, these rights are not protected under \textit{Cruzan}.

Although the Court's majority summarily rejected a generic concept of patient-family rights when there is \textit{no previous written directive}, the concept of a generic set of "family rights" was discussed \textit{vis-à-vis express} proxy appointments. Justice O'Connor noted in her concurring opinion that because patients are likely to select a family member as a surrogate, "giving effect to [the] proxy's decisions may also protect the 'freedom of personal choice in matters of . . . family life.'\textsuperscript{57} Thus, arguably, the concurring opinion would protect those patient-family rights that are triggered by express proxy appointments. An incompetent who has not had the foresight or the opportunity to execute an express proxy appointment, however, receives far less protection for her freedom of personal choice in the matter of family life.

None of the majority or concurring opinions in \textit{Cruzan}, however, separately addressed an individual's right to have his family act on his behalf (absent a proxy appointment), and the distinct right of a family to substitute its judgment. The majority did not distinguish between the two rights and summarily rejected the family's "substituted judgment" argument,\textsuperscript{58} holding that a state could repose the decision-making


\textsuperscript{57.} \textit{Cruzan}, 110 S. Ct. at 2858 (O'Connor, J., concurring).

\textsuperscript{58.} The "substituted judgment" standard refers to those decisions made by proxies or members of the patient's family which essentially step into the shoes of the incompetent patient in an attempt to make the judgment that the patient herself would have made. See \textit{Developments in the Law—Medical Technology and the Law}, 103 HARV. L. REV. 1519, 1646–51 (1990) (defining the substituted judgment standard
authority solely in the patient. The majority never identified or discussed independently an incompetent individual's "right" to have a spouse or family member act on her behalf.

In light of national opinion polls and other statistical surveys suggesting that a great majority of Americans would choose to have their families make the decision in the event of their incapacity, such cursory treatment of the issue by the majority leaves serious "family rights" concerns, as well as individual autonomy rights concerns, inadequately addressed.

Finally, Justice Stevens in his dissent objected strongly to the majority's failure to extend a recognized constitutional


59. Cruzan, 110 S. Ct. at 2856.

60. See infra notes 139-43 and accompanying text.

61. As in the case of a parent acting for a minor, such family rights should run to family members acting on behalf of an incompetent patient who never executed an advance health-care directive, as well as to the incompetent himself. Many decry the erosion of the role of the family in this area:

[T]here has been an erosion of the role of the family in medical decision making. Because of advanced age, because of emotional strains and family life, because of the technological imperative that is a part of medicine, and because of the fear of legal action on the part of providers and health-care institutions, the family unit is no longer the source of decision making for incapacitated, critically ill persons.

135 CONG. REC. S13,571 (daily ed., Oct. 17, 1989) (remarks on Federal Patient Self-Determination Act by Father Dennis Brodeur, Senior Vice President-Stewardship at the St. Mary's Health Care System, St. Louis, Missouri); see also Nancy Gibbs, Love and Let Die, TIME, Mar. 19, 1990, at 62, 68 ("The [Cruzan] decision severs family ties . . . by substituting the moral and religious judgment of the state for that of the person." (quoting an amicus brief filed in Cruzan by the Evangelical Lutheran Church in America)). As one court stated:

Family members are best qualified to make substituted judgments for incompetent patients not only because of their peculiar grasp of the patient's approach to life, but also because of their special bonds with him or her. . . . It is they . . . who treat the patient as a person, rather than a symbol of a cause.

In re Jobes, 529 A.2d 434, 445 (N.J. 1987); see also supra note 56.

62. Similarly, there may be a separate right running to the individual which ensures that upon her incapacitation she may have her family act on her behalf even without an express directive.
right to refuse medical treatment to incompetent individuals who had never executed an advance health-care directive.\(^{63}\) Almost eerily anticipating the Christine Busalacchi case which was to generate much national attention only six months later,\(^{64}\) he noted that for such incompetent persons, express wishes as to their own treatment will be forever unknown because of their failure or inability to execute clear and convincing evidence of their own wishes for further medical treatment decision making.\(^{65}\) Justice Stevens decried what he believed amounted to a "waiver rationale" in the majority's opinion under which "the dying patient's best interests are put to one side and the entire inquiry is focused on her prior expressions of intent."\(^{66}\)

Following \textit{Cruzan}, therefore, a few generalizations may be made as to the current status of right-to-die jurisprudence:

1. A constitutional right probably exists for a competent person to refuse or withdraw medical treatment, and "medical treatment" may include food and hydration.\(^{67}\)
2. The \textit{Cruzan} opinions suggest, but do not hold, that a person's protected liberty interest also requires that a previously appointed proxy be recognized should the patient become incompetent.\(^{68}\)
3. Under certain circumstances, incompetents may have surrogates make life-support decisions for them; however, states are not constitutionally required to effectuate a surrogate's decision to withhold treatment absent clear and convincing evidence of the patient's own intent regarding the withdrawal or withholding of medical treatment expressly made while the patient was previously competent.\(^{69}\)
4. \textit{Cruzan} renders suspect those existing state statutes which do not recognize the validity of living wills, do

---

66. \textit{Id.} at 2882.
67. \textit{See supra} notes 41–44 and accompanying text.
68. \textit{See supra} notes 45–47 and accompanying text.
69. \textit{See supra} notes 30–34 and accompanying text.
not include artificial feeding and hydration within "medical treatment" that may be withdrawn, and do not recognize express health-care proxy appointments or durable power of attorney for health-care decisions.70

5. There is no constitutionally protected right running to the incompetent individual or, alternatively, to that individual's family to have a spouse or other family member substitute his or her judgment on behalf of an incompetent who has left no previously expressed evidence of his own intent regarding the withdrawal or withholding of medical treatment.71

6. States are free to provide more protection than the foregoing, but are not constitutionally compelled to do so.72

In sum, other than potentially protecting a competent person's right to effectuate the terms of a living will (including the removal of artificial feeding and hydration) or a health-care proxy appointment, *Cruzan*'s constitutional analysis does little else to upset today's existing judicial and legislative framework. Presumably, states are free to provide extra protections if they choose to do so, but they are not constitutionally compelled to do so. As such, protections are left to "the 'laboratory' of the States."73

B. A "Reverse Cruzan": *In re Conservatorship of Wanglie*

Eight months following the Court's decision in *Cruzan*, Helga Wanglie, an eighty-six year old woman,74 and her family captured the attention of the nation with what was really a reverse *Cruzan* case. Until July 1991, Helga Wanglie lay in a persistent vegetative state in Hennepin County Medical Center (HCMC) in Minneapolis, Minnesota.75 As in

---

70. See infra notes 161–63 and accompanying text (discussing states' living-will and proxy appointment statutes).
71. See supra notes 48–54 and accompanying text.
72. See supra notes 30–34 and accompanying text.
74. *Brain-Damaged Woman at Center of Lawsuit over Life-Support Dies*, N.Y. TIMES, July 6, 1991, at A8 (late ed.).
Nancy Cruzan's case, there was no medical evidence to suggest that Helga Wanglie's condition would improve. Like Nancy Cruzan's family, Helga Wanglie's family appeared to be in agreement as to what Helga Wanglie would decide to do about her respirator and feeding tubes if she were competent to decide. Also similar to the Cruzans' situation, the Wanglie family's wishes directly conflicted with the wishes of the hospital and staff treating Helga Wanglie, and as a result, the case ended up in court. In a reverse of Cruzan, however, Helga Wanglie's family did not want her life support system to be removed. In this case, it was the hospital and its County Board of Commissioners who petitioned for the appointment of a conservator to make treatment decisions on Helga

76. She was being kept alive by a respirator and artificial feeding through tubes. She had severe brain damage, was unresponsive and had been tied to life support systems at HCMC since early 1990. See Life in the Balance, N.Y. TIMES, Jan. 13, 1991, at E7.

77. See generally Steinbrook, supra note 4, at A40-41.

78. As a county hospital, HCMC is governed by elected county commissioners who act as the Board of Trustees. In January 1990, the Board voted 4-3 to petition a court to appoint a conservator for Helga Wanglie. See Lisa Belkin, As Family Protests, Hospital Seeks an End to Woman's Life Support, N.Y. TIMES, Jan. 10, 1991, at A1, D22.

79. Petition for Appointment of General Conservator, In re Conservatorship of Wanglie, No. PX-91-283 (Minn. Dist. Ct. June 28, 1991) (filed Feb. 7, 1991); see also Tifft, supra note 4, at 67. Authorities at HCMC failed to persuade Mr. Wanglie to transfer his wife to another health-care facility or, alternatively, to file for an injunction forcing them to continue care for Mrs. Wanglie. Mr. Wanglie refused, stating, "I want her to stay where she is, . . . and I don't think I need a court order to ask a hospital to provide medical care." See Belkin, supra note 78, at D22. The hospital had the option of pursuing a declaratory judgment action or petitioning the court to disqualify the family from taking part in Mrs. Wanglie's care and to appoint a conservator who would decide whether the respirator and artificial feeding tubes should be disconnected. The proposed conservator was Robert J. Sheran, retired Chief Justice of the Minnesota Supreme Court. Petition for Appointment of General Conservator at 4.

Because there was no possibility of recovery, HCMC officials asserted that despite the family's insistence on using the respirator, it was not in Helga Wanglie's best interests. See B.D. Colen, Fight over Life: Against Family Wishes, A Minnesota Hospital May Go to Court in an Effort to End Measures Keeping a Woman Alive by Artificial Means, NEWSDAY, Jan. 29, 1991, at 59, 65; Steinbrook, supra note 4, at A41. Additionally, they questioned whether the family's view reflected what the patient would really want. See Steinbrook, supra note 4, at A41.

In a letter to the Wanglie family, which explained the hospital's position, HCMC Director Michael Belzer wrote:

"We do not believe that we are obligated to provide care that cannot medically advance the patient's personal interests. Though Ms. Wanglie has a right to refuse any medical treatment, she does not have a right to oblige us to provide care to her that is medically inappropriate to her condition."

Colen, supra, at 65.
Wanglie's behalf, despite objections from Wanglie's family who insisted that they were certain what Helga would do if she were in fact competent to decide for herself.\textsuperscript{80}

Billed as a "pure ethics case,"\textsuperscript{81} all of Mrs. Wanglie's medical bills, estimated at between $800,000 and $1,000,000, were paid by Medicare and private insurers.\textsuperscript{82} Thus, neither the hospital nor the Wanglie family would bear the cost of continued medical treatment.

The Wanglie and Cruzan cases are disturbing because in each the court was asked to ignore the ostensibly clear and express wishes of both the patient and her family, and to allow the medical community to determine what was in her best interest. Although HCMC petitioned for a conservator to be appointed to determine independently Helga Wanglie's best interest, it was motivated by a conflict which developed when Wanglie's family refused to transfer Helga to a long-term care facility, and refused to petition a court to compel HCMC to continue medical treatment. The Center's Board of Trustees voted 4-3 to petition the court for a legal resolution of the issue, and filed the petition in probate court.\textsuperscript{83}

Dr. Michael Belzer, director of HCMC, defined the legal issue as whether a hospital staff may be compelled to render medical treatment and provide care that cannot medically advance the patient's personal interests,\textsuperscript{84} or which it believes to be "medically inappropriate".\textsuperscript{85} When framed as a

\begin{itemize}
\item \textsuperscript{80} See supra note 4.
\item \textsuperscript{81} At Odds with Family, Hospital Seeks to End Life, supra note 4, § 1, at 4.
\item \textsuperscript{82} See Wagner, supra note 3, at 3.
\item \textsuperscript{83} See Belkin, supra note 78, at D22. Commissioner Randy Johnson said, "As a strictly legal question, it . . . appears that no patient (or patient's family) has a unilateral right to compel the medical staff of any hospital to administer a treatment that the medical staff believes is futile and inappropriate." Case of Vegetative Woman Headed to Court, UPI, Jan. 10, 1991, available in LEXIS, Nexis Library, Wires File (quoting Johnson's prepared statement).
\item \textsuperscript{84} Telephone conversation with Dr. Michael Belzer, Director, HCMC (Jan. 26, 1991).
\item \textsuperscript{85} See Colen, supra note 79, at 65. But Dr. Henry Silverman, a physician and chairman of the Medical Ethics Committee at the University of Maryland Hospital, disagrees:

Deciding that a patient is in a persistent vegetative state represents a medical judgment, whereas the judgment that a patient in a persistent vegetative state should be allowed to die is a moral judgment and should not be recast as a medical judgment based on a misguided appeal to a futility argument.

Henry Silverman, Will Society Defend Our Right to Live?: Medical v. Moral, N.Y. Times, Jan. 31, 1991, at A22. Also very interesting is that pursuant to the passage of the Illinois Health Care Surrogate Act, see infra notes 224–41 and accompanying
purely medical issue, the hospital's argument is compelling. The situation has been likened to one where a family of a patient dying of cancer seeks to compel the treating physician to provide antibiotics, or to perform an appendectomy—both of which requests could be denied by the physician as futile and not in the patient's best interests. Disturbing evidentiary issues aside, Helga Wanglie's family insisted that when she was still competent Helga had stated that she would not wish her life support system to be withdrawn. Consequently, her family believed that they should not be required to get a court order compelling treatment, or alternatively to transfer Wanglie to another health-care facility that would continue to treat her.

On June 28, 1991, a Minnesota County probate judge rejected the hospital's petition and retained Helga Wanglie's husband as her conservator. The judge ruled that decisions of life and death should be left to competent family members, and rejected the argument that Wanglie's husband was incompetent to serve as her guardian. As her husband, he

---

text, the Illinois General Assembly expressly amended the proposed legislation to exclude treatment considered "futile" from the definition of medical treatment that could be withdrawn. Compare S. 1092, 87th Ill. G.A. § 10 (1991–92) (including "futile" treatment within the definition of "life-sustaining treatment" that could be withdrawn) with Health Care Surrogate Act, Pub. Act 87-749, § 10, 1991 Ill. Legis. Serv. 3507, 3509 (West) (to be codified at ILL. ANN. STAT. ch. 110 1/2, para. 851-10) (excluding futile treatment from the definition).

86. Dr. Stanley Reiser, Director of the Program on Humanities and Technology in Health Care at the University of Texas Medical School in Houston, used the analogy of a patient "who has cancer and whose family demands that he be given antibiotics or have his appendix removed." At Odds with Family, Hospital Seeks to End Life, supra note 4, § 1, at 4. According to Reiser, if that would not cure him, the doctors would not follow his family's wishes. Similarly, if a cancer patient was being treated with a drug that was not working, it would be stopped, despite family objections. Id.

87. Exclusive reliance on previously expressed wishes can put tremendous pressure on friends and family members and can create evidentiary disputes. For example, administrators at Wanglie's hospital stated that Wanglie's family never said anything to them regarding Helga's expressed wishes or statements until after hospital officials announced that they were taking the dispute to court. Steinbrook, supra note 4, at A41. And in the second, postremand evidentiary hearing before Judge Teel in Cruzan, three additional witnesses testified for the first time about Nancy Cruzan's expressed wishes. The witnesses had been drawn out by the publicity of the case. See supra note 36.

88. See supra note 4.
89. See Belkin, supra note 78, at D22.
91. Id.
was in the best position to determine his wife's interests.\textsuperscript{92} The hospital stated that it would not appeal,\textsuperscript{93} but its attorney correctly noted that although Wanglie's case is closed, the issue of care for patients who have no hope of surviving awaits a needed public policy solution.\textsuperscript{94} Because the issue in the Wanglie case was cast in terms of the competence or incompetence of her legal guardian, the real legal issues surrounding surrogate decision makers and death with dignity were never fully briefed nor resolved. Three days after the judge ruled, Mrs. Wanglie died of natural causes.\textsuperscript{95}

Although factually the reverse of each other, both \textit{Cruzan} and \textit{Wanglie} ultimately involve the same issue: Who should decide what is in a patient's best interests when that patient has left insufficient evidence of his own wishes about continued medical treatment? \textit{Cruzan} suggests that a protected liberty interest exists when a patient has left clear and convincing evidence, thus requiring a state to effectuate those wishes.\textsuperscript{96} But where an individual leaves no evidence of, or insufficient evidence of, her own wishes, who is to decide? \textit{Cruzan} states clearly that nothing in the United States Constitution compels a state to give the patient's family the right to decide by substituting its judgment for the patient's, even in the event of a conflict between the family and the medical personnel. If the family has no right to decide, does the medical staff therefore decide?\textsuperscript{97} Or should a court

\textsuperscript{92} The "best interest" standard refers to a decision made by a patient's proxy or family member on behalf of an incompetent patient in accordance with the patient's best interest, and not exclusively on the basis of the substituted judgment standard, discussed \textit{supra} note 58. For a discussion of the best interests standard, see \textit{Medical Technology and the Law, supra} note 58, at 1651–53.

\textsuperscript{93} \textit{See Wagner, supra} note 3, at 3.

\textsuperscript{94} \textit{Woman at Center of Right-to-Life Case Dies, UPI, July 5, 1991, available in LEXIS, Nexis Library, Wires File.}

\textsuperscript{95} \textit{Id.}

\textsuperscript{96} 110 S. Ct. at 2854–55.

\textsuperscript{97} A recent survey reported that about one-third of doctors surveyed "believed that their training and experience gave them greater authority than patients to make decisions about withholding heroic treatment." \textit{Medical Technology and the Law, supra} note 58, at 1658 n.115 (quoting Kent W. Davidson, et al., \textit{Physicians' Attitudes on Advance Directives}, 262 JAMA 2415, 2419 (1989)).

The New Jersey Supreme Court, however, in \textit{In re Quinlan}, 355 A.2d 647 (N.J.), \textit{cert. denied}, 429 U.S. 922 (1976), reversed the lower court decision which had stated: "It is a medical decision not a judicial one." \textit{Id.} at 671 (quoting 348 A.2d 801, 819 (N.J. Super. Ct. 1975)). Even the medical community will differ as to specific cases. \textit{See Gibbs, supra} note 61, at 65 (noting that in their amicus briefs to the United States Supreme Court in \textit{Cruzan}, the American Academy of Neurology sharply differed with the Association of American Physicians and Surgeons regarding the obligation of physicians to continue treatment of patients they cannot cure).
determine what would be in a patient's best interest?\textsuperscript{98} Should an insurance company or other third party be able to petition? If no one is allowed to decide, is a patient destined to linger for twenty or thirty years hooked up to machines providing medical treatment?

The paradox, of course, is that modern medical technology can "provide artificial hearts or kidneys, but not artificial judgment."\textsuperscript{99} Another observer has cast the paradox a little differently, suggesting that "'you can't have a natural death unless you do it the right way or fill out the right forms. That's the perversity of it."	extsuperscript{100} Finally, one physician has noted the ethical difficulty of spending $800,000 on a persistent vegetative state patient while 37 million Americans go uninsured or underinsured, and commented that in order to obtain maximum health care in this country perhaps one must fall into a persistent vegetative state.\textsuperscript{101} For Helga Wanglie, the paradox was not so academic. She failed to leave a written advance health-care directive. Her family asserted that she would wish to be sustained by medical treatment, yet her medical care providers insisted that providing treatment was futile and not in her personal interests. Her family argued vociferously that she would wish to be sustained by any means,\textsuperscript{102} yet from a constitutional perspective \textit{Cruzan} renders legally irrelevant their substituted judgment on her behalf.\textsuperscript{103}

\section*{C. The Case of Christine Busalacchi: Foreshadowed in Stevens's Cruzan Dissent}

Christine Busalacchi has lain in a persistent vegetative state\textsuperscript{104} in the Missouri Rehabilitation Center (the same

\textsuperscript{98} \textit{See, e.g., In re Spring}, 405 N.E.2d 115, 120 (Mass. 1980) (holding that the ultimate decision should lie with the court); Superintendent of Belchertown State Sch. v. Saikewicz, 370 N.E.2d 417, 431 (Mass. 1977) (same). \textit{But see Rhoden}, supra note 58 (arguing that nontreatment decisions made by courts are rarely justified by the legal standards they actually articulate).


\textsuperscript{100} De Benedictis, supra note 36, at 27 (quoting attorney Giles Scofield).

\textsuperscript{101} Judge Denies Request to Cut Life Support, \textit{CHI. TRIB.}, July 2, 1991, § 1, at 3 (final ed.).

\textsuperscript{102} See supra note 4.

\textsuperscript{103} See supra notes 48–59 and accompanying text.

\textsuperscript{104} Recently, the State contested whether Christine Busalacchi is in a persistent vegetative state. The State did not challenge her persistent vegetative state status until Peter Busalacchi sought to have his daughter transferred to Minnesota. \textit{In re
hospital in which Nancy Cruzan lay) for almost five years after she was injured in a tragic automobile accident at the age of seventeen. Like Nancy Cruzan, Christine has been sustained through artificial feeding and hydration through a gastrostomy tube. Also like Nancy Cruzan, Christine is not “dying.” Christine’s family has been told that Christine could remain as she is for twenty or thirty years.

Unlike Nancy Cruzan, however, whose housemate and co-workers testified regarding oral statements she made to them as a competent adult before her automobile accident, Christine Busalacchi was much younger when she had her auto accident and entered into her persistent vegetative state. Consequently, according to her father, Peter Busalacchi, she never executed any written form of health-care directive nor did she ever discuss what exactly she would wish to have happen in the event she moved into a permanently unconscious state. Even had she “discussed” the issue, because Christine Busalacchi was a minor at the time of her accident, courts would probably not find her competent to express binding wishes about her future medical treatment.

Christine Busalacchi thus represents exactly the type of case eerily presaged by Justice Stevens in his Cruzan dissent, issued only six months earlier:

The best interests of the incompetent individual who had never confronted the issue—or perhaps had been incompetent since birth—are entirely irrelevant and unprotected under the [Missouri Supreme Court’s Cruzan opinion.]

... [Today’s majority opinion] affords no protection to children, to young people who are victims of unexpected
accidents or illnesses, or to the countless thousands of elderly persons who either fail to decide, or fail to explain, how they want to be treated . . . . 112

Christine Busalacchi's father wants to transfer Christine from the Missouri Rehabilitation Center in Missouri to Minnesota so that she can be examined by Dr. Ronald Cranford, a neurologist at HCMC in Minneapolis. 113 Minnesota law gives physicians and family members more leeway in deciding to remove treatment from patients than does Missouri law. 114

Recently, a Missouri appellate court ruled that more evidence of what was in Christine Busalacchi's best interests was needed before she could be transferred from Missouri for medical evaluation in Minnesota. 115 The Missouri Supreme Court has decided to hear the appeal after the evidentiary hearing. 116 Thus, Peter Busalacchi is temporarily prohibited from moving his daughter to Minnesota. The appellate court did not hold, however, that Peter Busalacchi had any specific intent to transfer his daughter for the sole purpose of terminating her life support in Minnesota. 117 Instead, the court cast the issue as one of guardianship, and not the right to die. 118 It noted that there is now disagreement as to whether Christine is actually in a persistent vegetative state, and that

---


113. See Right to Die Ruling, NEWSDAY, Jan. 18, 1991, at 12. Although Dr. Cranford works at HCMC, should Christine Busalacchi arrive in Minneapolis, she would actually be examined by Cranford at St. Mary's Rehabilitation Center in Minneapolis. See Another Right to Die Case Poses New Questions, supra note 110, at A12.

114. In Minnesota, a probate court may empower a conservator to terminate lifesupport systems if such systems are no longer in the patient's best interests. See In re Conservatorship of Torres, 357 N.W.2d 332, 338–39 (Minn. 1984).


116. See Order, In re Busalacchi, No. 73677, 1991 Mo. LEXIS 107 (Oct. 16, 1991). The trial court has since completed its hearing, thus paving the way for a decision from the Missouri Supreme Court. See Father Backed in Right-to-Die Ruling, supra note 104.

117. Busalacchi, 1991 Mo. App. LEXIS 315, at *15–17, 1991 WL 26851, at *5-6 (instructing the trial court to reconsider the evidence relevant to the guardian's burden of showing a reasonable need to move the patient, including the guardian's motivation for the move). As noted in Judge Gerald Smith's dissenting opinion, the lower court found that Busalacchi's primary intent in making the move was not to disconnect the life support. Id. at *27, 1991 WL 26851, at *9 (Smith, J., dissenting).

118. Id. at *13, *16, 1991 WL 26851, at *4-5.
Busalacchi seeks a transfer in order to have her evaluated, with the possibility that at a later date he may choose to have the life support removed.\textsuperscript{119}

Somewhat incongruously, although the appellate court declined to find that Peter Busalacchi had any predetermined intent to withhold or withdraw life-prolonging treatment, it also stated: “Specifically, we will not permit [a] guardian to forum shop in an effort to control whether Christine lives or dies.”\textsuperscript{120} The appellate court’s underlying premise thus seems clear: Busalacchi must show that Christine was receiving insufficient care in Missouri before she can be moved. As such, the court’s ruling appears to be based upon some parochial notion that harm—and not proper medical evaluation and treatment—would befall her if she were allowed to transfer.\textsuperscript{121}

As the father and guardian of a brain-damaged woman kept alive by a feeding tube, Peter Busalacchi feels that it is his right, and not the state’s, to decide whether he can move his daughter to a state with a more lenient death-with-dignity law.\textsuperscript{122} As discussed, \textit{Cruzan} dictates that because she is in Missouri and because there is no clear and convincing evidence of Christine’s expressed intent, Christine Busalacchi has no constitutional right to have a guardian decide to withdraw treatment.\textsuperscript{123} Moreover, because she was a minor at the time of her accident, it is doubtful that Christine could ever have expressed the requisite intent.\textsuperscript{124} Notwithstanding all of the foregoing, under \textit{Cruzan} Missouri is not required to substitute Peter Busalacchi’s judgment on behalf of his daughter.

In addition to the question of patient-family rights, i.e., Peter Busalacchi’s rights and Christine’s right to have her father decide on her behalf, substantial questions arise when the exercise of such fundamental rights varies from state to state. Unlike competent persons, most incompetent persons have no constitutionally protected right to die. From a

\textsuperscript{119} Id. at *12, 1991 WL 26851, at *4.

\textsuperscript{120} Id. at *17, 1991 WL 26851, at *5.

\textsuperscript{121} As Judge Smith wrote in dissent: “Minnesota is not a medical or ethical wasteland.... There is a parochial arrogance in suggesting, as the State does, that only in Missouri can Christine’s medical, physical and legal well being be protected....” Id. at *29, 1991 WL 26851, at *10 (Smith, J., dissenting).


\textsuperscript{123} \textit{See supra} notes 30–34 and accompanying text.

constitutional perspective, they are forever precluded from exercising what Cruzan presumed was a protected liberty interest. Moreover, incompetent persons—as a class—receive substantially different treatment in the exercise of these protected rights depending solely upon the state in which they are located. Finally, at least one state (Missouri) has denied an incompetent’s petition to transfer out of that state in order to seek legal remedies elsewhere. On one level, this disparity may interfere with citizens’ rights to be free from irrational and arbitrary legislation. On another level, it triggers equal protection problems.

Cruzan presumes that a protected right to die exists for competent persons who have previously left clear and convincing evidence of their wishes. Thus, competent persons in fifty states are afforded this constitutional protection if they meet the threshold evidentiary requirement. Specifically, however, as a minor and an incompetent, Christine Busalacchi is forever precluded from exercising that same constitutionally protected right, and her family has no right to effectuate a decision on her behalf.

If the Court has elevated this right to some level of protection, then it is also disturbing that Christine—even as an incompetent—does not have the same level of protection in Missouri that she would have in Minnesota, and the appellate court has temporarily prohibited her from transferring there. In Cruzan, the United States Supreme Court dismissed in a footnote an equal protection claim raised by the Cruzans. However, that discussion was cursory and only dealt with disparate treatment received by incompetents vis-à-vis competent patients. The Court did not discuss any equal protection problems that result from disparate treatment of incompetents in one state vis-à-vis incompetents in another state. Thus, under current law, in Missouri, Christine Busalacchi will likely remain on life support for the indeterminate future, and neither she nor her family has any say in the matter, whereas in Minnesota, her wishes or her family’s wishes to terminate life support would be respected.

An analysis of the Busalacchi case within the framework of the majority opinion in Cruzan suggests that (questions

125. See id. at *18, 1991 Mo. App. LEXIS 315, at *18, 1991 WL 26851, at *6 (Stephan, J., concurring) (supporting a permanent injunction of Christine’s travel until her guardian’s decision to move her is in her best interests).
127. See id.
regarding her minority status aside) prior to her automobile accident, Christine Busalacchi should have either signed a living will or proxy directive, or contemplated her own death sufficiently to formally articulate her wishes to her father or some other party with sufficient specificity, clarity and detail to meet Missouri's "clear and convincing" evidentiary standard. Both of these options are obviously unrealistic. Yet her failure to have done either of these things by the time of her accident means that Christine Busalacchi may remain an unconscious patient in the Missouri Rehabilitation Center, suspended somewhere between life and death for the next twenty to thirty years or longer. Her father is prohibited from acting on her behalf because there is no clear and convincing evidence of her intent, and even if there were, her minority status at the time of the accident would render her wishes unenforceable. He is also temporarily prohibited from moving her out of Missouri and to another state.

From a constitutional perspective, the right to die is protected only for those few competent patients who leave behind clear and convincing evidence of their wishes. The vast majority of persons, however, fail to create clear and convincing evidence of their own wishes, or are incompetent to do so, and the laboratories of the states deal with these individuals and their families in a myriad of confusing and conflicting ways.

D. National Statistics

Christine Busalacchi's situation is not unique. There are an estimated 10,000 to 25,000 patients today in the United States who are diagnosed as persistent vegetative state patients.129

128. The Arizona Supreme Court has described this place as a "twilight zone." Rasmussen v. Fleming, 741 P.2d 674, 678 (Ariz. 1987) (en banc) ("Medical technology has effectively created a twilight zone of suspended animation where death commences while life, in some form, continues."); see also Cruzan, 110 S. Ct. at 2863 (Brennan, J., dissenting) (citing Rasmussen); Goodman, supra note 8, at 15 (using the term "high-tech 'twilight zone'").

Those numbers will likely increase as medical technology improves. Another 1.5 million have severe dementia, and an estimated 4 million Americans have some form of Alzheimer's disease.\textsuperscript{130} The American Medical Association recently estimated that 10,000 Americans "fall into irreversible comas each year and that approximately 70\% of all Americans will face a decision to refuse life-sustaining treatment for themselves or a family member at some point in their lives."\textsuperscript{131}

The demographics of dying in America are changing also. As America ages, more citizens are entering nursing homes.\textsuperscript{132} Further, they are dying in hospitals and nursing homes and not at home as in the past.\textsuperscript{133} In 1939, only 37\% of the population died in institutions. Now between 80\% and 85\% die in institutions.\textsuperscript{134} About 70\% of these deaths in nursing homes and hospitals involve some decision to apply, withhold, or withdraw medical treatment or technology,\textsuperscript{135} and involve scenarios in which patients are "likely to meet their end... 'in a sedated or comatose state; betubed nasally, abdominally and intravenously.'"\textsuperscript{136} This situation is far different from death as envisioned and experienced by the framers of the United States Constitution 200 years ago.

Not surprisingly, as the place of death changes and the medical technology of life and death changes, Americans are increasingly and overwhelmingly clear about their beliefs that they do not wish to end up in a position like Nancy Cruzan or

\textsuperscript{130} Clarence Page, \textit{Modern Medicine and 'Living Dead'—Another Tough Case}, CHI. TRIB., Jan. 3, 1990, § 1, at 11.


\textsuperscript{132} The number of people in U.S. nursing homes nearly tripled between 1964 and 1985. \textit{Nursing Homes Playing Larger Roles, Survey Finds}, CHI. TRIB., Feb. 28, 1991, § 1, at 17. One study projects that "of 2.2 million Americans who turned 65 last year, more than 900,000 of them, or 43\%, are expected to enter a nursing home at least once before they die." \textit{Id.}

\textsuperscript{133} \textit{See Cruzan v. Director, Mo. Dep't of Health,} 110 S. Ct. 2841, 2883 (1990) (Stevens, J., dissenting).

\textsuperscript{134} 136 CONG. REC. E943 (daily ed. Apr. 3, 1990) (statement of Rep. Levin); \textit{see also Cruzan,} 110 S. Ct. at 2882–83 (Stevens, J., dissenting). A President's Commission Report estimates that 80\% of all deaths in the United States occur in hospitals and long-term care institutions. \textit{President's Comm'n For the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Deciding to Forego Life-Sustaining Treatment} 17–18 (1983).

\textsuperscript{135} \textit{See} Belkin, \textit{supra} note 78, at A1.

\textsuperscript{136} \textit{Cruzan,} 110 S. Ct. at 2878 (Brennan, J., dissenting) (quoting Anne Fadiman, \textit{The Liberation of Lolly and Gronky}, LIFE, Dec. 1986, at 70, 72 (quoting medical ethicist Joseph Fletcher)).
Christine Busalacchi. Most people, estimated at between 75% and 85%, say they would not want to have their own lives maintained with artificial nutrition and hydration if they became permanently unconscious.

Other studies suggest that Americans are equally clear about who should make the decision in the event an individual patient becomes incompetent. According to public opinion polls shortly after the Cruzan decision, 95% would like to leave their own specific instructions regarding life support should they become incompetent. And two studies suggest that between 80% and 88% believe that when there are no expressed instructions "it should be up to the family to decide whether to end artificial life supports when an individual is in a coma with no hope of recovery." Beyond that, one poll reports that only 8% of Americans believe that doctors should make the decision on behalf of the patient, 1% believe the court should decide, and 0% believe that the state should make the determination. The Vatican and other religious organizations echo this national consensus. The

---

137. Medical Technology and the Law, supra note 58, at 1647 n.35.
140. Gibbs, supra note 61, at 64 (citing a Time/CNN poll by Yankelovich Clancy Schulman which found that 80% of Americans would prefer that such decisions were made by their families and doctors rather than lawmakers).
141. Matchan, supra note 8, at 10.
142. Id. This trend coincides with increasing scholarly support for family discretion in decision making for incapacitated patients. See, e.g., Rhoden, supra note 58, at 437; Daniel Gindes, Case Comment, Judicial Postponement of Death Recognition: The Tragic Case of Mary O'Connor, 15 AM. J.L. & MED. 301 (1989); see also Steven M. Richard, Note, Someone Make Up My Mind: The Troubling Right to Die Issues Presented by Incompetent Patients with No Prior Expression of a Treatment Preference, 64 NOTRE DAME L. REV. 394, 413–20 (1989) (arguing that a patient’s family and attending physicians should make treatment decisions).
143. Matchan, supra note 8, at 10.
145. See 135 CONG. REC. S13,571 (daily ed. Oct. 17, 1989) (remarks of Rabbi Rav. A. Soloff); see also American Jewish Congress Says ‘Patient Self-Determination Act’
medical community also increasingly accepts the idea of non-treatment, as evidenced in 1986 by the American Medical Association's statement that "it is ethical for physicians to discontinue life-prolonging treatment, including medical nutrition and hydration, from terminally ill and irreversibly comatose patients."\textsuperscript{146}

In short, recent polls and studies indicate that most Americans do not wish to prolong their own lives with artificial means of support when they are irretrievably comatose or terminally ill. Moreover, they exhibit a strong preference to have a family member make the decision for them in the event they cannot, or their wishes are unclear. Finally, the great majority of Americans will in fact be faced with this situation, as four out of five will actually die in hospitals and nursing homes, and about 70% of those deaths will involve some type of decision to continue or to withhold life support.

Shockingly, despite a clear national will to effectuate individual wishes, surveys show that only a very small minority of Americans, estimated at between 9%\textsuperscript{147} and 20%,\textsuperscript{148} have actually executed living wills or other advance directives. That low number may be on the rise as a direct result of the 	extit{Cruzan} decision and the publicity it has generated.\textsuperscript{149} If so, it is consistent with the emerging national consensus of Americans wishing to direct their own deaths with dignity by leaving express directives as to health-care decision making in the event of their own incompetency. Presumably, as this "information vacuum" is filled, more individuals will create advance directives.

There is also, however, quite an information vacuum at the treatment site. Although between 75% and 80% of Americans now die in institutions, only 4% of hospitals ask patients upon


\textsuperscript{146} Dresser, \textit{supra} note 58, at 436 (citing \textit{AMERICAN MEDICAL ASS'N, CURRENT OPINION OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS} 12–13 (1986)).


\textsuperscript{148} 	extit{Cruzan} v. Director, Mo. Dept' of Health, 110 S. Ct. 2841, 2875 n.21 (1990) (Brennan, J., dissenting).

\textsuperscript{149} Since the 	extit{Cruzan} ruling, right-to-die advocates have distributed between 500,000 and 750,000 living will forms on which patients can state their desires about life-sustaining treatment. \textit{See The Next Cruzan Case}, \textit{U.S. NEWS & WORLD REP.}, Jan. 14, 1991, at 8; De Benedictis, \textit{supra} note 36, at 26.
admission whether they have executed an advance directive. A high number of physicians have never heard of or are unfamiliar with their state's provisions on living wills or durable power of attorney for health care. Incredibly, there are also surveys which show that many physicians simply do not honor living-will directives unless they agree with the directive or unless the patient actually reaffirmed her living will during her hospitalization. Physicians also express very legitimate concern over the usefulness or accuracy of advance directives, which are often vague, outdated, or too general to be of use to the physician.

Given the information vacuum at both the patient level and the treatment site, the opportunity for erroneous decision making seems enormous. Moreover, the attendant costs for unenforced wishes to terminate treatment can be enormous. Cost estimates for the care of patients in persistent vegetative states are staggering: Christine Busalacchi's treatment alone costs $125,000 per year and a nationwide estimate, based


151. See Medical Technology and the Law, supra note 58, at 1659 n.122 (reporting that 85% of California physicians surveyed either had never heard of, or knew no details about, the state's living-will statute).

152. See 136 CONG. REC. E944 (statement of Rep. Levin) (citing a study which found that in Colorado, 23% of the physicians surveyed were unfamiliar with living wills and 74% were unfamiliar with durable power of attorney provisions, and in Arkansas, 38.4% were unfamiliar with state law on advance health-care directives).


155. De Benedictis, supra note 36, at 27 (describing living wills as too abstract and too ambiguous because they require an individual to anticipate types of treatment); Goodman, supra note 8, at 15 (exploring the practical problems of having to leave "behind a full record of your attitudes about the major bioethics questions of the day" in order to provide "clear and convincing evidence" of your own wishes); Shari Roan, Last Wishes, L.A. TIMES, July 17, 1990, at E1, E4; Rosenthal, supra note 144, at 9 (stating that the major flaw with living wills is that they are too general and are subject to interpretation). Precisely because many living-will directives are vague and unenforceable, two doctors have developed a new proposed detailed "Medical Directive" which is "treatment specific" and is designed to give physicians and hospital administration much more comprehensive information regarding exactly what a patient's wishes are vis-à-vis different types of incapacity. A patient checks 48 boxes specifying exactly what types of treatment she wants under specific circumstances. The "Medical Directive" is thus designed to give better information and will be more enforceable than existing directives. Emanuel & Emanuel, supra note 154, at 3290.

156. Matchan, supra note 8, at 10.
on a total number of 5000–10,000 persistent vegetative state patients in the United States, reaches $120 million to $1.2 billion annually. Those staggering figures do not even include the high costs of the first year of medical care after the original injury when the patient generally spends a great deal of time in a hospital’s intensive care unit. The total figure climbs to $3 billion annually if one uses the high-end figure of 25,000 persistent vegetative state patients nationwide. The potential waste—in human life as well as valuable health-care dollars—is inexcusable for those persistent vegetative state patients whose wishes to terminate treatment might otherwise have been ascertained accurately and efficiently prior to their illnesses with a nationally coordinated preventative program.

In short, the emerging national consensus must be used to persuade legislatures in “the state laboratories” to do two things. First, states must recognize the importance of prevention and uniformity. They must streamline and make uniform a system of advance health-care directives in order to effect an emerging national consensus that Americans want to make their own decisions as to withdrawal of their own life support. We must create uniformity among the states to increase fairness and decrease forum shopping. It is also essential to prevent wherever possible Cruzan-like tragedies by obtaining the best evidence possible of each patient’s wishes, before a crisis arises, by increasing the number of adults making advance health-care directives as well as increasing the enforceability and reliability of those directives. By making prevention and uniformity our new national objectives, we can reduce the national cost in human and financial resources where such costs could clearly be prevented.

Second, the states must extend more comprehensive protection by recognizing the existence of patient-family rights. They must acknowledge that a clear national consensus is emerging that people do not wish to end their lives like Nancy Cruzan or Christine Busalacchi and that their families

157. Shapiro, supra note 129, at 443.
158. Id.
159. For estimates of the number of persistent vegetative state patients, see supra note 129.
are the best decision makers when they have not previously executed an express directive.

II. LEGISLATIVE DISARRAY REQUIRES NEW INITIATIVES

A. Existing State Legislative Responses

The personal and public tragedies of Nancy Cruzan, Helga Wanglie, and Christine Busalacchi could have been prevented. Throughout the nation, most state legislatures simply have not responded effectively to the enormity of the problem and the enormity of the personal and public costs. Because America is aging and medical technology is improving, this problem clearly will not go away. Moreover, the country spends enormous amounts of money at the back-end of the problem. The current state legislative and judicial responses to the issue promote confusion, inequity, and disarray, as seen, for example, in Peter Busalacchi’s frustrated attempts to transfer his daughter from Missouri to Minnesota. Deference to “the state laboratories” as directed by Cruzan, however, should not mean that the current patchwork response to the problem is effective or even warranted. It is time to recognize the need for uniformity and the national plea for assistance.

Currently, forty-three states and the District of Columbia have some type of living-will legislation. Additionally, all

---

fifty states and the District of Columbia have durable power of attorney statutes, which provide for express proxy appointments for general decision-making authority after an individual is disabled. Finally, forty states have either durable power of attorney statutes which (more specifically) expressly provide for health-care decisions, or, alternatively, health-care proxy statutes which are included in the living-will legislation. Both of these types of advance directives have been
analyzed and discussed extensively. Current commentary favors the proxy appointment directive, as the living-will provisions have many limitations.

B. Problems with State Legislative Treatment of Living Wills

The Uniform Rights of the Terminally Ill Act (URTIA), promulgated in 1985, forms the basis for many of the individual states’ living-will statutes. Generally, the Act


Judicial treatment of the issue has also been thoroughly and extensively discussed. For an exhaustive discussion of case law treatment of the issue, see Peters, supra note 58; see also Cruzan v. Mo. Dep’t of Health, 110 S. Ct. 2841, 2888 n.21 (1990) (Stevens, J., dissenting) (providing an extensive compilation of judicial treatment of this issue).


Id. historical note, 9B U.L.A. 609.
provides that a competent adult may execute in writing health-care directives which would apply should he later become terminally ill, incompetent, and required to make a medical decision about whether to terminate life support.\(^{168}\)

The problems with the various states' living-will provisions, however, are legion. First and foremost, they do not reach the majority of Americans who have not yet executed formal living wills. The URTIA living-will provisions and similar statutes only apply to those individuals who have prepared formal living wills prior to their subsequent incompetence, which is estimated to be only 9–20% of Americans.\(^{169}\) That means 80–91% of Americans are virtually unprotected by living-will legislation.

Executing a living will, however, will not solve every situation. Living-will statutes apply only to adults and previously competent individuals,\(^{170}\) and they generally apply only to "terminally ill" patients for whom death is "imminent,"\(^{171}\) and thus, by definition, do not reach persistent vegetative state patients like Cruzan, Busalacchi, and Wanglie. Further, state statutes often expressly exclude artificial provision of food and hydration from the definition of medical treatment which may be withdrawn\(^{172}\) even if such wishes are clearly and convincingly expressed.\(^{173}\) Cruzan, Busalacchi, and Wanglie all received medical treatment by forced tube feeding and hydration and thus also would not be covered by this provision.

---

168. Id. prefatory note, 9B U.L.A. 609 (explaining the general purpose of the Act).
169. See supra notes 147–48 and accompanying text. Presumably in recognition of this problem, URTIA was amended in 1989 to protect individuals who did not leave living wills. URTIA (1989 act) § 7, 9B U.L.A. 90 (Supp. 1991). This language has been adopted—in widely varying degrees—by very few states. See infra note 210 and accompanying text.
170. URTIA § 2(a), 9B U.L.A. 614.
171. Id. § 1(7), 9B U.L.A. 611.
173. Cruzan renders these provisions constitutionally suspect. See supra notes 30–47 and accompanying text.
Moreover, state living-will statutes often apply only to the citizens of that state; only twelve states recognize living wills executed in another state,\textsuperscript{174} sometimes additionally requiring that the other state's requirements be substantially similar to their own.\textsuperscript{175} These statutes also lack enforcement bite, as many physicians do not even ask patients if they have a living will,\textsuperscript{176} do not know their own state's laws as to living wills,\textsuperscript{177} and will not follow the patient's living-will directives, even when the physician is made aware of them.\textsuperscript{178} Even were physicians aware of living wills, many states make them advisory only and not binding;\textsuperscript{179} and many living wills are so poorly drafted and vague as to be poor indications of a patient's true intent.\textsuperscript{180} States also vary as to how frequently their living wills must be updated,\textsuperscript{181} how many witnesses must execute the document,\textsuperscript{182} and who may be a witness.\textsuperscript{183}

Further, living-will statutes in many jurisdictions make no provision for health-care proxy appointments. Although some


\textsuperscript{176} See supra note 150 and accompanying text. This problem could be alleviated somewhat by noting the existence of a health-care directive on the back of a person's driver's license, as organ donation preferences are currently noted. The new Patient Self-Determination Act will require most hospitals to ask patients upon admission whether they have a directive. See infra notes 194–200 and accompanying text.

\textsuperscript{177} See supra notes 151–52.

\textsuperscript{178} See supra note 153 and accompanying text.

\textsuperscript{179} See, e.g., IND. CODE ANN. § 16-8-11-11(f) (West Supp. 1991); NEV. REV. STAT. § 449.640(1) (1991); see also Condie, supra note 164, at 118–19.

\textsuperscript{180} See supra note 155 and accompanying text.

\textsuperscript{181} See also Chapman, supra note 14, at 375 n.258 (describing various state provisions). Compare CAL. HEATH & SAFETY CODE § 7189.5 (Deering Supp. 1991) (providing that a directive is effective for five years from the day of execution unless it is revoked sooner) with IDAHO CODE § 39-4507 (Supp. 1991) (providing that a directive is effective indefinitely from the day of execution unless it is revoked).

\textsuperscript{182} Compare ME. REV. STAT. ANN. tit. 18-A, § 5-702(a) (West Supp. 1991) (requiring two witnesses) with OKLA. STAT. ANN. tit. 63, § 3103 (requiring two witnesses and a notary public).

of these states have enacted separate health-care proxy legislation, ten states and the District of Columbia have not, thus providing no protection for patients who have not met the requirements of the living-will provisions.

Finally, perhaps the biggest problem with living-will statutes, and indeed with all advance-directive legislation, is that the wide disparity between the states as to living-will provisions and proxy appointment provisions promotes confusion, inequity, and forum shopping. Often, citizens of one state do not have the same rights to continue or withhold medical treatment as citizens of another. This has prompted one commentator to remark that "[n]ow, basic rights change when you move across state borders." Americans are now shopping for cities or states with more sympathetic laws on many different social and medical issues, which creates a trend that will burden a handful of states with the most pressing and expensive problems.

In short, there is an enormous gap between America's need and the current response to that need. For all of the foregoing reasons, recent calls to revise URTIA, or to achieve general legislative and judicial uniformity, such as the Model Aid-In-Dying Act, are laudable but incomplete. Certainly, living-will legislation must be made more uniform. But because living-will statutes generally do not address nonterminal patients, nor patients who have not executed any directives at all, more comprehensive legislation is needed. Additionally, dicta in Cruzan now renders suspect those state laws which do not recognize living wills or express proxy appointments or directives to withhold artificial food and hydration. States must therefore considerably revamp their existing legislation. Because Cruzan directed most

184. See supra note 163.
186. Id.
187. See, e.g., Chapman, supra note 14; see also supra note 169.
188. See, e.g., Karen M. Spallina, I Want to Die—Our Constitutional Right to End Artificial Life-Support, CHI. BAR ASS'N REC. 17, 21 (Jan. 1991) (advocating the development of uniform national right-to-die legislation including standardized use of living wills and durable power of attorney).
189. Model Act, Model Aid-In-Dying Act, 75 IOWA L. REV. 125, 127–28 (1989) (providing a model act that applies to terminally ill and "technologically dependent" patients, includes a highly controversial provision that makes no distinction between active and passive euthanasia, and provides no statutory hierarchy for surrogate decision makers).
190. See supra notes 41–47 and accompanying text.
aspects of the problem back to the laboratory of the states, the states must now provide more comprehensive and uniform protection.

A new Uniform Patient-Family Determination Rights Act is therefore needed. Efforts must be directed away from the current piecemeal approach, which results in profoundly disparate treatment across state lines and which is focused almost exclusively on the problem long after much of it could have been prevented. The new patient-family determination rights movement must refocus and articulate three new goals:

1. The movement must expend enormous effort and resources on prevention, recognizing that it is always best to effectuate the patient's own expressed wishes whenever possible. Therefore it must increase the legitimacy, enforceability, and the use of advance health-care directives (up from the current 9%) to avoid as many Cruzan-like tragedies as possible.

2. It must promote nationwide efforts to combine living-will legislation with health-care proxy appointment legislation in order to provide more comprehensive coverage in the event of subsequent incompetency. It can do this by protecting persistent vegetative state patients and not just terminally ill patients, including food and hydration within "medical treatment," and making the directives more uniform and specific.\(^\text{191}\)

3. It must provide a catch basin for those thousands of persistent vegetative state patients who have no enforceable directive by providing in all fifty states a statutory framework granting presumptive authority\(^\text{192}\) to the patient's family to decide whether to terminate or withhold life support based on a combined "substituted judgment/best interest" analysis.\(^\text{193}\) An alternative framework should also be created for

---

191. *See supra* note 155.
192. The proposed Uniform Patient-Family Determination Rights Act sets forth a statutory hierarchy of family members who may make decisions as surrogates when no advance health-care directive is executed. *See infra* note 261 and accompanying text; *see also* Rhoden, supra note 58, at 437 (advocating a legal presumption on behalf of the family of the incompetent patient). The proposed legislation simply sets forth a hierarchy of those surrogates who would be able to assist.
193. *See infra* note 261.
incompetent patients without family members who have left no executed directives.

As I discuss below, much of this groundwork has already been done because national and state legislation that could be used in part as a framework for a new Uniform Patient-Family Determination Rights Act currently exists. Thus, it is important to note that the problem results not from a lack of legislation, but from a lack of coordinated effort. Efforts must be directed not so much to creating even more new legislation, but instead to coordinating and streamlining existing legislation. National goals must be rearticulated. The focus must change to prevention, uniformity, and patient-family determination rights, and away from the existing parochial, confusing, and inequitable piecemeal approach.

C. Federal Initiative: The National Patient Self-Determination Act

The United States Congress recently answered the call for far-reaching death-with-dignity legislation by enacting the Patient Self-Determination Act (PSDA) as part of the Omnibus Budget Reconciliation Act of 1990. An example of preventive legislation, the PSDA goes a long way toward increasing Americans' awareness of advance health-care directives by requiring the following from all hospitals, nursing homes, hospices and other facilities that receive federal Medicaid and other funding:

1. They are required to maintain written policies and procedures with respect to all adults receiving medical care by or through the provider or organization.
2. Upon a patient's admission to the facility, they must inquire as to whether a patient has executed an advance health-care directive; if a patient has not, the

195. Id. § 4206(a)(2), 104 Stat. at 1388-115 (to be codified at § 1395cc(f)(1)).
facility must advise the patient of relevant state law and the opportunity to create a health-care directive while competent. 196

3. If a patient has previously executed an advance health-care directive, the facility must alert medical treating personnel to the existence of the directive by marking the patient's medical chart. 197

4. Treating personnel are directed to effectuate express advance health-care directives, and a health-care facility may not condition the provision of care or otherwise discriminate against an individual based on whether or not the individual has executed an advance directive. 198

Failure on the part of a health-care facility receiving federal funds to comply with the Act subjects it to a possible termination of federal funds; 199 as such, the Act requires those states that do not recognize advance directives to enact such a law and will withhold Medicaid reimbursement from those that do not.

It is important to note that the new federal legislation defers totally to local state law provisions with respect to living wills, health-care proxies, and other advance directives. 200 Thus, the new federal legislation does not create any new rights for patients; it only provides an opportunity to exercise existing rights provided by state statute.

The PSDA is a laudable first nationwide effort to recognize the pivotal importance of prevention in the death-with-dignity debate. Cruzan suggests that there is a constitutional right

---

196. Id. (to be codified at § 1395cc(f)(1)(A)).
197. Id. (to be codified at § 1395cc(f)(1)(B)).
198. Id., 104 Stat. at 1388-115 to -116 (to be codified at § 1395cc(f)(1)(C)-(D)). However, the Act includes a "conscience clause" which recognizes the validity of state laws allowing an individual health-care provider to refrain from implementing an advance directive on the basis of conscience. Id. § 4206(c), 104 Stat. at 1388-116 (to be codified at § 1395cc note).
199. Id. § 4206(b), 104 Stat. at 1388-116 (to be codified at §§ 1395mm(c)(8), 1395l(r)).
200. Id. § 4206(a)(2), 104 Stat. at 1388-115 (to be codified at § 1395cc(f)(1)(A)(i)) (requiring only that the hospital inform the patient of "an individual's rights under State law (whether statutory or as recognized by the courts of the State) to make decisions concerning such medical care, including the right to accept or refuse medical or surgical treatment and the right to formulate advance directives . . . ." (emphasis added)).
for a competent person to withhold or withdraw life-support systems, including feeding and hydration tubes.\textsuperscript{201} The case also suggests that where that individual has previously created clear and convincing evidence of her own intent, such as a living will, a guardian may terminate life support on her behalf if she becomes incompetent.\textsuperscript{202} The PSDA, therefore, effectuates the \textit{Cruzan} mandate by increasing the awareness of and the opportunity for many Americans to generate legally sufficient, clear and convincing evidence of their wishes while they are still competent. It does so by directing them, upon their admission to a covered health-care facility, to relevant state law on living-will and health-care proxy appointments. Thus, in cases involving those patients who have been prompted to create in advance clear and convincing evidence of their own wishes, the statute lifts a significant burden from other parties, who no longer need to decide whether to withhold or withdraw care. Ultimately, the patient’s clear wishes are effectuated and fewer cases should end up in court.

Successful implementation of this new legislation should direct precious human, judicial, and financial resources away from unnecessary and litigious dispute resolutions, and away from unwanted artificial life support for those patients who had the foresight to execute advance health-care directives. Moreover, the legislation has the potential to affect millions of lives because of its sweeping applicability to all types of health-care facilities receiving federal funds.\textsuperscript{203}

The effectiveness of the PSDA, however, is limited for at least two reasons. First, because the Act only aids competent adults who are capable of executing an advance health-care

\begin{itemize}
\item \textsuperscript{201} \textit{See supra} notes 41–44 and accompanying text.
\item \textsuperscript{202} \textit{See supra} notes 45–47 and accompanying text.
\item \textsuperscript{203} Omnibus Budget Reconciliation Act of 1990, Pub. L. No. 101-508, § 4751(a)(1)(c), 104 Stat. 1388, 1388-204 (to be codified at § 1396a(a)(57)). Senator Danforth, a Senate cosponsor of the PSDA, noted that, “For the first time, adult patients will be provided with knowledge of their legal rights to make decisions about their own care. This will occur in a systematic way that puts basic information in the hands of millions of people.” Keith White, \textit{Budget Bill Contains Medical Rights Measure}, Gannett News Serv., Oct. 29, 1990 (quoting Danforth), \textit{available in} LEXIS, Nexis Library, Wires File. \textit{See also} 135 CONG. REC. S13,567 (daily ed. Oct. 17, 1989) (remarks of John C. Fletcher, Ph.D., Director of the Center of Biomedical Ethics, University of Virginia Health Sciences Center) (“This Act will create literally millions of such educational opportunities.”).
\end{itemize}
directive, it will not reach those who cannot or will not have the opportunity to execute advance health-care directives.

Second, the Act defers completely to the existing state legislative framework. The PSDA is designed only to discover whether a patient already has a health-care directive and to advise the patient of the availability of advance health-care directives in his health-care facility's jurisdiction, should he wish to execute an advance directive. In short, the Federal Act only waltzes the patient to the state door. As I have discussed above, the current piecemeal and patchwork state legislative treatment of the death-with-dignity issue is in total disarray, and its problems are legion. Unless and until state legislatures provide a uniform and more comprehensive response, the PSDA simply feeds a patient into the existing ineffective and inequitable state legislative framework.

As a result of these limiting factors, the PSDA does not create any new rights; it merely advises a patient of existing rights. Thus, for personal tragedies represented by Christine Busalacchi, for example, the PSDA serves no purpose at all. It leaves unprotected those who cannot or have not executed an advance health-care directive, and those whose directives are legally insufficient. Thus, the Act fails to help many people who are not covered by either their state's legislation or Cruzan's constitutional reasoning.

In sum, the apparent goal of the PSDA—prevention—is sensible, practical, and capable of averting much tragedy and many wasted resources. Because the Act defers totally to existing state patchwork legislation, however, the Act by itself will not effectively or fully benefit even those it was designed to protect until the states clean up the disarray in existing living-will, proxy appointment, and other advance health-care directive legislation. Finally, the Act fails to extend coverage to individuals who have not executed an enforceable advance health-care directive. Thus, newly articulated goals of uniformity and more comprehensive protection must also be advanced.

204. See supra note 200.
205. See supra notes 166–86 and accompanying text.
206. See supra notes 104–13 and accompanying text.
III. NEWLY ENACTED AND PROPOSED STATE LEGISLATION PROTECTING PATIENTS WITHOUT ADVANCE HEALTH-CARE DIRECTIVES

In reality a large number of presently competent Americans will never execute written advance health-care directives, nor will they generate legally enforceable clear and convincing evidence of their own wishes. Their reasons may vary, from feelings of invincibility often accompanying youth, to the lack of access often faced by the elderly; many may simply choose not to deal with questions of their own mortality. Moreover, there is the additional reality that minors and mentally incompetent persons are incapable of executing binding advance health-care directives. These realities, along with concern for the 10,000–25,000 persistent vegetative state patients existing in the United States today, require further legislative initiative.

Only one state, Illinois,\(^{207}\) fully protects by legislative enactment an incompetent, nonterminal individual who leaves insufficient evidence of her own wishes, although some state courts\(^{208}\) and one federal court\(^{209}\) have authorized decisions by proxies on the basis of a patient's best interest or substituted judgment. Legal recognition of patient-family rights, therefore, is grossly disproportionate to the national wish for such protected rights.

For example, only recently have any types of patient-family rights begun to find limited expression in state statutes. While the great majority of states have not yet responded to the problem, thirteen states now provide a surrogate decision-making procedure, which allows a surrogate to make medical treatment decisions on behalf of an incompetent patient who

---

207. See Health Care Surrogate Act, Pub. Act 87-749, 1991 Ill. Legis. Serv. 3507 (West) (to be codified principally at ILL. ANN. STAT. ch. 110 1/2, paras. 851-1 to -55); see also infra notes 224-43 and accompanying text (discussing the Illinois Health Care Surrogate Act).

208. As discussed extensively in Justice Stevens' Cruzan dissent, there are numerous state court decisions which have "authorized procedures for the cessation of treatment of patients in persistent vegetative states." Cruzan v. Director, Mo. Dept't of Health, 110 S. Ct. 2841, 2887-88 (1990) (Stevens, J., dissenting); see also id. at 2888 n.21 (citing cases). Justice Stevens argues that as a result, the Missouri Supreme Court's Cruzan decision is "anomalous." Id. at 2888.

has left no advance health-care directive. However, the majority of those statutes apply only to terminally ill patients, thus excluding persistent vegetative state patients from their coverage. Some statutes also exclude artificial feeding or hydration from the treatment that may be withdrawn by the surrogate.

Thus, although a few states have begun recognizing patient-family rights, under most existing statutory law neither Nancy Cruzan, Helga Wanglie, nor Christine Busalacchi would be protected, nor would their families. Existing statutory law is not comprehensive or uniform enough to grant any of those families presumptive rights to act on behalf of the patients to continue or to withdraw medical treatment, including artificial feeding and hydration. Uniform and more comprehensive laws are necessary, and it is essential that they be passed in all states.

The recently enacted Illinois Health Care Surrogate Act and legislation proposed in Missouri would fully protect

---


212. Arkansas and Oregon expressly exclude artificial feeding and hydration from medical treatment which may be withdrawn on this basis. See Ark. Code Ann. § 20-17-206(b) (Michie Supp. 1991); Or. Rev. Stat. § 127.605(3) (1989). Under the New Mexico Right to Die Act, N.M. Stat. Ann. § 24-7-1 to -10 (Michie 1991), it is unclear whether a surrogate decision maker may terminate artificial feeding and hydration. The Act defines the "maintenance medical treatment" that may be withdrawn as "medical treatment designed solely to sustain the life process." Id. § 24-7-2(c). To date, there are no reported cases interpreting this provision.


214. Missouri Attorney General William Webster endorsed legislation in Missouri which would have granted surrogate decision-making authority to withdraw
patients like Helga Wanglie, Nancy Cruzan, and Christine Busalacchi because they expressly apply to terminal and nonterminal patients, including persistent vegetative state patients, and they expressly allow a surrogate to decide to withhold medical treatment, including artificial feeding and hydration, without an express advance directive and without resort to the courts. Because the Illinois legislation is the most comprehensive,215 and because it broadly protects individual autonomy rights as well as family rights, the new Illinois act is discussed extensively below,216 following a brief discussion of the Missouri proposal. This Article recommends that Section Three of the proposed Uniform Patient-Family Determination Rights Act pattern itself after the Illinois legislation and the Missouri proposal because of the quality of protection they provide.217

A. The Webster Proposal

In an arena already replete with paradox, the death-with-dignity debate took another interesting turn in the spring of 1990. Missouri Attorney General William Webster, who, as representative of Missouri Rehabilitation Center (a state hospital), had opposed the Cruzans' legal fight to withdraw their daughter's life-support system,218 endorsed new legislation that would have provided increased protection for persistent vegetative patients and their families.219 The legislation, which ultimately was not passed,220 would have

215. For example, the Illinois legislation carefully defines the factors that a surrogate must take into account when deciding whether to withdraw or withhold treatment. See infra notes 233–34 and accompanying text. Other states simply require that decisions be made in the “best interest” of the patient. See, e.g., ME. REV. STAT. ANN. tit. 18-A, § 5-707(d) (West Supp. 1991).
216. See infra notes 224–43 and accompanying text.
217. See infra note 261 and accompanying text.
219. See S. 508, 735 & 736, 85th Mo. G.A., 2d Sess. (1990); see also Gibbs, supra note 61, at 62, 71. Webster is reported to have realized that few people have living wills, and that the Cruzans' ordeal had been "torturous." Thus, he endorsed the proposal for new legislation because it would try to find a careful resolution. Id.
allowed families of patients who had been continuously unconscious for three or more years to petition to withdraw medical treatment, including artificial feeding and hydration, thus allowing the patient to die. The family had to be unanimous in their opinion that this was what the patient would have wanted, and three independent, nontreating physicians had to certify that the coma was irreversible. The proposed initiative thus contained significant procedural safeguards against potential abuse.

B. The Illinois Health Care Surrogate Act

In a similar direct response to a local tragedy, the Illinois General Assembly recently passed the broadest-reaching legislation in the nation to date on the death-with-dignity issue. The Illinois Health Care Surrogate Act (HCSA) grants comprehensive legal rights to incompetent patients to die with dignity. The legislation took two years to pass both houses of the Illinois General Assembly and was signed into law by Governor Jim Edgar on September 26, 1991. The bill is a sweeping and comprehensive measure

---

221. S. 508 § A (to have been codified at Mo. REV. STAT. § 475.122(8)).
222. Id. (to have been codified at § 475.122(8)(3)).
223. Id. (to have been codified at § 475.122(8)(4)).
224. In April 1989, Rudy Linares, the 23-year old father of a 15-month old child being treated in a Chicago hospital, entered the hospital armed with a .357 Magnum. While holding medical personnel at bay, Linares disconnected his son's respirator. See Peter Kendall, Panel Asks Legal Way to Halt Life Support, CHI. TRIB., Apr. 12, 1990, § 2, at 2. The child had swallowed a balloon which cut off oxygen to his brain, and he had been in a vegetative state for several months. The hospital advised Linares that they would not terminate the respirator. It was reported that Linares was driven to desperation when the hospital called to tell him it was going to transfer his child to a health facility 70 miles away. See Illinois: Panel Urges Right to Refuse Life-Support, L.A. TIMES, Apr. 13, 1990, at A23. Following the Rudy Linares tragedy, then-Cook County State's Attorney Cecil Partee created a Model Task Force composed of lawyers, doctors, and ethicists. See Kendall, supra. One year later, the Task Force, under the sponsorship of Senator John D'Arco (D-Chicago), introduced the first version of the Illinois Health Care Surrogate Act. See infra note 226.
and provides a very useful starting point for the proposed Uniform Patient-Family Determination Rights Act.

The HCSA accomplishes five things. First, where an individual lacks decisional capacity and has met the Act's "qualifying conditions,"[227] the HCSA provides a hierarchy of decision-making "surrogates," who have presumptive legal authority[228] to make a determination as to medical treatment (including artificial feeding and hydration) on behalf of an incompetent patient who has left no evidence of, or insufficient evidence of, her own personal wishes:

(a) When a patient has a qualifying condition and lacks decisional capacity, ... surrogate decision makers, as identified by the attending physician, are then authorized to make decisions whether to forgo life-sustaining treatment on behalf of the patient without court order or judicial involvement in the following order of priority:

(1) the patient's guardian of the person;
(2) the patient's spouse;
(3) any adult son or daughter of the patient;
(4) either parent of the patient;
(5) any adult brother or sister of the patient;
(6) any adult grandchild of the patient;
(7) a close friend of the patient;
(8) the patient's guardian of the estate;

... Where there are multiple surrogate decision makers at the same priority level in the hierarchy, it shall be the responsibility of those surrogates to make reasonable


227. The Act defines "qualifying condition" as the existence, as certified by two physicians, of one or more of the following conditions: "terminal condition," "permanent unconsciousness," or an "incurable or irreversible condition." HCSA § 10 (to be codified at ILL. ANN. STAT. ch. 110 1/2, para. 851-10).

228. *Id.* § 30(a) (to be codified at ILL. ANN. STAT. ch. 110 1/2, para. 851-30(a)).
efforts to reach a consensus as to their decision on behalf of the patient regarding the forgoing of life-sustaining treatment.

(d) . . . In the event an individual in a higher, a lower, or the same priority level or a health care provider seeks to challenge the priority of or the life-sustaining treatment decision by the recognized surrogate decision maker, the challenging party may initiate guardianship proceedings in accordance with the Probate Act of 1975. 229

Second, the Act provides extensive procedural checks on decision-making authority. These checks include requirements that two physicians must certify the existence of "a qualifying condition"; where appropriate among "same-level" surrogates, a consensus must also exist among relevant family members unless a minority institutes actual guardianship proceedings under the Illinois Probate Act. 230

Third, the express purpose of the HCSA is to keep the decision making private and out of the courts. 231 No petition to the court is necessary for a family decision maker to terminate or withhold medical treatment. Instead, because of the presumptive authority of the relevant family member or surrogate to decide, courts only intervene when challenge procedures are triggered upon a suggestion of impropriety or undue bias under the Illinois Probate Act. 232

---

229. Id. § 25 (to be codified at ILL. ANN. STAT. ch. 110 1/2, para. 851-25).
230. Id. This is unlike the Webster proposal which requires unanimity. See supra note 222 and accompanying text. Unfortunately, in the amended legislation that was ultimately passed there are no express "dispute resolution" procedures set forth which are designed solely to protect the incompetent from improper bias or undue influence of family members, physicians, or others. An earlier version of the Act had included such procedures. See S. 1092, 87th Ill. G.A. § 30 (1991–92).
231. The Act's "Legislative findings and purposes" section states:

Uncertainty and lack of clarity in the law concerning the making of private decisions to forgo life-sustaining treatment, without judicial involvement, causes unnecessary emotional distress to the individuals involved and unduly impedes upon the individual right to forgo life-sustaining treatment.

The enactment of statutory guidelines for private decision making will bring improved clarity and certainty . . . and will substantially reduce the associated emotional distress for involved parties.

232. See id. § 25(d) (to be codified at ILL. ANN. STAT. ch. 110 1/2, para. 851-25(d)).
Fourth, the HCSA expressly directs a decision maker to use a hybrid substituted judgment/best interest analysis. A surrogate decision maker is first required to make a decision based on her substituted judgment:

A surrogate decision maker shall make decisions for the adult patient conforming as closely as possible to what the patient would have done or intended under the circumstances, taking into account ... the patient's personal, philosophical, religious and moral beliefs and ethical values relative to the purpose of life, sickness, medical procedures, suffering, and death. Where possible, the surrogate shall determine how the patient would have weighed the burdens and benefits of initiating or continuing life-sustaining treatment against the burdens and benefits of that treatment. 233

If that is not possible, the surrogate is free to base her decision on the patient's best interests:

If the adult patient's wishes are unknown and remain unknown after reasonable efforts to discern them or if the patient is a minor, the decision shall be made on the basis of the patient's best interests as determined by the surrogate decision maker. In determining the patient's best interests, the surrogate shall weigh the burdens on and the benefits to the patient of initiating or continuing life-sustaining treatment against the burdens and benefits of that treatment . . . 234

Thus, the legislation does away with the legal fiction of substituted judgment 235 where it is inappropriate and authorizes a best interest determination where it is appropriate.

233. Id. § 20(b)(1) (to be codified at ILL. ANN. STAT. ch. 110 1/2, para. 851-20(b)(1)).
234. Id.
235. A number of scholars have examined the inconsistent and troubling application of the fictional substituted judgment test to persistent vegetative state patients. See Peters, supra note 58, at 940–42; Dresser, supra note 58, at 425–27; see also Shapiro, supra note 129, at 445 ("[I]t is impossible to apply the substituted judgment approach when incompetent patients . . . have no close family member or friends, and knowledge of their values and previously expressed treatment preferences is unavailable.").
Fifth, the Act is more expansive than any other existing legislation. Its surrogacy provisions are triggered by "qualifying conditions" which include a terminal condition where death is imminent as well as "[p]ermanent unconsciousness." Interestingly, the HCSA goes one step further and also protects the patient suffering from an incurable or irreversible condition for whom death is not necessarily imminent, but whose condition will ultimately cause his death even if life-sustaining treatment is initiated or continued. This category is designed to cover patients like Tim Wirth, who, suffering from advanced AIDS, was required by a court to receive antibiotics to treat a serious brain infection, contrary to expressed wishes he left in a previously executed living will.

Finally, the Act guards against the potential for abuse. For example, it expressly excludes "assisted feeding such as spoon or bottle feeding" from its definition of "[a]rtificial nutrition and hydration" that may be withdrawn. The Act also expressly provides that it "is not intended to condone, authorize, or approve mercy killing or assisted suicide." Of course, the HCSA applies only when no enforceable express advance health-care directive is available; a competent individual is always free to make an advance health-care directive and/or appoint a proxy other than a spouse or

236. HCSA § 10 (to be codified at ILL. ANN. STAT. ch. 110 1/2, para. 851-10).
237. Section 10, defining "qualifying condition," provides:

(3) "Incurable or irreversible condition" means an illness or injury (i) for which there is no reasonable prospect of cure or recovery, (ii) that ultimately will cause the patient's death even if life-sustaining treatment is initiated or continued, (iii) that imposes severe pain or otherwise imposes an inhumane burden on the patient, and (iv) for which initiating or continuing life-sustaining treatment, in light of the patient's medical condition, provides only minimal medical benefit.

Id. One possible example of a case which would fall under this definition of "qualifying condition" is the use of a respirator for a patient with terminal cancer who develops pneumonia. Right to Die Law: A Sad Necessity, CHI. TRIB., June 6, 1990, § 1, at 18.
238. See Rosenthal, supra note 144.
239. HCSA § 10 (to be codified at ILL. ANN. STAT. ch. 110 1/2, para. 851-10).
240. Id. § 5(b) (to be codified at ILL. ANN. STAT. ch. 110 1/2, para. 851-5(b)).
241. By express provision the Act does not apply to instances in which the patient has an operative living will or an authorized agent under a durable power of attorney for health care. See id. § 15 (to be codified at ILL. ANN. STAT. ch. 110 1/2, para. 851-15).
other family member to make a determination on her behalf in the event of future incompetency. The Act therefore reposes no power in a patient's family to veto a patient's own previously expressed wishes. Instead, the HCSA is a "catch basin" designed to protect those individuals and their families who currently are virtually unprotected by state legislation because they never executed advance health-care directives.

The HCSA thus pays deference to three distinct sets of rights: the patient's autonomy rights, by protecting him with procedural safeguards against abuse through the provisions of the Probate Act; the patient's right to have his family substitute its judgment on his behalf or act in his best interest; and finally, the family's right to act on his behalf. The Illinois Act is interesting because it recognizes what is intuitive for many persons: that they would want their spouse, parent, adult child, or other appropriate family member to decide on their behalf if they were unable to make their own decision.\(^2\)

By placing the decision back in the hands of the family, the Act pays deference to the enormity and the difficulty of the decision. In response to the Webster proposal in Missouri, which also places the decision back into the families' hands, one commentator wrote:

> Long after the decision is made, the resolution may continue to haunt. But, in a sense, the abiding difficulty of these choices has a value of its own. It reflects the deep desire to do the right thing and respect the wishes of a loved one—and also an unshakable sense that life is neither to be taken nor relinquished lightly, even in mercy's name.\(^2\)

Acknowledgment that "life is neither to be taken nor relinquished lightly, even in mercy's name"\(^2\) must come before any new national legislative initiative.

In order to have legitimacy, any new initiative also must safeguard against potential evils. The evil emerging from this

---

242. See Gibbs, supra note 61, at 64 (citing a Time/CNN poll, in which 80% of those polled wanted family members and doctors to decide on their behalf in the event they became incompetent).

243. Id. at 71.

244. Id.
particular Pandora's box, of course, is the danger that an incompetent individual may be subject to abuse by virtue of her incompetency, and more broadly, that a right to die with dignity can be perverted by society into a duty to die, or a diminished commitment to the sanctity of life and the protection of the vulnerable.

Failure to act, however, must be distinguished from caution in acting. Paradoxically, failure to act out of fear of abuse can create abuse. Failure to act ignores the medical-technological reality of modern death. Until thirty years ago, cessation of heart and lungs—the medical definition of death at that time—was the only other side of "life," but now death is not so neatly defined: We have created a new place where human beings can be forced to remain suspended between life and death. The failure to act also creates inequity in the enforcement of important rights between families, between citizens of different levels of competency, and between citizens of different states.

The story of Pandora's box is similar to the concept of the slippery slope: both represent the fear of a loss of control where there is a potential for evil. Like the various evils that fly out of Pandora's box unchecked and unguarded, we fear the uncontrolled fall down the slippery slope. The proper response to that fear, however, is not failure to act in a comprehensive, uniform fashion. Failure to act deprives individuals and

---

245. Id. at 67.
246. For an excellent commentary on the danger of the "slippery slope," see Cantor, supra note 25. I strongly support Cantor's suggestion that we draw the line at a patient who is permanently unconscious (and not, for example, terminal but conscious). See id. at 410. But cf. Tracy L. Merritt, Note, Equality for the Elderly Incompetent: A Proposal for a Dignified Death, 39 STAN. L. REV. 689, 690 (1987) (arguing that the right to refuse life-sustaining treatment "should be extended to include elderly incompetent but conscious patients with serious mental and physical impairments" (footnote omitted)).
247. Shapiro, supra note 129, at 440. Shapiro proposes amending the current "whole brain" definition of death under which death is declared when all functions of the brain and brain stem cease, id. at 440, to include those who are in a permanently vegetative state, but only after diagnosis of permanent vegetative state becomes more certain. Id. at 448.
248. Judge Teel in Nancy Cruzan's original evidentiary hearing, Cruzan v. Harmon, No. CV 384-9P (Mo. Cir. Ct., Jasper County July 27, 1988), writes of man's role in creating this new place: "Nancy's present unresponsive and hopeless existence is not the will of the Supreme Ruler but of man's will to forcefully feed her while she herself cannot swallow . . . ." Id., slip op. at 6.
families of profoundly personal and inviolate rights. The proper response is to act cautiously. It is also to acknowledge that the potential for evil exists and to create comprehensive procedural safeguards to guard against it.

As discussed in *Cruzan*, Missouri's heightened evidentiary standard provides one example of a procedural safeguard against abuse. By requiring clear and convincing evidence of a person's intent regarding the withholding or withdrawal of medical treatment, the Missouri legislature and later the Supreme Court placed the burden and the risk of error on the one proposing to terminate life support. The problem with that particular procedural safeguard, standing alone, is that it disenfranchises the large number of incompetent patients without advance health-care directives (like Christine Busalacchi) of any right to death with dignity. It also renders legally irrelevant what the family believes the patient would want, and what it believes is in her best interest.

IV. THE PROPOSED SOLUTION

This Article advocates that state and federal legislatures completely reorient their focus on the death-with-dignity issue and articulate three new national objectives: prevention, uniformity, and patient-family determination rights.

Prevention is achieved through initiatives like the newly enacted federal Patient Self-Determination Act, which could positively affect millions of lives, but only if it is coordinated properly with the states. The proposition is a simple one: If, as *Cruzan* holds, a state may require clear and convincing evidence of a patient's wish to withhold or withdraw medical treatment, then we must make every effort to generate legally enforceable clear and convincing evidence while a patient is competent to leave such directions. Tragedies like Cruzan's and Wanglie's may be avoided by creating a national awareness of the need and the opportunity to draft

249. In many writings, family relationships are viewed as sacred. See, e.g., JOHN MASEFIELD, THE EVERLASTING MERCY 43 (1914) ("And he who gives a child a home/Builds palaces in Kingdom come.").


251. *See supra* notes 194–206 and accompanying text.

252. *See supra* note 203 and accompanying text.
explicit advance directives for health care. Thus, prevention is achieved by the increased use, recognition, and enforceability of advance health-care directives. Such directives should effectuate the clearly expressed wishes of the patient and are the best evidence of her intent.  

It should also dramatically reduce the unnecessary grief families are put through when they must make decisions on behalf of the patient, or in the best interest of the patient, because patients will have left enforceable advance health-care directives.

When it is reprioritized as a national objective, the doctrine of prevention also recognizes that it is more humane to protect citizens before a crisis develops than after. Further, a new focus on prevention complements the *Cruzan* presumption that certain of these rights are so fundamental as to be constitutionally protected by both the Fourteenth Amendment’s liberty interest and the common-law doctrine of informed consent.

It also means that as a nation we can acknowledge and respect the fact that “death with dignity” means different things to different people, and that it is each individual’s definition of death with dignity that must be adhered to whenever possible. In fact, the shift to prevention acknowledges that the very complexity of the questions “what is life” and “what is death” triggers moral, ethical, medical, legal, and religious concerns which virtually require an individual response.

In short, the national shift in focus to prevention will preempt the vast majority of death-with-dignity disputes. More people will prepare advance health-care directives which are uniform, clear and legally enforceable. This will avoid the need for familial or judicial intervention.

Prevention alone, however, will not eliminate the problem. The nation also needs a uniform statutory framework within which to make necessary decisions. The primary fault of the Patient Self-Determination Act is that it defers totally to

---


254. *See supra* note 58.

255. *See supra* note 92.

256. For a discussion of the development of a right to refuse treatment, first from the common-law right to informed consent, and later from the constitutional privacy right, see *Cruzan v. Director*, Mo. Dep’t of Health, 110 S. Ct. 2841, 2846–47 (1990).
existing state law. State and federal legislatures must commit
to developing a more uniform approach to this issue so as to
alleviate the existing inequity and confusion. This approach
must include a simpler legislative framework that protects
more people and, to the greatest extent possible, uniformly
protects rights across state lines. Existing legislation may be
used as a starting point, but it must be modified. The
Uniform Rights of the Terminally Ill Act\textsuperscript{257} (URTIA), the
separate Model Health-Care Consent Act,\textsuperscript{258} and all other
disparate patient determination legislation must be stream-
lined and combined into one complete and uniform act. This
would prevent confusion, unfairness, and forum shopping.

The recent \textit{Cruzan} ruling as well as the current disarray in
state law provide a new opportunity for states to go back and
revise existing law. State legislatures, through the National
Conference of Commissioners on Uniform Laws,\textsuperscript{259} should
revise existing law to reach more Americans \textit{before} the crisis
arises, and to provide more comprehensive, enforceable protec-
tion when a crisis does arise.

Finally, the states must uniformly adopt new legislation
which thus far has not been part of most states' Natural Death
Acts.\textsuperscript{260} This new legislation should recognize patient-family
determination rights by granting an incompetent patient's
family the presumptive legal right to make a determination to
withhold medical treatment on behalf of an incompetent
patient who has left no expressed wishes as to medical
treatment. This right should be available equally in every
state in the Union and should not vary between the states.
The definition of medical treatment should expressly include
artificial feeding and hydration. Finally, to protect against
abuse, the legislation should include procedural protections

\textsuperscript{257} URTIA, 9B U.L.A. 609 (1987). For an extensive discussion of URTIA, see
Chapman, \textit{supra} note 14, at 320–21, which advocates revision of URTIA. This Article
draws on that suggestion and advocates that the 1989 version of URTIA, the Model
Health-Care Consent Act, and a brand new family-determination statute be sub-
sumed into one Uniform Patient-Family Determination Rights Act.

\textsuperscript{258} 9 U.L.A. pt. 1, at 453 (1988). The Model Health-Care Consent Act sets forth,
in a separate statutory provision, model provisions for durable power of attorney for

\textsuperscript{259} For an extensive discussion of the role of the National Conference of Commiss-
ioners on Uniform Laws in the promulgation of uniform nationwide state statutory
provisions, see Chapman, \textit{supra} note 14, at 343–55.

\textsuperscript{260} "Natural Death Act" is one of the titles some states have adopted for their
living-will statutes. \textit{See} Condie, \textit{supra} note 164, at 105, 107.
such as waiting periods, physician certification requirements, majority or unanimity requirements, and dispute resolution mechanisms.

This Article proposes the framework for a new Uniform Act, entitled the Uniform Patient-Family Determination Rights Act. The proposed legislation should be an amalgam of existing and new legislation, combined and streamlined into essentially three parts. First, Section One should acknowledge and replicate the federal Patient Self-Determination Act, and extend its coverage to include nursing homes and hospitals within the state, which are currently not covered by the new federal law. This will provide all state residents in a home or hospital with specific information regarding advance health-care directives. Section Two of the Act should combine existing URTIA and all proxy and durable powers of attorney for health-care legislation, to cover all ill persons, whether terminal or not, who leave advance health-care directives. This will simplify the current disarray and will broaden existing protection. Finally, to protect all those who are currently unprotected, Section Three should be modeled after the Illinois Health Care Surrogate Act to create a legally enforceable hierarchy of surrogates to make the decision on behalf of an individual who has not executed, or cannot execute, her own advance directive. In the absence of an advance health-care directive, it must give presumptive legal authority to a patient’s family to determine whether to withhold or withdraw medical treatment for an incompetent based on a combined substituted judgment/best interest analysis.261

The proposed new legislative framework combines existing law and advocates new law to protect those whom Cruzan leaves unprotected. Although it presents a uniform hierarchy of decision making, the proposed Uniform Act does not dictate the outcome of the decision whether to continue or withhold medical treatment. The great advantage of the proposed Uniform Act is that it respects the complexity of the problem

261. The proposed Uniform Patient-Family Determination Rights Act should combine a “substituted judgment” analysis with a “best interest” analysis. A surrogate may make a decision on behalf of an incompetent patient who meets the “qualifying condition” requirement modeled after the new Illinois Health Care Surrogate Act. See supra note 226; see also supra text accompanying note 234.
as well as the diversity of answers. Thus, it effectuates personal and familial autonomy and keeps private tragedies out of public forums in all but the most compelling cases.\(^{262}\)

Granting presumptive legal authority to the family pursuant to this proposed framework protects inviolate relationships while yielding different results for different patients. For example, application of the proposed Uniform Patient-Family Determination Rights Act to the *Busalacchi* and *Wanglie* cases should produce two different results because the Busalacchi family believes strongly that Christine would want medical treatment removed\(^ {263}\) and the Wanglie family strongly believed that Helga would wish her life support to be maintained.\(^ {264}\) Because neither patient left her own enforceable expressed wishes, the proposed Uniform Patient-Family Determination Rights Act would allow each family to effectuate those strong beliefs and to act on behalf of their loved one. Christine would be allowed to die and Helga would be allowed to remain on life support. The different results in these two cases mirror and respect the deeply personal nature of the decision each family must make; family members who know the incompetent patient best must be given the opportunity to effectuate what they believe the individual would want. To best approximate the individual's wishes is to act in the best interest of the family member. It validates the individual's autonomy interest as well as the interests of his family.

**CONCLUSION**

According to at least one survey, many Americans do not believe that the death-with-dignity issue is a legal issue at all. Of those surveyed, 0% believed that the state should decide when to withhold or terminate medical treatment, and only

---

262. Unlike the Illinois Health Care Surrogate Act, the Uniform Patient-Family Determination Rights Act should provide a dispute mechanism. In the event of a dispute as to the withholding of medical treatment, resort should first be had to the health-care facility Ethics Committee. Thereafter, resort should be had to the courts if a successful resolution of the dispute is not yet effected. The amended Illinois legislation resorts to the Illinois Probate Code for dispute resolution. *See supra* note 230. "Compelling cases" that may require judicial review of a resolution would include cases where there is a suspicion of abuse, undue influence, or bias.

263. *See Matchan, supra* note 8, at 10.

1% believed that the courts should decide. An overwhelming majority of Americans (95%) think that they themselves should decide whether to withhold or terminate treatment, barring that, an astonishingly high number (between 80% and 88%) think that a family member should decide for them if they become incompetent to decide for themselves. Yet there is no existing nationwide framework that facilitates and effectuates this emerging national will.

A person’s right to die is, of course, in some respects a legal issue. The United States Constitution provides a minimum floor of protection for individuals to die with dignity, that is grounded in the Fourteenth Amendment’s protection of liberty interests as reflected in Cruzan. Further, a state’s parens patriae or police power requires that state to protect the sanctity of life and to protect the vulnerable from abuse.

But it is more than just a legal issue. It is an issue with profound religious, moral, ethical, and medical implications. It is not an issue capable of easy resolution because it is not an issue capable of only one resolution.

Consequently, it is imperative that the nation not fixate on “one resolution” for everyone but instead refocus its attention back to the individual. We must restate and rethink our national objectives. In the past thirty years, medicine and technology have created a brand new “suspended” place that can sustain individuals indefinitely—a place somewhere between life and death. The jurisprudential and legislative response to this new place is inadequate. Following Cruzan, only competent persons are constitutionally allowed to leave this suspended place, because only they can generate the required clear and convincing evidence of their own wishes before they slip into incompetency or terminal illness. Moreover, even the previously competent are hindered because the patchwork and piecemeal response to the problem in state legislatures means that persons in one state frequently do not

265. See Matchan, supra note 8, at 10.
266. See supra note 139 and accompanying text.
267. See supra notes 140–41 and accompanying text. If, as I suggest, the goal of any statutory hierarchy is to replicate the proxy choices a competent person might make, further statistical study is needed to analyze which persons competent individuals most frequently choose as health-care proxies.
268. For an exhaustive discussion of the four state interests identified in the right-to-die debate, see Peters, supra note 58.
269. See supra notes 128, 248.
have the same rights as persons in another. The current patchwork approach causes confusion, inequity, and forum shopping. Judicial resolution of the issue on a case-by-case basis will also be inadequate. Less than six months after the Supreme Court’s landmark decision in *Cruzan*, for example, the nation already was faced with a “reverse *Cruzan*” case and a “*Cruzan* dissent” case.

What is needed, therefore, is a coordinated state and federal program. New priorities must be articulated. These new priorities should be prevention, uniformity and patient-family determination rights. The federal Patient Self-Determination Act goes a long way toward shifting national awareness to prevention of the problem. Because it defers totally to the disparate laws of the fifty states, however, the Patient Self-Determination Act will not achieve its objective of prevention until state legislatures revise their existing advance health-care directive laws. As noted above, the primary problem with the federal legislation is that it only waltzes the patient to the state’s front door.

The proposed framework for a Uniform Patient-Family Determination Rights Act furthers the emerging national will by doing three things: it works in conjunction with the new federal legislation to advise Americans of their rights; it brings clarity and uniformity to the existing law on advance health-care directives; and, for the first time, it fully and uniformly legislatively protects those who have not and will not execute an advance health-care directive.

By changing the national focus to prevention and uniformity, private tragedies like *Cruzan* and *Wanglie* may be kept out of the public forum. Presumably, as previously competent, adult, married women, Helga Wanglie and Nancy Cruzan—had they had an opportunity to do so easily—might have prepared written advance health-care directives. Had they done so, their cases would likely never have gotten to court and their protected individual autonomy interests would have been fully actualized.

Any new national initiative, however, must also fully protect all incompetent patients. Any proposed Uniform Patient-Family Determination Rights Act must recognize the reality that thousands of citizens, now and in the future, will not or cannot generate clear and convincing evidence of their own wishes. By establishing a hierarchy of authority and granting
family members "presumptive rights" to act on behalf of the patient, the proposed legislation, based on the new Illinois Act and the Missouri proposal, will protect the rights of the incompetent individual—her rights to patient autonomy and to have a family member decide on her behalf—as well as the rights of her family. Any proposed uniform act must also protect incompetents without families by including in the hierarchy guardians, friends, and third parties who, where appropriate, may act in the best interests of an incompetent who has left no express directive.

Procedural safeguards for both competent and incompetent patients must be streamlined and made uniform. Procedural safeguards are necessary to protect all patients who, by virtue of their illness (and often, advanced age) are extremely vulnerable. Finally, procedural safeguards recognize the possibility of a slippery slope and provide concrete control over the possibility of abuse. These safeguards should include: medical certification by independent physicians of requisite "qualifying conditions"; extensive waiting periods; the requirement of family unanimity, or "majority approval" where appropriate; and the creation of legal presumptions which are rebuttable and subject to judicial review.

Recent medical technology now makes it imperative. To respect the sanctity of life we must also acknowledge the sanctity of death. Persons should not be denied fundamental rights because they live in different states or because they are very young or very old or, for whatever reason, fail to provide sufficient evidence of their own interests regarding the decision to withdraw or withhold medical treatment.

Finally, respecting the sanctity of life also means respecting the sanctity of the family. The proposed coordinated state and federal campaign places primary emphasis on prevention and uniformity and thus, wherever possible, keeps the hard decisions in the hands of the best decision makers—the individuals themselves. By placing presumptive decision-making authority in family members' hands, it also provides the same

270. Former Senator Jacob Javits, upon contemplation of his own terminal illness and total paralysis, beautifully stated, "[A]s the Bible teaches, the road which opens with birth leads to the grave. Birth and death are the most singular events we experience and, therefore, the contemplation of death as of birth should be a thing of beauty and not of ignobility." Dying with Dignity: Difficult Choices, Hearing Before the House Select Committee on Aging, 99th Cong., 1st Sess. 5–6 (1985) (testimony of former Sen. Jacob Javits).
opportunity for death with dignity to thousands of incompetent patients who, until now, have been disenfranchised and locked in a new, ignoble place, suspended between life and death—a place which is neither of their creation nor of their choosing.

271. See supra note 270.
272. See supra note 128.