

WITHDRAWAL OF TREATMENT FOR MINORS IN A PERSISTENT VEGETATIVE STATE: PARENTS SHOULD DECIDE

Ann MacLean Massie*

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* Assistant Professor, Washington and Lee University School of Law; B.A. 1966, Duke University; J.D. 1971, University of Virginia. The assistance of the Frances Lewis Law Center, Washington and Lee University School of Law, is gratefully acknowledged, along with special gratitude to Dean Randall P. Bezanson and Professor Brian C. Murchison, Washington and Lee University School of Law, and Professor Michael S. Jacobs, De Paul University College of Law, for their thoughtful critiques of the manuscript, and to my able research assistants, Martha Drum, Ginger Jonas Largen, and Georgia Sullivan.

I. INTRODUCTION

A. The Problem Delineated

Loss of a loved one, though a universal experience, is never easy. The loss is particularly poignant and difficult to bear when it is one's own child who has died. Yet even more horrifying is the situation facing close family members when one of their number lies in the condition that has come to be described as a "persistent vegetative state" (PVS)—a death-in-life, where vital organs may continue to function, but consciousness has been irretrievably lost, and the brain has ceased to function on all but the most primitive level.¹ The fact that persons in this condition can frequently be kept alive for indeterminate periods of time through technological means² has in recent years prompted both court decisions³ and legislation⁴ often described as defining a "right to die."⁵ This concept refers primarily to the right of a competent adult to execute advance directives that either specify the limits of life-sustaining measures the person would wish to see

1. See generally Ronald E. Cranford, *The Persistent Vegetative State: The Medical Reality (Getting the Facts Straight)*, HASTINGS CENTER REP., Feb.-Mar. 1988, at 27. Unlike whole brain death, the persistent vegetative state is a condition in which the brain stem, or lower center of the brain, which controls such vegetative functions as respiration and primitive reflexes (for example, the pupillary response to light) remains relatively intact. Higher cerebral functions cease. *Id.* at 27. Persons in a persistent vegetative state have sleep-wake cycles but are totally unaware of themselves and their surroundings. *Id.* at 28. It is estimated that there are 5,000-10,000 PVS patients in the United States, and the number is expected to grow. *Id.* at 31. See also William M. Feinberg & Peggy C. Ferry, *A Fate Worse Than Death: The Persistent Vegetative State in Childhood*, 138 AM. J. OF DISEASES OF CHILDREN 128 (1984) (dealing specifically with diagnosis of persistent vegetative state in children and advocating early discontinuation of life support "if the situation is truly hopeless." *Id.* at 130).

2. Given adequate nutrition and hydration, these patients may survive for a number of years; one documented survival was 37 years, 111 days. Cranford, *The Medical Reality*, *supra* note 1, at 31.

3. SOCIETY FOR THE RIGHT TO DIE, RIGHT-TO-DIE COURT DECISIONS, Vol. I (1987), Vol. II (1987-1989), and Vol. III (1990-) [hereinafter, RIGHT-TO-DIE COURT DECISIONS] currently contain "Fact Sheets" analyzing 67 significant court decisions in the area. This quarterly subscription service regularly lists numerous other cases, some of which are unreported. See, e.g., CHOICE IN DYING, RIGHT-TO-DIE CASE & STATUTORY CITATIONS: STATE-BY-STATE LISTING (June 23, 1992) [hereinafter CASE & STATUTORY CITATIONS]. Choice in Dying is the successor organization to Concern for Dying and the Society for the Right to Die. Its board chairman has described it as "a patient advocacy organization working to improve the way we die in America," and defined its mission as "improving the conditions in which people spend the last days of their lives." Evan R. Collins, Jr., *Choice in Dying Renews Commitment to Its Mission*, 1 CHOICE IN DYING NEWS 1 (Spring 1992). In addition to its publishing activities, the non-profit corporation regularly consults with legislators, attorneys, health care providers, and patients and their families to help promote and preserve the rights of individuals to control treatment decisions. See generally *id.*; SOCIETY FOR THE RIGHT TO DIE, IN SUPPORT OF DYING WITH DIGNITY (1988) (brochure).

4. See SOCIETY FOR THE RIGHT TO DIE, REFUSAL OF TREATMENT LEGISLATION (1991) [hereinafter REFUSAL OF TREATMENT LEGISLATION] (containing over 70 statutes, consisting of all state legislation pertaining to advance directives, durable powers of attorney, and surrogate health care decision-making, updated as of October 1991). Choice in Dying, successor to the Society, regularly updates this compendium through its subscription service, *supra* note 3.

5. In his opinion for the Court in *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 277 (1990), Chief Justice Rehnquist noted, "This is the first case in which we have been squarely presented with the issue of whether the United States Constitution grants what is in common parlance referred to as a 'right to die.'" The terminology is also reflected in the name, "Society for the Right to Die," as well as in the former Society's publications; see *supra* notes 3-4.

utilized in the event of certain terminal conditions or permanent loss of consciousness,⁶ or else name a person or persons empowered to make such decisions.⁷ An increasing number of jurisdictions are also passing surrogate/family decision-making statutes, designating in preferential order individuals who may make medical decisions for a patient who has failed to execute a valid advance directive, including decisions to forego life-sustaining treatment.⁸

In the highly visible case of *Cruzan v. Director, Missouri Department of Health*,⁹ the United States Supreme Court entertained arguments, accepted by a number of state courts, that federal constitutional guarantees give incompetent patients the right to have others make refusal-of-treatment decisions for them when they have failed to make their wishes known while competent.¹⁰ In his 1990 opinion for the Court, Chief Justice Rehnquist conceded that "[t]he principle that a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions,"¹¹ and, for purposes of the decision, assumed "that the United States Constitution would grant a competent person a constitutionally protected right to refuse lifesaving hydration and nutrition."¹² Nonetheless, the majority in *Cruzan* held that the state of Missouri, relying on its "interest in the protection and preservation of human life,"¹³ could prohibit the termination of medical treatment for a PVS patient, absent clear and convincing evidence that such would be her wishes.

Although *Cruzan* was hailed for its recognition of a constitutionally protected right to forego unwanted life-sustaining medical treatment,¹⁴ it was also

6. As of June 1992, 47 states and the District of Columbia had "living will" or "natural death" statutes, which permit individuals to specify in writing their wishes about the use of artificial life support. REFUSAL OF TREATMENT LEGISLATION, *supra* note 4, at Intro.-1; CHOICE IN DYING, LEGAL DEVELOPMENTS, MARCH 1992-JUNE 1992 (June 24, 1992); CHOICE IN DYING, STATE LAW GOVERNING LIVING WILLS/DECLARATIONS AND APPOINTMENT OF A HEALTH CARE AGENT (Feb. 26, 1992) (chart).

7. As of June 1992, 46 states and the District of Columbia had enacted statutes which specifically permit individuals to designate others to make medical decisions for them, including decisions concerning the withholding or withdrawal of artificial means of life support. In two additional states, general durable power of attorney statutes have been construed by court decisions, Attorney General opinions, or by other statutes to permit the making of such medical decisions. CHOICE IN DYING, STATE LAW GOVERNING DURABLE POWER OF ATTORNEY, HEALTH CARE AGENTS, PROXY APPOINTMENTS (June 23, 1992) (chart).

8. As of June 1992, 20 states and the District of Columbia had such statutes, while in three additional states, court decisions had interpreted existing laws to permit surrogate decision-making, including termination of care decisions. REFUSAL OF TREATMENT LEGISLATION, *supra* note 4, at Intro.-2; CHOICE IN DYING, STATUTES AUTHORIZING SURROGATE/FAMILY DECISIONMAKING (June 23, 1992). See *infra* notes 20-21 and accompanying text.

9. 497 U.S. 261 (1990).

10. See, e.g., *Rasmussen v. Fleming*, 154 Ariz. 207, 741 P.2d 674 (1987); *John F. Kennedy Memorial Hosp. v. Bludworth*, 452 So. 2d 921 (Fla. 1984); *In re Quinlan*, 355 A.2d 647 (N.J. 1976), *cert. denied*, 429 U.S. 922 (1976); *Leach v. Akron Gen. Medical Ctr.*, 426 N.E.2d 809 (Ohio Ct. C. P. Summit County Prob. Div. 1980); *In re Colyer*, 660 P.2d 738 (Wash. 1983).

11. 497 U.S. 261, 278 (1990).

12. 497 U.S. at 279.

13. *Id.* at 280.

14. See, e.g., Ezekiel J. Emanuel, *Securing Patients' Right to Refuse Medical Care: In Praise of the Cruzan Decision*, 92 AM. J. MED. 307 (1992) (asserting that the Supreme Court "clearly strengthened" the rights of competent and incompetent patients); John Kenneth

damned for its limitations.¹⁵ In his dissenting opinion, Justice Stevens lamented, "The Court's decision 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 if they should experience a similar fate."¹⁶

In the wake of the decision, there has been a flurry of state legislative activity aimed primarily at easing the means for competent persons to issue valid advance directives.¹⁷ In addition, a new federal law requires health care providers to install institutional policies regarding advance directives, to inform patients about their rights under state law, and to document whether or not patients have directives.¹⁸ Evidence of increased public interest in taking advantage of these measures is strong.¹⁹ Nevertheless, the flaw noted by Justice Stevens remains,

Gisleson, Commentary, *Right to Die, Forced to Live: Cruzan v. Director, Missouri Department of Health*, 7 J. CONTEMP. HEALTH L. & POL'Y 401 (1991) (suggesting that the Court's holding could serve as a springboard for broader decisions in the future); L. Gregory Pawlson, *Impact of the Cruzan Case on Medical Practice*, 19 LAW, MED. & HEALTH CARE 69, 70 (1991) ("Cruzan has reinforced the physicians' duty to respect self determination by competent persons in making health care decisions. A further positive result has been the increased awareness by both physicians and patients of the need to discuss issues related to the use of life sustaining treatments") [Dr. Pawlson also sharply criticized the decision's failings, however; see *infra* note 15]; Otto Friedrich, *A Limited Right to Die: the Court Affirms the Principle, but Not for Nancy Cruzan*, TIME, July 9, 1990, at 59 (noting right-to-die advocates' approval of the Court's recognition of right to refuse medical treatment, including artificial nutrition and hydration; this article also considers some experts' reservations about the decision, see *infra* note 15); Linda Greenhouse, *Liberty to Reject Life: Court Decision to Protect the Right to Die Marks Opening of a Constitutional Frontier*, N.Y. TIMES, June 27, 1990, at A16.

15. See, e.g., Larry Gostin, *Life and Death Choices After Cruzan*, 19 LAW, MED. & HEALTH CARE 9 (1991); Patricia A. King, *The Authority of Families to Make Medical Decisions for Incompetent Patients after the Cruzan Decision*, 19 LAW, MED. & HEALTH CARE 76 (1991); Tracy E. Miller, *Public Policy In the Wake of Cruzan: a Case Study of New York's Health Care Proxy Law*, 18 LAW, MED. & HEALTH CARE 360, 365 (1990); Pawlson, *supra* note 14, at 70 ("[T]he Court's narrow focus for its decision, and the resultant failure to limit the power of states to intrude on medical decision-making, have substantially damaged, rather than helped, decision-making regarding life sustaining treatment"); Fenella Rouse, *Advance Directives: Where Are We Heading After Cruzan?*, 18 LAW, MED. & HEALTH CARE 353 (1990); David O. Stewart, *Right to Die, But ...*, A.B.A. J., Sept. 1990, at 36; Friedrich, *supra* note 14; Ellen Goodman, *The High-Tech Twilight Zone*, THE BOSTON GLOBE, June 28, 1990, at 15; Tamar Lewin, *Despite Daughter's Death, Parents Pursue Right-to-Die Case*, N.Y. TIMES, July 28, 1991, at A14. See generally, Symposium, *Medical Decision-Making and the "Right to Die" after Cruzan*, 19 LAW, MED. & HEALTH CARE 5-104 (1991).

16. *Cruzan*, 497 U.S. at 339, accord, Gostin, *supra* note 15, at 10.

17. REFUSAL OF TREATMENT LEGISLATION, *supra* note 4, Intro. (1991). When this compendium appeared in the spring of 1991, plans were simultaneously announced for its update, which was published in the fall, along with a list of changes in 27 states. CHOICE IN DYING, REFUSAL OF TREATMENT LEGISLATION: UPDATE FOR 1991; Paul Katzeff, *States Go to Work after Cruzan*, NAT'L L.J., Sept. 24, 1990, at 16 (noting the increase in durable power-of-attorney statutes, specifically, which may be perceived as preferable to living will statutes because the designated decision-maker can guard against abuse of the incompetent patient's rights).

18. The Patient Self-Determination Act, part of the 1990 Omnibus Budget Reconciliation Act, took effect on December 1, 1991. Pub. L. No. 101-508, 104 Stat. 1388 (1990).

19. See, e.g., Dolores Kong, *Final Wishes: Court Ruling Spurs Rise in Living Wills*, BOSTON GLOBE, Dec. 4, 1990, at 1 (reporting, *inter alia*, that the Society for the Right to Die and Concern for Dying had sent out more than 400,000 forms for advance directives since *Cruzan* was handed down on June 25, 1990); Jill Smolowe, *Bringing an End to Limbo: A Missouri Court Affirms Nancy Cruzan's Right to Die After Hearing "Clear and Convincing" Evidence to Support the Move*, TIME, Dec. 24, 1990, at 64 (noting, "While the Cruzans' legal

particularly with respect to patients who are minors. Even where laws permit designated surrogates to make medical decisions for incompetent patients who have never voiced their preferences, the legislation may either specifically exclude minors²⁰ or else fail to specify that its protections extend to minors as well as to adults.²¹ As a result, if a child falls into a persistent vegetative state, it is often unclear who has authority to make decisions about her care, what liabilities health care facilities may incur, and whether judicial intervention is required before treatment can be terminated. Loving parents may be unable to bring closure to a nightmare that precludes the possibility of even the normal grieving process facing those who lose a child—at least, not without resort to time-consuming and costly legal procedures that only add to an already overwhelming emotional burden.²²

Although courts and commentators alike sometimes point to the paucity of cases on the issue as evidence that withdrawal-of-treatment decisions for children

odyssey is ending, their struggle has persuaded many Americans to seek to avoid the same fate. Since the Supreme Court decision, right-to-die advocates report that inquiries about living wills have surged 550-fold").

20. Five states have surrogate decision-making statutes that fall into this category. Arizona, Arizona Living Wills and Health Care Directives Act, ARIZ. REV. STAT. ANN. § 36-3231 (Supp. 1992); Colorado, Colorado Proxy Decision-Makers for Medical Treatment Act, 1992 Colo. Legis. Serv. 321 (West), COLO. REV. STAT. § 15-18.5-101 to -103 (Supp. 1992); Ohio, OHIO REV. CODE ANN. § 2133.08(A)(1) (Baldwin Supp. 1991); Utah, UTAH CODE ANN. § 75-2-1105(2) (Supp. 1992); and Virginia, VA. CODE ANN. § 54.1-2986 (Michie Supp. 1992), as amended by 1992 Va. Acts ch. 748. In Ohio, Utah, and Virginia, these statutes contain "preservation of rights" clauses, specifying that their provisions do not affect any other legal rights that persons may have to effect termination of life support systems. OHIO REV. CODE ANN. § 2133.12(C)(2); UTAH CODE ANN. § 75-2-1117(4) (Michie Supp. 1992); VA. CODE ANN. § 54.1-2992 (1991) (referring specifically to "a minor or incompetent patient"). The nature of these "other legal rights" is not clear.

21. The following 13 jurisdictions have ambiguously worded statutes with general language which may or may not authorize medical decision-making to withhold or withdraw life support systems for minors: Connecticut, CONN. GEN. STAT. ANN. § 19a-571 (West Supp. 1992); the District of Columbia, D.C. CODE ANN. § 21-2210 (1989); Florida, FLA. STAT. ANN. § 765.401 (West Supp. 1993); Hawaii, HAW. REV. STAT. § 327D-21 (Supp. 1991), as interpreted by *In re Crabtree*, No. 86-0031 (Haw. Fam. Ct. 1st Cir. Apr. 26, 1990); Iowa, IOWA CODE ANN. § 144A.7 (West 1989); Maine, ME. REV. STAT. ANN. tit. 18-A, § 5-707 (West Supp. 1991); Maryland, MD. CODE ANN., HEALTH-GEN. § 20-107(d) (1990 & Supp. 1991), as interpreted by 73 Op. Att'y Gen. 88-046; Montana, MONT. CODE ANN. § 50-9-106 (1991); Nevada, NEV. REV. STAT. § 449.626 (1991); North Carolina, N.C. GEN. STAT. § 90-322 (1990 & Supp. 1991); Oregon, OR. REV. STAT. § 127.635 (1991); South Carolina, S.C. CODE ANN. §§ 44-66-10 to -80 (Law. Co-op Supp. 1992); and Wyoming, WYO. STAT. §§ 3-5-209(b), 35-22-105(b) (1992). The language of the Uniform Rights of the Terminally Ill Act is also ambiguous. Unif. Rights of the Terminally Ill Act, § 7, 9B U.L.A. 96 (Supp. 1989). Only six states specifically provide that designated persons may make decisions to withhold or withdraw life-sustaining treatment on behalf of minors: Arkansas, ARK. CODE ANN. § 20-17-214 (Michie 1991); Illinois, ILL. REV. STAT. ch. 110 1/2 para. 851-25 (Supp. 1992); Indiana, IND. CODE ANN. § 16-8-12-4 (Burns 1990 & Supp. 1992), as interpreted by *In re Lawrance*, 579 N.E.2d 32 (Ind. 1991); Louisiana, LA. REV. STAT. ANN. § 40:1299.58.6 (West Supp. 1992); New Mexico, N.M. STAT. ANN. § 24-7-4 (Michie 1991); and Texas, TEX. HEALTH & SAFETY CODE ANN. § 672.006 (West Supp. 1992).

22. See, e.g., *In re Barry*, 445 So. 2d 365 (Fla. Dist. Ct. App. 1984) (parents' petition for withdrawal of treatment for infant in persistent vegetative state); *In re L.H.R.*, 321 S.E.2d 716 (Ga. 1984) (same); *In re P.V.W.*, 424 So. 2d 1015 (La. 1982) (same); *In re Swan*, 569 A.2d 1202 (Me. 1990) (parents petitioned as court-appointed guardians on behalf of 18-year-old son, a PVS patient injured in auto accident at age 17). See also *Griffith v. Florida*, 548 So. 2d 244, 245 (Fla. Dist. Ct. App. 1989) (first-degree murder defendant shot and killed his three-year-old daughter, lying in her hospital bed in a persistent vegetative state, because "I didn't want her to suffer anymore"; the primary defense was insanity).

in a persistent vegetative state are routinely handled as private matters between parents and treating physicians,²³ we must not allow the undoubted truth of this assertion to cloud our remembrance of tragic counter examples. While Nancy Cruzan's case was awaiting argument in the Supreme Court, a desperate Rudolfo Linares entered Chicago's Rush-Presbyterian-St. Lukes Medical Center and brandished a gun to keep hospital staff at bay in the pediatric intensive care unit while he disconnected his six-month-old son, Sammy, from a mechanical ventilator and held the child in his arms until the infant died.²⁴ The hospital, particularly its attorney, was commonly criticized for failure to obtain the legal help that was universally assumed available for resolving the situation without such violence.²⁵ Nonetheless, the fact remains that the hospital's refusal to disconnect the respirator at Mr. Linares' request was predicated on a perception of potential civil and criminal liability if it acted without court order²⁶—a perception shared by some commentators,²⁷ despite the lack of prosecutions in such situations.²⁸ The same considerations have impelled other institutions to require court orders before acting on parents' wishes, in proceedings that have sometimes reached the appellate level.²⁹ Within months of the Linares incident, the Illinois Supreme Court affirmed the need for a court order prior to withdrawal of artificial life support from an incompetent patient.³⁰

23. See, e.g., ALAN MEISEL, *THE RIGHT TO DIE* § 1.4 (1989 & Supp. 1991) ("most right to die 'cases' are resolved in the clinical, rather than the judicial, setting"); *id.* § 13.6 ("The number of [court] cases involving children is much smaller than that concerning adult patients, which is probably explained by the lesser uncertainty about the authority of parents to make such decisions for their minor children"); Larry Gostin, *Editor's Introduction: Family Privacy and Persistent Vegetative State*, 17 *LAW, MED. & HEALTH CARE* 295, 296 (1989) (introduction to a symposium issue); Alan Meisel, *Refusing Treatment, Refusing to Talk, and Refusing to Let Go: On Whose Terms Will Death Occur?*, 17 *LAW, MED. & HEALTH CARE* 221 (1989) ("Each day, hundreds, if not thousands, of decisions must be made about administering or withholding life-sustaining treatment for critically ill patients" *id.* at 221); Rouse, *supra* note 15, at 355 ("Conventional wisdom is that now perhaps 70 percent of all deaths occur as the result of a decision to do or not to do something").

24. Gostin, *supra* note 23. See generally, Symposium, *Family Privacy and PVS: A Symposium on the Linares Case*, 17 *LAW, MED. & HEALTH CARE* 295 (1989).

25. See, e.g., Gostin, *supra* note 23, at 295-96; John D. Lantos et al., *The Linares Affair*, 17 *LAW, MED. & HEALTH CARE* 308, 309 (1989); Lawrence J. Nelson & Ronald E. Cranford, *Legal Advice, Moral Paralysis and the Death of Samuel Linares*, 17 *LAW, MED. & HEALTH CARE* 316, 316-17 (1989); *Could an Ethics Committee Have Prevented Linares Tragedy?*, 5 *MED. ETHICS ADVISOR* 69 (1989); *Life-Support Withdrawal Creates Ethical, Legal Dilemmas*, *AMER. HOSP. ASS'N NEWS*, May 15, 1989, at 8.

26. Gilbert M. Goldman et al., *What Actually Happened: An Informed Review of the Linares Incident*, 17 *LAW, MED. & HEALTH CARE* 298, 302-03 (1989).

27. MEISEL, *supra* note 23, § 13.6, at 422; Gostin, *supra* note 23, at 296.

28. Gostin, *supra* note 23, at 296. *But see* Barber v. Superior Court, 195 Cal. Rptr. 484 (Ct. App. 1983) (issuing writ of prohibition on behalf of two doctors charged with murder after acceding to family's request for withdrawal of life support from PVS patient); *In re Rosebush*, 491 N.W.2d 633 (Mich. App. 1990) (county prosecutor interceded to enjoin removal of life support from 13-year-old PVS patient, citing potential criminal liability).

29. *In re Barry*, 445 So. 2d 365 (Fla. Dist. Ct. App. 1984); *In re L.H.R.*, 321 S.E.2d 716 (Ga. 1984); *In re P.V.W.*, 424 So. 2d 1015 (La. 1982); *In re Swan*, 569 A.2d 1202 (Me. 1990). In each of these cases, physicians agreed with parents that life support systems should be withdrawn, but legal uncertainties impelled the parties to seek a court order.

30. *In re Longeway*, 549 N.E.2d 292 (Ill. 1989). Illinois has since passed a surrogate decision-making statute which specifically applies to minors as well as adults; *ILL. REV. STAT.* ch. 110 1/2, para. 851 (Supp. 1992). A health facility in Missouri would surely require a court's permission for withdrawal of life-sustaining treatment for a minor in a persistent vegetative state; indeed, it is highly questionable whether court approval would be forthcoming. See *In re Busalacchi*, No. 59582, 1991 WL 26851 (Mo. Ct. App. Mar. 5, 1991),

The situation of minor children in a persistent vegetative state is particularly worthy of attention. The inherently wrenching nature of their circumstances calls for public policy aimed at easing the families' burdens to the greatest extent possible; yet, unlike formerly competent adults, these patients have never had the capacity to voice their preferences. This fact makes it particularly problematic to apply the "substituted judgment" doctrine³¹ espoused by most courts in cases concerning patients whose general life views, if not actual preferences, were once known. Furthermore, minority status precludes the possibility of meeting the Missouri requirement of clear and convincing evidence of a patient's wishes expressed while competent, a standard validated by the Supreme Court in *Cruzan*. In Missouri, this "Catch-22" permitted the tragic saga of Christine Busalacchi, whose case appeared to be truly unresolvable. Injured in an automobile accident at age seventeen, Christine lay for years in an apparent persistent vegetative state in the same institution where Nancy Cruzan was hospitalized.³² Peter Busalacchi, Christine's father and legal guardian, was unsuccessful in his attempt to remove her to Minnesota for further evaluation and possible withdrawal of care if a diagnosis of persistent vegetative state were to be confirmed.³³

appeal dismissed, 1993 WL 32356 (Mo. Jan. 26, 1993). In its opinion, the Missouri Court of Appeals noted that, given the passage of Christine Busalacchi's eighteenth birthday after her incapacitation, her father's request to transfer his daughter out of state must be evaluated from the standpoint of his role as her guardian, not as her natural father, but "the obligations of a guardian and of a natural parent are not incongruous; both are guided by what is in the best interests of the ward or of the child." *Busalacchi*, 1991 WL 26851 at *3. The court denied Peter Busalacchi's petition, largely, it appears, because it perceived that he was attempting to evade Missouri's stringent laws by transferring his daughter to a health care facility in Minnesota, where a confirmed PVS diagnosis would permit him to withdraw life support systems. *Id.* at *6. See *infra* notes 32-34 and accompanying text. See also *Cruzan v. Harmon*, 760 S.W.2d 408, 424 (Mo. 1988) (construing Missouri's guardianship statute to place an "affirmative duty on guardians to assure that the ward receives medical care" but finding "no statutory basis for the argument that the guardian possesses authority, as a guardian, to order the termination of medical treatment").

31. The "substituted judgment" standard was first enunciated on behalf of a PVS patient in the landmark case of *In re Quinlan*, 355 A.2d 647, 664 (N.J.), *cert. denied*, 429 U.S. 922 (1976): "If a putative decision by Karen to permit this non-cognitive, vegetative existence to terminate by natural forces is regarded as a valuable incident of her right of privacy, as we believe it to be, then it should not be discarded solely on the basis that her condition prevents her conscious exercise of the choice. The only practical way to prevent destruction of the right is to permit the guardian and family of Karen to render their best judgment ... as to whether she would exercise it in these circumstances." Numerous cases have since relied on this kind of analysis. See, e.g., *John F. Kennedy Memorial Hosp. v. Bludworth*, 425 So. 2d 921 (Fla. 1984); *Brophy v. New Eng. Sinai Hosp.*, 497 N.E.2d 626 (Mass. 1986); *In re Colyer*, 660 P.2d 738 (Wash. 1983). Some surrogate decision-making statutes also set forth standards relating to the patient's wishes, if known, or system of values, if known. See *infra* note 145. See also *infra* notes 45-83 and accompanying text (discussing substituted judgment doctrine).

32. See Nancy Gibbs, *Love and Let Die*, TIME, Mar. 19, 1990, at 62. This story, featuring a photograph of Pete Busalacchi and Christine on the cover, describes the situations of both Nancy Cruzan and Christine Busalacchi, as well as others; it appeared before the *Cruzan* decision was handed down.

33. *In re Busalacchi*, No. 59582, 1991 WL 26851 (Mo. Ct. App. Mar. 5, 1991), *appeal dismissed*, 1993 WL 32356 (Mo. Jan. 26, 1993). The Court of Appeals remanded Christine's case to the Probate Court for further evidentiary hearings regarding her condition and prognosis. *Id.* at *6. On appeal, the Missouri Supreme Court affirmed the decision. *High Court Orders Assessment of Busalacchi*, ST. LOUIS POST DISPATCH, Oct. 17, 1991, at 4A. In November 1991, Probate Judge Louis Kohn again ruled in favor of Mr. Busalacchi's right to move Christine to Minnesota. Theresa Tighe, *Judge Rules for Busalacchi*, ST. LOUIS POST DISPATCH, Nov. 30, 1991, at 1A. The Missouri Supreme Court recently dismissed the case, with no opinion on the merits, at the request of the newly-elected State Attorney General. Terry Ganey, *Court Dismisses Busalacchi Case*, ST. LOUIS POST DISPATCH, Jan. 27, 1993, at

The Missouri appellate court's decision suggested that because of Christine's minority at the time of the accident, her case would never be able to meet the *Cruzan* standard required for termination of medical treatment in Missouri.³⁴

This Article takes the position that, absent extraordinary circumstances such as incapacity, conflict of interest, or disagreement between parents, the parents of a minor child with an established diagnosis of persistent vegetative state should have the right to decide whether to terminate medical treatment, including nutrition and hydration. Resort to court intervention should be unnecessary, so long as another disinterested examining physician confirms the treating physician's diagnosis and prognosis of no reasonable hope of return to consciousness. Consultation with an advisory group, such as a hospital ethics committee, may be useful to the parents if they desire it, but should in no way be required or incorporated into the formal channels of a decision-making process.

The right of parental decision-making on behalf of children, including medical decision-making, is well grounded in both common law³⁵ and constitutional jurisprudence.³⁶ While the state has both power and responsibility under the concept of *parens patriae* to act for the best interests of all children,³⁷ this doctrine justifies intervention on behalf of minors only when their parents are guilty of abuse or neglect,³⁸ or when they cannot agree about a vital matter pertaining to the child's welfare, such as in the situation of custody disputes.³⁹ Because withdrawal of treatment is a medically reasonable choice for a PVS patient, no such justification for state intrusion exists when parents make that

1A. More than five years after her accident, Christine finally died at Barnes Hospital in St. Louis, where her feeding tube was withdrawn shortly after the dismissal. Theresa Tighe, *Christine Dies at 22; Father Says "Nobody Won" As Life, Legal Struggle End*, ST. LOUIS POST-DISPATCH, Mar. 8, 1993, at 1A. See also Theresa Tighe, *Busalacchi's Death Offers Few Answers; Missouri Law Remains Silent on Some Life Support Choices*, ST. LOUIS POST-DISPATCH, Mar. 9, 1993, at 1A.

34. *In re Busalacchi*, No. 59582, 1991 WL 26851 at *4 (Mo. Ct. App. Mar. 5, 1991), appeal dismissed, 1993 WL 32356 (Mo. Jan. 26, 1993).

35. See generally MEISEL, *supra* note 23, § 13; JAMES M. MORRISSEY ET AL., CONSENT AND CONFIDENTIALITY IN THE HEALTH CARE OF CHILDREN AND ADOLESCENTS: A LEGAL GUIDE 1-2 (1986); Angela R. Holder, *Special Categories of Consent: Minors and Handicapped Newborns*, in 3 TREATISE ON HEALTH CARE LAW (Michael G. MacDonald et al. eds., 1991) § 19.01, at 19-4, 19-5 (noting, *inter alia*, that at common law, medical treatment of a child without the father's permission made the physician liable to the father for assault and battery, as it constituted an interference with his right to control the child; *id.* at 19-5); Karen H. Rothenberg, *Medical Decision Making for Children*, in I BIOLAW: A LEGAL AND ETHICAL REPORTER ON MEDICINE, HEALTH CARE, AND BIOENGINEERING § 8-2.1 (James F. Childress et al. eds., 1989).

36. See, e.g., *Parham v. J.R.*, 442 U.S. 584 (1979) (right to commit child to state mental institution, so long as review procedures were in place); *Wisconsin v. Yoder*, 406 U.S. 205 (1972) (right to withdraw children from school after eighth grade, based on religious values); *Pierce v. Society of Sisters*, 268 U.S. 510 (1925) (right to send children to private or religiously affiliated school); *Meyer v. Nebraska*, 262 U.S. 390 (1923) (right to employ foreign language teacher for children). For further discussion, see *infra* notes 95-103 and accompanying text.

37. See generally HOMER H. CLARK, JR., THE LAW OF DOMESTIC RELATIONS IN THE UNITED STATES § 9.3, at 335 (2d ed. 1988) (using the term "*parens patriae*" to refer to "the power of the state to intercede for the protection of the child's health, safety or welfare").

38. See *id.* § 9.3, at 336, and cases cited therein (when a state seeks to use its *parens patriae* power to order medical treatment for a child whose parents have refused consent, the common procedure is a court declaration that the child is dependent or neglected, followed by appointment of a temporary guardian invested with authority to consent to the medical care).

39. See generally *id.* § 19.1

decision on behalf of their minor child. Furthermore, the same rationale should apply whenever the event responsible for the child's persistent vegetative state occurs during minority, even if the actual diagnosis or decision-making opportunity does not arise until after the patient has attained the age of eighteen. Because the law in this respect is so unclear, and because courts are ill equipped in any given case to provide guidelines covering all potential future cases within their jurisdictions, state legislatures should provide clear surrogate/family decision-making statutes which will include minors and which will insulate from civil or criminal liability health care providers who in good faith act on the decision-makers' directions, provided that the original diagnosis and prognosis were determined in accordance with accepted standards of medical care.

B. Why Are Minors Different?

Obviously, all persons in a persistent vegetative state are incompetent; therefore someone else must make any relevant decisions concerning their medical care. Beginning in 1976 with the seminal case of *In re Quinlan*,⁴⁰ courts began to recognize the validity of the concept that appropriate medical care for a person in a persistent vegetative state could entail a decision to withhold or to withdraw certain life-sustaining measures which could properly be characterized as prolonging the dying process rather than providing any possible hope for the patient's improvement. In the same year that *Quinlan* was decided, California passed the nation's first Natural Death Act.⁴¹ Thus the stage was set for the national debate over the appropriate parameters and mechanisms for defining and effectuating an individual's "right to die."⁴² Since then, in addition to voluminous legislative enactments,⁴³ there have been more than sixty reported court decisions concerning the withholding or withdrawal of life-sustaining treatment.⁴⁴ An analysis of their bases clarifies why the situation of minors in a persistent vegetative state presents special problems.

In the first case of its kind, *In re Quinlan*,⁴⁵ the New Jersey Supreme Court concluded that Karen Ann Quinlan had a right, grounded in the right of privacy protected by the federal constitution,⁴⁶ to refuse unwanted medical care. This right encompassed a right to decide to withdraw the respirator which doctors had testified was keeping Karen alive.⁴⁷ The court entertained "no doubt ... that if Karen were herself miraculously lucid for an interval ... and perceptive of her irreversible condition, she could effectively decide upon discontinuance of the life-support apparatus, even if it meant the prospect of natural death,"⁴⁸ and ruled that Karen should not lose her right simply by virtue of her incompetency.⁴⁹ It followed that the only practical manner in which her right could be exercised was by a guardian who would be sufficiently familiar with her views to exercise

40. 355 A.2d 647 (N.J.), *cert. denied*, 429 U.S. 922 (1976).

41. REFUSAL OF TREATMENT LEGISLATION, *supra* note 4, at Intro.-1.

42. See *supra* note 5 and accompanying text.

43. See generally REFUSAL OF TREATMENT LEGISLATION, *supra* note 4.

44. See RIGHT-TO-DIE COURT DECISIONS, *supra* note 3; *Cruzan v. Harmon*, 760 S.W.2d 408, 412-13 n.4 (Mo. 1988) (54 cases reported between 1976 and 1988 are collected by state).

45. 355 A.2d 647 (N.J.), *cert. denied*, 429 U.S. 922 (1976).

46. *Id.* at 662-63.

47. *Id.* at 663-64.

48. *Id.* at 663.

49. *Id.*

"substituted judgment"⁵⁰ on her behalf.⁵¹ Karen's father, Joseph Quinlan, was found to be an appropriate guardian to perform this function.⁵²

It is important to note that the New Jersey Supreme Court specifically rejected Mr. Quinlan's arguments based on his parental relationship with Karen, stating that "Insofar as a parental right of privacy has been recognized, it has been in the context of determining the rearing of infants and ... involved 'continuing life styles.'"⁵³ Karen was a twenty-two-year-old adult at the time of the decision.⁵⁴ It is true that the court mentioned that Karen's family should be included in the guardian's decision-making process,⁵⁵ and that we do not know how the court might have treated Mr. Quinlan's claims to decision-making power based on his parental relationship if Karen had been a minor. However, the court insisted upon keeping its decision grounded firmly in "substituted judgment" concepts by noting that the decision to withdraw life support would not involve "the unlawful taking of the life of another," inasmuch as it would be "a matter of [Karen's] self-determination."⁵⁶ If self-determination is the necessary key to valid refusal-of-treatment decisions, a minor, definitionally never competent by reason of age, is in danger of legal limbo where such decisions are concerned.

The question of making a refusal-of-treatment decision for a never-competent person arose a year after *Quinlan* in *Superintendent of Belchertown State School v. Saikewicz*.⁵⁷ In analyzing whether to follow the advice of a guardian to forego painful chemotherapy for a profoundly retarded sixty-seven-year-old man with leukemia, the Massachusetts Supreme Court agreed with its New Jersey counterpart that individuals do have a right to refuse medical treatment,⁵⁸ including, in appropriate circumstances, potentially life-prolonging treatment.⁵⁹ Furthermore, "[t]he recognition of that right must extend to the case of an

50. *Id.* at 666 (referring to "the doctrine of 'substituted judgment'" by name; see *supra* note 31 for the court's definition of that concept).

51. *Id.* at 664.

52. *Id.* at 670-71.

53. *Id.* at 664 (citing and quoting the trial judge's reasoning, 348 A.2d 801, 822 (N.J. Ct. Ch. Div. 1975)). An additional reason why the trial court found the parental right to privacy argument lacking is based upon the fact that the right to privacy is never an absolute power, whether exercised by or on behalf of an individual. 348 A.2d at 822. Therefore, to uphold the parental right to refuse medical treatment on behalf of a child would be to undermine the "doctor's duty to provide life-giving care." *Id.* In sum, the trial court held that "[t]here is no constitutional right to die that can be asserted by a parent for his incompetent adult child." *Id.*

54. 355 A.2d at 664.

55. *Id.* at 664, 671.

56. *Id.* at 670.

57. 370 N.E.2d 417 (Mass. 1977).

58. The Massachusetts court grounded the right in both common law concepts of the right to be "free from nonconsensual invasion of ... bodily integrity," *id.* at 424, which gave rise to the doctrine of informed consent, and in the "constitutional right of privacy found in the penumbra of specific guaranties of the Bill of Rights." *Id.*

59. The court identified four potentially countervailing state interests which might outweigh a person's right to refuse medical treatment: "(1) the preservation of life; (2) the protection of the interests of innocent third parties; (3) the prevention of suicide; and (4) maintaining the ethical integrity of the medical profession." *Id.* at 425. The preservation of human life was identified as the most significant interest implicated in the case, but the court found that in the situation of an incurable illness, where "the issue is not whether but when, for how long, and at what cost to the individual that life may be briefly extended The value of life ... is lessened not by a decision to refuse treatment, but by the failure to allow a competent human being the right of choice." *Id.* at 426. See *infra* notes 220-22 and accompanying text (discussing state interests).

incompetent, as well as a competent, patient because the value of human dignity extends to both."⁶⁰ The court also agreed that the "substituted judgment" standard delineated in *Quinlan* "[c]ommends itself simply because of its straightforward respect for the integrity and autonomy of the individual."⁶¹ The Massachusetts court echoed *Quinlan's* reference to a hypothetical "lucid interval"⁶² when it characterized the decision as "that which would be made by the incompetent person, if that person were competent, but taking into account the present and future incompetency of the individual as one of the factors which would necessarily enter into the decision-making process of the competent person."⁶³

There is a clear analogy between minors and never-competent adults. The age of majority is generally eighteen;⁶⁴ it is also usually the requisite for executing a valid advance directive.⁶⁵ It may additionally be perceived as the necessary age for voicing preferences of sufficient probative value to meet the *Cruzan* standard.⁶⁶ The question arises whether the *Quinlan/Saikewicz* "lucid interval" analysis, which posits first that incompetent persons must be accorded the same

60. *Id.* at 427.

61. *Id.* at 431.

62. See *supra* note 48 and accompanying text.

63. 370 N.E.2d at 431.

64. See CLARK, *supra* note 37, § 8.1, at 309 (noting that most states have amended age of majority statutes to include persons age 18 and older). *But see* ALA. CODE § 26-1-1 (1986 & Supp. 1990) (age of majority reduced from 21 to 19); MISS. CODE ANN. §§ 1-3-21, -27 (1972) (age of majority remains 21); NEB. REV. STAT. § 43-2101 (1988) (same); 1 PA. CONS. STAT. ANN. § 1991 (Purdon Supp. 1991) (same); WYO. STAT. § 8-1-102 (1989) (age of majority reduced to 19).

65. *But see* ALA. CODE § 22-8A-4(a) (1990) and *supra* note 64 (restricting applicability of act to adult persons, which in Alabama means age 19 or older); IDAHO CODE § 39-4503(2) (1985 & Supp. 1991) (including emancipated minors within provisions of advance directive statute); ILL. REV. STAT. ch. 110 1/2, para. 703(a) (Supp. 1992) (same); N.C. GEN. STAT. § 90-321(a)(1), (d) (1990 & Supp. 1991) (stating only that person be of sound mind and making no specific references to age requirement); OKLA. STAT. ANN. tit. 63, § 3102(5) (West Supp. 1991) (requiring that persons issuing advance directives be 21 years or older, although age of majority in Oklahoma is 18); WYO. STAT. § 35-22-102(a) (Supp. 1991) and *supra* note 64 (authorizing adult persons to issue advance directives, which under Wyoming law means age 19 or older). Note that although Maryland incorporates no specific age requirement or "adult person" language in its advance directive statute, the restriction of applicability to "any individual qualified to make a will," results in an age limitation of 18. See MD. CODE ANN., HEALTH-GEN. § 5-602 (1990) and MD. CODE ANN., EST. & TRUSTS § 4-101 (1991).

66. *But see In re E.G.*, 549 N.E.2d 322 (Ill. 1989) (17-year-old girl with leukemia who refused blood transfusions on religious grounds was found to be sufficiently mature to exercise her right to refuse medical treatment; the decision was based on both her common law right and her constitutional rights); *In re Swan*, 569 A.2d 1202 (Me. 1990) (oral statements by PVS patient made at age 17 held to be sufficiently mature and deliberative to govern treatment withdrawal decision). Given the attitudes evinced by the Missouri courts, however, it is highly doubtful that desires expressed before age 18 regarding the termination of life support would ever be honored in that state. See *Cruzan v. Harmon*, 760 S.W.2d 408, 419-20 (Mo. 1988) (citing the state's strong interest in the sanctity of life, which "rests on the principle that life is precious and worthy of preservation without regard to its quality" and linking the state's policy "strongly favoring life" with Missouri's particularly restrictive "Living Will" statute, MO. ANN. STAT. § 459.010 (Vernon Supp. 1991), under which a declarant must be at least 18 years old, and nutrition and hydration are specifically excluded from procedures that may be withdrawn; *In re Busalacchi*, No. 59582, 1991 WL 26851 (Mo. Ct. App. Mar. 5, 1991), *appeal dismissed*, 1993 WL 32356 (Mo. Jan. 26, 1993). *Cf. In re Long Island Jewish Medical Ctr.*, 557 N.Y.S.2d 239, 243 (Sup. Ct. Queens County 1990) (summarily dismissing 17-year-old Jehovah's Witness's attempt to refuse blood transfusion).

rights as competent individuals and secondly that "substituted judgment" is the only appropriate standard, is actually a sound approach for decision-making on behalf of a never-competent person, particularly a minor.

The first supposition—that incompetent persons are entitled to the same rights as competent persons—has been almost universally accepted by state courts. In 1983, the Washington Supreme Court crisply stated, "[a]n incompetent's right to refuse treatment should be equal to a competent's right to do so. No court has denied an individual the right because of incompetency to exercise it."⁶⁷ This tenet has also been relied upon in refusal-of-treatment cases dealing specifically with minors. In 1982, the Massachusetts Supreme Court applied its *Saikewicz* rationale to approve a "do-not-resuscitate" order for an abandoned infant who had become a ward of the state.⁶⁸ That same year, the Louisiana Supreme Court upheld on grounds of "the child's independent right" the validity of a state statute permitting parents and physicians to discontinue life support systems for a permanently comatose child.⁶⁹ In *In re Barry*,⁷⁰ where parents sought to discontinue life support for their ten-month-old son who was in a persistent vegetative state, a Florida court reasoned that "the constitutional right of privacy would be an empty right if one who is incompetent were not granted the right of a competent counterpart to exercise his rights."⁷¹ Again, in *In re L.H.R.*,⁷² also dealing with an infant in a chronic vegetative state, the Georgia Supreme Court, citing *Barry* extensively, held that the right to refuse medical treatment in the absence of a conflicting state interest "rises to the level of a constitutional right which is not lost because of the incompetence or youth of the patient."⁷³

In the eyes of the Missouri Supreme Court, however, the right of an incompetent person to refuse life-sustaining treatment—whether rooted in common law principles⁷⁴ or in a constitutional right of privacy⁷⁵—could not be exercised by a third party "absent the most rigid of formalities."⁷⁶ The court based its conclusion in part on the basic prerequisites of informed consent:

the patient must have the capacity to reason and make judgments, the decision must be made voluntarily and without coercion, and the patient

67. *In re Colyer*, 660 P.2d 738, 744 (Wash. 1983). A year later, the same court applied this concept to a never-competent adult. *In re Hamlin*, 689 P.2d 1372 (Wash. 1984).

68. *Custody of a Minor*, 434 N.E.2d 601 (Mass. 1982). The court reiterated its preference for the "substituted judgment" doctrine over the alternative "best interests of the child" test, noting, however, that in the case of a young child, the two standards involve basically the same reasoning. *Id.* at 608–09 n.10.

69. *In re P.V.W.*, 424 So. 2d 1015, 1018 (La. 1982). The court implied that it would reach the same result even absent the statute when it cited another court's conclusion that "the right of a terminally ill and comatose person to refuse extraordinary means for prolonging life should be accorded equally to competent and incompetent persons, so that the judiciary (in the absence of legislation) must provide the incompetent person with a method by which that right might be exercised." *Id.* (citing *Eichner v. Dillon*, 420 N.E.2d 64 (N.Y. 1981)).

70. 445 So. 2d 365 (Fla. Dist. Ct. App. 1984).

71. 445 So. 2d 365 (Fla. Dist. Ct. App. 1984). The reasoning of *Barry* was specifically cited with approval by the Florida Supreme Court in *John F. Kennedy Memorial Hosp. v. Blutworth*, 452 So. 2d 921 (Fla. 1984).

72. 321 S.E.2d 716 (Ga. 1984).

73. *Id.* at 722.

74. *Cruzan v. Harmon*, 760 S.W.2d 408, 416–17 (Mo. 1988).

75. *Id.* at 417–18.

76. *Id.* at 425. The court's meaning is clarified by its reference to "the formalities required under Missouri's Living Will statutes or the clear and convincing, inherently reliable evidence absent here." *Id.*

must have a clear understanding of the risks and benefits of the proposed treatment alternatives or nontreatment, along with a full understanding of the nature of the disease and the prognosis.⁷⁷

In light of these criteria, reasoned the court, "it is definitionally impossible for a person to make an informed decision—either to consent or to refuse—under hypothetical circumstances"⁷⁸ The court also quoted renowned constitutional law commentator Laurence Tribe: "Given the fact that these patients are irreversibly comatose or in a chronic vegetative state, attributing "rights" to these patients at all is somewhat problematic"⁷⁹

The United States Supreme Court was even more overtly troubled by the assertion that an incompetent person should possess the same rights as a competent one. The opinion states:

The difficulty with petitioners' claim is that in a sense it begs the question: an incompetent person is not able to make an informed and voluntary choice to exercise a hypothetical right to refuse treatment or any other right. Such a "right" must be exercised for her, if at all, by some sort of surrogate. Here, Missouri has in effect recognized that under certain circumstances a surrogate may act for the patient in electing to have hydration and nutrition withdrawn in such a way as to cause death, but it has established a procedural safeguard to assure that the action of the surrogate conforms as best it may to the wishes expressed by the patient while competent. Missouri requires that evidence of the incompetent's wishes as to the withdrawal of treatment be proved by clear and convincing evidence.⁸⁰

In light of the importance of the state's asserted interest in the "protection and preservation of human life,"⁸¹ the Court approved Missouri's standard, which eschews the "lucid interval" analysis of *Quinlan* and *Saikewicz* in favor of requirements that the patient (1) must have made prior statements of sufficient probative value concerning her preferences in such a situation; and (2) must have been competent (*i.e.*, an adult not suffering from a disqualifying mental incapacity) at the time the statements were made.

Even though New York and Missouri are the only two states whose courts have insisted upon such a rigid standard,⁸² there is obvious logic to the position that, absent an advance directive or clearly expressed preferences, it is difficult at best to "don the mental mantle"⁸³ of an incompetent person for purposes of making a "substituted judgment" about whether to forego life-sustaining treatment. The fiction of the "lucid interval" might make sense as applied to patients who have been competent adults and whose general life views and values are known to accessible, concerned people, such as close family members. However, it is totally without foundation, and thus analytically unsatisfactory, in situations

77. *Id.* at 417 (citing Sidney H. Wanzer et al., *The Physician's Responsibility Toward Hopelessly Ill Patients*, 310 NEW ENG. J. MED. 955, 957 (1984)).

78. 760 S.W.2d at 417.

79. *Id.* at 425 (quoting LAURENCE TRIBE, *AMERICAN CONSTITUTIONAL LAW*, 1368 n.25 (1975)).

80. *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 280 (1990).

81. *Id.*

82. In addition to *Cruzan*, see *In re Westchester County Medical Ctr.* (O'Connor), 531 N.E.2d 607 (N.Y. 1988) and *In re Storar*, 420 N.E.2d 64 (N.Y. 1981).

83. *Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417, 431 (Mass. 1977) (quoting *In re Carson*, 241 N.Y.S.2d 288, 289 (N.Y. Sup. Ct. 1962)).

where patients have never been competent, due either to mental incapacity or to minority. Furthermore, given the Supreme Court's validation of the Missouri/New York perspective, the failure to develop a different approach will continue to leave some cases virtually insulated from any decision-making process.

At least where minors are concerned, however, this intolerable state of affairs is resolvable in a manner that will protect both the rights of the minor patients and the legitimate needs of their grieving families. The solution lies at hand in tools of jurisprudence that are already well established and familiar.

II. THE RIGHTS OF PARENTS TO MAKE DECISIONS ON BEHALF OF THEIR MINOR CHILDREN

A. Sources and Scope of the Right

The rights of parents to make decisions concerning the welfare and upbringing of their children have roots in both common law and constitutional doctrine.⁸⁴ Historically, the common law regarded children as the property of their parents, with few, if any, rights of their own.⁸⁵ As the natural guardians of their children, liable for their maintenance and care, parents have the power to consent to medical treatment for their children, who are generally considered too immature to consent for themselves.⁸⁶ In the traditional view, a physician who, in the absence of an emergency, treats a child or performs surgery without the informed consent of the child's parent or legal guardian is liable for the tort of battery.⁸⁷ Exceptions may exist for emancipated minors⁸⁸ or under the "mature minor" rule recognized by some jurisdictions.⁸⁹ In addition, constitutionally protected privacy rights extend some medical decision-making powers to minors,⁹⁰ and most states have statutes permitting minors to consent to certain forms of medical care.⁹¹ By and large, however, the requisite "informed

84. See *supra* notes 35-36.

85. See Holder, *supra* note 35, § 19.01[1]; Rothenberg, *supra* note 35, § 8-2.1.

86. MEISEL, *supra* note 23, § 13.2; Rothenberg, *supra* note 35, § 8-2.1.

87. CLARK, *supra* note 37, § 9.3, at 335 (physician's liability to child in tort); Holder, *supra* note 35, § 19.01[2] (tort liability to father); Rothenberg, *supra* note 35, § 8-2.1.

88. See generally CLARK, *supra* note 37, § 8.3; MEISEL, *supra* note 23, § 13.3; MORRISSEY ET AL., *supra* note 35, at 32-35; Holder, *supra* note 35, § 19.03[3]; Rothenberg, *supra* note 35, § 8-4.2. Some advance directive statutes include emancipated minors among those qualified to execute such documents. IDAHO CODE § 39-4503(2) (1985 & Supp. 1991); ILL. REV. STAT. ch. 110 1/2, para. 851-10 (Supp. 1992); IND. CODE ANN. § 16-8-12-2(2) (Burns 1990 & Supp. 1992). See also *supra* note 65.

89. See CLARK, *supra* note 37, § 8.1, at 311 (noting "a body of case law which holds that if the minor is mature enough to understand the proposed medical or surgical procedure, he may give binding consent to it, perhaps with the additional qualification that the procedure is not one involving serious risk to life or health"). See also *id.* § 9.3, at 335; MEISEL, *supra* note 23, § 13.3; MORRISSEY ET AL., *supra* note 35, at 43-48; Holder, *supra* note 35, § 19.01[4]; Rothenberg, *supra* note 35, § 8-4.1.

90. These include rights to make decisions about procreation, birth control, and abortion. *Bellotti v. Baird*, 443 U.S. 622 (1979) (abortion); *Carey v. Population Servs. Int'l*, 431 U.S. 678 (1977) (contraception); *Planned Parenthood v. Danforth*, 428 U.S. 52 (1976) (abortion). See generally MORRISSEY ET AL., *supra* note 35, at 63-70; Holder, *supra* note 35, §§ 19.06[3]-[4]; Rothenberg, *supra* note 35, § 8-2.2.

91. Public policy has been particularly supportive of statutes permitting minors to consent on a confidential basis to treatment for sexually transmitted diseases and for substance abuse problems. MORRISSEY ET AL., *supra* note 35, at 74-78; Holder, *supra* note 35,

consent"⁹² to nonemergency medical care for children still equates to parental permission.⁹³

In addition to parental prerogatives recognized by the common law, constitutionally protected privacy rights vest in parents' broad rights to make basic decisions concerning the welfare, upbringing, and education of their children.⁹⁴ In *Parham v. J.R.*,⁹⁵ a decision upholding a statute that permitted parents to commit their minor children to state mental hospitals under voluntary commitment procedures, the Supreme Court delineated the foundation for its views:

Our jurisprudence historically has reflected Western civilization concepts of the family as a unit with broad parental authority over minor children. Our cases have consistently followed that course; our constitutional system long ago rejected any notion that a child is "the mere creature of the State" and, on the contrary, asserted that parents generally "have the right, coupled with the high duty, to recognize and prepare [their children] [sic] for additional obligations." ... Surely, this includes a "high duty" to recognize symptoms of illness and to seek and follow medical advice. The law's concept of the family rests on a presumption that parents possess what a child lacks in maturity, experience, and capacity for judgment required for making life's difficult decisions. More important, historically it has recognized that natural bonds of affection lead parents to act in the best interests of their children.⁹⁶

Constitutional rights of the minor patients themselves were implicated in the case, as the Court acknowledged: "[A] child, in common with adults, has a substantial liberty interest in not being confined unnecessarily for medical treatment"⁹⁷ Nonetheless, based on its presumption that parents will act in the best interests of their children, the Court held that, absent abuse or neglect, parents had the right to make the commitment decision on behalf of their minor children, so long as the decision was sustainable on medical grounds.⁹⁸ In this connection, the Court noted that Georgia's requirement of independent diagnostic verification by a physician better served a child's due process rights than would adversarial proceedings in a courtroom, for "neither judges nor administrative hearing officers are better qualified than psychiatrists to render psychiatric judgments."⁹⁹

§ 19.01[3]. Many states have also enacted more general medical consent statutes for minors, frequently designating age of consent at 16. *Id.* § 19.01[3][c]; Rothenberg, *supra* note 35, § 8-4.3.

92. For a general discussion of informed consent and its relationship to minors and their parents, see MORRISSEY ET AL., *supra* note 35, at 12-17.

93. *But see* Holder, *supra* note 35, § 19.01[4] (noting that "there are no reported cases within the past 30 years in the United States in which a parent has recovered damages from a physician for appropriate treatment for which consent had been given not by the parent but by the minor patient who was over the age of 15").

94. *See supra* note 36 and cases cited therein.

95. 442 U.S. 584 (1979).

96. *Id.* at 602 (quoting *Pierce v. Society of Sisters*, 268 U.S. 510, 535 (1925)) (other citations omitted). In his concurrence, Justice Stewart observed, "for centuries it has been a canon of the common law that parents speak for their minor children. So deeply imbedded in our traditions is this principle of law that the Constitution itself may compel a State to respect it." 442 U.S. at 621 (citations omitted).

97. 442 U.S. at 600.

98. *Id.* at 602.

99. *Id.* at 607 (quoting *In re Roger S.*, 569 P.2d 1286, 1299 (Cal. 1977) (Clark, J., dissenting)). The *Parham* Court's opinion also stated: "common human experience and scholarly opinions suggest that the supposed protections of an adversary proceeding to

It is true that the constitutionally protected right of parents to make decisions concerning the welfare of their children is not unlimited and may well be subject to greater restriction in the field of medical decision-making than in any other area.¹⁰⁰ The state's *parens patriae* power permits it not only to enforce broad regulations for the health, welfare, and safety of children, such as compulsory education laws,¹⁰¹ but also to sustain requirements for specific medical procedures, such as universal immunization, even over parental objections based on religious grounds.¹⁰² In individual cases, a court may order medical treatment to which parents have refused consent, and a finding of abuse or neglect, including failure to obtain appropriate medical care for a child, will invariably justify state intervention.¹⁰³ Chief Justice Burger's opinion in *Parham v. J.R.* took account of these premises, and nonetheless found that, unless the individual case presented an instance of abuse or of medically unsound judgment, parental decision-making was to be respected. The reasoning of this case applies as well to other areas of medical decision-making for minors, including the decision to withhold or withdraw treatment from a minor child in a persistent vegetative state: so long as the decision is based upon a confirmed medical diagnosis and there is neither conflict between parents nor any basis upon which to disqualify them as competent decision-makers, they should have the sole right to make the termination-of-treatment decision, without judicial intervention.

B. When Should Parents Be Disqualified?

While parents have broad rights to make decisions on behalf of their minor children, including medical decisions, these rights are not absolute, and under certain circumstances, they may be lost altogether.¹⁰⁴ Several criteria appear to be essential for parents to make a responsible decision to forego life-sustaining treatment for a child in a persistent vegetative state: the parents must be competent to make the decision and must be fully apprised of the information necessary to give their informed consent to the decision; there must not be a disqualifying conflict of interest between the parents and their child; there must be no basis upon which a reasonable person could characterize the parents as guilty of abuse or neglect with respect to their child; and, if the decision is to be effectuated

determine the appropriateness of medical decisions for the commitment and treatment of mental and emotional illness may well be more illusory than real." 442 U.S. at 609. This article suggests that the same observation holds true for medical decisions concerning the withholding or withdrawal of life-sustaining treatment for minors in a persistent vegetative state.

100. See, e.g., CLARK, *supra* note 37, § 9.3, at 335 ("Broad state intervention in children's health occurs pursuant to statutes which require immunization against certain diseases, medical examinations for children entering the public schools, and certain treatments for newborn children"). See generally Holder, *supra* note 35, § 19.05; Rothenberg, *supra* note 35, §§ 8-2.3, 8-2.4.

101. CLARK, *supra* note 37, § 9.2.

102. *Id.* § 9.3, at 335-36.

103. See generally *id.* § 9.3, at 336-38, and cases cited therein; MEISEL, *supra* note 23, § 13.5, at 418-19, and cases cited therein; MORRISSEY ET AL., *supra* note 35, at 94-101; Holder, *supra* note 35, § 19.05 and cases cited therein; John C. Williams, Annotation, *Power of Court or Other Public Agency to Order Medical Treatment for Child over Parental Objections Not Based on Religious Grounds*, 97 A.L.R.3d 421 (1980); Kenneth J. Rampino, Annotation, *Power of Court or Other Public Agency to Order Medical Treatment over Parental Religious Objections for Child Whose Life Is Not Immediately Endangered*, 52 A.L.R.3d 1118 (1973).

104. See *supra* notes 100-03 and accompanying text.

without judicial supervision, there should be no conflict or difference of opinion on the issue between the two parents.¹⁰⁵ Finally, if the child is an older minor of demonstrable maturity and has expressed views about how she would want to be treated,¹⁰⁶ the question arises whether that expression should be sufficient to override a contrary parental decision.

1. Competence

Valid medical decision-making is in every instance predicated upon informed consent.¹⁰⁷ The necessity that informed consent be given prior to the

105. These or similar factors have been generally referenced in cases concerning withdrawal of treatment for minors. See *In re Barry*, 445 So. 2d 365, 371 (Fla. Dist. Ct. App. 1984) (parents were "adequately informed," had consulted religious advisors, were "not motivated by any financial strain" and judgment was "backed by uncontroverted medical evidence"). Cf. *In re L.H.R.*, 321 S.E.2d 716, 722-23 (Ga. 1984) ("In a case of suspected neglect or abuse or when the parent assumes a stance which in any way endangers the child, the parent's right to speak for the child may be lost [C]ourts remain available in the event of disagreement between the parties, any case of suspected abuse, or other appropriate instances"); *In re Doe*, No. D-93064, slip op. at 14 (Ga. Super. Ct. Fulton County Oct. 17, 1991) ("[A]ny interference in family privacy by state action must be viewed as a drastic remedy which should be resorted to only in extreme cases where a child has been grossly neglected or abandoned, where there is a substantial risk that the child will imminently suffer serious moral harm or serious mental, emotional, sexual, physical abuse, harm or cruelty from the parents, or when the court otherwise finds a parent unfit or that the conduct or condition of a parent is such as to render that parent unable to properly care for the child, or if there is serious conflict of interest") (citing *In re L.H.R.*, Georgia statutes on termination of parental rights, and *In re Baby Doe*), *aff'd*, 418 S.E.2d 3 (Ga. 1992) (court involvement necessary because of parental disagreement); *In re Doe*, No. D-62058, slip op. at 5 (Ga. Super. Ct. Fulton County Nov. 30, 1988) [hereinafter cited as *In re Baby Doe* to prevent confusion with *In re Doe* from the same court] (pursuant to the ruling in *In re L.H.R.*, father suspected of abuse lost right to speak for child; the court and the mother must decide, *id.* at 9); *In re Rosebush*, No. 88 349180 AZ, slip op. at 7-8 (Mich. Cir. Ct. Oakland County July 29, 1988) (noting the thoroughness of the parents' decision-making process, including consultation with physicians, a hospital ethics committee, and spiritual advisors for over 15 months to arrive at a decision that "was not reached hastily or arbitrarily" and "was made in good faith"). Commentators have also emphasized the importance of these factors as prerequisites to parental decision-making. See ANGELA RODDEY HOLDER, LEGAL ISSUES IN PEDIATRICS AND ADOLESCENT MEDICINE 118-19 (2d ed. 1985) (requiring correct diagnosis, prognosis, and absence of abuse); MEISEL, *supra* note 23, § 13.10, at 425 (citing *In re Barry*, 445 So. 2d 365 (Fla. Dist. Ct. App. 1984) and *In re L.H.R.*, 321 S.E.2d 716 (Ga. 1984)); Lantos et al., *supra* note 25, at 311, 313 (requiring parental agreement).

106. This was the situation in *In re E.G.*, 549 N.E.2d 322 (Ill. 1989), *reh'g denied*, (1990) (17-year-old Jehovah's Witness wished to refuse blood transfusion; her mother acquiesced in her decision) and *In re Swan*, 569 A.2d 1202 (Me. 1990) (PVS patient injured in auto accident at age 17 had previously stated desire not to be maintained in such a condition). In each case, the court based its decision on the minor's expressed wishes. See also John E. Schowalter et al., *The Adolescent Patient's Decision to Die*, 51 PEDIATRICS 97 (Jan. 1973) (relating story of handling at Yale-New Haven Hospital of 16-year-old conscious renal patient's decision to halt treatment, in which her parents acquiesced; after psychiatric work with the patient and her family, the medical staff overcame its initial reluctance and supported the choice).

107. This common law doctrine is frequently traced to a famous statement by Justice Cardozo, while sitting on the Court of Appeals of New York: "Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages." *Schloendorff v. Society of New York Hosp.*, 105 N.E. 92, 93 (1914). See *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 269 (1990). See generally TOM L. BEAUCHAMP & JAMES F. CHILDRESS, PRINCIPLES OF BIOMEDICAL ETHICS 74-111, 78 (3d ed. 1989), (discussing the "elements of informed consent" as "1. Disclosure; 2. Understanding; 3. Voluntariness; 4. Competence; 5. Consent."); PRESIDENT'S COMM'N FOR

administration of medical care (absent emergency) is frequently characterized as the basis for the validity of refusal-of-treatment decisions as well.¹⁰⁸ Except in special situations, parents must give their informed consent to medical treatment of their children.¹⁰⁹ As pointed out by the Missouri Supreme Court in its *Cruzan* opinion, informed consent requires, at a minimum, (1) "the capacity to reason and make judgments"; (2) "the decision must be made voluntarily and without coercion"; (3) "a clear understanding of the risks and benefits of the proposed treatment alternatives or [the alternative of] nontreatment"; and (4) "a full understanding of the nature of the disease and the prognosis."¹¹⁰

Thus, in order to make a valid refusal-of-treatment decision for a minor child in a persistent vegetative state, parents must be competent, both in the sense of having the requisite mental capacity¹¹¹ and in the sense of having the appropriate information upon which to base their decision. Providing the information is the task of the involved medical personnel, primarily the treating physician.¹¹² As in other situations, mental capacity can normally be presumed.¹¹³ If involved medical personnel doubt capacity in any given instance of parental decision-making, this would justify resort to judicial intervention.¹¹⁴

THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, I MAKING HEALTH CARE DECISIONS, 1-111 (1982) [hereinafter HEALTH CARE DECISIONS] ("Informed consent is rooted in the fundamental recognition—reflected in the legal presumption of competency—that adults are entitled to accept or reject health care interventions on the basis of their own personal values and in furtherance of their own personal goals." *Id.* at 2-3); ARNOLD J. ROSOFF, INFORMED CONSENT: A GUIDE FOR HEALTH CARE PROVIDERS (1981).

108. See *Cruzan*, 497 U.S. at 270 ("The logical corollary of the doctrine of informed consent is that the patient generally possesses the right not to consent, that is, to refuse treatment"); *In re Conroy*, 486 A.2d 1209, 1222 (N.J. 1985) ("The patient's ability to control his bodily integrity through informed consent is significant only when one recognizes that this right also encompasses a right to informed refusal"); *In re Quinlan*, 355 A.2d 647, 663 (N.J.), *cert. denied*, 429 U.S. 922 (1976). See generally THE HASTINGS CENTER, GUIDELINES ON THE TERMINATION OF LIFE-SUSTAINING TREATMENT AND THE CARE OF THE DYING (1987) [hereinafter THE HASTINGS CENTER]; PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT 43-90 (1983) [hereinafter DECIDING TO FOREGO].

109. See *supra* notes 86-103 and accompanying text.

110. *Cruzan v. Harmon*, 760 S.W.2d 408, 417 (Mo. 1988) (quoting Wanzer et al., *supra* note 77). See also *supra* note 107 and sources cited therein.

111. See BEAUCHAMP & CHILDRESS, *supra* note 107, at 79-85. See also *id.*, at 99-106 (discussing "understanding"); DECIDING TO FOREGO, *supra* note 108, at 45; HEALTH CARE DECISIONS, *supra* note 107, at 55-62, 57 (discussing as "elements of capacity" "(1) possession of a set of values and goals; (2) the ability to communicate and to understand information; and (3) the ability to reason and to deliberate about one's choices").

112. See BEAUCHAMP & CHILDRESS, *supra* note 107, at 85-99; THE HASTINGS CENTER, *supra* note 108, at 20-22; DECIDING TO FOREGO, *supra* note 108, at 51-60; HEALTH CARE DECISIONS, *supra* note 107, at 70-111; Norman L. Cantor, Quinlan, *Privacy, and the Handling of Incompetent Dying Patients*, 30 RUTGERS L. REV. 243, 255 (1977). See also *In re Conroy*, 486 A.2d 1209, 1222 (N.J. 1985) ("In general, it is the doctor's role to provide the necessary medical facts and the patient's role to make the subjective treatment decision based on his understanding of those facts").

113. All the cases dealing with parental decision-making for minors in a persistent vegetative state seem to rely on this assumption, as they contain no separate discussion of the issue. See cases cited *supra* notes 29 and 105. Advance directive statutes frequently specify that a health care provider may assume competence of the declarant. See, e.g., ARIZ. REV. STAT. ANN. § 36-3205(B) (1990); D.C. CODE ANN. § 6-2426(b) (1991); IND. CODE ANN. § 16-8-11-15 (Burns 1990 & Supp. 1992); WIS. STAT. ANN. § 154.07(2) (1990).

114. For example, some of the health care professionals involved in the care of Sammy Linares later expressed doubt about the capacity of the Linares family, particularly Rudy

2. Conflict of Interest

In holding that the parents of a ten-month-old child in a chronic vegetative state could order discontinuation of life support, and further that parents similarly situated need not obtain judicial permission to make such a decision, a Florida District Court of Appeal took note of the physicians' testimony that the parents' decision "was not motivated by any financial strain because one hundred percent of all the medical expenses were being covered by their insurance."¹¹⁵ Other courts ruling in favor of the rights of surrogates to make decisions for incompetent patients have observed the inherent potential for conflict of interest.¹¹⁶ Logically, the question would appear most likely to arise either in the event that the patient's death would mean relief of a financial burden to the decision-maker or in circumstances where the decision-maker might stand to benefit financially upon the patient's death. Often, however, expenses are borne either by insurance coverage or by the state itself.¹¹⁷ Furthermore, instances in which parents will

Linares, to have made a reasoned decision, if given the opportunity. Goldman et al., *supra* note 26, at 302-03 (citing Mr. Linares' alleged alcohol and drug abuse problems, along with previous trouble with the police).

115. *In re Barry*, 445 So. 2d 365, 371 (Fla. Dist. Ct. App. 1984).

116. See, e.g., *In re Drabick*, 245 Cal. Rptr. 840, 861 (Ct. App.), *cert. denied*, Drabick v. Drabick, 488 U.S. 958 (1988) (requisite good faith "precludes a decision affected by a material conflict of interest"); Barber v. Superior Court, 195 Cal. Rptr. 484, 493 (Ct. App. 1983) (noting lack of evidence of any motivation "other than love and concern for the dignity of their husband and father"); John F. Kennedy Memorial Hosp. v. Blutworth, 452 So. 2d 921, 926-27 (Fla. 1984) ("[E]vidence of wrongful motives ... may require judicial intervention"); *In re Conroy*, 486 A.2d 1209, 1218 (N.J. 1985) (noting that "[T]here was no question that the nephew had good intentions and had no real conflict of interest due to possible inheritance ..."); *In re Colyer*, 660 P.2d 738, 747 (Wash. 1983) (pointing to general laws controlling guardianships as safeguards against potential conflicts of interest). The Illinois surrogate decision-making statute expressly provides that the surrogate "shall not be liable merely because the surrogate may benefit from the act" or "has individual or conflicting interests in relation to the care and affairs of the patient ..." ILL. REV. STAT. ch. 110 1/2, para. 851-30(c) (Supp. 1992). Cf. *In re Steinhaus*, (Minn. Redwood County Ct. Juv. Div. Sept. 11, 1986), *rev'd*, (Redwood County Ct. Fam. Div. Oct. 13, 1986). In *Steinhaus*, the Juvenile Division judge, refusing to allow termination of treatment, stated in a memorandum following his decision that ending treatment "would certainly have some benefits. ... The child's death would ... put an end to the extensive medical care which must by this time amount to tremendous expense." *Id.* slip op. at 17. This decision was reversed in the Family Division when additional medical evidence proved the child to be in a persistent vegetative state.

117. In *In re Barry*, 445 So. 2d 365, 371 (Fla. Dist. Ct. App. 1984), the court noted that "one hundred percent of all the medical expenses were being covered by ... insurance." Nancy Cruzan's expenses were borne entirely by the state of Missouri. *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 266 (1990). Christine Busalacchi was in the same state-run facility. Gibbs, *supra* note 32. The fact that only one of the other cases pertaining to PVS minors even mentions financial considerations (in an opinion later reversed, see *In re Steinhaus*, (Minn. Redwood County Ct. Juv. Div. Sept. 11, 1986), *rev'd*, (Redwood County Ct. Fam. Div. Oct. 13, 1986)) suggests that the courts did not find them relevant, despite the obvious high costs associated with such intensive care. See, e.g., *In re Rosebush*, No. 88 349180 AZ, slip op. at 4 (Mich. Cir. Ct. Oakland County July 29, 1988), *appeal filed*, No. 111082 (Mich. Ct. App. 1990) (PVS child injured in a car accident at age 12 "has had around-the-clock private duty nurses; a team of rehabilitation therapists; and medical treatment and consultation" in failed attempts at rehabilitative therapy. Even so, the parents' decision "was an agonizing one which took some fifteen months to make." *Id.* at 8). But see Goldman et al., *supra* note 26, at 303, citing the fact that the Linares family had received a letter from the Illinois Department of Public Aid that medical benefits for Sammy's care would be cut off on April 30, 1989; Mr. Linares forcibly removed Sammy from his ventilator on Apr. 26. Cf. Gibbs, *supra* note 32, at 70 (quoting the Rev. Harry Cole, whose wife fell into a coma after a severe stroke from which she was not expected to recover: "If she were to go on that way, our family faced not only the incredible pain of watching her vegetate, but we also faced harsh practical realities. [Given that

actually benefit financially from the death of a minor child are likely to be rare.¹¹⁸ Even where surrogate decision-makers could expect to be beneficiaries of an estate upon an incompetent patient's death, courts have not found that fact, standing alone, necessarily disqualifying.¹¹⁹ Where close family ties are involved, emotional bonds can ordinarily be counted on to serve as the primary impelling force in the decision-making process.¹²⁰ Nonetheless, if involved medical personnel perceive that conflict of interest is playing an inappropriate role in the parents' decision, they might well seek resort to judicial validation.

Of course, there can be noneconomic conflicts of interest. The emotional burden on parents of coping with their unconscious child's condition, particularly acute upon regular visits to the hospital (or the guilt incurred by staying away), could clearly engender an attitude of seeking the relief of resolution. The toll on other family members, and on family life in general, could exacerbate this

nursing home care would likely cost over \$30,000 per year] [h]ow could I continue to send three kids to college with the additional financial strain?" Cole sought to have his wife's respirator removed; six days after a judge stayed the decision, Jackie Cole woke up).

118. None of the cases concerning minors mentioned anticipated financial benefit upon the minor's death. This kind of expectation has been noted, however, in cases concerning adult patients. *In re Conroy*, 486 A.2d 1209, 1218 (N.J. 1985); *In re Colyer*, 660 P.2d 738, 747 (Wash. 1983).

119. *Colyer*, 660 P.2d at 747 (noting that "a guardian might act on the basis of less than worthy motives, i.e., an interest in the incompetent's estate or a desire to alleviate the financial burden of the life sustaining treatment," the court expressed faith in the safeguards provided in guardianship laws. In a footnote, it said: "While we are aware that a family member who petitions to be a guardian may be a beneficiary of the estate of the incompetent, this alone should not disqualify the petitioner. In most instances, the familial relationship will strengthen, and not undermine, the guardian's best judgment in exercising the personal rights of the incompetent." *Id.* n.40); *cf. In re Drabick*, 245 Cal. Rptr. 840, 861 n.38 (Ct. App.), *cert. denied*, 488 U.S. 958 (1988) (where conservator was the beneficiary of a \$40,000 life insurance policy on his brother, the conservatee, the court stated, "While it is hard to avoid the conclusion that this financial interest is logically relevant to the conservator's good faith, it does not follow that this interest would compel the superior court to disapprove the petition or, more appropriately, to appoint a new conservator. Conservators will often be chosen from the conservatee's immediate family, since family members are most likely to appreciate the conservatee's personal values." Noting that California's Probate Code preferred designated family members as conservators, the court observed, "Since immediate family members are likely to have some testamentary or beneficial interest, an inflexible rule in this area would often eliminate those persons most qualified to serve as conservators." *Id.*). This reasoning would surely apply to a number of instances, particularly where the patient is an adult. Illinois's surrogate decision-making statute includes a provision that "The surrogate shall not be liable merely because the surrogate may benefit from the act, has individual or conflicting interests in relation to the care and affairs of the patient, or acts in a different manner with respect to the patient's and the surrogate's own care or interests." ILL. REV. STAT. ch. 110 1/2, para. 851-30(c) (Supp. 1992). Illinois' explicit faith in surrogates who may also be heirs is implicit in almost all other surrogacy statutes, which list as authorized decision-makers spouses, parents, children, and siblings, all of whom are potential heirs at probate. *See, e.g.*, ARK. CODE ANN. § 20-17-214 (Michie Supp. 1991); IOWA CODE ANN. § 144A.7 (West 1989); MD. CODE ANN., HEALTH-GEN. § 20-107(d) (1990 & Supp. 1991); TEX. HEALTH & SAFETY CODE ANN. § 672.009 (West. Supp. 1992).

120. *See, e.g., Colyer*, 660 P.2d 738; *Drabick*, 245 Cal. Rptr. 840; *In re Barry*, 445 So. 2d 365, 371 (Fla. Dist. Ct. App. 1984) ("[D]ecisions of this character have traditionally been made within the privacy of the family relationship based on competent medical advice and consultation by the family with their religious advisors, if that be their persuasion"); *In re L.H.R.*, 321 S.E.2d 716, 722 (Ga. 1984) ("[N]atural bonds of affection lead parents to act in the best interests of their children") (quoting *Parham v. J.R.*, 442 U.S. 584, 602 (1979)), *see supra* notes 95-99 and accompanying text). *See also* DECIDING TO FOREGO, *supra* note 108, at 127-28 (citing five reasons why family members are the best surrogate decision-makers, beginning with, "The family is generally most concerned about the good of the patient").

desire.¹²¹ These considerations might raise troubling conflicts in other medical contexts. Here, however, the requirement that parents receive a firm PVS diagnosis, with a prognosis of no reasonable hope of return to consciousness, before they can decide to withdraw life support systems, mitigates substantial conflict-of-interest concerns. Some commentators have indeed suggested that when the diagnosis is clear, it is altogether appropriate for decision-makers to take into account general family interests¹²² as well as their own religious viewpoint.¹²³

3. Cases of Abuse or Neglect

The Supreme Court in *Parham v. J.R.* specifically acknowledged an obligation on the part of parents "to recognize symptoms of illness and to seek and follow medical advice."¹²⁴ All states include medical neglect as grounds for state intervention in their child abuse statutes,¹²⁵ and a finding of neglect is the common predicate for ordering medical care for a minor over parental objection, even when that objection is religiously based.¹²⁶ Involved medical personnel have a statutory duty to seek government intervention in situations where they suspect child abuse or neglect.¹²⁷ As with conflict of interest criteria, however, abuse or

121. See generally Gibbs, *supra* note 32. The article recounts the agonies of the Cruzans and other families of terminal or PVS patients, and quotes Pete Busalacchi, Christine's father: "This has been a 34-month funeral." *Id.* at 62. See also Griffith v. Florida, 548 So. 2d 244, 245 (Fla. App. 1989) (distraught defendant shot his three-year-old PVS daughter in her hospital bed because "I didn't want her to suffer anymore"); *In re Quinlan*, 355 A.2d 647 (N.J.), *cert. denied*, 429 U.S. 922 (1976); Pete Busalacchi, *How Can They?*, HASTINGS CENTER REP., Sept.-Oct. 1990, at 6; Rebecca S. Dresser, *Life, Death, and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law*, 28 ARIZ. L. REV. 373, 395-96 (1986); Goldman et al., *supra* note 26, at 301 (noting the impact of Sammy Linares' condition on the rest of the family, particularly the sister who had allowed him to play with her balloon, which he aspirated); John A. Hardwig, *What About the Family?*, HASTINGS CENTER REP., Mar.-Apr. 1990, at 5-6; DECIDING TO FOREGO, *supra* note 108, at 185.

122. The concept of the need for developing a family-centered medical ethic (and concomitant laws), particularly in cases of the kind at issue here, has recently been gaining increasing ground. See Dresser, *supra* note 121, at 395; Gostin, *supra* note 23, at 297 ("The right to privacy that is actually being asserted is a right belonging to the family unit which includes the patient"); Hardwig, *supra* note 121, at 5; King, *supra* note 15; Hilde Lindemann Nelson, *The Patient and the Family*, THE HASTINGS CENTER CENTERPIECE, Dec. 1991, at 5; James Lindemann Nelson, *Taking Families Seriously*, HASTINGS CENTER REP., July-Aug. 1992, at 6; Nancy K. Rhoden, *Litigating Life and Death*, 102 HARV. L. REV. 375, 437-39 (1988). For earlier expressions of similar ideas, see Ferdinand Schoeman, *Parental Discretion and Children's Rights: Background and Implications for Medical Decision-Making*, 10 J. MED. & PHIL. 45 (1985); Robert M. Veatch, *Limits of Guardian Treatment Refusal: A Reasonableness Standard*, 9 AM. J.L. & MED. 427, 436-37 (1984). But see Charles H. Baron, *Why Withdrawal of Life-Support for PVS Patients Is Not a Family Decision*, 19 LAW, MED. & HEALTH CARE 73 (1991) (suggesting, however, that we spare families the burdens posed by PVS patients by broadening the definition of death to include this condition).

123. The family's consultation with religious advisers is approvingly noted in several cases; see *In re Barry*, 445 So. 2d 365, 371 (Fla. Dist. Ct. App. 1984); *In re Rosebush*, No. 88 349180 AZ, slip op. at 8 (Mich. Cir. Ct. Oakland County July 29, 1988); *In re Quinlan*, 355 A.2d 647, 657-58 (N.J.), *cert. denied*, 429 U.S. 922 (1976).

124. 442 U.S. 584, 602 (1979). See *supra* notes 95-99 and accompanying text.

125. MORRISSEY ET AL., *supra* note 35, at 96; Holder, *supra* note 35, § 19.05[1]; Rothenberg, *supra* note 35, § 8-2.3(b). See also Child Abuse Prevention and Treatment Act, 42 U.S.C. §§ 5101-5115 (1989), and regulations thereunder, 45 C.F.R. § 1340.2(d)(2)(i) (1991) (providing funding to appropriate state and local agencies; "negligent treatment or maltreatment" specifically includes "failure to provide adequate ... medical care").

126. See Williams, *supra* note 103; Rampino, *supra* note 103.

127. MORRISSEY ET AL., *supra* note 35, at 96; Holder, *supra* note 35, § 19.05[2]; Rothenberg, *supra* note 35, § 8-2.3(b).

neglect appears to be a highly questionable finding if based solely on a parental decision to withhold or withdraw life sustaining treatment in the face of a confirmed diagnosis of persistent vegetative state. On the other hand, any situation where there is reason to suspect that a PVS child has been the victim of parental abuse or neglect poses an appropriate case for judicial intervention; a court should at least terminate the suspected parent's authority, leaving the decision in the hands of the remaining parent.¹²⁸

4. Conflict Between Parents

If both parents of a child in a diagnosed persistent vegetative state are reasonably available, both should agree to the request to withhold or withdraw life sustaining treatment before it is acted upon. This should be true regardless of whether the parents are still married or living together, and regardless of which is the custodial parent. In the words of one court, "parental rights ... are fully vested in each individual parent, not shared as a parental unit."¹²⁹

On the other hand, if a disagreement on the issue should persist over a long period of time, such as six months or more, without any change in the patient's condition, the parent wishing to end treatment should be entitled to resort to a court and request the appointment of a guardian ad litem to make recommendations for resolution in a judicial proceeding.¹³⁰ At some point, it seems just as

128. This was the situation in *In re Baby Doe*, No. D-62058, slip op. at 9 (Ga. Super. Ct. Fulton County Nov. 30, 1988), where suspected child abuse on the father's part resulted in deprivation of his "right to speak for the child," and the conclusion that "the Court and the mother must make the decision for the child." The case was governed by *In re L.H.R.*, 321 S.E.2d 716, 722 (Ga. 1984) ("In a case of suspected neglect or abuse ... the parent's right to speak for the child may be lost"). See also *In re Barry*, 445 So. 2d 365, 368-69 (Fla. Dist. Ct. App. 1984). An abusive parent may in fact be likely to oppose withdrawal of life support from a PVS child, out of fear of criminal charges based on homicide. *Dority v. Superior Court*, 193 Cal. Rptr. 288, 292 (Ct. App. 1983); *In re Haymer*, 450 N.E.2d 940 (Ill. App. Ct. 1983).

129. *In re Doe*, No. D-93064, slip op. at 16 (Ga. Super. Ct. Fulton County Oct. 17, 1991), *aff'd* 418 S.E.2d 3 (Ga. 1992). Even if the parents are separated or only one has custody, the basic presumption recognized in *Parham v. J.R.* that parents have their children's best interests at heart should apply equally, at least until proven otherwise. The six states that have enacted statutes specifically dealing with surrogate/family decision-making for minors, see *supra* note 21, have generally recognized this, but not always with sufficient protection for each parent's interests: see ARK. STAT. ANN. § 20-17-214(2) (Michie Supp. 1991) (naming, "in the case of an unmarried patient under the age of eighteen (18), the *parents* of the patient") (emphasis added); ILL. REV. STAT. ch. 110 1/2, para. 851-25(a) (Supp. 1992) ("either parent of the patient," but in the case of disagreement, the parent with custodial rights controls unless the parent without custodial rights initiates guardianship proceedings); IND. CODE ANN. § 16-8-12-4(b) (Burns 1990 & Supp. 1992) ("a parent" if there is no appointed guardian; no specific provision made for parental disagreement); LA. REV. STAT. ANN. § 40:1299.58.6 (Supp. 1992) ("either the parent or guardian," but that person may not make the statutory declaration if he or she "has actual notice of opposition" by the other parent); N.M. STAT. ANN. § 24-7-4 (Michie 1991) (same); TEX. HEALTH & SAFETY CODE ANN. § 672.006 (West 1992) ("the patient's parents"). *In re Doe*, No. D-93064 (Ga. Super. Ct. Fulton County Oct. 17, 1991) presented a situation where the child's mother appeared willing to accede to a recommended "do-not-resuscitate" order but did not wish life support withdrawn, while her father not only wished to maintain life support, but also to use resuscitative measures in the event of cardiac or respiratory arrest. The judge ruled that in such a case the court must "yield to the presumption in favor of life," *id.* slip op. at 18; the Georgia Supreme Court affirmed, but based its holding on custodial rights. 418 S.E.2d 3, 7 (Ga. 1992).

130. One parent may be hoping that "nature will take its course" without the need for an active decision. That appeared to be the mother's position in *In re Doe*; she was willing to commit to writing her apparent agreement to a "do-not-resuscitate" order, and, in the court's words, was "not sure whether she would like to see Jane's life supporting medical procedure

cruel to force the parent desiring closure to endure prolongation of the child's dying process as it is initially to force the parent favoring life support to endure withdrawal of treatment against that parent's wishes. Similarly, if the parent desiring termination of treatment has reasonable grounds to believe that the dissenting parent's refusal to act is based upon ulterior considerations,¹³¹ judicial intervention would be in order.¹³²

5. *Where a Mature Minor Has Expressed an Opinion*

Although the execution of a valid advance directive requires attainment of the age of majority,¹³³ it may be that a minor capable of understanding the implications of the situation has in fact expressed her wishes about life-sustaining treatment in the event that she should fall into a persistent vegetative state. If so, should the minor's known declarations be sufficient to override her parents' decision?

The wishes of older minors to refuse life-sustaining measures have been decisive in two reported cases. In *In re Swan*,¹³⁴ the Supreme Judicial Court of Maine held that where a normally mature high school senior was left in a persistent vegetative state by an auto accident at age seventeen and one-third, his prior "serious and deliberative"¹³⁵ statements that he would not want to be maintained in that condition must be respected by health care professionals.¹³⁶ In *In re E.G.*,¹³⁷ the Illinois Supreme Court affirmed the right of a seventeen-year-old

deescalated." *In re Doe*, No. D-93064, slip op. at 7 (Ga. Super. Ct. Fulton County Oct. 17, 1991), *aff'd*, 418 S.E.2d 3 (Ga. 1992). Some of the medical personnel involved in the case of Samuel Linares also have indicated that one reason why the hospital did not attempt more actively to assist Mr. Linares in seeking legal resolution of the dilemma was that Sammy was expected to die at almost any moment. Goldman et al., *supra* note 26, at 302. Reluctance to reach the decision was also evident in *In re Rosebush*, No. 88 349180 AZ (Mich. Cir. Ct. Oakland County July 29, 1988), *appeal filed*, No. 111082 (Mich. Ct. App. 1990). After agonizing for 15 months, the parents finally decided to terminate care, only to find themselves confronted by a courtroom proceeding.

131. For example, animosity between parents, as in situations where there has been a bitter divorce, could lead one to oppose the other's wishes on that basis alone, without regard to the child's best interests or to other relevant considerations. In that case, the parent seeking resolution should have the opportunity to disqualify the other as decision-maker by evidence concerning the other's motives, presented to an impartial tribunal.

132. One reason why judicial intervention should normally be unnecessary in these cases is that usually they are not truly adversarial proceedings. Where an adversarial posture continues to exist between the parties vested with decision-making power, resort to the court process seems appropriate.

133. See *supra* notes 64-65 and accompanying text (noting that a few states allow emancipated minors to sign advance directives).

134. 569 A.2d 1202 (Me. 1990).

135. *Id.* at 1203.

136. The court held that Chad Swan's case was governed by its earlier decision of *In re Gardner*, 534 A.2d 947 (Me. 1987), which concerned a 21-year-old patient. *In re Swan*, 569 A.2d 1202, 1204 (Me. 1990).

137. 549 N.E.2d 322 (Ill. 1990) (a combination of transfusions and chemotherapy would achieve remission in about 80% of such patients, although long-term survival prospects were only 20-25%; without the treatments, the patient was expected to die within a month). Citing statutes permitting minors to make medical and other kinds of decisions prior to age 18, as well as cases recognizing constitutionally protected rights of minors, the court held that a trial court must find the minor to be sufficiently mature to make the medical decision under a clear and convincing standard of evidence. *Id.* at 327. Furthermore, "If a parent or guardian opposes an unemancipated minor's refusal to consent to treatment for a life-threatening health problem, this opposition would weigh heavily against the minor's right to refuse." *Id.* at 328 (note, however, that the parent's opposition apparently would not be dispositive).

leukemia victim to refuse blood transfusions on religious grounds, and specifically found her acquiescing mother not to be guilty of neglect. In other cases as well, older minors who asserted agreement with their parents' religious beliefs and refused medical treatment on that basis have had their wishes respected by courts.¹³⁸

In all these cases, the minors and their parents have been in agreement. When that is the situation, this Article argues that the parents' agreement alone suffices to control the decision without judicial intervention, and therefore no inquiry need be made about even an older child's expression of views. It follows that so long as the two parents are in agreement with each other, the same result should obtain *even if* an older minor has expressed a differing viewpoint,¹³⁹ *unless* the state legislature has lowered the age of competence to choose to forego life-sustaining treatment. This is true because the objective of any legislation concerning refusal-of-treatment choices should be to keep the issue out of the courts except when necessary to protect the patient's rights or to resolve disputes. Thus, statutes providing for surrogate decision-makers often state that the named actor is to make choices in accordance with the patient's own likely preferences, where possible, or in accordance with the patient's best interests; but in any event, the person is empowered to decide without court supervision.¹⁴⁰ The basic underlying premise for these statutes is that the patient could have executed an advance directive but failed to do so. If the patient is a minor and the legislature wishes to accord the same weight to the minor's known preferences as it accords to the preferences of a formerly competent adult, then it can do so simply by lowering the age of capacity for making refusal-of-treatment decisions on one's own. Any other approach leads back to the courtroom, for when a minor's parents agree on the decision, there is only one way in which the minor's views could be used to override their choice: someone would have to challenge the parents in an adversarial proceeding and prove to the satisfaction of a judge that the minor had clearly expressed a differing viewpoint in a thoughtful, reflective manner.

138. *In re D.L.E.*, 614 P.2d 873 (Colo. 1980) (12-year-old boy with seizures permitted to remain with mother, where both believed in spiritual healing); *In re Green*, 307 A.2d 279 (Pa. 1973) (17-year-old who objected to surgery was not neglected child, where surgery was not matter of life or death). *Cf. In re Long Island Jewish Medical Ctr.*, 557 N.Y.S.2d 239, 243 (N.Y. Sup. Ct. 1990) (finding particular minor to be immature, but finding "much merit" in mature minor doctrine and suggesting its adoption by legislature and appellate courts); *In re Seiferth*, 127 N.E.2d 820 (N.Y. 1955) (noting that if minor with harelip and cleft palate wanted corrective surgery, his wishes would override parental religious objections).

139. The legislatures of some states that specifically permit surrogate decision-making for minors do not necessarily agree with this point. LA. REV. STAT. ANN. § 40:1299.58.6 (Supp. 1992) (a surrogate decision-maker may not make a declaration for a terminally ill minor "[i]f he has actual notice of contrary indications by the minor who is terminally ill," although the reach of this provision with respect to making decisions for minors is unclear, as elsewhere the statute stipulates that the making of a declaration is "a nonexclusive means by which life-sustaining procedures may be withheld or withdrawn," § 40:1299.58.8C.(1)); N.M. STAT. ANN. § 24-7-8.1 (Michie 1991) (same); again, there is ambiguity, due to the statute's preservation of rights clause at § 24-7-9, "Nothing in the Right to Die Act ... shall impair or supersede any existing legal right or legal responsibility which any person may have to effect the withholding or nonutilization of any maintenance medical treatment in any lawful manner"; TEX. HEALTH & SAFETY CODE ANN. § 672.007 (West 1992) ("The desire of a competent qualified patient, including a competent qualified patient younger than 18 years of age, supersedes the effect of a directive"); again, there is ambiguity because of the preservation of rights clause at § 672.021.

140. *See infra* notes 144-46.

On the other hand, if a minor's parents disagree with each other, an adversarial proceeding might well be initiated by one of them.¹⁴¹ In that case, the thoughtfully expressed views of an older minor ought to be introduced into evidence. If both the child's maturity and the deliberative nature of the verbal expression are demonstrable by clear and convincing evidence, those findings should have substantial probative weight, although other considerations might well enter into the judge's final decision.¹⁴²

C. Good Faith as the Governing Standard

Given competent, loving parents of unquestionable motive who mutually agree on behalf of their minor child to forego life-sustaining treatment, the only condition which should be necessary to validate their decision is a confirmed medical diagnosis of persistent vegetative state, with an accompanying prognosis of no reasonable hope of return to consciousness.¹⁴³ Some state statutes authorizing surrogate decision-making to forego life-sustaining measures take this approach and offer no guidelines other than medical criteria.¹⁴⁴ Others, however, make it clear that the decision-maker is to act according to the patient's intentions, where

141. See *supra* notes 130-32 and accompanying text. Logic suggests that ordinarily the party bringing the action would be the parent seeking to change the status quo—*i.e.*, the one wishing to withdraw life support systems.

142. There are pitfalls in stating that even the mature minor's known wishes should control when parents disagree with each other. If the minor's views were based upon unrealistic expectations belied by the medical diagnosis and prognosis ("I'm young; maybe if they kept me on machines for 20 years someone would discover a miracle cure"), then the judge might find other factors more persuasive, such as the reasons for the disagreement between the two parents, their apparent motives, and the medical evidence itself. In a truly adversarial proceeding, the impartial factfinder should be free to weigh the evidence in a manner that appears appropriate to the individual situation. Any decision on behalf of a patient in a persistent vegetative state—even a patient who has made definitive wishes known—has a hypothetical element to it, because no one can give truly "informed consent" ahead of time. See Dresser, *supra* note 121, at 381; Rebecca S. Dresser & John A. Robertson, *Quality of Life and Non-Treatment Decisions for Incompetent Patients: A Critique of the Orthodox Approach*, 17 LAW, MED. & HEALTH CARE 234, 236 (1989); John A. Robertson, *Second Thoughts About Living Wills*, HASTINGS CENTER REP., Nov.-Dec. 1991, at 6. In *Werth v. Taylor*, 475 N.W.2d 426 (Mich. App. 1991), the court followed this reasoning to find that a hospital properly refused to honor a pregnant woman's refusal to accept blood transfusions because she signed the refusal anticipating an ordinary delivery, but unexpectedly required lifesaving postnatal surgery.

143. It seems safe to say that a reliable diagnosis of PVS by definition entails a prognosis of no reasonable hope of return to consciousness. There have apparently been only two reported cases of return to consciousness after PVS was believed to have been reliably diagnosed. One of these patients suffered from paralysis of three limbs accompanied by emotional instability, and was completely dependent for the rest of his life. The other recovered normal cognitive functioning but suffered from "locked-in syndrome," a condition of complete paralysis, where blinking was his only possible form of communication. DECIDING TO FOREGO, *supra* note 108, at 179 n.22; cited in Cranford, *supra* note 1, at 30 n.8.

144. ARK. CODE ANN. § 20-17-214 (Michie Supp. 1991) (providing for appointment of a surrogate decision-maker who would have authority to execute a valid advance directive when the patient is a minor or an incompetent adult); HAW. REV. STAT. § 327D-21(a) (Supp. 1988) ("In the absence of a declaration, ordinary standards of current medical practice will be followed"); N.C. GEN. STAT. § 90-322 (1990 & Supp. 1991) (physician and named surrogate may decide to terminate treatment when the patient's condition meets specified medical criteria); OR. REV. STAT. § 127.635 (1991) (life-sustaining measures may be withdrawn provided that medical criteria are met and the terminal condition is confirmed by a committee of physicians); UTAH CODE ANN. § 75-2-1107 (1991) (physician and named surrogate may agree to withdraw life-sustaining procedures when medical criteria are met and another physician concurs in the diagnosis).

possible (the "substituted judgment" standard¹⁴⁵) or to act in the patient's best interests.¹⁴⁶ Eschewing both the ambiguities of "what the patient would desire"¹⁴⁷ and the conundrum posed by the "best interests"¹⁴⁸ of a permanently unconscious patient, the surrogate decision-making provision of the Uniform Rights of the Terminally Ill Act¹⁴⁹ combines the medical standard with respect for the declared wishes of the patient:

145. Arizona Living Wills and Health Care Directives Act, 1992 Ariz. Legis. Serv. 193 (West) (to be codified at ARIZ. REV. STAT. ANN. § 36-3231(A)) (surrogate "shall follow the patient's wishes if they are known"); CONN. GEN. STAT. § 19a-571 (Supp. 1992) (the attending physician is insulated from liability in a medically appropriate situation when he has obtained the informed consent of the patient's next of kin, if known, or legal guardian, if any, and "has considered the patient's wishes as expressed by the patient directly, through his next of kin or legal guardian, or in the form of a document"); Health Care Advance Directives, 1992 Fla. Sess. Law Serv. ch. 92-199, sec. 765.401(2) (West) (to be codified at FLA. STAT. ANN. § 765.401(2)) (proxy must act as patient would have "under the circumstances," but decision to withdraw life-sustaining treatment "must be supported by clear and convincing evidence" that patient would want such treatment withdrawn); IOWA CODE ANN. § 144A.7 (West 1989) (surrogates "shall be guided by the express or implied intentions of the patient"); MD. HEALTH-GEN. CODE ANN. § 20-107(d) (1990 & Supp. 1991), *as interpreted by* 73 Op. Att'y Gen. 88-046 (Oct. 17, 1988) (withdrawal of treatment is lawful only if "foregoing treatment is what the disabled person would want done"); N.M. STAT. ANN. § 24-7-8.1.A (Michie 1991) (life-sustaining treatment may be terminated "when all family members who can be contacted through reasonable diligence agree in good faith that the patient, if competent, would choose to forego that treatment"); VA. CODE ANN. § 54.1-2986 (Michie 1991), *as amended by* 1992 Va. Acts ch. 748 (decision must be based on patient's "religious beliefs and basic values and any preferences previously expressed"); TEX. HEALTH & SAFETY CODE § 672.009(c) (West 1992) (surrogate's decision on behalf of incompetent adult "must be based on knowledge of what the patient would desire, if known"); WYO. STAT. § 35-22-105(b) (1991), *as amended by* 1992 Wyo. Sess. Laws ch. 80 (all family members must agree that if competent, patient would choose to forego treatment). Some statutes provide that a decision to withhold or withdraw treatment is invalid if the surrogate decision-maker has actual notice of the patient's contrary wishes. *See, e.g.*, MONT. CODE ANN. § 50-9-106 (1991); NEV. REV. STAT. § 449.626 (1991); N.M. STAT. ANN. § 24-7-8.1 (Michie 1991); OHIO REV. CODE ANN. § 2133.08 (Baldwin Supp. 1991); LA. REV. STAT. ANN. § 40:1299.58.6.B (West 1992); TEX. HEALTH & SAFETY CODE ANN. § 672.006 (West 1992). Three statutes concerning minors have similar provisions; *see supra* note 139. For discussion of the substituted judgment doctrine, *see supra* notes 45-83 and accompanying text.

146. D.C. CODE ANN. § 21-2210(b) (1989) (when patient's wishes are unknown, surrogate's decision must be based on "a good faith belief as to the best interests of the patient"); ILL. REV. STAT. ch. 110 1/2, para. 851-20 (Supp. 1992) (when adult patient's wishes are unknown, "the decision shall be made on the basis of the patient's best interests" with surrogate decision-maker using benefit and burden analysis to determine best interests); IND. CODE ANN. § 16-8-12-4(d) (Burns 1990 & Supp. 1992), *as interpreted by* *In re Lawrance*, 579 N.E.2d 32 (Ind. 1991) (person authorized to consent "shall act in good faith and in the best interest of the individual incapable of consenting"); ME. REV. STAT. ANN. tit. 18-A, § 5-707 (Supp. 1990) (providing that "[a] decision to grant or withhold consent must be made in the best interest of the individual consistent with the individual's desires, if known, and in good faith. A consent is not valid if it conflicts with the expressed intention of the individual." Furthermore, "[a]ny person with a significant relationship with the individual may petition a court of competent jurisdiction to determine whether a decision made" in accordance with the statute actually meets the specified criteria); MD. HEALTH-GEN. CODE ANN. § 20-107(d) (Supp. 1992), *as interpreted by* 73 Op. Att'y Gen. 88-046 (Oct. 17, 1988) (when patient's preference is unknown, family member must determine best interests).

147. *See, e.g.*, TEX. HEALTH & SAFETY CODE ANN. § 672.009(c), *supra* note 145.

148. *See, e.g.*, D.C. CODE ANN. § 21-2210(b) (1989), *supra* note 146. *See also infra* notes 168-74 and accompanying text (discussing the "best interests" test).

149. Unif. Rights of the Terminally Ill Act § 7, 9B U.L.A. 96, 109 (Supp. 1989). The addition of § 7 was the primary change to the original act, Unif. Rights of the Terminally Ill Act, 9B U.L.A. 609 (1987), made by the National Conference of Commissioners on Uniform State Laws in 1989; Prefatory Note, 9B U.L.A. at 97 (Supp. 1989).

A decision [by a surrogate]¹⁵⁰ to grant or withhold consent [to the withholding or withdrawal of life-sustaining treatment]¹⁵¹ must be made in good faith. A consent is not valid if it conflicts with the expressed intention of the individual.¹⁵²

It is clear from both the context of this provision¹⁵³ and the appended comment¹⁵⁴ that the Act contemplates only once-competent adult patients.

The suggestion presented here is that the simple "good faith" requirement of the Uniform Act is the appropriate standard for parental decision-making for minors in a persistent vegetative state. While neither the Act nor its comments define its specified "good faith," the concept as used there undoubtedly refers to honest conformity with the statute's provisions. This would include appropriate reliance on the requisite medical diagnosis;¹⁵⁵ belief that the qualified patient has no effective declaration;¹⁵⁶ belief that one belongs to the appropriate priority class of designated surrogates;¹⁵⁷ and belief that one's decision does not "conflict with the expressed intention of the individual."¹⁵⁸ Because termination of treatment is a medically reasonable choice for a PVS patient,¹⁵⁹ a "good faith" standard for parental decision-making on behalf of minor children would require only an absence of the disqualifying factors already discussed¹⁶⁰ and appropriate reliance on the requisite medical diagnosis. This approach respects the values of family privacy with no compromise to the patient's rights or to the state's legitimate interests in the decision-making process. As the next section shows, it serves all these concerns more satisfactorily than does application of either the

150. The Act designates surrogates in order of priority. *Id.* § 7(b).

151. *Id.* § 7(a).

152. *Id.* § 7(d).

153. Section 7 applies to "an individual who: (1) [meets the medical criteria and is] no longer able to make decisions regarding administration of life-sustaining treatment; and (2) has no effective declaration." *Id.* § 7(a). Any individual who once could have made such a decision (as presumed by § 7(a)(1)) or could have made a declaration (§ 7(a)(2)) would have to be a "qualified patient" under the Act: "a patient [18][sic] or more years of age" *Id.* § 1(7). (The bracket around the number 18 indicates that a state is to choose its own qualifying age; the Commissioners undoubtedly chose 18 as the common age of majority.) *See also id.* § 2(a) (specifying age for making a declaration, again suggested by the Act as age 18).

154. *Id.* § 7, comment:

Section 7 authorizes binding consent to the withholding or withdrawal of life-sustaining treatment for *qualified patients*. Members of the patient's family in designated priority order may consent to withholding or withdrawal of life-sustaining treatment, and such consent will be treated *as if the individual had given it*. Consent by the designated family members, however, must be given in good faith, and is not valid if it would conflict with the expressed intention of the patient.

Id. (emphases supplied). A "qualified patient" is defined by the Act as "a patient [18] or more years of age" *Id.* § 1(7). In the appropriate context (*e.g.*, circumstances that would call § 7 into play), it also refers to a patient who has "been determined to be in a terminal condition." *Id.* comment.

155. *Id.* § 1(4) (defining "life-sustaining treatment") and § 1(9) (defining "terminal condition") and comment; *id.* § 3 and comment (specifying when a declaration becomes operative).

156. *Id.* § 7(a)(2).

157. *Id.* § 7(b), (c).

158. *Id.* § 7(d).

159. *See infra* notes 202-18 and accompanying text.

160. *See supra* notes 105-32 and accompanying text.

"substituted judgment" standard or the "best interests" test commonly applied by courts¹⁶¹ and, as noted, frequently adopted by statutes.¹⁶²

1. *The Problems with "Tests" in Relation to the PVS Minor*

The "substituted judgment" standard developed in *Quinlan* and relied upon by most courts considering treatment withdrawal cases¹⁶³ arguably makes sense when the patient is a formerly competent adult who has expressed actual preferences or whose general life views and values are ascertainable. Application of the self-determination concept promotes the values of equality among patients and of respect for autonomous decision-making,¹⁶⁴ thereby preserving the principle of informed consent so key to legitimate medical treatment or its refusal.¹⁶⁵ Even so, there is at least an element of fiction inherent in any substitution of one person's judgment for another's; when the subject of the decision has never been competent, the degree of unreality is sufficient to compel abandonment of the analytical enterprise as unworkable.

A number of analysts have recognized the flaws inherent in applying the substituted judgment concept to never-competent patients, including minors.¹⁶⁶ One of these was the authoritative President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research.¹⁶⁷ As early as 1983, the President's Commission recommended that decision-makers for never-competent patients try to act in the patient's best interests, taking into account "such factors as the relief of suffering, the preservation or restoration of functioning, and the quality as well as the extent of life sustained."¹⁶⁸ The Commission was careful to define its use of the phrase "quality of life" to refer to

161. See cases cited *supra* note 31 (applying substituted judgment); cases cited *infra* note 171 (applying the "best interests" test).

162. See *supra* notes 145-46 and accompanying text.

163. See *supra* note 31.

164. See, e.g., *In re Barry*, 445 So. 2d 365, 370 (Fla. Dist. Ct. App. 1984) ("... the constitutional right of privacy would be an empty right if one who is incompetent were not granted the right of a competent counterpart to exercise his rights"); *Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417, 427 (Mass. 1977) ("The recognition of that right [to refuse medical treatment] must extend to the case of an incompetent, as well as a competent, patient because the value of human dignity extends to both"); *In re Quinlan*, 355 A.2d 647, 664 (N.J.), *cert. denied*, 429 U.S. 922 (1976) ("If a putative decision by Karen to permit this non-cognitive, vegetative existence to terminate by natural forces is regarded as a valuable incident of her right of privacy, as we believe it to be, then it should not be discarded solely on the basis that her condition prevents her conscious exercise of the choice"). See also *DECIDING TO FOREGO*, *supra* note 108, at 132-33.

165. See *supra* notes 107-10 and accompanying text.

166. See generally Dresser, *supra* note 121; Rebecca Dresser, *Relitigating Life and Death*, 51 OHIO ST. L.J. 425 (1991); Dresser & Robertson, *supra* note 142; Rhoden, *supra* note 122; John A. Robertson, *Cruzan and the Constitutional Status of Nontreatment Decisions for Incompetent Patients*, 25 GA. L. REV. 1139, 1159-63 (1991); Veatch, *supra* note 122. See also ALLEN E. BUCHANAN & DAN W. BROCK, *DECIDING FOR OTHERS: THE ETHICS OF SURROGATE DECISION MAKING* (1983), at 112-22.

167. *DECIDING TO FOREGO*, *supra* note 108, at 132-34. The President's Commission was established by federal statute in 1978 and completed its work (the issuance of some thirteen volumes of reports, including appendices) in 1983. According to one source, it considered its role "as primarily educational, and ... became a vehicle for developing a national consensus on policies that would inevitably be incorporated into law." BARRY R. FURROW ET AL., *HEALTH LAW* (2d ed. 1991), at 1220. As such, it has remained one of the "most constantly cited sources on every issue ... studied." *Id.*

168. *DECIDING TO FOREGO*, *supra* note 108, at 135.

"the value of the patient's life for the patient."¹⁶⁹ In 1986, the American Medical Association, through its Council on Ethical and Judicial Affairs, issued a statement manifesting its agreement:

In treating a terminally ill or irreversibly comatose patient, the physician should determine whether the benefits of treatment outweigh its burdens. At all times, the dignity of the patient should be maintained.¹⁷⁰

Some courts¹⁷¹ and commentators,¹⁷² as well as some statutes,¹⁷³ have heeded this reasoning and called for withdrawal-of-treatment decisions to be made in light of the patient's best interests. As suggested by the President's Commission and the AMA's Council, application of the best interests standard generally involves weighing the benefits to the patient conferred by treatment against the burdens imposed on the patient by the medical procedures employed.¹⁷⁴

Often cases which purport to apply a substituted judgment framework in fact speak in terms of the patient's best interests, or at least intertwine the two modes of analysis, or conclude that either would lead to the same result. For example, in *Custody of a Minor*, the Massachusetts Supreme Court—the first to apply the substituted judgment test to never-competent patients¹⁷⁵—quoted one of its own earlier applications of the doctrine to a medical decision on behalf of a minor:

In a case like this one, involving a child who is incompetent by reason of his tender years, we think that the substituted judgment doctrine is consistent with the 'best interests of the child' test. It is true that, when applying

169. *Id.* at 135 n.43.

170. COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS, AMERICAN MEDICAL ASSOCIATION, WITHHOLDING OR WITHDRAWING LIFE PROLONGING MEDICAL TREATMENT, Mar. 15, 1986 [hereinafter, AMA COUNCIL STATEMENT]. *Accord*, *Position of the American Academy of Neurology on Certain Aspects of the Care and Management of the Persistent Vegetative State Patient*, 39 NEUROLOGY 125, 125–26 (Jan. 1989) [hereinafter, *Am. Acad. of Neurology*]. *See also Guidelines on the Vegetative State: Commentary on the American Academy of Neurology statement*, 39 NEUROLOGY 123, 123–24 [hereinafter *Guidelines*].

171. *Rasmussen v. Fleming*, 154 Ariz. 207, 741 P.2d 674 (1987) (if guardian is unable to use substituted judgment, best interests approach should govern); *In re Drabick*, 245 Cal. Rptr. 840 (Ct. App.), *cert. denied*, 488 U.S. 958 (1988); *Barber v. Superior Court*, 195 Cal. Rptr. 484 (Ct. App. 1983) (best interests approach should be used if it is not possible to ascertain patient's choice); *In re Torres*, 357 N.W.2d 332 (Minn. 1984) (substituted judgment and best interests intermingled in court's language); *In re Grant*, 747 P.2d 445 (Wash. 1987) (guardian should use substituted judgment, if possible, or best interest standard; here, daughter had never been competent and mother's determination of her best interests was appropriate); *In re Hamlin*, 689 P.2d 1372 (Wash. 1984) (guardian has duty to act in best interests of ward).

172. *See Dresser*, *supra* note 121; *Dresser*, *supra* note 166; *Dresser & Robertson*, *supra* note 142; *Robertson*, *supra* note 166, at 1194–95; *John A. Robertson, Assessing Quality of Life: A Response to Professor Kamisar*, 25 GA. L. REV. 1243 (1991).

173. IND. CODE ANN. § 16–8–12–4(d) (Burns 1990 & Supp. 1992), *as interpreted by In re Lawrence*, 579 N.E.2d 32 (Ind. 1991). Some statutes apply the best interests standard when the wishes of the patient are unknown. *See, e.g.*, ILL. REV. STAT. ch. 110 1/2, para. 851–20(1) (Supp. 1992); D.C. CODE ANN. § 21–2210(b) (1989); MD. HEALTH–GEN. CODE ANN. § 20–107(d) (1990 & Supp. 1991), *as interpreted by* 73 Op. Att'y Gen. 88–048 (Oct. 17, 1988); VA. CODE ANN. § 54.1–2986(A) (Michie 1991), *as amended by* 1992 Va. Acts ch. 748.

174. *Rasmussen v. Fleming*, 154 Ariz. 207, 217–18, 741 P.2d 674, 684–85 (1987) (quoting AMA COUNCIL STATEMENT, *supra* note 170); *In re Drabick*, 245 Cal. Rptr. 840, 861 (Ct. App.), *cert. denied*, 488 U.S. 958 (1988); *Barber v. Superior Court*, 195 Cal. Rptr. 484, 491 (Ct. App. 1983); *In re Torres*, 357 N.W.2d 332, 338 (Minn. 1984) (quoting DECIDING TO FOREGO, *supra* note 108); *In re Grant*, 747 P.2d 445, 454, 457 (Wash. 1987).

175. *Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417 (Mass. 1977). *See supra* notes 57–63, and accompanying text.

the 'best interests' test, the inquiry is essentially objective in nature, and the decisions are made not by, but on behalf of, the child. ... Nevertheless, the best interests analysis, like that of the substituted judgment doctrine, requires a court to focus on the various factors unique to the situation of the individual for whom it must act. ... [sic] As a practical matter, the criteria to be examined and the basic applicable reasoning are the same.¹⁷⁶

Similarly, in *In re Barry*,¹⁷⁷ a Florida appellate court noted that the substituted judgment test "is difficult to apply to children or young adults."¹⁷⁸ Although it still maintained that the trial court's use of that standard was correct,¹⁷⁹ the court did not proceed to talk in terms of a "lucid interval"¹⁸⁰ or attempt to "don the mental mantle"¹⁸¹ of the child. Instead, it stated that "the court must be guided primarily by the judgment of the parents *who are responsible for their child's well-being*, provided, of course, that their judgment is supported by competent medical evidence."¹⁸² In *In re L.H.R.*,¹⁸³ the Georgia Supreme Court, after a thorough discussion of the *Barry* case,¹⁸⁴ followed its application of a substituted judgment framework. The Georgia court also cited *Parham v. J.R.*, however, and noted that "the right of the parent to speak for the minor child is so imbedded in our tradition and common law" that, absent suspected neglect, abuse, or other posture which might endanger the child, "the beginning presumption is that the parent has the *child's best interest* at heart."¹⁸⁵ The court held that the child's parent or guardian may exercise the child's right to forego life-sustaining treatment without judicial intervention, once there has been a confirmed medical diagnosis of irreversible persistent vegetative state.¹⁸⁶ Indeed, the court extended its holding to encompass a family right to make refusal-of-treatment decisions for incompetent adult patients who have no advance directive.¹⁸⁷

Thus, courts dealing with decision-making for minors, obviously mindful of traditional parental rights and responsibilities, have tended to mix the lan-

176. *Custody of a Minor*, 434 N.E.2d 601, 608-09 n.10 (Mass. 1982) (quoting *Custody of a Minor*, 379 N.E.2d 1053, 1065 (Mass. 1978) (other citations omitted). *But see In re Conroy*, 486 A.2d 1209, 1231-32 (N.J. 1985) (identifying and defining three tests: substituted judgment (where once-competent patient's wishes were known), on the one hand, and two "best interests" tests, on the other—a "limited objective" test, where there is some trustworthy evidence of the patient's general views, and a "pure objective" benefit/burden analysis, applicable when trustworthy evidence is lacking that the patient would have declined life-sustaining treatment). The New Jersey Supreme Court later held that the *Conroy* "best interests" tests do not apply to PVS patients; rather, such cases are governed by *Quinlan*. *In re Peter*, 529 A.2d 419, 423-24 (N.J. 1987); *see also In re Jobes*, 529 A.2d 434, 443 (N.J. 1987) (decided the same day as *Peter*).

177. 445 So. 2d 365 (Fla. Dist. Ct. App. 1984).

178. *Id.* at 371.

179. *Id.*

180. *See In re Quinlan*, 355 A.2d 647, 663 (N.J.), *cert. denied*, 249 U.S. 922 (1976). *See supra* notes 45-56 and accompanying text.

181. *See Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417, 431 (Mass. 1977) (citations omitted). *See supra* notes 57-63 and accompanying text.

182. *In re Barry*, 445 So. 2d 365, 371 (Fla. Dist. Ct. App. 1984) (emphasis added).

183. 321 S.E.2d 716 (Ga. 1984).

184. *Id.* at 718-19.

185. *Id.* at 722 (emphasis added). *See supra* notes 95-99 and accompanying text (discussing *Parham v. J.R.*, where the Supreme Court relied on a basic presumption that parents generally act in the best interests of their children).

186. *Id.* at 722-23.

187. *Id.* at 723.

guages of substituted judgment and of the child's best interests. As a guiding standard for a court, or for any non-parental decision-maker, the best interests of the child test appears to present fewer conceptual difficulties than does a tortuous attempt at "substituted judgment" for a person who was never legally capable of making the decision. The best interests standard is, after all, the traditional criterion for decision-making when the state asserts its *parens patriae* power to protect minors in guardianship proceedings or to make decisions regarding their welfare in disputed situations.¹⁸⁸

Even though a best interests standard may be more analytically satisfactory than a substituted judgment approach, it is not without flaws. Some analysts find that it rests upon an even more disturbing fiction than substituted judgment—namely, the assumption that death could ever be in the "best interests" of anyone, particularly a child.¹⁸⁹ Because concern for the patient's welfare is the value underlying the best interests framework,¹⁹⁰ its benefit/burden analysis does necessarily entail a conclusion about the patient's "quality of life."¹⁹¹ To engage in such an enterprise, critics assert, violates basic notions of equality and undermines the state's interest in preserving life;¹⁹² some fear the "slippery slope" of

188. See, e.g., CLARK, *supra* note 37, § 19.1 (discussing custody of children); Robertson, *supra* note 165, at 1170; Superintendent of Belchertown State Sch. v. Saikewicz, 370 N.E.2d 417, 427 (Mass. 1977) ("the State has a traditional power and responsibility, under the doctrine of *parens patriae*, to care for and protect the 'best interests' of the incompetent person"). See also Rasmussen v. Fleming, 154 Ariz. 207, 221, 741 P.2d 674, 688 (1987), *appeal dismissed*, 1993 WL 32356 (Mo. Jan. 26, 1993) (Arizona caselaw holds "best interests" to govern guardianship); *In re Busalacchi*, No. 59582, 1991 WL 26851, at *5 (Mo. Ct. App. Mar. 5, 1991) (citing state guardianship statute), *appeal dismissed*; 1993 WL 32356 (Mo. Jan. 26, 1993); *In re Grant*, 747 P.2d. 445, 457 (Wash. 1987); *In re Hamlin*, 689 P.2d 1372, 1375 (Wash. 1984) (citing state guardianship statute). Cf. *In re Torres*, 357 N.W.2d 332, 338 (Minn. 1984) (state law requires the probate court to "act in the 'best interests' of the ward or conservatee in a guardianship proceeding").

189. See, e.g., Cruzan v. Harmon, 760 S.W.2d 408, 424 (Mo. 1988) (state statute empowering guardian to consent to medical care on ward's behalf does not include the power to consent to withdrawal of life support); *id.* at 425 (as delegatee of state's *parens patriae* power, guardian may not consent to terminate ward's life support); *In re Storar*, 420 N.E.2d 64, 73 (N.Y. 1981) (profoundly retarded adult should be assessed as an infant, and a parent "may not deprive a child of life saving treatment, however well intentioned"). Cf. *In re Busalacchi*, No. 59582, 1991 WL 26581, at *5 (Mo. Ct. App. Mar. 5, 1991) (guardian has affirmative duty to act in ward's best interest and to procure appropriate medical care), *appeal dismissed*, 1993 WL 32356 (Mo. Jan. 26, 1993); 1991 WL 26581 at *8-11 (court, acting under *parens patriae* duty to act in ward's best interests, could appropriately prohibit guardian from moving ward to another jurisdiction, where guardian might remove ward's feeding tube after medical evaluation). Cf. also Yale Kamisar, *When Is There a Constitutional "Right to Die"?* *When Is There No Constitutional "Right to Live"?*, 25 GA. L. REV. 1203 (1991).

190. See DECIDING TO FOREGO, *supra* note 108, at 135.

191. See *supra* notes 168-70 and accompanying text; DECIDING TO FOREGO, *supra* note 108, at 135 n.43 (clarifying the Commission's concern as "the value of the patient's life for the patient," as distinguished from "the value that others find in the continuation of the patient's life, perhaps in terms of their estimates of the patient's actual or potential productivity or social contribution"). See also BUCHANAN & BROCK, *supra* note 166, at 123-24; Dresser, *supra* note 166, at 430; Dresser & Robertson, *supra* note 142, at 242; Robertson, *supra* note 172. Cf. Nancy K. Rhoden, *Treatment Dilemmas for Imperiled Newborns: Why Quality of Life Counts*, 58 S. CAL. L. REV. 1283, 1318-23 (1985).

192. This criticism has been leveled at all third party withdrawal-of-treatment decision-making on behalf of incompetent patients, whether based on substituted judgment or best interests analysis. See *In re Longeway*, 549 N.E.2d 292, 306 (Ill. 1989) (Ward, J., dissenting) (noting that a surrogate cannot help judging the patient's quality of life on the surrogate's own terms, thereby entailing the "risk that the surrogate will allow the patient to die simply because he is incompetent"); Cruzan v. Harmon, 760 S.W.2d 408, 422 (Mo. 1988) (accusing Quinlan

arrogating to surrogate decision-makers the potential power to withdraw treatment from persons considered "burdensome" or "undesirable," such as the senile or profoundly retarded.¹⁹³

A number of commentators who support the best interests standard as generally appropriate for medical decision-making on behalf of incompetent patients nonetheless maintain that it cannot be applied to patients in a persistent vegetative state because by definition these persons have no interests susceptible of evaluation.¹⁹⁴ Anyone suffering a total loss of consciousness is incapable of "benefitting" from continued life support; by the same token, such a person is not "burdened" by invasive medical procedures, because, so far as we can ascertain, the patient has no sensations of pain and certainly no awareness of any dignitary interest at stake.¹⁹⁵ If the loss of consciousness is permanent and irreversible, the language of "burden/benefit" rests upon notions just as fictitious¹⁹⁶ as the concept of "substituted judgment." For analysts persuaded by this line of argument, a best interests approach to PVS patients poses a conundrum incapable of resolution.

2. Who Is the Best Decision-Maker?

Clearly, various parties contemplating treatment decisions for a child in a persistent vegetative state—whether they be jurists, health care providers, commentators, or family or friends of such a patient—will bring different perspectives and values to the decision-making process. Under these circumstances, the primary question is not, "Which standard should apply?" but rather, "Who should make the decision?" So long as the decision-maker does not disserve the patient or society's interest in the patient's welfare—that is, so long as the choice is made in good faith and is one that society is prepared to accept as medically reasonable—compassion dictates that the decision-making process be as speedy, as humane, and as respectful of both patient and family privacy as the medical situation will allow.¹⁹⁷

of "recast[ing] the state's interest in life as an interest in the quality of life" and characterizing Missouri's interest in life as "unqualified"); *In re Westchester County Medical Ctr. (O'Connor)*, 531 N.E.2d 607, 613 (N.Y. 1988) (third party decision-making is "unacceptable because it is inconsistent with our fundamental commitment to the notion that no person or court should substitute its judgment as to what would be an acceptable quality of life for another"); *In re Grant*, 747 P.2d 445, 463 (Wash. 1987) (Goodloe, J., dissenting) (objecting to "the majority's obvious judgment that Barbara's life is not of value" and to the authorization of a guardian "to determine that the ward's life is not worth living because the guardian deems that 'life' to be negligible").

193. In addition to cases cited *supra* note 192, see James Bopp, Jr., *Choosing Death for Nancy Cruzan*, HASTINGS CENTER REP., Jan.-Feb. 1990, at 42; James Bopp, Jr. & Thomas J. Marzen, Cruzan: *Facing the Inevitable*, 19 LAW, MED. & HEALTH CARE 37 (1991); Kamisar, *supra* note 189.

194. BUCHANAN & BROCK, *supra* note 166, at 126-32; Dresser, *supra* note 121, at 383-84; Dresser & Robertson, *supra* note 142, at 241-42; Robertson, *supra* note 166, at 1157-59; Robertson, *supra* note 172, at 1246-47. Cf. Rhoden, *supra* note 122, at 397-401 (noting that under an objective analysis of benefits and burdens, permanently unconscious persons have no interests).

195. Cranford, *supra* note 1, at 31; *Am. Acad. of Neurology*, *supra* note 170, at 125.

196. Some courts have begun to make this observation. *In re Peter*, 529 A.2d 419, 425 (N.J. 1987) (characterizing a benefit/burden analysis as "essentially impossible" with respect to PVS patients, as they do not experience either); *accord, In re Jobes*, 529 A.2d 434, 443 (N.J. 1987) (citing the reasoning of *In re Peter* as grounds for distinguishing cases involving PVS patients from all others).

197. For a thorough and strong argument that guardians who had a "bonded" (*i.e.*, generally familial) relationship with their wards prior to the guardianship should be allowed to

These concerns point firmly to the parents of a diagnosed PVS minor, acting in good faith, as the appropriate persons to make treatment decisions for the child, just as they would be entitled to do with respect to most other decisions regarding the child's health and welfare.¹⁹⁸ Our underlying societal assumptions, expressed by the Supreme Court in *Parham v. J.R.*,¹⁹⁹ that parents can generally be expected to have their child's best interests at heart, and that they are better situated to evaluate those interests than is any judge, guardian ad litem, or other third party,²⁰⁰ should apply in this context just as in others. Even if we think that the occasional parent might make a withdrawal-of-treatment decision on grounds that most of us would not approve, appropriate legislative safeguards can help to protect against that occurrence. Judicial intervention, with its attendant costs, delays, and intrusion into family privacy, is too high a price to pay to try to "get it right" every time.²⁰¹ Judges themselves make mistakes; the judicial process is a blunt instrument for dealing with these delicate and highly personal matters. Therefore, resort to a court is unwarranted unless parents disagree or unless involved parties have reason to suspect a disqualifying factor. Withdrawal of life support systems from a PVS child is a medically reasonable course of action. That parental choice, standing alone, is therefore not sufficient to trigger traditional safeguards against abuse or neglect or to call into question the presence of good faith underlying the decision.

3. *Withdrawal of Treatment Is a Medically Reasonable Choice*

The reasonableness of a decision to withdraw life support systems from a PVS patient is attested to simply by the number of cases permitting that course of action²⁰² and by the volume of legislation establishing procedures to permit that choice.²⁰³ At least in its official statements, the medical community has long recognized termination of treatment, including the withdrawal of artificial nutrition and hydration, to be an appropriate response when the PVS patient has been reliably diagnosed.²⁰⁴

Indeed, the past few years have seen an interesting reversal in the positions of some members of the legal and medical professions towards treatment of PVS patients. Existing court cases, legislation, and scholarly commentary have commonly pitted the rights of patients and their proxies or surrogates to make treat-

make refusal-of-treatment decisions within a discretionary realm bounded by "medical reasonableness," see Veatch, *supra* note 122. Veatch states that this approach "protects the patient, acknowledges the importance of familial responsibility, and avoids involving the courts in most routine cases." *Id.* at 443-44.

198. See *supra* notes 83-92 and accompanying text.

199. 442 U.S. 584 (1979).

200. See *supra* notes 96-99 and accompanying text.

201. Cf. BUCHANAN & BROCK, *supra* note 166, at 88-89: "Even if a surrogate ought to try to act in the incompetent's best interest, requiring success in this effort is too stringent. ... Although parents ought primarily to be guided by what is best for their children, it is generally recognized that it would be intolerably intrusive to intervene to transfer custody whenever doing so would result in a net increase of benefit to the child. The fact that another, wealthier couple could provide a better education is not a sufficient reason for removing a child from his or her natural parents, even if this could be done without psychological harm to the child."

202. See RIGHT-TO-DIE COURT DECISIONS, *supra* note 3.

203. See REFUSAL OF TREATMENT LEGISLATION, *supra* note 4. The statutes typically allow the withdrawal decision to be made by a competent patient contemplating future possibilities or by a proxy decision-maker designated by the patient or by the legislature.

204. See AMA COUNCIL STATEMENT, *supra* note 170; *Am. Acad. of Neurology*, *supra* note 170. See also *Guidelines*, *supra* note 170..

ment withdrawal decisions against the perceived bias of health care providers to maintain life under any conditions.²⁰⁵ Recently, however, some health care providers have done an about-face and have aggressively advocated withdrawal of life support systems from PVS patients on the grounds that any other course of action is futile or inhumane.

This new posture in the termination-of-treatment debate came to the public's attention with the case of Mrs. Helga Wanglie,²⁰⁶ who suffered respiratory failure followed by "severe and irreversible brain damage" after she fell and broke her hip.²⁰⁷ When attempts to wean Mrs. Wanglie from the respirator failed, the Hennepin County Medical Center finally urged the family to discontinue treatment as "no longer serving the patient's personal medical interest" and as therefore "inappropriate."²⁰⁸ When the family insisted that all forms of treatment be continued, citing Mrs. Wanglie's views and their own religious and personal values, the hospital petitioned a court for permission to discontinue life support. The court refused and upheld the family's request; the hospital decided not to appeal, and Mrs. Wanglie died shortly thereafter.²⁰⁹ The case paved the way, however, for a health care provider's argument that it should not be legally required to provide care deemed medically inappropriate by the physicians in charge.

The Georgia case of *In re Doe*²¹⁰ presented a similar issue. There, the parents of a thirteen-year-old child diagnosed as "varying between stupor and coma"²¹¹ were unable to agree even on consent to a DNR order; both refused to authorize withdrawal of life support systems. The Scottish Rite Hospital for Crippled Children in Atlanta petitioned the trial court to permit withdrawal of treatment on the grounds that life support maintenance was "abusive and inhumane."²¹² This assessment was shared by three attending physicians, the hospital's Bioethics Committee, and two examining disinterested physicians.²¹³ The trial court concluded that, in the face of parental disagreement, it could not order termination of treatment but must "yield to the presumption in favor of life."²¹⁴ On appeal, the hospital's only question was whether it should follow the

205. See, e.g., Rhoden, *supra* note 122. Dresser believes that Rhoden exaggerates "the physician's overwhelming desire to preserve life," noting that currently "medical norms governing life-sustaining treatment are in flux." Dresser, *supra* note 166, at 435-36.

206. *In re Wanglie*, No. PX-91-283 (Minn. Dist. Ct. Hennepin County filed Feb. 8, 1991).

207. Ronald E. Cranford, *Helga Wanglie's Ventilator*, HASTINGS CENTER REP., July-Aug. 1991, at 23. See also Felicia Ackerman, *The Significance of a Wish*, HASTINGS CENTER REP., July-Aug. 1991, at 27; Daniel Callahan, *Medical Futility, Medical Necessity: The Problem-Without-A-Name*, HASTINGS CENTER REP., July-Aug. 1991, at 30; Michael A. Rie, *The Limits of a Wish*, HASTINGS CENTER REP., July-Aug. 1991, at 24.

208. Cranford, *supra* note 207, at 23.

209. Joan Beck, *Death and Dying: More People Fight to Stay in Control*, CHICAGO TRIB., Aug. 26, 1991, at 17; Tom Majeski, *Judge Refuses to Let Hospital Unplug Patient*, ST. PAUL PIONEER PRESS DISPATCH, July 2, 1991, at 1A.

210. No. D-93064 (Ga. Super. Ct. Fulton County Oct. 17, 1991), *aff'd*, 418 S.E.2d 3 (Ga. 1992).

211. 418 S.E.2d at 4. Although Jane Doe's diagnosis was not PVS but rather "a degenerative neurological disease," characterized by a brain stem that was "shrinking or degenerating," *id.*, her case presents the same questions as those under consideration in this article.

212. No. D-93064, slip op. at 5 (Ga. Super. Ct. Fulton County Oct. 17, 1991), *aff'd*, 418 S.E.2d 3 (Ga. 1992).

213. *Id.* slip op. at 6.

214. *Id.* slip op. at 18.

mother's wishes and enter the DNR order, or whether it must abstain because the father did not agree. The court ruled that the father had a right to revoke the order; hence, the hospital could not act.²¹⁵

As *Doe* and *Wanglie* demonstrate, a number of health care providers have abandoned their bias against withdrawal of treatment. Indeed, some argue that withdrawal is the *only* medically reasonable course of action. The issues thus raised appear certain to become increasingly prevalent, not only in courts but in legislatures.²¹⁶ For example, the Virginia legislature, in a recent amendment to the state's Health Care Decisions Act, included a "futility clause" relieving physicians from any requirement to provide medical treatment "that the physician determines, in the exercise of reasonable medical judgment, would neither promote nor improve the health of the patient nor alleviate the patient's suffering."²¹⁷ While this clause has not been construed in any reported court opinion, it seems to codify the legislature's belief that withdrawal of treatment is medically reasonable under certain circumstances.

It is clearly beyond the scope of this Article to engage in the emerging "medical futility" debate.²¹⁸ For present purposes, the relevance of the issue is simply to underscore the medical reasonableness of a choice by parents to terminate life support systems for their PVS minor child. So long as the decision is made in good faith, it poses no basis for a finding of parental neglect or abuse, the usual necessary predicate for governmental intrusion into parental decision-making for minor children.

4. Values Served by the Good Faith Standard

Application of a simple "good faith" standard to parental choice, accompanied by appropriate safeguards against disqualifying factors, clearly serves the values of family privacy and parental autonomy long protected under both the common law and under constitutional doctrine. Because our societal institutions are based on the presumption that parents will act in the best interests of their children and indeed are the parties best situated to perceive those best interests, it follows that a good faith standard serves the value that we place on the individual child's welfare as well. The occasional exception does not disprove this premise; it simply points up the need for permitting a health care provider concerned with the child's welfare to raise the good faith issue and demand resort to court intervention when there is reason to doubt that the standard has been met in a particular instance of parental decision-making.

A legislatively imposed good faith standard in this context serves the state's legitimate interests. Case law traditionally identifies four state interests in

215. 418 S.E.2d at 7.

216. Some commentators would support judicial or legislative action actually requiring cessation of treatment. Based on his position that permanently unconscious patients have no interests, Robertson argues that state policy could constitutionally withhold public or private insurance from these patients or could define irreversible coma as brain death. Robertson, *supra* note 166, at 1197-99. Another view is that distributive justice concerns make it very difficult to justify use of limited health care resources on life support systems for PVS patients. See Baruch Brody, *Special Ethical Issues in the Management of PVS Patients*, 20 LAW, MED. & HEALTH CARE 104 (1992).

217. VA. CODE ANN. § 54.1-2986 (Michie 1991), as amended by 1992 Va. Acts ch. 748.

218. See, e.g., Callahan, *supra* note 207.

any termination-of-treatment decision: "(1) the preservation of life; (2) the protection of the interests of innocent third parties; (3) the prevention of suicide; and (4) maintaining the ethical integrity of the medical profession."²¹⁹ Invariably, courts cite preservation of life as the primary value implicated.²²⁰ This interest involves "two separate concerns: an interest in the prolongation of the life of the individual patient and an interest in the sanctity of life itself."²²¹ Most courts find that factors favoring the right of a guardian or family member to decide to withdraw treatment from a PVS patient outweigh these state interests, even when the patient was never competent or never expressed preferences relevant to the situation.²²² This value judgment in favor of privacy also underlies state statutes that permit surrogate decision-making; in the Uniform Rights of the Terminally Ill Act, it finds expression in the good faith standard.

Besides the state interests traditionally identified in cases concerning withdrawal-of-treatment decisions, there are legitimate societal concerns in the establishment of decision-making processes that serve the welfare of our primary social institution, the family. Interests in the efficient administration of the judicial process and in the wise allocation of governmental resources are also at stake. We should not employ unnecessarily the machinery of courts, guardians ad litem, and social service agencies in situations where judges are not equipped to serve as the best decision-makers.²²³ Only when a minor child's parents are incapable of a mutual good faith decision is the public interest served by judicial intervention in these cases.

219. *Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417, 425 (Mass. 1977) (the first case to enumerate the four concerns). *See also, e.g., In re Brophy*, 497 N.E.2d 626, 634 (Mass. 1986); *In re Torres*, 357 N.W.2d 332, 339 (Minn. 1984); *In re Farrell*, 529 A.2d 404, 410-11 (N.J. 1987); *In re Colyer*, 660 P.2d 738, 743 (Wash. 1983). *Cf. Cruzan v. Harmon*, 760 S.W.2d 408, 419 (Mo. 1988) (citing "prevention of homicide" as well as suicide). *See also* DECIDING TO FOREGO, *supra* note 108, at 31-32.

220. *Cruzan v. Harmon*, 760 S.W.2d 408, 419 (Mo. 1988). *See also* cases cited *supra* note 219.

221. *Cruzan*, 760 S.W.2d at 419.

222. The courts of Missouri and New York are the only exceptions. *See supra* note 82 and accompanying text.

223. *Cf. Parham v. J.R.*, 442 U.S. 584, 607 (1979), quoting *In re Roger S.*, 569 P.2d 1286, 1289 (Cal. 1977) (Clark, J., dissenting) (noting that judges are not as equipped as psychiatrists to render psychiatric judgments, *see supra* note 99 and accompanying text); *In re Jobs*, 529 A.2d 434, 449 (N.J. 1987) (withdrawal-of-treatment decision for PVS patient) ("No matter how expedited, judicial intervention in this complex and sensitive area may take too long. Thus, it could infringe the very rights that we want to protect") (quoting *In re Farrell*, 529 A.2d 404, 415 (N.J. 1987)).

5. *The Special Problem of the Minor Who Has Expressed an Opinion*²²⁴

Section 7 of the Uniform Rights of the Terminally Ill Act qualifies its good faith standard with the stipulation that "A [surrogate's] consent [to withdrawal of treatment] is not valid if it conflicts with the expressed intention of the individual."²²⁵ Where the patient was once competent, it would be a logical contradiction of "good faith" for a surrogate to make a decision directly counter to the patient's previously expressed desires. If incorporated into a valid advance directive, those wishes would without question govern.²²⁶ Part of the rationale of Section 7 is that the patient's choices, where known, should not lose all force simply because of her failure to formalize a prior declaration or because a prior declaration might be ineffective.²²⁷

Should the same reasoning apply where an older minor has expressed thoughtful views about whether she would want treatment terminated under appropriate medical conditions? Psychological evidence indicates that "children by age fourteen or fifteen usually have developed the various capacities necessary for competence in health care decision-making to a level roughly comparable to that attained by most adults."²²⁸ States commonly permit older minors to make some kinds of medical decisions,²²⁹ and constitutional protections accorded procreative liberties extend to minors as well as adults.²³⁰

Different considerations apply to treatment decisions for PVS patients, however. Generally, policy permitting minors to consent to their own medical treatment is actually premised not on the child's competence, but on the desire to encourage minors to seek treatment in instances where they might be reluctant to consult parents (for instance, substance abuse, venereal disease, contraception,

224. As a personal note, I would like to clarify that my conclusions in this section are not based on any perception that older minors are incapable of thoughtful decision-making on end-of-life treatment issues. My husband and I have two teenagers whose intelligence and judgment we respect enormously. We have discussed these matters with them, are aware of their thinking, and would expect to follow their wishes if the need should arise and the law would permit. Rather, I base my conclusions in this article on respect for family privacy in decision-making and the realities of relevant legal considerations. All states that provide for advance directives require legal competency, meaning age of majority. If an older minor (not legally competent to execute a binding directive) were to have expressed a desire for treatment withdrawal under certain circumstances, but the minor's parents were unwilling to execute a parental directive in accordance with those wishes, I do not believe that any health care provider or any court in this country would consider termination of treatment over parental objection. On the other hand, if the minor had expressed a desire to continue treatment, perhaps based on hopes that, given enough time, a restorative cure might be found, I do not think that the minor's parents should forever be saddled with expectations that are demonstrably unrealistic. Therefore, I advocate leaving the final decision to the minor's parents, if they agree, unless a legislature chooses to lower the age at which a person can execute a valid advance directive.

225. Unif. Rights of the Terminally Ill Act § 7(d), 9B U.L.A. 96 (Supp. 1989).

226. *Id.* §§ 2, 3.

227. *Id.* § 7, comment: "Prior declarations might not be effective for a variety of reasons, including for example the expiration of a time limit, the failure to have the declaration properly witnessed, or the absence of a condition precedent contained in the declaration, such as the death or disability of a designated decision-maker." The appropriateness of deference to a patient's stated intentions is underscored by the comment's observation that the surrogate's consent "will be treated as if the individual had given it." *Id.*

228. BUCHANAN & BROCK, *supra* note 166, at 222-23.

229. See *supra* notes 88-89, and note 91 and accompanying text.

230. See *supra* note 90 and accompanying text.

and abortion).²³¹ Although independent parental interests in bringing up their children as they see fit²³² are clearly implicated in these situations, those interests are deemed to be outweighed by the minors' own privacy rights and by the social desirability of providing them with access to appropriate medical treatment.²³³

When a child has been diagnosed as a PVS patient, the balance shifts. Her rights of confidentiality are not at issue. Her interest in self-determination may be worthy of respect, although, as noted earlier, some analysts see PVS patients as no longer possessing independent interests of their own.²³⁴ On the other hand, her parents' interests in her welfare and in her appropriate treatment are beyond question. They (and other family members) are profoundly affected by her situation. They are also the parties whom social policy traditionally trusts to act in her best interests. They are more likely than anyone else to be aware of her values, particularly inasmuch as they have been the chief inculcators of those values.²³⁵ Under these circumstances, if the minor child has expressed views on the issue, the underlying premise should be that her parents can be counted upon to take those views into account—and to accord them appropriate weight²³⁶—in reaching their own decision.

The suggestion here, therefore, is that when parents mutually agree upon termination of treatment for their PVS minor child, their decision should normally govern, without the need for judicial permission. If the child has expressed contrary intentions, that factor alone should not defeat the right of parental choice. In some situations, the child's known contrary views may constitute appropriate grounds for questioning the parents' good faith and may therefore provide a basis for an appropriate party to seek court intervention. Nonetheless, a minor's expressed opposition should not be an automatic trigger evidencing bad faith unless the legislature has chosen to lower the age at which a person may make a valid prior declaration.

On the other hand, whenever judicial resolution is sought on the grounds of parental disagreement, or whenever both parents are disqualified,²³⁷ the thoughtfully expressed views of an older minor are entitled to substantial probative weight. Third parties making decisions on behalf of minors will undoubtedly employ some version of a "substituted judgment"/"best interests" analysis, and either approach would make a mature child's known views highly relevant, if not, in fact, decisive.²³⁸ The opinion of this Article is that the "best interest" standard, which usually governs the state's exercise of its *parens patriae* power, is preferable to the fiction of attributing "judgment" to one who was never

231. BUCHANAN & BROCK, *supra* note 166, at 241. See also Holder, *supra* note 35, § 19.01[3][a], [b].

232. See *supra* notes 84–99 and accompanying text.

233. See, e.g., *Carey v. Population Servs. Int'l*, 431 U.S. 678 (1977) (protecting minors' right of access to contraceptive devices).

234. See *supra* notes 194–96 and accompanying text.

235. Accord, BUCHANAN & BROCK, *supra* note 166, at 233–34.

236. This does not necessarily mean decisive weight. For the view that the interests of other family members may appropriately be taken into account in making a withdrawal-of-treatment decision for a PVS patient, see Rhoden, *supra* note 122, at 394–96; Veatch, *supra* note 122, at 436–38.

237. For a discussion of disqualifying factors justifying court intervention, see *supra* notes 105–32 and accompanying text.

238. See *supra* notes 134–38 and accompanying text (discussing cases concerning mature minors).

legally competent to exercise it.²³⁹ If a court follows that suggestion, it will accord considerable weight, but not total deference, to the minor patient's known attitudes. In any event, however, those attitudes should not be permitted to override a mutual parental choice where no bad faith or other disqualifying characteristic is shown.

III. MECHANISMS FOR PARENTAL DECISION-MAKING

A. The Need for Legislation

Both the common law²⁴⁰ and the constitutionally protected right to privacy²⁴¹ already invest in parents certain rights to make medical decisions on behalf of their minor children. Arguably, principles derived from these sources alone encompass a right to make treatment withdrawal decisions on behalf of minor children in a persistent vegetative state. Yet no court to date has defined parental rights so broadly.²⁴² The rights of parents must always yield to sufficiently important state interests;²⁴³ certainly, the state's *parens patriae* power to protect the welfare of children²⁴⁴ permits it to intervene when the issue is so substantial as the difference between life and death for a child.²⁴⁵

More successful arguments, grounded in the common law right of informed consent to medical treatment,²⁴⁶ the constitutionally protected right of privacy,²⁴⁷ or a combination of the two,²⁴⁸ have been mounted on behalf of incompetent patients, including minors, to permit surrogates to make refusal-of-treatment decisions that the patients are unable to make for themselves. Courts which permit surrogate decision-making have on occasion constructed elaborate frameworks to guide the actions of lower courts, of health care providers, and of potential surrogates who may find themselves faced with a painful situation in relation to a close family member.²⁴⁹ Courts, however, have a limited ability,

239. See *supra* notes 164-88 and accompanying text (comparing the two approaches).

240. See *supra* notes 85-93 and accompanying text.

241. See *supra* notes 94-99 and accompanying text.

242. *I.e.*, no court has to date defined parental rights *qua* parental rights as including the right to withdraw treatment from a PVS minor child. Rather, courts considering these cases have substantially relied upon the *child's* rights and the "substituted judgment" doctrine. See *supra* notes 45-73 and accompanying text.

243. See *supra* notes 100-03 and accompanying text.

244. See *supra* note 188 and accompanying text.

245. See, e.g., *In re E.G.*, 549 N.E.2d 322, 327 (Ill. 1989) ("Where the health care issues are potentially life threatening, the State's *parens patriae* interest is greater than if the health care matter is less consequential").

246. See, e.g., *Barber v. Superior Court*, 195 Cal. Rptr. 484, 489 (Ct. App. 1983); *In re Longeway*, 549 N.E.2d 292, 297 (Ill. 1989); *In re Gardner*, 534 A.2d 947, 951-52 (Me. 1987); *Eichner v. Dillon*, 420 N.E.2d 64, 70-71 (N.Y. 1981).

247. The Supreme Court indicated that a competent person has a constitutionally protected liberty interest in refusing unwanted medical care, including life-sustaining treatment. *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 278-80 (1990); see *supra* notes 8081 and accompanying text. See also *In re Severns*, 425 A.2d 156, 158 (Del. 1980); *John F. Kennedy Memorial Hosp. v. Bludworth*, 452 So. 2d 921, 923-24 (Fla. 1984); *In re Quinlan*, 355 A.2d 647, 662-64 (N.J.), *cert. denied*, 429 U.S. 922 (1976).

248. See, e.g., *Rasmussen v. Fleming*, 154 Ariz. 207, 214-16, 741 P.2d 674, 681-83 (1987); *Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417, 242 (Mass. 1977); *In re Colyer*, 660 P.2d 738, 741-43 (Wash. 1983).

249. With respect to minors, see, e.g., *In re L.H.R.*, 321 S.E.2d 716, 722-23 (Ga. 1984) (parents or guardian of minor may decide after diagnosis is confirmed by two physicians otherwise unrelated to the case); *In re Barry*, 445 So. 2d 365, 372 (Fla. Dist. Ct. App. 1984)

within the confines of any one case, to anticipate future factual variations which may present essentially the same question in a slightly different guise. Nor is that their function.

Pleas for legislation to answer the agonizing questions of parents and other close relatives, of health care providers, and of the courts themselves abound in decisions dealing with the withholding or withdrawal of life support systems from incompetent patients.²⁵⁰ An abundance of legislation has in fact been passed, particularly dealing with advance directives.²⁵¹ A number of states have also begun to appreciate the need for surrogate/family decision-making statutes; however, most of these are inadequate to answer the questions posed by the situation of parents wishing to terminate medical treatment for a minor child in a persistent vegetative state.²⁵² State legislatures should act to confront this problem directly, in a manner designed to ensure that family tragedies may be dealt with as privately, expeditiously, and humanely as possible, while at the same time protecting the interests of both parents and their minor children.

B. Necessary Safeguards: A Proposal

1. A Written Parental Directive

Absent disqualifying criteria,²⁵³ a conflict between the two parents, or other grounds for a reasonable suspicion of bad faith,²⁵⁴ the parents of a minor child in a persistent vegetative state should be legislatively enabled to execute a valid directive to withhold or withdraw life-sustaining treatment, so long as their judgment is supported by a reliable medical diagnosis and prognosis. The mechanism of a solemnly executed directive, generally requiring two witnesses, is the

(medical diagnosis must be confirmed by at least two physicians; advisory committee recommended); *In re P.V.W.*, 424 So. 2d 1015, 1020-21 (La. 1982) (child's right may be judicially asserted either after or before the event; court's primary role is to ensure appropriate safeguards and underlying conditions; juvenile court has jurisdiction). Cases involving incompetent adults include *Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417, 433-35 (Mass. 1977) (probate court should appoint a guardian and, when necessary, a guardian ad litem, make appropriate findings of incompetency, and apply substituted judgment test; judge may consider views of ethics committees, but may not shift decision-making responsibility away from court); *In re Conroy*, 486 A.2d 1209, 1237-42 (N.J. 1985) (detailed procedure prescribed where patient is non-comatose incompetent adult in a nursing home); *In re Quinlan*, 355 A.2d 647, 670-72 (N.J.), cert. denied, 429 U.S. 922 (1976) (court-appointed guardian may decide after physician's diagnosis and prognosis are confirmed by a prognosis committee); *id.* at 668-69 (general hospital ethics committees are recommended); *In re Colyer*, 660 P.2d 738, 749-51 (Wash. 1983) (similar to *Quinlan*; prognosis board must include at least two physicians otherwise unrelated to the case).

250. See, e.g., *Rasmussen v. Fleming*, 154 Ariz. 207, 225, 741 P.2d 674, 692 (1987); *Barber v. Superior Court*, 195 Cal. Rptr. 484, 488 (Ct. App. 1983); *Severns v. Wilmington Medical Ctr.*, 421 A.2d 1334, 1346 (Del. 1980); *Satz v. Perlmutter*, 379 So. 2d 359, 360 (Fla. 1980); *In re Longeway*, 549 N.E.2d 292, 301 (Ill. 1989); *In re Jobes*, 529 A.2d 434, 449-50 (N.J. 1987) (citing *In re Conroy*, 486 A.2d 1209 (N.J. 1985)); *In re Storar*, 420 N.E.2d 64, 74 (N.Y. 1981); *In re Hamlin*, 689 P.2d 1372, 1379 (Wash. 1984).

251. See REFUSAL OF TREATMENT LEGISLATION, *supra* note 4.

252. Twenty-four jurisdictions currently have some form of surrogate/family decision-making statute. However, only six of these clearly include minors within their purview. See *supra* note 21.

253. For a discussion of disqualifying criteria (incompetency, conflict of interest, suspected abuse or neglect), see *supra* notes 105-32 and accompanying text.

254. An older minor's expressed contrary views might be one grounds for alleging bad faith, but even that need not be an automatic trigger for suspicion. See *supra* notes 223-38 and accompanying text.

pattern of a number of the surrogate/family decision-making statutes that now exist.²⁵⁵ This mirrors the common requirements for a competent patient's execution of a valid advance directive²⁵⁶ and reflects the fact that a surrogate is deemed to stand in the stead of the patient, who simply failed to act while still competent.

The rationale of this Article suggests that parents of a minor child should not be looked upon as the child's "surrogates," strictly speaking,²⁵⁷ but rather as the adult persons responsible for medical decision-making on her behalf, so long as the child is legally incapable of deciding for herself. Whichever underlying theory a legislature finds persuasive, the formality of a signed, witnessed document helps to ensure that the actors have given their decision due consideration and appreciate its weight. Furthermore, a validly executed directive serves as proof to insulate from potential civil or criminal liability health care providers who rely on it in good faith.²⁵⁸ As with advance directives executed by patients while competent, health care providers should be entitled to assume the competency of those executing the document.²⁵⁹ Only if they become aware of facts which would put a reasonable person on notice of incompetence, conflict of interest, abuse or neglect, disagreement between the parents, or other indication of bad faith should health care providers be held accountable for failure to act in good faith themselves when carrying out a validly executed parental directive. If any of the medical personnel directly connected with the patient's care should

255. See ARK. CODE ANN. § 20-17-214 (Michie Supp. 1991) (providing that declaration executed on behalf of an incompetent patient is to be same in form as those executed in advance by a competent patient under § 20-17-202); LA. REV. STAT. ANN. § 40:1299.58.5(B) (Supp. 1992) (requiring written documentation and presence of at least two witnesses); ME. REV. STAT. ANN. tit. 18-A, § 5-707(a) (West Supp. 1991) (requiring written documentation and presence of at least two witnesses); TEX. HEALTH & SAFETY CODE ANN. § 672.006 (West Supp. 1992) (implying written documentation and presence of at least two witnesses in provision providing for "execution of directive on behalf of patient younger than 18 years of age"); UTAH CODE ANN. § 75-2-1107 (1991) (requiring written concurrence along with presence and signatures of at least two witnesses). *But see* CONN. GEN. STAT. § 19a-571 (Supp. 1991) (making no mention of written documentation or witnesses); D.C. CODE ANN. § 21-2210 (1989) (silent as to written documentation and requiring presence of only one witness); HAW. REV. STAT. § 327D-21 (Supp. 1991) (including no reference to written documentation or witnesses); IOWA CODE ANN. § 144A.7 (West 1989) (providing for written agreement but requiring presence of only one witness); LA. REV. STAT. ANN. § 40:1299.58.6 (Supp. 1992) (requiring written documentation but excluding any specific reference to witnesses, in contrast to adult surrogate decision-making provision § 40:1299.58.5); N.M. STAT. ANN. §§ 24-7-4, -7 (Michie 1991) (making no reference to written documentation or witnesses); N.C. GEN. STAT. § 90-322 (1990 & Supp. 1991) (making no mention of written documentation or witnesses); OR. REV. STAT. § 127.635 (1991) (silent as to written documentation and witnesses); VA. CODE ANN. § 54.1-2986 (1991) (requiring presence of at least two witnesses but silent as to written documentation); TEX. HEALTH & SAFETY CODE ANN. § 672.009 (West Supp. 1992) (requiring presence of at least two witnesses but silent as to need for written documentation).

256. See, e.g., ARK. CODE ANN. § 20-17-202(a) (Michie Supp. 1991); N.C. GEN. STAT. § 90-321(c)(3) (1990 & Supp. 1991); OR. REV. STAT. § 127.610(2) (1991).

257. WEBSTER'S THIRD NEW INTERNATIONAL DICTIONARY 2302 (3d ed. 1986) lists the first definition for "surrogate" as "a person appointed to act in place of another." This concept suggests the substituted judgment test and appears properly applicable when a person was once competent. This Article suggests that is not the appropriate analysis where a minor child is concerned.

258. See, e.g., IOWA CODE ANN. § 144A.9 (West 1989); NEV. REV. STAT. § 449.630.1 (1991); UTAH CODE ANN. § 75-2-1114 (1991).

259. See, e.g., ARIZ. REV. STAT. ANN. § 36-3205(B) (1990); D.C. CODE ANN. § 6-2426(b) (1989); IND. CODE ANN. § 16-8-11-15 (Burns 1990 & Supp. 1992).

become aware of a disqualifying characteristic in one or both of the parents, that person should have standing to refer the matter for expedited court resolution.

2. *A Confirmed Medical Diagnosis and Prognosis*

The key to the validity of parental decision-making under this proposal is a confirmed diagnosis of persistent vegetative state and prognosis of no reasonable chance of return to consciousness. The diagnosis and prognosis should come from the patient's treating physician. Because of the seriousness and irreversibility of any decision to withhold or withdraw life support systems, both surrogate/family decision-making statutes²⁶⁰ and courts dealing with the issue²⁶¹ have required that the treating physician's judgments be well confirmed. An independent evaluation from a second examining physician, competent to render the diagnosis and otherwise unconnected with the case, should serve to provide the necessary confirmation. The evaluations should be independently entered into the patient's records in written form. These written records can serve as proof to insulate from potential civil or criminal liability both the parents who rely on them in good faith in executing a refusal-of-treatment directive and others (medical personnel or members of ethics committees, perhaps) who rely on them in good faith in advising the parents or in carrying out the terms of a directive. As with all their professional actions, the physicians' evaluations should meet the standards of accepted medical practice.

3. *The Role of Ethics Committees*

Increasingly, hospitals and other health care providers name ethics committees, often consisting of both medical personnel and members of the local community.²⁶² In fact, current accreditation standards promulgated by the Joint Commission on Accreditation of Healthcare Organizations require hospitals to have in place "a mechanism(s) for the consideration of ethical issues arising in the care of patients and to provide education to caregivers and patients on ethical issues in health care."²⁶³ The mission and workings of ethics committees vary, but their most likely functions are policy formulation and education.²⁶⁴ In some institutions, committee members may be called upon to consult in individual patient-care decisions. In these consultations, the committee may simply serve as

260. See, e.g., ILL. REV. STAT. ch. 110 1/2, para 851-20(e) (Supp. 1992); N.M. STAT. ANN. § 24-7-5 (Michie 1991); TEX. HEALTH & SAFETY CODE ANN. § 672.009 (West 1992).

261. See *supra* note 249 and accompanying text.

262. See generally AMERICAN HOSPITAL ASS'N, REPORT OF THE SPECIAL COMMITTEE ON BIOMEDICAL ISSUES, VALUES IN CONFLICT: RESOLVING ETHICAL ISSUES IN HOSPITAL CARE (1985), at 30-35 [hereinafter AMERICAN HOSPITAL ASS'N]; ETHICS CONSULTATION IN HEALTH CARE (John C. Fletcher et al. eds., 1989); INSTITUTIONAL ETHICS COMMITTEES AND HEALTH CARE DECISION MAKING (Ronald E. Cranford & A. Edward Doudera eds., 1984) [hereinafter INSTITUTIONAL ETHICS COMMITTEES]; JUDITH WILSON ROSS ET AL., HANDBOOK FOR HOSPITAL ETHICS COMMITTEES (1986). See also THE HASTINGS CENTER, *supra* note 108, at 99-105 (suggesting guidelines for ethics committees); DECIDING TO FOREGO, *supra* note 108, at 160-70 (describing current practices and making recommendations).

263. JOINT COMMISSION ON ACCREDITATION OF HEALTHCARE ORGANIZATIONS, ACCREDITATION MANUAL FOR HOSPITALS (1992).

264. See AMERICAN HOSPITAL ASS'N, *supra* note 262, at 33-34; THE HASTINGS CENTER, *supra* note 108, at 100-04; DECIDING TO FOREGO, *supra* note 108, at 162-63; ROSS ET AL., *supra* note 262, at 49-56.

a sounding board for airing the issues, or it may take a more active role, and offer advice to relevant decision-makers.²⁶⁵

Some courts have suggested that refusal-of-treatment decisions should be made in consultation with ethics committees, although most of them stop short of imposing such a requirement.²⁶⁶ If competent parents are the appropriate decision-makers for their minor children, the only requirement for a valid directive should be basically uncontroversial medical evidence. Any other requirement undercuts the hypothesis that parents are appropriate decision-makers who generally act in their children's best interests—the beginning presumption of *Parham v. J.R.*²⁶⁷

Of course, parents should feel free to consult health care provider ethics committees, where they exist and are available for individual consultation. Undoubtedly, such a group could offer valuable advice and support to parents facing an extremely difficult decision under the most trying of circumstances. Courts often note that termination-of-treatment decisions have been made after consultation with moral or ethical advisors, such as other family members, clergy, or ethics committees.²⁶⁸ To require that such committees exist and that their approval be necessary in the decisions at issue here, however, would be to create a situation inviting delay, irresolution, and, eventually, resort to courts in the face of disagreement.²⁶⁹ It might also raise questions of potential liability on the part of ethics committee members for decisions carried out with their

265. See AMERICAN HOSPITAL ASS'N, *supra* note 262, at 34–35; THE HASTINGS CENTER, *supra* note 108, at 104–05; DECIDING TO FOREGO, *supra* note 108, at 163–65; John A. Robertson, *Committees as Decision Makers: Alternative Structures and Responsibilities, in INSTITUTIONAL ETHICS COMMITTEES*, *supra* note 262, at 85; ROSS ET AL., *supra* note 262, at 32–33. For discussions of specific institutional experiences, see Troyen A. Brennan, *Ethics Committees and Decisions to Limit Care: The Experience at the Massachusetts General Hospital*, 260 JAMA 803 (1988); Diane E. Hoffmann, *Does Legislating Hospital Ethics Committees Make a Difference? A Study of Hospital Ethics Committees in Maryland, the District of Columbia, and Virginia*, 19 LAW, MED. & HEALTH CARE 105 (1991); Katherine Bouton, *Painful Decisions: The Role of the Medical Ethicist*, N.Y. TIMES MAGAZINE, Aug. 5, 1990, at 22 (describing the work of ethicist Ruth Macklin at Albert Einstein College of Medicine).

266. The idea that consultation with a hospital ethics committee might actually be required before withdrawal of life-sustaining treatment stems from *In re Quinlan*, 355 A.2d 647, 671 (N.J.), *cert. denied*, 429 U.S. 922 (1976), where the court ordered Karen's guardian, family, and attending physicians to consult such a body before carrying out their own mutual decision. The function ascribed by the court to the committee, however, was not one of ethical decision-making but simply a confirmation of the prognosis that Karen had no reasonable hope of return to a sapient state. Elsewhere, the court discussed the advantages of ethics committees established to help share the responsibility by advising patients, families, and medical personnel. *Id.* at 668–69. *Cf. In re Barry*, 445 So. 2d 365, 372 (Fla. Dist. Ct. App. 1984) (recommending availability of advisory committee); *In re Torres*, 357 N.W.2d 332, 335–36 & n.2 (Minn. 1984) (citing views of ethics committees where conservator was non-family member); *In re Colyer*, 660 P.2d 738, 749–50 (Wash. 1983) (requiring unanimous confirmation of diagnosis by a "prognosis board").

267. 442 U.S. 584 (1979); *accord, In re L.H.R.*, 321 S.E.2d 716, 723 (Ga. 1984).

268. See, e.g., *In re Barry*, 445 So. 2d 365, 371 (Fla. Dist. Ct. App. 1984); *In re Rosebush*, No. 88 349180 AZ, slip op. at 4–5 (Mich. Cir. Ct. Oakland County, July 29, 1988), *appeal filed*, No. 111082 (Mich. Ct. App. 1990); *In re Quinlan*, 355 A.2d 647, 657–60 (N.J.), *cert. denied*, 429 U.S. 922 (1976).

269. See DECIDING TO FOREGO, *supra* note 108, at 165. Others have also expressed the need for caution in assessing the appropriate role of ethics committees *vis-à-vis* prospective case review. See AMERICAN HOSPITAL ASS'N, *supra* note 262, at 30–32, 35; ROSS ET AL., *supra* note 262, at 56–63.

approval.²⁷⁰ This possibility would surely have a chilling effect on recruitment of committee members and, by creating a stake in outcomes, inhibit members' abilities to serve as concerned but disinterested sounding boards or advisors to troubled families. Thus, while the existence of ethics committees is to be encouraged, they properly have no official role in the decision itself.

4. *The Appropriate Scope of Parental Decision-Making Authority: The Mature Minor and the Patient Incapacitated as a Minor*

For reasons already stated,²⁷¹ the thesis that parents are the appropriate decision-makers for their PVS minor child should hold true even where a mature minor has expressed her own preferences. Unless a legislature chooses to lower the age of autonomous decision-making for refusal-of-treatment cases, any other rule creates an impasse in which the concerned parties are powerless to act. Only when parents disagree, or are perceived to be acting in bad faith, and as a consequence the issue in fact receives a judicial hearing, should the child's preferences receive probative weight. In the event that the court must choose the views of one parent over the other, clear and convincing proof of deliberative statements from a child of demonstrable maturity may well deserve careful consideration. In the final analysis, however, the court should be guided by the criterion of the child's best interests.

The same considerations suggest that when the incapacitating event or illness occurs while the child is a minor, parents should not lose their decision-making authority just because the child turns eighteen years of age, even if the diagnosis of persistent vegetative state is not made until after the age of majority.

A different rule leads to the kind of seemingly unresolvable dilemma evident in the situation of Christine Busalacchi.²⁷² If the patient has never been capable of making her own decisions or of stating preferences to which the state's courts are willing to accord "clear and convincing" weight, her parents should be empowered to make the decision.

5. *The Appropriate Role of the Courts*

Enactment of legislation clarifying the rights of parents to make refusal-of-treatment decisions for their minor children in medically appropriate circumstances would eliminate a number of needless time-consuming and expensive court hearings. But of course, situations would still arise where judicial intervention would be necessary. If medical personnel involved in the patient's care were

270. The Hastings Center recommends insurance coverage for all ethics committee members. THE HASTINGS CENTER, *supra* note 108, at 105.

271. See *supra* notes 233-39 (discussing the weight to be given a mature minor's expression of opinion).

272. *In re Busalacchi*, No. 59582, 1991 WL 26851 (Mo. Ct. App. Mar. 5, 1991), *appeal dismissed*, 1993 WL 32356 (Mo. Jan. 26, 1993). See *supra* notes 32-33 and accompanying text (discussing facts). Differing with the majority, the dissent expressed the view that Peter Busalacchi's status as Christine's father was not irrelevant. Given the onset of her incapacity while still a minor, Missouri law imposes on her father the obligation of parental support for his lifetime. In the dissenting judge's view, he should therefore be accorded a parent's latitude to make medical decisions on behalf of his daughter, including the right to take her elsewhere for diagnosis and treatment. *Id.* at *8-9 (Smith, J., dissenting). Similar facts obtained in *In re Lawrance*, 579 N.E.2d 32 (Ind. 1991) (PVS patient, age 42 at time of parents' petition, was nine when permanently brain damaged), and *In re Grant*, 747 P.2d 445 (Wash. 1987) (22-year-old patient was declared legally incompetent at age 14).

to have reason to doubt the parents' competence or to suspect a conflict of interest, abuse, or neglect, they should have standing to raise the issue before a court. If the parents disagree, either could seek court resolution.

Once involved, a court would likely appoint a guardian ad litem to represent the child's interests by presenting appropriate information to the court concerning the issues raised in the litigation. A threshold question would be whether the court should invest any individual with decision-making authority, or whether the judge should make the treatment decision. If the court were to find that one parent should be disqualified, the appropriate course of action would be to invest the other with sole decision-making power.²⁷³ If both parents were disqualified or were unavailable, the appropriate question would be whether someone else had the kind of intimate relationship with the child that would justify investing that person with the full panoply of parental authority suggested by this Article (for example, a grandparent or an adult sibling).²⁷⁴

If there is no appropriate parent substitute, or in cases of parental disagreement, the court should make the decision, based on an assessment of the child's best interests.²⁷⁵ This conclusion rests on the fact that a court-appointed guardian, no matter how conscientious, cannot be presumed to have the kind of loving concern that justifies parental decision-making authority on the child's behalf. Furthermore, if parents disagree, investment of decision-making power in only one of them seems inevitably disruptive of marital and other familial relationships.²⁷⁶ Courts, therefore, have an appropriate role to play in withdrawal-of-treatment decisions affecting minor children in a persistent vegetative state, but only when there are sound reasons for finding that the usual presumptions favoring good-faith parental decision-making do not apply.

IV. CONCLUSION

In most jurisdictions in this country, parents of a medically diagnosed PVS minor child exist in legal limbo if they wish to bring closure to an intolerable situation by terminating life-sustaining treatment. Their instincts may tell them that such a course of action is in their child's best interests: the unconscious child receives no benefits from a respirator or a gastronomy tube, and her daily care

273. Cf. *In re Baby Doe*, No. D-62058 (Ga. Super. Ct. Fulton County Nov. 30, 1988) (father suspected of abusing his PVS child; mother was permitted to make the withdrawal of treatment decision).

274. This seems unlikely, unless the person were actually the child's primary caretaker and therefore likely to have the kind of relationship with the child normally held by a parent.

275. This Article takes the position that the best interests standard is the most appropriate in this situation. See *supra* note 188 and accompanying text. However, in jurisdictions where the substituted judgment approach governs case law, a court could apply it as well; as noted, the two standards may well lead to the same result in cases dealing with PVS patients. See *supra* notes 176-87 and accompanying text.

276. If parents are separated or divorced and there are no other children in the family, one can imagine that a court might find it appropriate to appoint the custodial parent to make the decision. Otherwise, considerations of other family members' interests suggest the desirability of taking the decision out of the hands of only one parent, where the other disagrees. Cf. *In re Doe*, No. D-93064 (Ga. Super. Ct. Fulton County Oct. 17, 1991) (finding that each parent has the same rights in relation to the child, and therefore it is not appropriate to allow only one to decide; so long as there was disagreement, the court thought it necessary to favor prolongation of life), *aff'd*, 418 S.E.2d 3 (Ga. 1992) (finding that under the Georgia statute one parent may consent to a DNR order, but the other revoke it; the appeals court, however, confined its discussion to custodial parents).

necessarily involves a number of procedures that most of us would consider to be indignities. Because the patient is a child, the situation could continue without change for a number of years, placing an overwhelming burden of grief and helplessness on parents and other family members. Yet when the treating physician and hospital personnel are consulted about the possibilities of withdrawing life support systems, concerns about legal liability may well impel them to refuse without the permission of a court order. Obtaining one is a costly, time-consuming, and emotionally wearing process; the trial court may well refuse, and appeals involve more expense and delay.

Only six states have enacted statutes specifically dealing with parental decision-making for minors in this situation, and one of those requires court supervision. Some other surrogate/family decision-making statutes are ambiguous at best; even the Uniform Rights of the Terminally Ill Act is not clear on the matter. What is needed is legislation clearly stating that in these circumstances parents acting in good faith have the right to make refusal-of-treatment decisions without judicial intervention. The only necessary predicate is the treating physician's medical diagnosis of persistent vegetative state and prognosis of no reasonable hope of return to consciousness, confirmed by a qualified independent physician. Only in a very narrow range of cases, where parents appear incompetent or otherwise disqualified to make the decision, or where they disagree, would resort to a court be needful or even appropriate. When judicial intervention becomes necessary, the court should appoint a guardian ad litem to make a recommendation and, absent an appropriate parental substitute, should decide according to the standard of the child's best interests, the usual norm for application of the state's *parens patriae* power on behalf of minors. This approach respects the family values which undergird both the common law and our concepts of the constitutionally protected right of privacy, while at the same time protecting the individual rights of the minor child. It permits, where appropriate, dignity to both the dying process and the family's grief.