

DÉJÀ VU ALL OVER AGAIN: THE FALSE DICHOTOMY BETWEEN SANCTITY OF LIFE AND QUALITY OF LIFE

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The case of Theresa Marie Schiavo aroused the longstanding claim that any judgment that death is preferable to life violates the important concept of sanctity of life.¹ Right-to-life advocates largely chose to ignore the judicial finding that Terri Schiavo had, by oral expressions, dictated her own medical course. Instead, they portrayed her husband's determination to let her die as reflecting his judgment that her impoverished quality of life in a permanently unconscious state had "no value."² In turn, the Florida courts' acceptance of such a determination supposedly contravened society's respect for the intrinsic value of all human life. This theme—that a quality-of-life ethic undermines sanctity of life—has long been a contention of right-to-life advocates.³ In 1987, one judge objected to the removal of life support from a permanently unconscious person:

By its very nature, every human life, without reference to its condition, has a value that no one rightfully can deny or measure. Recognition of that truth is the cornerstone on which American law is built. . . . [Any] declaration that not every human life has sufficient value to be worthy of the State's protection denies the dignity of all human life, and

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1. Linda Reid Chassiakos, *The Value of a Life*, http://www.salon.com/opinion/feature/2005/01/26/feeding_tube/print.html (Jan. 26, 2005); Steven W. Mosher, *Statement in Support of the Life of Terri Schiavo*, <http://lifeissues.net/msg.php?newsID=00007850&topic=> (Oct. 13, 2004).

2. E.g. Patricia David, *May God Forgive Us for Starving Terri*, Tampa Trib. Nation/World 15 (Mar. 24, 2005).

3. *Thor v. Super. Ct. of Solano County*, 855 P.2d 375, 382–383 (Cal. 1993) (en banc); J. Jioni Palmer, *A Schiavo Debate in Capitol*, *Newsday* (N.Y.C.) A03 (Mar. 21, 2005).

undermines the very principle on which American law is constructed.⁴

Every person's right to life and society's duty to protect that right supposedly preclude "all 'quality of life' judgments."⁵

Any determination—especially when made by a surrogate—that a person would be better off dead than alive is also regarded by the right-to-life movement as posing a grave danger to vulnerable populations such as the developmentally disabled, the elderly, and the seriously ill.⁶ These apprehensions include a concern that a person facing a critical medical condition will be deemed disposable because of the lack of worth to society or to affected individuals within society.⁷ Anyone who is a burden to others might be subject to a judgment that his life is not worth preserving.⁸ Another concern is that there are no objective criteria for assessing quality of life, so that surrogates will operate according to their own preconceptions, values, and biases in assessing a preservable quality of life.⁹ The argument is that in the absence of ways to quantify and compare the benefits and burdens of existence, subjective surrogate judgments will jeopardize the well-being of all vulnerable populations.¹⁰

Beyond premature disposal of helpless humans, a negative quality-of-life judgment is seen by some advocates for the disabled as conveying an offensive and alarming message to disabled popu-

4. *Brophy v. New Eng. Sinai Hosp.*, 497 N.E.2d 626, 646 (Mass. 1987) (O'Connor, J., concurring in part and dissenting in part).

5. Kevin P. Quinn, *The Best Interests of Incompetent Patients: The Capacity for Interpersonal Relationships as a Standard for Decisionmaking*, 76 Cal. L. Rev. 897, 926 (1988) (describing the position of the right-to-life movement).

6. Chris Tisch, *A Fate Unclear, a Legacy Assured*, St. Petersburg Times 1A (Feb. 27, 2005).

7. Conrad deFiebre, *Disabled Seek Law on Sustaining Life*, Star Trib. (Minneapolis) 4B (Mar. 29, 2005).

8. John Wyatt, *What's Wrong with Quality of Life as a Clinical Tool?* <http://www.ama-assn.org/ama/pub/category/print/14553.html> (last updated Feb. 1, 2005).

9. Quinn, *supra* n. 5, at 925; Elizabeth J. Sher, *Choosing for Children: Adjudicating Medical Care Disputes between Parents and the State*, 58 N.Y.U. L. Rev. 157, 185 (1983).

10. Tracy L. Merritt, Student Author, *Equality for the Elderly Incompetent: A Proposal for Dignified Death*, 39 Stan. L. Rev. 689, 726–727 (1987); Jennifer L. Sabo, *Survey of Development in North Carolina Law and the Fourth Circuit, 2000: Limiting a Surrogate's Authority to Terminate Life-Support for an Incompetent Adult*, 79 N.C. L. Rev. 1815, 1823–1824 (2000–2001); Wyatt, *supra* n. 8.

lations.¹¹ Even when a decision to reject life-sustaining treatment is made by a competent individual, the autonomous patient's negative judgment supposedly communicates that disabled lives are not worth living.¹² This message purportedly discourages disabled people and contradicts the sanctity-of-life notion that every human life is valuable without regard to its quality.¹³

All this aversion to quality-of-life judgments is understandable, particularly from the perspective of the 1970s and 1980s, when end-of-life medical decisions were relatively novel both from practical and jurisprudential viewpoints.¹⁴ The claims about the insidious consequences of a quality-of-life ethic prompted appropriate hesitation and reflection. Some courts reacted by eschewing end-of-life decisions unless pursuant to explicit prior instructions from a previously competent patient.¹⁵ Most courts were more intrepid and upheld the rejection of life-sustaining medical interventions both by competent patients and by surrogates acting on behalf of incompetent patients.¹⁶ Now, in 2005, Ms. Schiavo's protectors echo the original warnings about the dire consequences of a quality-of-life ethic for a society assertedly dedicated to the sanctity of life.¹⁷ Should these plaintive warnings be heeded, or are they an anachronism today, thirty years after the advent of a death-and-dying jurisprudence geared toward

11. *E.g.* Penney Lewis, *Rights Discourse and Assisted Suicide*, 27 *Am. J. L. & Med.* 45, 65–66 (2001).

12. *Id.*

13. Any practice that suggests that a disabled human is dispensable is subject to the same objection, even when the human is not yet born. Thus, right-to-life advocates object to prenatal screening of genetic traits such as Down's Syndrome because of the negative message about lack of value of disabled persons. *See e.g.* T.M. Reynolds, *Down's Syndrome Screening Is Unethical: Views of Today's Research Ethics Committees*, 56 *J. Clinical Pathology* 268, 270 (2003) (detailing ethical dilemmas associated with genetic screening).

14. Norman L. Cantor, *Twenty-Five Years after Quinlan: A Review of the Jurisprudence of Death and Dying*, 29 *J.L. Med. & Ethics* 182, 182–183 (Summer 2001).

15. *E.g.* *In re Gardner*, 534 A.2d 947, 950 (Me. 1987); *Cruzan ex rel. Cruzan v. Harmon*, 760 S.W.2d 408, 426 (Mo. 1988) (en banc), *aff'd sub nom. Cruzan v. Dir., Mo. Dept. of Health*, 497 U.S. 261 (1990); *In re Westchester County Med. Ctr.*, 531 N.E.2d 607, 611 (N.Y. 1988).

16. *E.g.* *In re Tavel*, 661 A.2d 1061, 1068 (Del. 1995); *Brophy*, 497 N.E.2d at 634–636; *In re Rosebush*, 491 N.W.2d 633, 636 (Mich. App. 1992); *In re Conroy*, 486 A.2d 1209, 1229–1230 (N.J. 1985); *In re Fiori*, 673 A.2d 905–911 (Pa. 1996).

17. *See e.g. In re Guardianship of Theresa Marie Schiavo: Brief of Amici Curiae Not Dead Yet et al.*, 19 *Issues L. & Med.* 145 (Fall 2003) (describing why Ms. Schiavo should be protected).

autonomy and the implementation of people's actual or likely preferences?

I. QUALITY OF LIFE AND COMPETENT MEDICAL PATIENTS

Every autonomous medical decision involves a quality-of-life determination according to the personal values and preferences of the competent patient. This is true for the simplest decision, such as whether to take an aspirin for a headache. The patient considers the chances of benefits, the likely quality of life with and without the medical intervention, the risks of treatment, and the alternatives available. The same goes for a competent patient's decision whether to undergo surgery for lumbar sciatica or for any other serious medical condition.¹⁸ How much pain and dysfunction is the sciatica causing? What is the likely quality-of-life improvement via surgery? What are the risks and discomforts of surgery and what are the alternatives?

A similar calculus guides an autonomous patient's choice even when the context is an end-of-life medical decision.¹⁹ A central factor is the nature of the hardship and debilitation to be encountered with and without life-extending medical intervention. As described by Philip Peters,

[W]hether a painful treatment is worthwhile inevitably requires consideration of the value of extended life to the patient. A painful treatment is only harmful if the additional life expectancy that it offers [i.e., the ensuing length and quality of life] is not worth the pain or burden of the treatment.²⁰

And as the California Supreme Court explained in 1993,

Since death is the natural conclusion of all life, the precise moment may be less critical than the quality of time preceding it. Especially when the prognosis for full recovery from

18. Bernd Will & Matthis Synofzik, *AMA Virtual Mentor Policy Forum, Assessing Quality of Life in Patients with Lumbar Sciatica*, <http://www.ama-assn.org/ama/pub/14553> (Feb. 7, 2005).

19. See *Rasmussen ex. rel. Mitchell v. Fleming*, 741 P.2d 674, 689 (Ariz. 1987) (en banc) (describing different factors that go into making an end-of-life decision).

20. Philip G. Peters, Jr., *The State's Interest in the Preservation of Life: From Quinlan to Cruzan*, 50 Ohio St. L.J. 891, 948 (1989).

serious illness or incapacitation is dim, the relative balance of benefit and burden must lie within the patient's exclusive estimation: "That personal weighing of values is the essence of self-determination."²¹

Even with an enduring societal respect for the intrinsic value of all human life, the reality is that, from the perspective of a fatally stricken medical patient, extended life is not always preferable to death. Anglo-American jurisprudence accepts that a competent patient facing a fatal affliction is entitled to determine whether, and for how long, the quality of prospective existence after treatment warrants accepting the proposed treatment.²² Because life-sustaining medical intervention constitutes both a bodily invasion and a personal choice regarding the appropriate response to an affliction, the competent patient's rights of bodily integrity and self-determination entitle her to assess personally the benefits and burdens of the contemplated medical intervention.²³ Think about the burn victim. Think about the cancer patient. Think about the patient with kidney failure facing dialysis. Think about the Amyotrophic Lateral Sclerosis (ALS) patient contemplating whether to continue to use a respirator in the face of inexorable deterioration. All of these patients are entitled to decide for themselves, using personal values and preferences, whether the prospective preservable state would be so intolerably painful or degrading as to make treatment unwanted.

American cases have uniformly allowed competent patients to make quality-of-life judgments in determining whether to accept further life-sustaining medical intervention.²⁴ This was the case, for example, when gangrene-stricken patients declined surgical amputation that could have preserved their lives for years.²⁵ Similar quality-of-life decisions have been made by seriously disabled persons—usually quadriplegics—who decide to discontinue

21. *Thor*, 855 P.2d at 384 (quoting *In re Gardner*, 534 A.2d at 955).

22. *Cruzan*, 497 U.S. at 279.

23. *E.g. Satz v. Perlmutter*, 362 So. 2d 161, 163 (Fla. 4th Dist. App. 1978); *McKay v. Bergstedt*, 801 P.2d 617, 624 (Nev. 1990); *In re Farrell*, 529 A.2d 404, 410 (N.J. 1987); *Fosmire v. Nicoleau*, 551 N.E.2d 77, 81 (N.Y. 1990).

24. *E.g. Satz*, 362 So. 2d at 163; *McKay*, 801 P.2d at 624; *In re Farrell*, 529 A.2d at 410.

25. *Lane v. Candura*, 376 N.E.2d 1232, 1235–1236 (Mass. App. 1978); *In re Quackenbush*, 383 A.2d 785, 789–790 (Morris County Ct., N.J. 1978).

respirator support or artificial nutrition and hydration necessitated by their debilitating medical conditions.²⁶ In each case, their medical conditions had stabilized so that the patients were capable of surviving for many years with continued medical support.²⁷ In like fashion, some sufferers of ALS reach a point when the physical debilitation is so frustrating and the struggle to survive so fatiguing that they decide to withdraw the respirator preserving their existence.²⁸ Indeed, competent persons making decisions whether to maintain life support frequently rely on quality-of-life factors—chronic pain, the indignity associated with being helpless and dependent, or the distasteful prospect of being a burden on family or others.²⁹ William Bartling—a victim dying of emphysema and cancer who was demanding the removal of a life-preserving respirator—described “the humiliating indignity of having . . . every bodily need and function tended to by others.”³⁰ For this formerly vital person, his gravely debilitated condition was “unbearable, degrading and dehumanizing.”³¹

Objections are frequently voiced about the judicial upholding of competent patients’ decisions to decline continued medical intervention capable of preserving their lives for considerable periods.³² Some objections rely on a religious precept that humans do not have dominion over their own bodies or lifespans, so that rejection of life-sustaining treatment violates divine will.³³ Other

26. *Bowia v. County of L.A.*, 225 Cal. Rptr. 297, 299 (Cal. App. 2d Dist. 1986); *State v. McAfee*, 385 S.E.2d 651, 651–652 (Ga. 1989); *McKay*, 801 P.2d at 619–620.

27. *Bowia*, 225 Cal. Rptr. at 299; *McAfee*, 385 S.E.2d at 651–652; *McKay*, 801 P.2d at 619–620.

28. *E.g. Satz*, 362 So. 2d at 161; *In re Farrell*, 529 A.2d at 406–409.

29. See Norman L. Cantor, *On Kamisar, Killing, and the Future of Physician-Assisted Death*, 102 Mich. L. Rev. 1793, 1833 n. 198 (2004) (noting that competent patients seeking physician-assisted dying also tend to invoke these kinds of quality-of-life factors); Linda Ganzini et al., *Oregon Physician’s Perceptions of Patients Who Request Assisted Suicide and Their Families*, 6 J. Palliative Med. 381, 387 (2003); Eric A. Johnson, *Assisted Suicide, Liberal Individualism, and Visceral Jurisprudence: A Reply to Professor Chemerinsky*, 20 Alaska L. Rev. 321, 325 (2003) (stating that a patient’s feelings concerning a loss of dignity impact his or her decision on dying); N.R. Zweibel, *Measuring Quality of Life near the End of Life*, 260 JAMA 839, 840 (1998).

30. *Bartling v. Super. Ct.*, 209 Cal. Rptr. 220, 222 (Cal. App. 2d Dist. 1984).

31. *Id.*

32. *E.g. Bowia*, 225 Cal. Rptr. at 298 (noting the defendant hospital’s resistance to the plaintiff’s desire to terminate her use of a ventilator); *McKay*, 801 P.2d at 620 (rejecting the Nevada Attorney General’s opposition to the plaintiff’s request to discontinue his ventilator use).

33. *E.g. Pope’s Stand on Life Support Unclear for Church Hospitals*, Balt. Sun A1

objectors see the competent patient's choice to remove life support based on dismal prospective life circumstances as a form of suicide—anathema to civilized society.³⁴ These objectors insist that neither medical personnel nor courts should cooperate with a patient's assessment that life with an affliction is not worth preserving.

Courts have always acknowledged that states have a significant interest in promoting the sanctity of life, meaning respect for the intrinsic value of human life.³⁵ However, in the context of competent patients determining their own course of medical treatment or nontreatment, any abstract state interest in preserving life is deemed outweighed by “the patient's much stronger personal interest in directing the course of his own life” and in determining how to respond to a natural affliction.³⁶

Some advocates for the disabled denounce the willingness of courts to accept a disabled patient's determination to reject life-sustaining treatment and die.³⁷ For them, the message flowing both from the patient's choice to decline treatment and the court's acceptance of that course is that “life as a disabled person is ‘undignified’ or ‘degraded,’” and not worth preserving.³⁸ That mes-

(Apr. 3, 2004) [hereinafter *Pope's Stand*] (detailing Pope John Paul II's statement that refusing to give food and water to persons in a persistent vegetative state is improper and constitutes “euthanasia by omission”).

34. *E.g. Ross v. Hilltop Rehab. Hosp.*, 676 F. Supp. 1528, 1539 (D. Colo. 1987) (involving hospital personnel who refused to remove the plaintiff's life support, fearing they were participating in a criminal suicide or homicide).

35. *See e.g. Bartling*, 209 Cal. Rptr. at 225 (noting that the state's interests are weighed against the interest of the individual in freedom from bodily intrusion); *In re Guardianship of Browning*, 568 So. 2d 4, 14 (Fla. 1990) (identifying the state's interest in preserving life as the most important state interest in cases concerning patient-directed termination of life support); *In re Guardianship of Doe*, 583 N.E.2d 1263, 1269 (Mass. 1992) (recognizing the state's interests in “(1) the preservation of life; (2) the protection of innocent third parties; (3) the prevention of suicide; and (4) the maintenance of the ethical integrity of the medical profession”); *McKay*, 801 P.2d at 622 (declaring the state's interest in preserving life fundamental and compelling).

36. *In re Conroy*, 486 A.2d at 1223 (holding that a state's interest, while present, must yield to the patient's personal interest at times); *see Foody v. Manchester Meml. Hosp.*, 482 A.2d 713 (Conn. Super. 1984) (same); *Severns v. Wilmington Med. Ctr.*, 421 A.2d 1334 (Del. 1980) (same); *Brophy*, 497 N.E.2d at 635 (same).

37. *Foody*, 482 A.2d at 715; *Severns*, 421 A.2d at 1341; *Brophy*, 497 N.E.2d at 627–628; *In re Conroy*, 486 A.2d at 1216.

38. Johnson, *supra* n. 29, at 323; *see Tia Powell & Bruce Lowenstein, Refusing Life-Sustaining Treatment after Catastrophic Injury: Ethical Implications*, 24 J.L. Med. & Ethics 54, 59-60 (1996) (describing how social stigmas facilitate a belief that the life of a disabled person is worth less than an average person's life). Recently, disability-rights advo-

sage, in turn, supposedly disparages people living disabled lives, undermines their morale, and reinforces the negative stereotypes harbored by society. Advocacy groups such as Not Dead Yet protest when courts uphold fatal decisions by competent disabled people.³⁹ Other advocates for the disabled lament the judicial focus on the helplessness and dependence of the patient as reinforcing the notion that being fed, cleaned, and toileted is intolerably undignified.⁴⁰ Advocates blame society's lack of support services for disabled individuals as being responsible for any disabled person's inclination to reject life-preserving medical intervention.⁴¹

Courts understandably reject the claim that medical or judicial acceptance of a competent person's refusal of life support devalues a handicapped existence or erodes respect for human life.⁴² When a court upholds a patient's choice to decline treatment, the court is not endorsing either the soundness of the decision or its morality.⁴³ The best examples are the lines of cases upholding the prerogatives of Jehovah's Witnesses to decline life-saving blood transfusions,⁴⁴ and of gangrene-stricken patients to decline amputations capable of extending their lives for years.⁴⁵ In all these instances, the court is upholding autonomy in medical decisions—i.e., the court is respecting self-determination as an aspect of human dignity—even though the patient's decision may be imprudent and distasteful to the judge.⁴⁶

cates blasted the film *Million Dollar Baby* for portraying voluntary euthanasia as the desirable response to the heroine's crippling accident. See e.g. Daniel Costello, *Assisted Suicide at Center Stage Once Again: Award Winning Movies and Upcoming Legislation Give New Urgency to the Contentious Issue*, L.A. Times (Fla.) F1 (Mar. 7, 2005) (discussing objections to the movie, the *Schiavo* case, and assisted suicide laws). Their objections would be warranted if directed toward the precipitousness of compliance with the paralyzed heroine's wishes. No effort is made in the film to offer psychological counseling or physical rehabilitation to the heroine. Moreover, the heroine is ventilator dependent, so that a lethal injection, rather than removal of life support, seems unnecessary. The protestors' absolute denunciation of a competent person's choice to forgo life-extending treatment, though, seems misplaced.

39. E.g. Laura Blumenfeld, *At Dawn, Activists Greet Matter of Death in Shades of Gray*, Wash. Post A1 (Jan. 9, 1997).

40. E.g. Lois Sheperd, *Face to Face: A Call for Radical Responsibility in Place of Compassion*, 77 St. John's L. Rev. 445, 502 (2003).

41. *Id.* at 506.

42. E.g. McKay, 801 P.2d at 627–629.

43. *In re Farrell*, 529 A.2d at 408.

44. E.g. *Littleton v. Poittrast*, 1985 Mass. LEXIS 1800 (Jan. 21, 1985).

45. E.g. *In re Quackenbush*, 383 A.2d at 785.

46. *Thor*, 855 P.2d at 382; Pres. Commn. for the Study of Ethical Problems in Med. &

Certainly, judicial or medical acquiescence in a competent patient's chosen medical course does not reflect a negative social utility assessment. Quality of life from the personal perspective of the patient is not the same as value of life to the state or others. "The phrase 'quality of life' can mean either the value of prolonged life for the *patient* or the value to *others* of prolonged life based on the patient's contribution to and consumption of society's resources."⁴⁷ Doctors as well as courts respect each competent person's treatment preferences as grounded in the individual's assessment of her own interests.⁴⁸ If quality-of-life considerations come into play, they do so according to the patient's own perspective and values. Nor does the acceptance of a competent patient's fatal choice single out disabled persons. "The autonomy of every patient receives equal protection, regardless of current health, age, or disability."⁴⁹

II. SURROGATES' ASSESSMENTS OF QUALITY OF LIFE

All the above objections to a "quality of life" ethic are asserted even more vigorously in the context of mentally incompetent medical patients whose course of treatment is being determined by others.⁵⁰ Again, a decision to terminate life-sustaining medical intervention is viewed by some objectors as a usurpation of a divine function.⁵¹ And any surrogate determination to end life support supposedly violates an important cultural commitment to sanctity of life and the precept that all human life is intrinsically valuable.⁵² From that perspective, illness and decline may undermine quality of life and human dignity, but not to an extent justifying a determination that a debilitated existence is not worth preserving. Any surrogate decision to end life support is

Biomed. & Behavioral Research, *Deciding to Forego Life-Sustaining Treatment: Ethical, Medical, and Legal Issues in Treatment Decisions* 26 (U.S. Govt. Printing Off. 1983).

47. *Developments in the Law: Medical Technology and the Law*, 103 Harv. L. Rev. 1519, 1652 (1990) [hereinafter *Developments in the Law*] (emphasis in original).

48. Am. Med. Assn., *AMA Code of Medical Ethics*, Opinions 2.17, 2.20, <http://www.ama-assn.org/ama/pub/category/8457.html> (last updated Aug. 22, 2005).

49. Peters, *supra* n. 20, at 919.

50. *Id.*

51. *E.g. Pope's Stand*, *supra* n. 33.

52. Leon Kass, *Life, Liberty and the Defense of Dignity* 234–244 (Encounter Books 2002).

also said to undermine the status, morale, and well-being of healthy disabled persons.⁵³ Terms like “quality of life” and “a life not worth living” are criticized as being so subjective as to endanger helpless patients.⁵⁴ Any negative quality-of-life determination by a surrogate is deemed to be unavoidably distorted by the decision-maker’s subjective perspective.⁵⁵ Distortions may include self-interest, insensitivity to the value of disabled persons’ lives, or even concern for utilitarian factors such as costs of care.⁵⁶

A few jurisdictions have responded to such objections by severely constricting the circumstances in which a surrogate decision-maker—no matter how loving and dedicated to the incompetent patient’s well-being—can withhold or withdraw life support.⁵⁷ The first judicial decision in that direction was issued in 1981 by then-Chief Judge Wachtler of New York’s highest court.⁵⁸ For Wachtler, protection of helpless people’s lives overrode any pain or discomfort of the incapacitated, dying patient.⁵⁹ In another case, Judge Wachtler rejected a mother’s plea to end discomforting treatment for her cancer-stricken, mentally disabled son, saying, “no person or court should substitute its judgment as to what would be an acceptable quality of life for another.”⁶⁰ The Missouri Supreme Court in 1988 also ruled that no surrogate could remove life support from an incompetent patient—even a patient mired in a permanently unconscious state—in the absence

53. “Critics . . . argue that a quality-of-life approach . . . is actually an invidious method of denigrating the social worth of individuals whom others perceive to be defective or subnormal.” *Developments in the Law, supra* n. 47, at 1602.

54. *E.g.* Elizabeth J. Sher, *Choosing for Children: Adjudicating Medical Care Disputes between Parents and the State*, 58 N.Y.U. L. Rev. 157, 185 (1983).

55. William A. Kraiss, Student Author, *The Incompetent Developmentally Disabled Person’s Right of Self-Determination: Right-to-Die, Sterilization and Institutionalization*, 15 Am. J.L. & Med. 333, 345–346 (1989); D. Don Welch, *Walking in Their Shoes: Paying Respect to Incompetent Patients*, 42 Vand. L. Rev. 1617, 1637 (1989).

56. *See* Welch, *supra* n. 55, at 1637 (noting that doctors’ decisions are influenced by their personal experiences and education, cultural values, local practices, and whether the patients have medical insurance or are married).

57. *See Cruzan*, 760 S.W.2d at 408 (finding no legal basis for allowing the surrogate decision-makers to choose the death of their ward); *In re Westchester County Med. Ctr.*, 531 N.E.2d at 607 (stating that “no person or court should substitute its judgment as to what would be an acceptable quality of life for another”).

58. *In re Storar*, 420 N.E.2d 64 (N.Y. 1981).

59. *In re Westchester County Med. Ctr.*, 531 N.E.2d at 613.

60. *Id.* at 73 (stating that “a court should not . . . allow an incompetent patient to bleed to death because someone, even someone as close as a parent or sibling, feels that this is best for one with an incurable disease”).

of clear instructions issued by the patient while still competent.⁶¹ Without a prior declaration by the now-incompetent patient, the Missouri court feared that vulnerable people would be subject to abusive or arbitrary terminal decisions.⁶²

In 1990, the United States Supreme Court found that Missouri's policy was constitutional (whether or not it represented good public policy).⁶³ Several other state courts subsequently adopted Missouri's policy of precluding withdrawal of life support absent clear-cut prior expressions from the now-incompetent patient.⁶⁴ Maryland,⁶⁵ Kentucky,⁶⁶ New York,⁶⁷ Michigan,⁶⁸ Wisconsin,⁶⁹ and California⁷⁰ initially followed that course. This policy presents a considerable barrier to any removal of an incompetent patient's life-sustaining treatment. Very few people are prescient enough to provide sufficiently clear advance instructions for the spectrum of scenarios that might ensue. Fortunately for dying patients in those states, some mitigating factors have emerged.⁷¹

In the few states that still adhere to the Missouri policy,⁷² the consequences are dire both for never-competent persons (who could never have given prior instructions or designated a health-care agent) and for previously competent persons who never is-

61. *Cruzan*, 760 S.W.2d at 425.

62. *Id.* at 426.

63. *Cruzan*, 497 U.S. at 280 (finding that a state could, in the interests of preventing unwarranted cessation of life support by a surrogate, insist on clear-cut prior expressions from the incompetent patient).

64. Mary Ann Buckley, Student Author, *In re Wendland: Contradiction, Confusion, and Constitutionality*, 11 J.L. & Policy 255, 265–267 (2003).

65. *Mack v. Mack*, 618 A.2d 744, 753–754 (Md. 1993).

66. *DeGrella v. Elston*, 858 S.W.2d 698, 706 (Ky. 1993), *superseded*, Kan. Stat. Ann. § 311.631 (2004).

67. *In re Westchester County Med. Ctr.*, 531 N.E.2d at 607.

68. *In re Martin*, 538 N.W.2d 399 (Mich. 1995).

69. *Spahn v. Eisenberg*, 563 N.W.2d 485 (Wis. 1997).

70. *In re Wendland*, 28 P.3d 151 (Cal. 2001).

71. In a few of these states, legislative adoption of healthcare decisionmaking acts has loosened the judicially constructed policy so that a conscientious surrogate may act according to the incompetent patient's best interests, even if that means an end to further life support. In some states, a person can expand treatment (or nontreatment) options by appointing someone as an agent with authority to make all health decisions should the declarant become incompetent. And a last resort for healthcare providers stymied by restrictive laws is to spur the patient's next of kin to somehow "remember" previous conversations in which the now-incompetent patient expressed opposition to treatment in the current circumstances.

72. Actually, Missouri itself has abandoned its former rigid policy, except as to artificial nutrition and hydration.

sued advance instructions or designated an agent. The main specter is indefinite medical maintenance in a status that the patient herself would deem intolerably painful or demeaning if miraculously able to express personal wishes.

The story of Sheila Pouliot provides an illustration.⁷³ Ms. Pouliot was a forty-two-year-old woman, moderately retarded as a result of childhood mumps.⁷⁴ She had lived with her loving family for over twenty years, but in December 1999, she was a resident in a New York state facility for the developmentally disabled.⁷⁵ On December 21, 1999, Ms. Pouliot was admitted to University Hospital in Syracuse, suffering from aspiration pneumonia, gastrointestinal bleeding, an acute abdomen manifested by severe abdominal pain, and a nonfunctioning intestine.⁷⁶

Ms. Pouliot's sister, in conjunction with the hospital's medical personnel, determined that Ms. Pouliot was unavoidably dying and that further medical intervention, including artificial nutrition and hydration (ANH), would only prolong Ms. Pouliot's dying process.⁷⁷ The hospital ethics committee concurred.⁷⁸ Only palliative care would be administered.⁷⁹ That medical course was followed for several days until the state Attorney General's office intervened.⁸⁰

The Attorney General insisted that New York law would not permit removal of ANH from a patient in the absence of prior instructions—prior instructions that Ms. Pouliot never could have issued because of her mental incapacity.⁸¹ Under this legal pressure, the treating physicians renewed ANH and the family acquiesced.⁸² For the next seven weeks, Ms. Pouliot lingered, unable to relate to her environment and occasionally moaning and grimac-

73. See *Blouin v. Spitzer*, 213 F. Supp. 2d 184, 194 (N.D.N.Y. 2002), *aff'd*, 356 F.3d 348 (2d Cir. 2004); Alicia R. Ouellette, *When Vitalism Is Dead Wrong: The Discrimination Against and Torture of Incompetent Patients by Compulsory Life-Sustaining Treatment*, 79 Ind. L.J. 1, 31 (2004); see also Kathy Faber-Langendoen, *Sheila Pouliot's Story*, <http://www.familydecisions.org/pouliot.html> (accessed Sept. 12, 2005).

74. Faber-Langendoen, *supra* n. 73.

75. *Id.*

76. *Blouin*, 356 F.3d at 352.

77. *Blouin*, 213 F. Supp. 2d at 186.

78. *Id.*

79. *Blouin*, 356 F.3d at 351.

80. *Id.* at 351, 355.

81. *Id.* at 351, 354.

82. *Id.* at 353.

ing from pain.⁸³ Her body swelled up with edema to grotesque proportions, and her skin broke down around the I.V. providing hydration.⁸⁴ On March 3, 2000, the family and medical staff secured a court order permitting removal of all life support.⁸⁵ Ms. Pouliot died shortly thereafter, her course of dying having violated both medical standards of palliative care and standards of humane treatment dictated by compassion and respect for human dignity.⁸⁶ In short, a policy demanding clear prior expressions as a prerequisite to withdrawal of life support is inhumane in disregarding the possible harm and degradation to the now-incompetent patient.

In contrast to the Missouri policy, most states permit a surrogate decision to withhold or withdraw life support according to the surrogate's conscientious determination that the patient herself would have wanted that course or according to the patient's best interests (including an interest in quality of life and dignity).⁸⁷ Many courts, including the Florida courts in *Schiavo*, have insisted that a person's right to refuse medical treatment is not lost when that person becomes mentally incompetent.⁸⁸ The way to preserve the incompetent patient's "right" is to allow a surrogate to vicariously choose a medical course according to what the patient would have wanted.⁸⁹

Some commentators have objected to the notion of an autonomy-based right to reject treatment when the now-incompetent patient can no longer make a considered choice based on personal preferences and values.⁹⁰ It is true that in the absence of prior

83. *Id.* at 355; Ouellette, *supra* n. 73, at 31.

84. *Blouin*, 356 F.3d at 355–356.

85. *Id.* at 356; *see* Ouellette, *supra* n. 73, at 30–31 (stating that “the consensus among palliative care specialists is that terminating life-sustaining treatment is an appropriate course of treatment in the final stages of dying”).

86. Cantor, *supra* n. 14, at 190–193; Ouellette, *supra* n. 73, at 22, 25, 29.

87. Cantor, *supra* n. 14, at 190–191 (discussing end-of-life issue interpretation in Delaware, Florida, North Carolina, and Texas, among others).

88. *In re Tavel*, 661 A.2d at 1068; *In re Browning*, 568 So. 2d at 12–13; *In re Schiavo*, 30 Fla. L. Weekly D743 (Mar. 16, 2005); *In re Quinlan*, 355 A.2d at 664; *In re Fiori*, 673 A.2d at 912; *In re Colyer*, 660 P.2d 738, 746–747 (Wash. 1983); *see also Woods v. Kentucky*, 142 S.W.3d 24, 50 (Ky. 2004) (applying that principle only for patients who are permanently unconscious or unavoidably dying within days).

89. Norman L. Cantor, *The Relationship between Autonomy-Based Rights and Profoundly Mentally Disabled Persons*, 13 *Annals Health L.* 37, 39 (2004).

90. *Id.* at 39 (citing Daniel B. Griffith, *The Best Interests Standard: A Comparison of the State's Parens Patriae Authority and Judicial Oversight in Best Interests Determina-*

competent expressions, the surrogate's medical decision cannot reflect informed choice by the patient herself.⁹¹ Without prior choice, the surrogate's decision is not self-determination, but rather a means of implementing a patient's right to have appropriate medical decisions made on the patient's behalf.⁹² Conscientious surrogate choice is the only way to avert unrelenting pumping of fluids and substances into a moribund patient until the last possible breath.

An appropriate surrogate decision, according to the bulk of end-of-life jurisprudence, is one that implements the patient's likely preferences.⁹³ Legislative backing of advance directives, legislative articulation of criteria for surrogate medical decision-makers, and judicially crafted standards for surrogate decision-making all aim at fulfilling the now-incompetent patient's likely wishes.⁹⁴ A number of jurisdictions use a substituted judgment approach under which a surrogate decision-maker's object is to replicate what the patient probably would have wanted.⁹⁵ This means first considering the patient's prior expressions and, if they are indeterminate, extrapolating from the patient's own relevant preferences and values, such as strong religious precepts.⁹⁶ In instances when the patient's personal values cannot be discerned (as in the case of infants, never-competent persons, or persons whose values do not speak to end-of-life medical decisions), the

tions for Children and Incompetent Patients, 7 Issues L. & Med. 283, 320 (1991); Sanford H. Kadish, *Letting Parents Die: Legal and Moral Reflections*, 80 Cal. L. Rev. 857, 870 (1992); John A. Robertson, *Cruzan and the Constitutional Status of Nontreatment Decisions for Incompetent Patients*, 25 Ga. L. Rev. 1139, 1160 (1991)).

91. See *Cruzan*, 497 U.S. at 280 (suggesting that "a 'right' must be exercised for [a disabled patient], if at all, by some sort of surrogate"); *In re Susan S.*, 1996 WL 75343 at *8 (Del. 1996) (stating that a surrogate choice is clearly "not a personal choice, and no amount of legal legerdemain can make it so"); *In re Conroy*, 486 A.2d at 1231 (asserting that "it is naive to pretend that the right to self-determination serves as the basis for substituted [decisionmaking]"); Cantor, *supra* n. 89, at 39 (discussing how "[a]n incompetent patient by definition [can]not have the capacity to understand the alternatives and to exercise informed choice").

92. Cantor, *supra* n. 89, at 48; Ghan-Shyan Lohiya et al., *End-of-Life Care for a Man with Developmental Disabilities*, 16 J. Am. Board Fam. Prac. 58, 61 (2003); Peters, *supra* n. 20, at 898.

93. Cantor, *supra* n. 14, at 189–192; Norman L. Cantor, *The Real Ethic of Death and Dying*, 94 Mich. L. Rev. 1718, 1731–1735 (1996). The American Medical Association concurs. Peters, *supra* n. 20, at 946.

94. Cantor, *supra* n. 93, at 1731.

95. *Id.*

96. *Id.* at 1733.

patient's likely wishes can be gleaned from "what most persons are likely to do in a similar situation."⁹⁷ I call this approach "constructive preference"—a technique for making a substitute judgment on behalf of an incompetent person who has not issued prior instructions. The premise is that the vast majority of people care about indignity or quality of life in the dying process, and that—at least as to certain commonly occurring end-of-life scenarios—common preferences about intolerable levels of indignity can be objectively ascertained and used as default presumptions to guide surrogates.

When insufficient knowledge prevents any conclusion about a patient's prior choice, some jurisdictions shift focus from patient self-determination to the patient's best interests.⁹⁸ The underlying assumption is that most people would probably want decisions on their behalf made according to their best interests.⁹⁹ A best interests formula—asking whether the burdens of the patient's prospective existence outweigh the benefits of continued existence—draws on the elements that people commonly define as their interests when facing a critical affliction. Severe pain is almost universally deemed a substantial burden, while pleasure and satisfaction are obvious benefits.¹⁰⁰ Accordingly, physical and emotional pain and pleasure are the most important elements in surrogate consideration of a patient's best interests.¹⁰¹ But quality of life, or indignity, is still part of a best interests calculus. Courts defining best interests factors commonly include not only pain, but humiliation, extreme dependence, and loss of dignity.¹⁰²

The reality is that under both standards of substituted judgment and best interests of the patient, quality of life is an unavoidable element in shaping a humane dying process. Pain and

97. *In re Boyd*, 403 A.2d 744, 750 n. 11, 751 (D.C. 1979). One scholar argued that "unexpressed but probable desires can be equated with implementing the patient's right of choice." Nancy K. Rhoden, *Litigating Life and Death*, 102 Harv. L. Rev. 375, 384 (1988); see also Richard A. McCormick, *The Quality of Life, the Sanctity of Life*, 8 Hastings Ctr. Rpt. 30, 36 (Feb. 1978) (discussing the patient's probable choice as the lodestar for judicial consideration in these circumstances).

98. *E.g. In re Boyd*, 403 A.2d at 750–751.

99. Cantor, *supra* n. 14, at 191.

100. *Id.*

101. *In re Conroy*, 486 A.2d at 1233; *In re Grant*, 747 P.2d 445, 457 (Wash. 1987).

102. *Rasmussen*, 741 P.2d at 689; *Woods*, 142 S.W.3d at 50–51; *In re Conroy*, 486 A.2d at 1229; *Grant*, 747 P.2d at 457.

pleasure are clearly quality-of-life factors. Extreme indignity is another quality-of-life factor—subjection of a formerly competent, fatally stricken patient to a dying process that most people would regard as unconscionable. At some level of degeneration and debilitation, a dying patient's condition reaches a point that the patient would find intolerably undignified. In some instances, the now-incompetent patient has previously defined this treatment boundary, but usually not. In the absence of a patient's prior expressions or determinative personal values, a conscientious surrogate, in conjunction with surrounding healthcare providers, can project that level of indignity according to what a strong majority of people would deem intolerably undignified for themselves.¹⁰³ There are certain situations, like permanent unconsciousness or semi-consciousness without the ability to recognize loved ones, when notions of indignity shared by most people fill out what the now-incompetent patient would consider to be an intolerably demeaning dying process.¹⁰⁴

Why do people care about indignity if they are not actually experiencing the kind of frustration and humiliation that William Bartling found intolerable? The answer is that people care mightily about the memories and image to be left behind with their loved ones, as well as the burdens placed on those loved ones.¹⁰⁵ This fact clearly emerges in a multitude of surveys in which people identify the factors they want considered for themselves by a surrogate making post-competence medical decisions.¹⁰⁶ People facing a fatal, degenerative affliction care about extreme mental debilitation, helplessness, and dependence in a dying process.

103. As noted, the patient's own preferences and values are the starting point for surrogate decisionmaking; resorting to constructive preference happens only when the patient's own preferences are indeterminable. Cantor, *supra* n. 14, at 192.

104. Norman L. Cantor, *Discarding Substituted Judgment and Best Interests: Toward a Constructive Preference Standard for Dying, Previously Competent Patients without Advance Instructions*, 48 Rutgers L. Rev. 1193, 1252 (1996).

105. *Id.* at 1260 n. 233, 1261.

106. *E.g.* Robert A. Pearlman et al., *Insights Pertaining to Patient Assessment of States Worse than Death*, 4 J. Clinical Ethics 35 (1993); Ashwini R. Sehgal et al., *How Strictly Do Dialysis Patients Want Their Advance Directives Followed?* 26 JAMA 59, 62 (1992); Peter A. Singer et al., *Life Sustaining Treatment Preferences of Hemodialysis Patients: Implications for Advanced Directives*, 6 J. Am. Socy. of Nephrology 1410, 1412–1413 (1995); Thomas Tomlinson et al., *An Empirical Study of Proxy Consent for Elderly Persons*, 30 Gerontologist 54 (1990).

In short, the diminished quality of life of a previously competent person is an essential consideration in shaping medical intervention in a now-incompetent person's dying process.¹⁰⁷ The American Medical Association acknowledges that "[q]uality of life, as defined by the patient's interests and values, is a factor to be considered in determining what is best for the individual."¹⁰⁸

The injection of indignity and quality of life into surrogate medical decisionmaking does not mean injection of social worth or utilitarian considerations.¹⁰⁹ All sources embracing a best-interests formula make "the distinction between patient-centered best interests analysis and decisionmaking based on social worth."¹¹⁰ The courts in question emphasize quality of life as "an objective inquiry into 'the value that the continuation of life has for the patient'" rather than an opportunity for surrogates to rely on their subjective views or on a utilitarian calculus of social utility.¹¹¹

A patient-centered focus excludes any prejudice that cognitive deficiency is to be equated with an intolerable quality of life.¹¹² For example, people with Alzheimer's disease retain capacity for

107. Peters, *supra* n. 20, at 946.

108. AMA, *AMA Code of Medical Ethics*, Opinion 2.17, <http://ama-assn.org/ama/pub/category/8454.html> (last updated Aug. 19, 2005).

109. Nicholas Smedira et al., *Withholding and Withdrawal of Life Support from the Critically Ill*, 322 *New Eng. J. Med.* 309, 314 (1990).

110. Peters, *supra* n. 20, at 974. "The phrase 'quality of life' can mean either the value of prolonged life for the *patient* or the value to *others* of prolonged life based on the patient's contribution to and consumption of society's resources. Courts generally agree that if quality-of-life considerations have any influence at all, the appropriate scope should be defined by the value to the patient." *Developments in the Law, supra* n. 47, at 1652 (emphasis in original).

111. *Woods*, 142 S.W.3d at 41; *In re Conroy*, 486 A.2d at 1232–1233.

112. Patrick Corrigan & Brett Duncan, *The Construct Validity of Subjective Quality of Life for the Severely Mentally Ill*, 183 *J. Nervous & Mental Disease* 281–285 (May 1995). Nor does reference to quality of life entail derision of a disabled existence as inferior. The phrase "quality of life" can be used in both the intrapersonal and interpersonal sense.

Used in the intrapersonal sense, it refers to a comparison between the patient's former quality of life and the same patient's likely quality of life with and without treatment. In the intrapersonal sense, it is irrelevant that the patient is retarded and deformed except insofar as these conditions may be exacerbated by treatment or failure to treat. Also, in the intrapersonal sense, comparisons to other persons and their qualities are inappropriate. By contrast, quality of life in the interpersonal sense implies a comparison with others and includes assessment of deformities and mental retardation.

T.S. Ellis III, *Letting Defective Babies Die: Who Decides?* 7 *Am. J.L. & Med.* 393, 406 n. 52 (1982).

emotional response to their environment that is a part of quality of life even without rationality or memory.¹¹³ At the same time, extreme deterioration may reach a level that reasonably can be deemed intolerably demeaning according to either the previous values and preferences of the now-incompetent patient or a concept of intolerable indignity held by an overwhelming number of people contemplating their own dying processes (and not contradicted by anything in the patient's own value history). A permanently unconscious state is the principal example of an intolerably undignified status. Over ninety percent of people consistently say that they would not want to be preserved in this condition devoid of emotion or interaction with a human environment.¹¹⁴ In other words, an overwhelming majority of people would rather die than live "in such a physically, emotionally, and socially impoverished state."¹¹⁵

None of this suggests that it is easy for a conscientious surrogate to determine when a previously competent person has reached a point of such extreme deterioration that, from the perspective of the patient, death can be deemed preferable to life. There is no easy algorithm to accomplish that task. At least next of kin usually know the patient's history best, meaning that they are most familiar with the patient's values and preferences and best able to interpret the now-incompetent patient's current feelings, emotions, and expressions—all of which are relevant factors in making a quality-of-life medical decision. Also, in the case of previously competent persons, a surrogate can assess both the patient's own history and any consensus about an intolerably undignified quality of life (as in the case of permanent unconsciousness) that has emerged over time from sources like advance medical directives and surveys of people's preferences for their own end-of-life decisions. Naturally, surrogates tend to err in favor of life; premature termination of life is rarely documented.

113. Stephen G. Post, *Dementia in Our Midst: The Moral Community*, 4 Cambridge Q. of Health Care Ethics 142 (1995).

114. While new imaging techniques may show some brain activity in coma patients (though not PVS patients), many people would not want to be medically sustained in that frustrating and degrading condition. That is, an existence devoid of capacity for interaction with others is also unwanted by the vast majority of people thinking about their own medical fates.

115. John Arras, *The Severely Demented, Minimally Functional Patient: An Ethical Analysis*, 36 J. Am. Geriatrics Socy. 938, 943 (1988).

The difficulty of end-of-life medical decisionmaking is exacerbated in the case of never-competent patients. This means people who never had capacity to formulate their own values and preferences about a dying process, and whose concepts of indignity are not interchangeable with those of competent or previously competent persons.¹¹⁶ The situation of newborn infants is illustrative. While the best interests of the vast majority of infants—disabled or abled—dictate life-extending treatment, that is not always the case. Some infants face a battery of painful and burdensome treatments that will dominate their shortened existences before unavoidable death.¹¹⁷ And some very premature infants face unvalidated, invasive, and painful procedures likely to result in prolonged dying or grievous future harm. A recent case involved a premature infant, born at 615 grams, whose aggressive treatment resulted in lung disease, brain hemorrhaging causing severe mental retardation, cerebral palsy, seizures, spastic quadriplegia in limbs, incontinence, and a need for skilled care twenty-four hours per day.¹¹⁸ Parents, in conjunction with medical personnel, may, in those rare instances, determine whether further medical intervention is consistent with the infant's best interests.¹¹⁹

A similar calculus applies in end-of-life medical decisions on behalf of life-long profoundly mentally disabled persons. A conscientious surrogate must interpret the wants, needs, and feelings of the incapacitated patient from sometimes cryptic sounds and gestures. Of course, in the vast majority of cases, the surrogate chooses continued medical intervention in the face of fatal affliction.¹²⁰ The fact that a person's functioning is limited or prognosis poor does not mean it is in that person's best interests to die. Sometimes, though, the patient's extreme deterioration warrants an end to life-extending medical intervention.¹²¹

116. See Norman L. Cantor, *Making Medical Decisions for Profoundly Mentally Disabled Persons* 26–31 (MIT Press 2005).

117. Brian S. Carter & Gerald B. Merenstein, *Letters: Neonatal Care for Premature Infants*, 35 *Hastings Ctr. Rep.* 4, 5 (Jan./Feb. 2005).

118. *Miller v. HCA*, 118 S.W.3d 758, 763–764 (Tex. 2003).

119. *In re Christopher I.*, 106 Cal. App. 4th 533, 548–550 (Cal. App. 4th Dist. 2003); George J. Annas, *Extremely Preterm Birth and Parental Authority to Refuse Treatment*, 351 *N. Eng. J. Med.* 2118, 2121 (2004); Nancy K. Rhoden, *Treatment Dilemmas for Imperiled Newborns: Why Quality of Life Matters*, 58 *S. Cal. L. Rev.* 1283, 1319–1320 (1985).

120. Ghan-Shyam Lohiya et al., *supra* n. 92, at 58, 60.

121. *E.g. Saikewicz v. Superintendent of Belchertown State Sch.*, 370 N.E.2d 417, 423

III. CONCLUSION

Some people believe that death with dignity is a false hope.¹²² They contend that dying is intrinsically traumatic and that an effort to preserve dignity, in the sense of a tranquil passing, is bound to fail.¹²³ Dignity for them consists of struggling and contending bravely against a fatal affliction, no matter how precipitous the decline in physical and mental condition, and no matter how divorced the now-incompetent person may be from previous mental acuity and previous capacity to relate to an environment. For them, no surrogate—no matter how loving and devoted to the interests of the patient—can be entrusted with determining that a fatally afflicted person's quality of life is so dismal that all life-extending medical support should be withdrawn.

Yet the majority of deaths in the United States are managed—meaning that caregivers end medical intervention even though the patient's life could be artificially prolonged.¹²⁴ That is the only humane way. The alternative is to keep pumping fluids and gases into a floundering, moribund patient until the last possible breath. That is demeaning and shameful. “To presume that the incompetent person must always be subjected to what many rational and intelligent persons may decline is to downgrade the status of the incompetent person”¹²⁵ To ignore quality of life in the context of fatally afflicted persons “transforms human beings into unwilling prisoners of medical technology.”¹²⁶

(Mass. 1977); *Matter of R.H.*, 622 N.E.2d 1071, 1074 (Mass. App. 1993); Bruce Nichols, *Hospital Ends Life Support of Baby*, Dallas Morn. News (Mar. 15, 2005) (available at <http://www.dallasnews.com/s/dws/dn/latestnews/stories/031605dntexbaby.bc467.html>) (describing withdrawal of life support from a critically ill five-month-old infant suffering from a fatal genetic disorder called thanatophoric dysplasia).

122. See e.g. Sherwin B. Nuland, *How We Die: Reflections on Life's Final Chapter* 141 (Alfred A. Knopf 1993) (asserting that “if peace and dignity are what we delude ourselves to expect, most of us will die wondering what we, or our doctors, have done wrong”).

123. See e.g. *id.* at 142 (contending that “dying is a messy business” and that only a lucky few experience “a measure of serenity during separation”).

124. Cantor, *supra* n. 29.

125. *Superintendent of Belchertown St. Sch.*, 370 N.E.2d at 428.

126. *In re Guardianship of L.W.*, 482 N.W.2d 60, 74 (Wis. 1992).