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Privacy and Personhood Revisited: A New Framework for Substitute Decisionmaking for the Incompetent, Incurably Ill Adult*

Linda C. Fentiman**

Introduction

This is an essay about the nature of human personhood in a modern, socially and technologically complex society. Its focus is the incompetent,¹ incurably ill² adult³, and the question of how, and by

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1. "Incompetent," for purposes of this Article, is defined to mean incompetent to make a medical treatment decision. While this would obviously include an individual in a coma or in a persistent vegetative state, it also encompasses many patients who, although conscious, suffer from confusion or delusion, alternating with periods of lucidity, due to serious illness, pain, or pain medication. *See, e.g.*, State Dep't of Human Servs. v. Northern, 563 S.W.2d 197, 207-10 (Tenn. Ct. App. 1978).

There is no universally applicable standard for incompetency because the test of incompetency must necessarily depend on the purpose for which the incompetency determination is being made. Applebaum & Roth, *Competency to Consent to Research: A Psychiatric Overview*, 39 ARCHIVES GEN. PSYCHIATRY 951, 956 (1982). Thus, it is not useful to talk about global incompetency; rather, a person may be incompetent to make a will, or to manage his financial affairs, or to make a medical treatment decision, without necessarily being incompetent to conduct many other aspects of daily living. Stromberg & Stone, *A Model State Law on Civil Commitment of the Mentally Ill*, 20 HARV. J. ON LEGIS. 275,

whom, medical treatment decisions for that adult should be made. Fundamentally, this essay seeks to identify both the justification for, and limits of, state power over the individual in the area of health care decisionmaking, and to define a sphere within which the individual, as a member of the human family, may choose the direction of his life and death.

As we near the end of the twentieth century, we face a troubling paradox. At the very time that modern medical technology makes it possible to extend and sustain human life almost indefinitely, two of the most essential attributes of that life—individual self-determination and the sharing of human connection—have been placed in jeopardy. Gone are the days when dying was a frequent event in everyday life, striking young as well as old, with its inevitability being a respected and accepted fact of human existence.⁴ Today, perhaps because death is less common, it is more feared,⁵ and indeed, one might argue that the ever-increasing armory of modern anti-death weaponry is itself testimony to our collective fear of death.

In the last two decades, organ transplants, organ repairs (such as coronary bypass operations), and organ substitutes (such as respirators, ventilators, and renal dialysis machines) have, along with the development of major pharmacological treatments for a number of classic diseases of old age, made it possible to greatly extend the average person's life span. Currently, twelve percent of all Americans are over age sixty-five and twenty percent are expected to be so by the year 2030.⁶ Furthermore, the fastest growing segment of the elderly are those over seventy-five, who are much more likely than

301 (1983); see also *Rivers v. Katz*, 67 N.Y.2d 485, 494-95, 495 N.E.2d 337, 342, 504 N.Y.S.2d 74, 79 (1986) (holding that the fact that appellant was mentally ill and involuntarily civilly committed was insufficient in itself to establish a lack of competence to make a medical treatment decision (citing Brooks, *Constitutional Right to Refuse Antipsychotic Medications*, 8 BULL. AM. ACAD. PSYCHIATRY & L. 179, 191 (1980))). The definitional problems of "incompetency" are compounded because it is both a medical and legal term that is often used with very different meanings by practitioners in these two fields.

2. "Incurably ill" is used in this essay to identify not only those patients who have traditionally been labeled as "terminally ill," such as those suffering from a form of cancer for which no known cure exists, but also to describe those persons for whom death or a permanent loss of consciousness is reasonably medically certain, although not imminent. Persons in this category include stroke victims who have been in a coma for a long period of time and persons who are in a persistent vegetative state. For examples of such individuals, see *infra* notes 18-25 and accompanying text.

3. The focus of this essay is limited to incompetent, incurably ill adults. No discussion of the special ethical problems surrounding decisionmaking for seriously ill children, including newborns, will be attempted here.

4. Thomas, *Dying As Failure*, 447 ANNALS 1, 2-4 (1980), reprinted in J. AREEN, P. KING, S. GOLDBERG & A. CAPRON, LAW, SCIENCE AND MEDICINE 1077, 1078-80 (1984) [hereinafter LAW, SCIENCE & MEDICINE].

5. *Id.*

6. John Beck, Epidemiology, Demography, and General Principles, Paper presented at Intensive Course in Geriatric Medicine and Board Review, American College of Physicians, in Beverly Hills, California 1 (Jan. 19-23, 1988) (copy on file at the *George Washington Law Review*); 3 M. PERLIN, MENTAL HEALTH LAW: CIVIL AND CRIMINAL § 18.03 (forthcoming 1989) (citing Farber, Petrakis & Bernadette, *The Health Status Of the Older Population*, in 1981 WHITE HOUSE CONFERENCE ON AGING, REPORT OF THE TECHNICAL COMMITTEE ON HEALTH MAINTENANCE & HEALTH PROMOTION 1).

Interestingly, about half of the elderly are concentrated in just eight states: California,

younger individuals to suffer from chronic disease and disability.⁷ When these elderly do die, they most often do so in an institutional setting—a hospital or nursing home—where complex and often highly invasive medical technology may be employed in an effort to stave off death as long as possible.⁸

For these individuals, the spectre is raised of a life in limbo. The phenomenal accomplishments of modern medical technology have made it possible for previously active adults to be incapable of any cognitive, sentient interaction with their environment or other human beings, but to have their biological and corporeal lives sustained indefinitely.⁹ At the same time, there are increasingly large numbers of people who are incurably ill, but whose death, as defined by current medical and legal criteria,¹⁰ is not imminent.¹¹

Reflecting on this possibility of a “high-tech” death, many people are afraid that when the moment of their own death nears, they will

Florida, Illinois, Michigan, New York, Ohio, Pennsylvania, and Texas. John Beck, *supra*, at 2.

7. John Beck, *supra* note 6, at 1. As long ago as 1968, one study of chronic diseases found that “half of the deaths were from conditions diagnosed at least twenty-nine months earlier.” Childress, *Refusal of Lifesaving Treatment by Adults*, 23 J. FAM. L. 191, 194 (1984-85) (citing R. DUFF & A. HOLLINGSHEAD, *SICKNESS AND SOCIETY* 307 (1968)). More and more, the question is being raised of whether the “life” that ought to be protected at all costs includes mere biological and corporeal existence, or whether we can distinguish what is particularly human, and therefore sacred, from simple physical existence. See, e.g., Engelhardt, *Medicine and the Concept of Person*, in CONTEMPORARY ISSUES IN BIOETHICS 94, 94-99 (T. Beauchamp & L. Walters 2d ed. 1982) (arguing that “human life has more than one meaning and that there is more than one sense of human person,” and that important medical consequences flow from this recognition), *reprinted in part in* LAW, SCIENCE & MEDICINE, *supra* note 4, at 1067-72.

8. More than 80% of Americans over age 65 die in an institutional setting. In recent years, the percentage of those dying in hospitals has decreased, from 65 to 61% over the period from 1981 to 1985, while those dying in nursing homes has increased, from 19 to 21.5% during the same period. Boston Globe, Feb. 16, 1989, at 87, col. 1; see also PRESIDENT’S COMM’N FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE & BIOMEDICAL & BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT 17-18 (1983) [hereinafter COMM’N REPORT]; M. PERLIN, *supra* note 6, § 1803 (citing Kovar, *Elderly People: The Population 65 Years and Over*, in U.S. DEPT. OF HEALTH, EDUCATION, AND WELFARE, HEALTH: UNITED STATES 1976-1977 at 3 (1977)).

9. Gray v. Romeo, 697 F. Supp. 580, 584 (D.R.I. 1988). The longest reported period of a patient being maintained in a comatose state is 37 years. COMM’N REPORT, *supra* note 8, at 177 n.16.

10. A number of states have adopted the 1968 “Harvard criteria” for death, which identify brain death, as determined by several factors, as the crucial test of non-life versus life. LAW, SCIENCE & MEDICINE, *supra* note 4, at 1064-65; Black, *Definitions of Brain Death*, in ETHICAL ISSUES IN DEATH AND DYING 5, 6 (T. Beauchamp & S. Perlin eds. 1978). By 1986, more than 40 states had adopted some group of neurological criteria for death, either by statute or judicial decision. J. AREEN, P. KING, S. GOLDBERG & A. CAPRON, LAW, SCIENCE & MEDICINE 208 (Supp. 1987).

11. At any one time, as many as 10,000 Americans are in the long-term unconscious condition known as a persistent vegetative state. See *infra* note 18; see also Brophy v. New England Sinai Hosp., 398 Mass. 417, 421-27 & nn. 4 & 6, 497 N.E.2d 626, 628-31 & nn. 4 & 6 (1986) (discussing at length the definition and physical consequences of being in a persistent vegetative state).

be unable to make choices concerning it. As Seneca declared nearly two thousand years ago, "Just as I choose a ship to sail in or a house to live in, so I choose a death for my passage from life. . . . Nowhere should we indulge the soul more than in dying."¹²

Ironically, in the past twenty-five years there have been a number of judicial decisions announcing both a constitutional¹³ and common law right to privacy,¹⁴ including the right, under certain circumstances, to refuse all life-sustaining¹⁵ medical treatment.¹⁶

12. Seneca, *Suicide*, in *THE STOIC PHILOSOPHY OF SENECA* 202, 204 (M. Hadas trans. 1968).

13. *E.g.*, *Roe v. Wade*, 410 U.S. 113, 152 (1973); *Griswold v. Connecticut*, 381 U.S. 479, 484-86 (1964).

14. A right to privacy, inherent in the right to be free from invasion of one's bodily integrity, has long been recognized at common law, both as a right *ex proprio vigore* and as an aspect of the right to be free from the tort of battery, an unconsented touching. *See, e.g.*, *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 738-39, 370 N.E.2d 417, 424 (1977) ("There is implicit recognition in the law . . . that a person has a strong interest in being free from nonconsensual invasion of his bodily integrity."); *Schloendorff v. Society of N.Y. Hosp.*, 211 N.Y. 125, 129, 105 N.E. 92, 93 (1914) (Cardozo, J.) (recognizing a competent adult's right to determine what will be done to his body, and that medical treatment without the patient's consent is a battery).

15. Life-sustaining medical treatment is used here to mean any medical treatment that substitutes for a normal bodily function in a way that sustains life. It includes not only such obvious examples as respirators, kidney dialysis machines, cardiopulmonary resuscitation, and organ transplantation, but also treatment with antibiotics and the provision of food and hydration by such means as intravenous feeding or a nasogastric tube.

Whether artificial means of supplying food and water should be defined as medical treatment that can be withheld or withdrawn under the same circumstances as any other medical treatment is the subject of intense controversy at present. In 1986 the American Medical Association (AMA) adopted a revised ethical opinion indicating that the artificial provision of nutrition and hydration should be viewed as medically and ethically comparable to other forms of medical treatment. *See COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS, AMA, CURRENT OPINIONS* § 2.18 (1986) [hereinafter *AMA COUNCIL*]. The underlying view here is that, "[f]ood and water should always be provided when they are needed for patient comfort, but when . . . all it does is lengthen the terminal period without adding comfort, . . . it may be more beneficial to withhold nutrition and hydration." Childress, *supra* note 7, at 212 (quoting Dr. Virginia Keeney). However, a vocal minority of critics of this position, led by Dr. Mark Siegler and Attorney Alan J. Weisbard, contends that artificial methods of providing food and water are *sui generis*, and should not be withheld or withdrawn as a matter of general medical practice, both because of their emotional significance as symbols of compassion and caring and because of a concern that permitting the withholding of food and water from the incurably ill is but the first step down the slippery slope of withholding nourishment from "the severely senile, the pleasantly senile, the retarded, . . . and perhaps, the aged." Siegler & Weisbard, *Against the Emerging Stream: Should Fluids and Nutritional Support Be Discontinued?*, 145 *ARCHIVES INTERNAL MED.* 129, 130-31 (1985).

16. The right to refuse medical treatment has been recognized during the past 30 years as an important aspect of a patient's right to participate in the medical decision-making process, frequently denominated the right to give informed consent to medical treatment. *E.g.*, *Canterbury v. Spence*, 464 F.2d 772, 780 (D.C. Cir.), *cert. denied*, 409 U.S. 1064 (1972); *Natanson v. Kline*, 186 Kan. 393, 406-07, 350 P.2d 1093, 1104 (1960). More recently, the right to refuse medical treatment has been asserted by involuntarily committed mental patients, who have sought, with some success, to refuse treatment with antipsychotic drugs. *See Rennie v. Klein*, 653 F.2d 836, 844 (3d Cir. 1981) (*en banc*), *vacated and remanded*, 458 U.S. 1119 (1982), *reaff'd on other grounds*, 720 F.2d 266 (3d Cir. 1983); *Rivers v. Katz*, 67 N.Y.2d 485, 497-98, 495 N.E.2d 337, 343-44, 504 N.Y.S.2d 74, 81 (1986); *Rogers v. Commissioner of the Dep't of Mental Health*, 390 Mass. 489, 497, 458 N.E.2d 308, 314 (1983).

A specific right to refuse life-sustaining medical treatment has been recognized by an increasing number of state courts as an important aspect of the constitutional and common law rights to privacy. The landmark case of *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, *cert. denied*, 429 U.S. 922 (1976), was one of the first in the nation to address this

However, the combination of advanced medical technology, increasing judicial involvement in the protection of individual liberties, and the rising tide of medical malpractice litigation¹⁷ has led to a situation in which the goal of private, personal decisionmaking about the manner and timing of one's death often exists more as a matter of abstract legal principle than as a practical reality.

The time has come for a reexamination of traditional approaches to thinking about death, and, in particular, the process by which we reach decisions about terminating medical treatment. The thesis of this Article is that there are two major aspects of human personhood that must be central to our thinking in this area. The first is that of individual autonomy and privacy: the fundamental principle that each person should be the architect of her own destiny, both because this is an inalienable human right and because, as a practical matter, she is in the best position to know her own needs and desires. Thus, substitute decisionmaking for an incompetent adult should seek to respect and promote that individual's right to autonomy and privacy, both by seeking to effectuate his medical treatment choice, to the extent that it can be determined once he is no longer competent, and by providing a sphere for *private* decisionmaking by that individual, his family, and his physician, into which the state cannot intrude.

The second fundamental aspect of human personhood, which has been virtually ignored by courts and commentators, is that each individual is a member of a community: we are *human* precisely because we can interact, communicate with, and care for other people. Thus, we are individuals in a web of relationships and connections—between spouses, between parents and children, within a family, and within a community.

Regrettably, most recent writing about decisionmaking for the incompetent, incurably ill patient has focused solely on the patient's right to autonomy, and indeed, on one particular aspect of that autonomy—the ability to *refuse* treatment. Because this writing

troubling area. More recently, the New Jersey Supreme Court has sought to answer some of the questions left open in *Quinlan* in: *In re Farrell*, 108 N.J. 335, 529 A.2d 404 (1987), *In re Jobs*, 108 N.J. 394, 529 A.2d 434 (1987), *In re Peter*, 108 N.J. 365, 529 A.2d 419 (1987), and *In re Conroy*, 98 N.J. 321, 486 A.2d 1209 (1985). The Massachusetts Supreme Judicial Court has also recognized a constitutional and common law right to refuse life-sustaining medical treatment. *Brophy v. New England Sinai Hosp.*, 398 Mass. 417, 497 N.E.2d 626 (1986); *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 370 N.E.2d 417 (1977). Numerous other state courts have reached similar conclusions. *E.g.*, *Foody v. Manchester Memorial Hosp.*, 40 Conn. Supp. 127, 130, 482 A.2d 713, 717-18 (Super. Ct. 1984); *In re Colyer*, 99 Wash. 2d 114, 120-21, 660 P.2d 738, 742 (1983); *Satz v. Perlmutter*, 379 So. 2d 359, 360 (Fla. 1980); *Leach v. Akron Gen. Medical Center*, 68 Ohio Misc. 1, 8-9, 426 N.E.2d 809, 814 (C.P. 1980).

17. P. DANZON, *THE FREQUENCY AND SEVERITY OF MEDICAL MALPRACTICE CLAIMS* 1-3, 7-8, 36-38 (1982).

neglects the need to preserve and promote the relational aspects of human personhood, it is seriously incomplete.

This Article is thus an exploration of the essentials of the human personhood *in community*, both the intimate community of family and close friends and the larger, more impersonal community of hospitals and health care providers, courts, legislatures, and lawyers. After undertaking an analysis of the sources of the autonomy model for decisionmaking in this area and the negative consequences of an exclusive reliance on that model, this Article will propose a new moral, legal, and medical framework for making medical treatment decisions for incompetent incurably ill adults. This model both provides maximum opportunities for each individual to determine for himself, without state interference, whether, and under what circumstances, he should receive life-sustaining medical treatment. Simultaneously, it recognizes that because all individuals are persons in community, decisionmaking in this area must promote and respect the connectedness of the human family by providing incentives and opportunity for conversation and compassion.

I. The Problem: The Incompetent, Incurably Ill Patient and the Risk of Erroneous Decisionmaking

To understand fully the problem of decisionmaking for incurably ill, incompetent adults we must examine first who they are, and second, the issues that make decisions in this area so problematic.

Perhaps the most famous example of a person suffering a prolonged dying is Karen Ann Quinlan, the young woman who, for reasons unknown, suffered brain damage and lost consciousness, remaining in a persistent vegetative state¹⁸ for almost ten years before she died.¹⁹ In the seminal case of *In re Quinlan*,²⁰ Quinlan's father persuaded the New Jersey Supreme Court to appoint him as his daughter's guardian in order to act as a surrogate and exercise her constitutional right to privacy. The court held that this right encompassed the right to refuse life-sustaining medical treatment under the particular circumstances of this case.

More recently, much attention has been given to the case of Paul Brophy, a Massachusetts fire fighter who suffered a cerebral aneurysm and lost consciousness.²¹ As a result of his stroke, Brophy entered a persistent vegetative state, unable to swallow and thus to ingest food. To keep him alive, Brophy's doctors surgically implanted a gastrostomy tube that provided him with nutrition and

18. Persistent vegetative state is the neurological condition that occurs post-coma, in which the autonomic nervous system continues to function after the cognitive functioning of the mind has ceased. Altman, *When the Mind Dies But the Brain Lives On*, N.Y. Times, Nov. 17, 1987, at C3, col. 5. In 1986, there were estimated to be 10,000 patients in a persistent vegetative state. Wallis, *To Feed or Not to Feed?*, TIME, March 31, 1986, at 60.

19. Karen Ann Quinlan lived for five years after her father was permitted to exercise her right to refuse treatment.

20. 70 N.J. 10, 355 A.2d 647, cert. denied, 429 U.S. 922 (1976).

21. *Brophy v. New England Sinai Hosp.*, 398 Mass. 417, 497 N.E.2d 626 (1986).

hydration.²² Ultimately, Brophy's wife persuaded the Massachusetts Supreme Judicial Court to act as a substitute decisionmaker on Brophy's behalf. The court determined that Brophy would have elected not to receive medical treatment under these circumstances, and accordingly, authorized the removal of the gastrostomy tube.²³

Less well-known than Quinlan and Brophy, but much more numerous, are those people, frequently elderly, suffering from incurable cancer, emphysema, strokes, and countless other degenerative diseases who eventually are so debilitated by illness, advancing senility, or necessary pain medication that they become incapable of communicating with others about their treatment desires.²⁴ Because any number of medical complications can be life-threatening for these individuals, the question is frequently raised as to whether continued aggressive medical treatment is appropriate.²⁵

Each of these cases raises profound medical, moral, and legal issues. Because the individual is incompetent, incapable of presently making a decision to accept or reject medical treatment, someone must make a decision on her behalf. But who should that decisionmaker be, and what approach should she employ in making the decision?

Historically, and to a large extent still today, decisions to treat or not treat the incurably ill, incompetent patient were made by the patient's physicians, or her family, or the two in combination.²⁶ But, often today, doctors and families are seeking the assistance of the courts to act either as the decisionmaker in the first instance, or as the arbiter of last resort. Many physicians are refusing to discontinue life-sustaining medical treatment without judicial authorization, due either to their own sense of professional ethics or to the fear of civil or criminal liability.²⁷

At the heart of the ethical conundrum raised by these cases is the

22. *Id.* at 421, 497 N.E.2d at 628.

23. *Id.* at 441-42, 497 N.E.2d at 639-40.

24. See Munetz, Lidz & Meisel, *Informed Consent and Incompetent Medical Patients*, 20 J. FAM. PRACTICE 273, 275-77 (1985); Hilfiker, *Allowing the Debilitated to Die*, 308 NEW ENG. J. MED. 716, 717 (1983).

25. See, e.g., Hilfiker, *supra* note 24, at 717 (suggesting that doctors frequently make a subconscious decision not to provide "maximal possible care" to incompetent, terminally ill patients).

26. See *In re Westchester County Medical Center*, 72 N.Y.2d 517, 552, 531 N.E.2d 607, 626, 534 N.Y.S.2d 886, 905 (1988) (Simons, J., dissenting); *In re Conroy*, 98 N.J. 321, 345, 486 A.2d 1209, 1227 (1985).

27. See *Brophy v. New England Sinai Hosp.*, 398 Mass. 417, 497 N.E.2d 626 (1986); *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, *cert. denied*, 429 U.S. 922 (1976); cf. *Barber v. Superior Court*, 147 Cal. App. 3d 1006, 195 Cal. Rptr. 484 (1983). *Barber* is apparently the only reported American murder prosecution based on a physician's withdrawal of life support systems. The *Barber* case was brought against physicians who, at the direction of a patient's family, disconnected all his life-support systems after he had suffered a post-surgery cardio-respiratory arrest that led to severe and permanent brain damage.

collective judgment of our society that human life and human personhood are sacred and must be zealously protected. When this belief is combined with the obvious reality that a decision to withhold life-sustaining treatment is irrevocable, it leads to a fear of error in decisionmaking²⁸ that may become paralyzing.²⁹ The awareness of this risk of error, and the possibility of abuse in a substituted judgment process, currently pervades much of the judicial and other writing in this area.³⁰

Although the circumstances of each individual patient are of course unique, there are three major factors that contribute to the risk of an improper decision being made. These are, first, the risk of an erroneous medical diagnosis of the patient's condition; second, the risk of an erroneous medical assessment of the patient's prognosis, even with a correctly diagnosed condition; and third, the risk that a substitute decisionmaker might erroneously assess the patient's treatment wishes.

There is limited data available about the frequency of medical misdiagnosis or prognosis,³¹ but most readers will be aware of some evidence that suggests that this is at least a minimal risk.³² A number of courts have implicitly recognized the possibility of

28. Whether it is a more egregious error to choose death for an incompetent person who would have opted for even a limited life, or to choose life for a person who would have preferred immediate death to a long and painful struggle is, of course, a question that can only be answered by resort to one's personal values and beliefs.

29. A distinguished group of American physicians has commented:

Fear of legal liability often interferes with the physician's ability to make the best choice for the patient. Assessment of legal risks is sometimes made by lawyers whose primary objective is to minimize liability, whether real or imagined. Unfortunately, this may be done at the expense of humane treatment and may go against the expressed wishes of the patient or family.

Wanzer, Adelstein, Cranford, Federman, Hook, Moertel, Safar, Stone, Taussig, & van Eys, *The Physician's Responsibility toward Hopelessly Ill Patients*, 310 NEW ENG. J. MED. 955, 956 (1984) [hereinafter *Physician's Responsibility*]. Of course, the fear of legal liability should not be invoked as an excuse for avoiding the hard choices that both adulthood and professional responsibility place upon all of us.

30. For example, Justice Lynch's dissenting opinion in *Brophy v. New England Sinai Hospital* states: "A substituted judgment standard is our best legal tool to divine individual intent and to protect autonomous choice. But it would be an error of great magnitude to conflate a substituted judgment with an actual judgment." 398 Mass. at 448, 497 N.E.2d at 643.

31. *Physician's Responsibility*, *supra* note 29, at 956.

32. As President Derek Bok noted in his 1983 report on medical education to the Harvard Board of Overseers:

[M]any studies have revealed that doctors make a disturbing number of major diagnostic errors. For example, a recent survey of 100 autopsies at a prominent teaching hospital disclosed such mistakes in 22 percent of the cases. In almost half of these instances, a correct diagnosis would have indicated a change in the treatment that might have prolonged life.

Bok, *NEEDED: A new way to train doctors*, HARV. MAG. 32, 39 (May-June 1984) (copy on file at the *George Washington Law Review*) (citing Goldman, Sayson, Robbins, Cohn, Bettman & Weinberg, *The Value of the Autopsy in Three Medical Eras*, 308 NEW ENG. J. MED. 1000 (1983)). Bok also noted that many internists frequently neglected routine "high yield" diagnostic tests:

[A] survey of 249 patients in the outpatient clinic of a teaching hospital revealed that internists often neglected simple high-yield procedures such as examining the prostate or asking for a urinalysis (omitted 20 percent of the time), ordering blood-sugar analysis (omitted 30 percent of the time), and testing the stool for blood (omitted 40 percent of the time).

mistaken diagnosis or prognosis, either by requiring the patient's condition to be concurred in by additional physicians,³³ by calling for an "ethics committee" to evaluate the likely prognosis of a patient in a persistent vegetative state,³⁴ or by requiring that evidence of the patient's hopeless prognosis and diagnosis be "clear and convincing," the highest civil standard of proof.³⁵ Many "natural death acts" recognize this risk by requiring two or more physicians to certify that a patient suffers from a "terminal condition" before the patient's attending physician can discontinue life-sustaining treatment.³⁶

In addition, although physicians may agree on a general prognosis for a particular patient, predicting the precise moment of an impending death is extremely difficult.³⁷ Thus, in cases in which a prognosis that a patient has only a few months to live may lead to a call for less aggressive treatment than would be afforded a patient who had a year or more to live, the risk that a prognosis of a very short life expectancy will become a self-fulfilling prophecy is apparent.³⁸

Yet perhaps the most significant concern about erroneous decisionmaking stems from the inherent inability of a substitute decisionmaker to know with certainty the incompetent patient's own wishes.³⁹ Here, the most common scenarios are that: (1) the decisionmaker has *no* information about the patient's values and priori-

Id. (citing Goetzel, Cohen, Downing, Erat & Jessiman, *Quality of Diagnostic Examinations in a University Hospital Outpatient Clinic*, 78 ANNALS INTERNAL MED. 481 (1983)).

33. *In re Conroy*, 98 N.J. 321, 384, 486 A.2d 1209, 1242 (1985); *In re Barry*, 445 So. 2d 365, 372 (Fla. Dist. Ct. App. 1984); *In re Colyer*, 99 Wash. 2d 114, 137, 660 P.2d 738, 751 (1983); *Foody v. Manchester Memorial Hosp.*, 40 Conn. Supp. 127, 132, 482 A.2d 713, 721 (Super. Ct. 1984).

34. *Colyer*, 99 Wash. 2d at 134-35, 660 P.2d at 749; *In re Quinlan*, 70 N.J. 10, 54, 355 A.2d 647, 671, *cert. denied*, 429 U.S. 922 (1976).

35. *In re Jobes*, 108 N.J. 394, 407-08, 529 A.2d 434, 441 (1987); *see* *Leach v. Akron Gen. Medical Center*, 68 Ohio Misc. 1, 11, 426 N.E.2d 809, 815 (C.P. 1980).

36. *See, e.g.*, IOWA CODE ANN. § 144A.5 (1987) (requiring another physician to confirm the attending physician's determination of a "terminal condition").

37. COMM'N REPORT, *supra* note 8, at 25. Indeed, "[e]xcept in patients who were very ill and had short prognosis [sic] of three to four months, survival was consistently underestimated." Aiken & Marx, *Hospices: Perspectives on the Public Policy Debate*, 37 AM. PSYCHOLOGIST 1271, 1275 (1982), *quoted in* COMM'N REPORT, *supra* note 8, at 25 n.44.

38. Pearlman, Inui & Carter, *Variability in Physician Bioethical Decision-making: A Case Study of Euthanasia*, 97 ANNALS INTERNAL MED. 420 (1982), *cited in* COMM'N REPORT, *supra* note 8, at 25 n.44.

39. Even in the case of a competent patient, it is often difficult to know whether the person is making a carefully thought-out and voluntary decision to reject all or certain types of medical treatment, or is acting, at least in part, on the basis of depression or a belief that others wish the patient to choose death. R. BURT, *TAKING CARE OF STRANGERS: THE RULE OF LAW IN DOCTOR-PATIENT RELATIONS* 6-7 (1979); Beschle, *Autonomous Decisionmaking and Social Choice: Examining the "Right to Die"*, 77 KY. L.J. 319, 354-58 (1988-89).

The importance of exploring a patient's apparent wishes in some detail, and through the process of conversation, is emphasized in Jackson & Youngner, *Patient Autonomy and*

ties in the matter of life-sustaining treatment, because the patient has never expressed any opinion on the question of refusing such treatment;⁴⁰ (2) the decisionmaker has *some* information about the patient's desires, but is not sure how to apply that information to the actual medical situation confronting the patient;⁴¹ and (3) whatever the information the substitute decisionmaker does have about the patient's wishes is viewed, consciously or not, through the lens of the decisionmaker's own self-interest, biases, and values. Indeed, such potential for distortion of the patient's wishes, even if they could be fully known, is inevitable, given the reality that it is not the decisionmaker's own imminent death that she is called upon to choose.⁴²

Thus, whenever the family of an incompetent person asserts a right to make the decision for him, the possibility exists that the family's claim that the patient had previously declared a wish "to die with dignity" is merely masking the family's wish to see the patient dead, either because of dislike, or avarice, or to end the drain on the family's dwindling financial and emotional resources.⁴³ Indeed, when the patient is incompetent, then it is at least arguable that it is the family's, rather than the patient's, privacy interest that is at stake, because the patient is neither aware of the offensive intrusion into her body nor the notoriety that her case may be evoking.⁴⁴ Conversely, a family, or one of its members, who asserts that the

"Death With Dignity," 301 NEW ENG. J. MED. 404, 407 (1979), *reprinted in* LAW, SCIENCE & MEDICINE, *supra* note 4, at 1127, 1132. Jackson and Youngner write:

Physicians . . . must be alert not to let the possibility of abuse keep them from the appropriate exercise of professional judgment. Physicians who are uncomfortable or inexperienced in dealing with the complex psychosocial issues facing critically ill patients may ignore an important aspect of their professional responsibility by taking a patient's or family's statement at face value without further exploration or clarification.

Id. For further discussion of the need for conversation in decisionmaking for the incompetent incurably ill, see Section III, *infra*.

40. *E.g.*, *In re Storar*, 52 N.Y.2d 363, 380, 420 N.E.2d 64, 72, 438 N.Y.S.2d 266, 275, *cert. denied*, 454 U.S. 858 (1981).

41. See *Brophy v. New England Sinai Hosp.*, 398 Mass. 417, 428, 497 N.E.2d 626, 632 (1986); *In re Conroy*, 98 N.J. 321, 340, 486 A.2d 1209, 1218 (1985) (involving a senile and confused nursing home patient sustained by a nasogastric feeding tube, whose nephew declared, "[a]ll [Ms. Conroy and her sisters] wanted was to . . . have their bills paid and die in their own house." (alterations by the court)).

42. In his recent article, Donald Beschle writes powerfully about our inherent inability either to accurately predict how *we* will feel when our own death is imminent or to meaningfully stand in the position of another and assess the choice that person would make when faced with the reality of incurable illness. Beschle, *supra* note 39, at 341-46.

43. *In re Colyer*, 99 Wash. 2d 114, 130, 660 P.2d 738, 747 (1983).

44. M. Hayes, Remarks during the Law, Science, and Medicine Seminar, Suffolk University Law School (Spring 1988). Others, however, have argued that an important aspect of the right to privacy is the present peace of mind that one feels when assured that one's wishes will be carried out even if one is not in a position to be aware of it, just as one feels more secure after having signed a will that one's minor children will be cared for and one's property will be disbursed in accordance with that document. Cantor, Conroy, *Best Interests, and the Handling of Dying Patients*, 37 RUTGERS L. REV. 543, 556 (1985). Further, "[s]ome languishing patients, though not sufficiently aware to make a competent medical decision, may have enough awareness to sense and appreciate relief when painful, intrusive, or embarrassing care is withdrawn in accordance with his or her prior instructions." *Id.*

patient wanted all possible treatment provided, might be reflecting the decisionmaker's own fear of dying, or a religious view that life must be prolonged at all cost, or even a perverse satisfaction in seeing the patient suffer.

Similarly, in the case of the physician decisionmaker, the physician's aggressive treatment may reflect his own fear of death and dying, his concern with demonstrating professional competence,⁴⁵ or his desire to generate a large fee. Or, in exactly the same situation, with the same patient statements, a different physician might argue against treatment, because the physician views her role as one of easing suffering and comforting the dying when sustaining life is no longer possible,⁴⁶ or because she needs an intensive care unit bed for a patient with a more hopeful prognosis.

These same risks of unconscious value bias apply to the judicial decisionmaker as well. For the judge, every bit as much as the physician or family member, there is the possibility that his retrospective assessment of the incompetent patient's wishes will be colored by his own fears of an existence in limbo, a life that he might not deem worth living. Thus, in *In re Quinlan*, the New Jersey Supreme Court seemed to validate Quinlan's father's exercise of her right to refuse medical treatment in part because "the overwhelming majority [of society] would, we think, in similar circumstances, exercise such a choice in the same way for themselves or for those closest to them."⁴⁷ Although both the New Jersey Supreme Court and other courts have subsequently eschewed any suggestion that they were making decisions based on the "quality" of the patient's life,⁴⁸ it is naive to suppose that any decision of this nature can be totally divorced from the values of the decisionmaker.

Indeed, over the past twelve years, many courts have easily dismissed what would seem to be an enormous state interest in the preservation of life.⁴⁹ Remarkably, they have often concluded, even

45. *Physician's Responsibility*, *supra* note 29, at 956; see Jaretzki, *Death with Dignity—Passive Euthanasia*, 76 N.Y. ST. J. MED. 539, 541 (1976).

46. In its most recent pronouncement on this aspect of medical ethics, The American Medical Association Council on Ethical and Judicial Affairs declared in pertinent part:

The social commitment of the physician is to sustain life and relieve suffering. Where the performance of one duty conflicts with the other, the choice of the patient, or his family or legal representative if the patient is incompetent to act in his own behalf, should prevail. In the absence of the patient's choice or an authorized proxy, the physician must act in the best interest of the patient.

AMA COUNCIL, *supra* note 15, at § 2.18 (Withholding or Withdrawing Life-Prolonging Medical Treatment).

47. 70 N.J. 10, 41-42, 355 A.2d 647, 664 (1976).

48. *Brophy v. New England Sinai Hosp.*, 398 Mass. 417, 434, 497 N.E.2d 626, 635 (1986); *In re Conroy*, 98 N.J. 321, 335, 486 A.2d 1209, 1226 (1985).

49. *Brophy*, 398 Mass. at 433-34, 497 N.E.2d at 635; *Conroy*, 98 N.J. at 348-49, 486

in the absence of significant evidence of what an incompetent individual would have chosen, that his privacy interest in terminating medical treatment is paramount.⁵⁰ Many courts forthrightly acknowledge the difficult moral and ethical terrain they are traversing and the agonizing nature of the decisions that they have been called upon to make.⁵¹ Nonetheless, some critics charge that this apparent solicitude for individual liberty masks impermissible judicial choices based upon the quality of a patient's life,⁵² and that such decisions launch us onto an ethical slippery slope that will soon lead to the active killing of a large number of socially undesirable individuals.⁵³ Judicial activism on behalf of the incompetent has been severely criticized as "paternalism masquerading as the mere ratification of autonomous choice."⁵⁴

The danger, of course, no matter who the decisionmaker,⁵⁵ is that what purports to be a concern for death with dignity is translated in fact into a lack of concern for the person who is dying. Respect for individual autonomy can translate quickly into abandonment, whether intended or not,⁵⁶ as has often been the case with the

A.2d at 1226; *In re Colyer*, 99 Wash. 2d 114, 122, 660 P.2d 738, 744 (1981); *Satz v. Perlmutter*, 362 So. 2d 160, 162, 164 (Fla. Dist. Ct. App. 1978), *aff'd*, 379 So.2d 359 (Fla. 1980); *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 741-42, 370 N.E.2d 417, 425-26 (1977); *In re Quinlan*, 70 N.J. 10, 40-41, 355 A.2d 647, 663-64, *cert. denied*, 429 U.S. 922 (1976).

50. See *infra* notes 146-214, and accompanying text. At the same time, however, some courts have refused to follow this trend, rigorously applying the requirement of "clear and convincing" evidence to err on the side of preserving life. *E.g.*, *In re Westchester County Medical Center*, 72 N.Y.2d 517, 531, 531 N.E.2d 607, 613, 534 N.Y.S.2d 886, 893-94 (1988); *In re Storar*, 52 N.Y.2d 363, 379, 420 N.E.2d 64, 72, 438 N.Y.S.2d 266, 274, *cert. denied*, 454 U.S. 858 (1981). For insightful discussions of the inherent difficulty in meeting the standard of "clear and convincing" evidence, see the concurring and dissenting opinions in *Westchester County Medical Center*, and Rhoden, *Litigating Life and Death*, 102 HARV. L. REV. 375, 377, 390-91 (1988).

51. See, *e.g.*, *In re Jobes*, 108 N.J. 394, 446, 529 A.2d 434, 461 (1987); *Brophy*, 398 Mass. at 419, 497 N.E.2d at 627; *Conroy*, 98 N.J. at 334, 486 A.2d at 1220.

52. Beschle, *supra* note 39, at 348-50.

53. *In re Grant*, 109 Wash. 2d 545, 747 P.2d 445 (1987).

54. *Brophy*, 398 Mass. at 448, 497 N.E.2d at 643 (Lynch, J., dissenting in part).

55. These risks of erroneous diagnosis, prognosis, and treatment choice exist equally in the "substituted judgment" model and the theoretically more objective "best interests of the patient" approach. Under both models, the decisionmaker's own biases, and the lack of access to complete information, combine to make the ultimate decision fraught with uncertainty. Under the "substituted judgment" approach, the decisionmaker attempts to put herself in the patient's position and make the choice that the patient would make if he could temporarily become capable of choosing a course of treatment, considering his incompetence as one of the factors bearing on that decision. *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 752-53, 370 N.E.2d 417, 430 (1977); *In re Quinlan*, 70 N.J. 10, 39, 355 A.2d 647, 663, *cert. denied*, 429 U.S. 922 (1976). Under a "best interests" approach, the decisionmaker attempts to determine what course of treatment would be superior, using ostensibly objective criteria to evaluate the impact of disparate treatments.

Yet in the case of incompetent patients, the distinction between these two standards must, of necessity, blur, because any assessment of what an incompetent person would choose if he were competent will inevitably include data based upon the choices of a reasonable person in the incompetent's present condition. *Quinlan*, 70 N.J. at 39-40, 355 A.2d at 663-64.

For an illuminating exploration of the deficiencies of both the "substituted judgment" and "best interests" approaches, see Rhoden, *supra* note 50, at 380-419.

56. Competent patients who have chosen to be allowed to die may experience a

deinstitutionalization of the civilly committed mentally ill.⁵⁷

This danger is a particular concern with nursing home patients, who are often socially and medically isolated, and can be subject to abuse by underpaid caretakers in an impoverished and often dangerous environment. Such patients usually suffer from a complement of chronic, progressively degenerative diseases, frequently accompanied by limited cognitive functioning.⁵⁸ This cognitive impairment, coupled with the traditional tendency of the elderly to be deferential to medical authority, often prevents nursing home residents from asserting their needs.

II. The Classic Approach: Autonomy as the Paramount Value

A. Sources of the Autonomy Model

Over the past dozen years, courts and legislatures have responded to the agonizing problems posed by substitute decisionmaking for the incurably ill by exalting individual autonomy as the primary value to be achieved. This exclusive focus on self-determination, however, has often led to the denigration of the very personhood that its advocates claim to be protecting by involving the machinery of the state in what ought to be a very private, family-centered affair.⁵⁹

Yet this reliance on an autonomy model is hardly surprising, because the right of the individual to be let alone, free from government interference, has long been a deeply cherished American value.⁶⁰ Its priority as a societal guiding principle is reflected by its

resultant feeling of abandonment after they have made this decision, as physicians and nurses are no longer displaying maximal, "heroic" efforts to sustain life. "The family may share this feeling on behalf of the dying patient and have difficulty grappling with the consequences of a decision in which they may or may not have played a part." *Physician's Responsibility*, *supra* note 29, at 957. Abandonment is particularly likely to be the case of the elderly in nursing homes. This concern is discussed at length by the New Jersey Supreme Court in *Conroy*, 98 N.J. at 375-77, 486 A.2d at 1237-38.

57. See Lamb, *Deinstitutionalization and the Homeless Mentally Ill*, in *THE HOMELESS MENTALLY ILL: A TASK FORCE REPORT OF THE AMERICAN PSYCHIATRIC ASSOCIATION* 55, 62, 66 (H. Lamb ed. 1984).

58. See *Conroy*, 98 N.J. at 375-77, 486 A.2d at 1237-38; Hilfiker, *supra* note 24, at 716.

59. It is of course true, as Martha Minow has noted with insight, that labelling the issue as one of state intervention versus personal privacy can obfuscate, rather than illuminate, the fundamental tensions involved. State intervention can take a variety of forms, from active judicial involvement to comprehensive legislation or regulation. The debate on the appropriateness of a particular action should be addressed on its merits, rather than through the invocation of political rhetoric. Minow, *Beyond State Intervention in the Family: For Baby Jane Doe*, 18 U. MICH. J.L. REFORM 933, 934-37, 946-53 (1985).

60. *Olmstead v. United States*, 277 U.S. 438, 478 (1928) (Brandeis, J., dissenting). In one of his most eloquent dissents, Brandeis declared that:

[i]n adopting the Fourth and Fifth Amendments, [t]he makers of our Constitution undertook to secure conditions favorable to the pursuit of happiness. They recognized the significance of man's spiritual nature, of his feelings and of his intellect. They knew that only a part of the pain, pleasure and

prominence in both state and federal constitutions, as well as the common law. The roots of this libertarian concern may be found in the writings of the seventeenth century political philosophers who so heavily influenced the founders of our republic. Thomas Hobbes and John Locke envisioned government as both necessary, in order to avoid the hardships of life in a state of nature, which was frequently "nasty, brutish, and short,"⁶¹ and consensual,⁶² existing by virtue of the joint agreement of the citizenry to cede just so much of their freedom and autonomy as was necessary to ensure a peaceful, and therefore more productive, society.⁶³ Drawing upon this vision of a limited government, and writing against the backdrop of what were perceived to be a despotic king and a heavy-handed parliament, the Framers of the Constitution created a federal government of limited and enumerated powers, leaving to the states and "the people" all powers not specifically granted to the federal government.⁶⁴

For many years courts did not address the precise scope of this residual liberty interest, although the principle that it encompassed freedom to contract received judicial support in the heyday of substantive due process,⁶⁵ and a more intimate, family-centered right to freedom in personal decisionmaking was recognized in *Meyer v. Nebraska*⁶⁶ and *Pierce v. Society of Sisters*.⁶⁷ However, in the last quarter century a major judicial revolution has occurred, during which the principle has been enshrined as absolute that the individual citizen retains a fundamental interest in liberty and privacy that cannot be intruded upon by the government, whether federal or state, absent a compelling countervailing interest.

In the landmark case of *Griswold v. Connecticut*,⁶⁸ the Supreme Court declared unconstitutional a Connecticut statute that made it criminal to use or prescribe any contraceptive device.⁶⁹ In so

satisfactions of life are to be found in material things. They sought to protect Americans in their beliefs, their thoughts, their emotions and their sensations. They conferred, as against the Government, the right to be let alone—the most comprehensive of rights and the right most valued by civilized men.

Id., quoted in *Griswold v. Connecticut*, 381 U.S. 479, 494 (1965) (Goldberg, J., concurring).

61. T. Hobbes, *LEVIATHAN* 100, 129 (1651) (Collier (MacMillan) ed. 1962).

62. *Id.* at 129; J. LOCKE, *TWO TREATISES OF CIVIL GOVERNMENT*, § 95 (Dent & Sons ed. 1924) (1st ed. 1690).

63. J. LOCKE, *supra* note 62, §§ 99, 123, 131.

64. The Ninth Amendment to the Constitution provides: "The enumeration in the Constitution, of certain rights, shall not be construed to deny or disparage others retained by the people." U.S. CONST. amend. IX. The Tenth Amendment provides that: "The powers not delegated to the United States by the Constitution, nor prohibited by it to the States, are reserved to the States respectively, or to the people." U.S. CONST. amend. X. For further discussion of this retained liberty interest of the individual and role of the Ninth and Tenth Amendments in protecting it, see *Griswold v. Connecticut*, 381 U.S. 479, 486-96 (1965).

65. *Lochner v. New York*, 198 U.S. 45 (1905).

66. 262 U.S. 390 (1923).

67. 268 U.S. 510 (1925).

68. 381 U.S. 479 (1965).

69. *Id.* at 480.

holding, the Court relied upon the fundamental constitutional right to privacy, which it found existed in the marital relationship. Citing the Ninth Amendment, the Court found that certain fundamental rights are protected by the Constitution even though not specifically enumerated in the Bill of Rights or subsequent constitutional amendments.⁷⁰ Included among these rights is the right to privacy—the right to a sphere of personal thought and action free from government invasion—which the Court found to be implicit in the First, Third, Fourth, and Fifth Amendments.⁷¹

Following *Griswold*, the Supreme Court announced a series of decisions that upheld the right of the individual to be let alone, free from state intrusion, absent a compelling state interest. These included *Stanley v. Georgia*,⁷² which recognized a right to exercise First Amendment rights in the privacy of one's own home, even if the material that one was viewing might be deemed pornographic,⁷³ and *Roe v. Wade*,⁷⁴ which found that the fundamental right to privacy encompassed the right of a woman to decide to terminate her pregnancy, free from state interference, during the first trimester of pregnancy.⁷⁵

Following *Griswold*, *Stanley*, and *Roe*, a number of state and lower federal courts found this fundamental constitutional right to privacy to encompass the right to refuse medical treatment, drawing upon both the federal and state constitutional rights to privacy and the tort law doctrines of battery and informed consent. Aside from cases in which the patient seeks to refuse life-sustaining medical treatment, this issue has arisen most often in the case of involuntarily committed mental patients, who have sought to refuse unwanted treatment with psychotropic medication. Generally, such a right to refuse such medication has been recognized in all except narrowly defined emergency situations.⁷⁶

70. *Id.* at 482-85, 486-99 (Goldberg, J., concurring), 499-502 (Harlan, J., concurring). Eschewing the notion that it might be calling for a revitalization of the doctrine of substantive due process, the Court declared:

We do not sit as a super-legislature to determine the wisdom, need, and propriety of laws that touch economic problems, business affairs, or social conditions. This law, however, operates directly on an intimate relation of husband and wife and their physician's role in one aspect of that relation.

Id. at 482.

71. *Id.* at 482-85.

72. 394 U.S. 557 (1969).

73. *Id.* at 565-68.

74. 410 U.S. 113 (1973).

75. *Id.* at 153-54, 164. In enunciating this right of privacy, the Court found it unnecessary to determine whether its source was the personal liberty interest protected from state intrusion by the Fourteenth Amendment or the "Ninth Amendment's reservation of rights to the people." *Id.* at 153.

76. *Rennie v. Klein*, 653 F.2d 836 (3d Cir. 1981) (en banc), *vacated and remanded*, 458 U.S. 1119 (1982), *reaff'd on other grounds*, 720 F.2d 266 (3d Cir. 1983); *Rivers v. Katz*, 67 N.Y.2d 485, 495 N.E.2d 337, 504 N.Y.S.2d 74 (1986); *Rogers v. Commissioner of the*

Like the cases invoking the federal constitutional right to privacy, these decisions have emphasized the centrality of individual autonomy and self-determination to their analysis. For example, in *Rivers v. Katz*,⁷⁷ the New York Court of Appeals relied upon the common law action for battery for unauthorized medical treatment and the state constitutional guarantees of liberty and due process to hold that civilly committed mental patients have a right to refuse unwanted treatment. The court declared:

[T]he right of a competent adult to refuse medical treatment must be honored, even though the recommended treatment may be beneficial or even necessary to preserve the patient's life. . . .

In our system of a free government, where notions of individual autonomy and free choice are cherished, it is the individual who must have the final say in respect to decisions regarding his medical treatment in order to insure that the greatest possible protection is accorded his autonomy and freedom from unwanted interference with the furtherance of his own desires. This right extends equally to mentally ill persons who are not to be treated as persons of lesser status or dignity because of their illness.⁷⁸

This emphasis on individual self-determination and inviolability is seen more generally in the common law principle that one has a right to be free from battery—an unconsented touching. Its application to unauthorized medical treatment has had a long history. As early as *Schloendorff v. Society of New York Hospital*⁷⁹ and *Pratt v. Davis*,⁸⁰ courts have invoked the principle of individual autonomy in recognizing a cause of action in tort against physicians who performed surgical procedures against the patient's wishes.⁸¹

Today, this concern for patient autonomy receives judicial

Dep't of Mental Health, 390 Mass. 489, 504, 458 N.E.2d 308, 318 (1983). Emergencies are generally defined as situations in which a failure to forcibly medicate the patient presents a substantial risk of serious harm to others or to the patient himself, including the risk of an "immediate, substantial, and irreversible deterioration of a serious mental illness." *Rogers*, 390 Mass. at 510-11, 458 N.E.2d at 322 (quoting *Guardianship of Roe*, 383 Mass. 415, 441, 421 N.E.2d 40, 55 (1981)).

77. 67 N.Y.2d 485, 495 N.E.2d 337, 504 N.Y.S.2d 74 (1986).

78. *Id.* at 493, 495 N.E.2d at 341, 504 N.Y.S.2d at 79 (citations omitted). The highest courts of Massachusetts and New Jersey have employed similar reasoning. In *Superintendent of Belchertown School v. Saikewicz*, 373 Mass. 728, 370 N.E.2d 417 (1977), the court declared:

There is implicit recognition in the law of the Commonwealth, as elsewhere, that a person has a strong interest in being free from nonconsensual invasion of his bodily integrity. . . . [T]he law recognizes the individual interest in preserving "the inviolability of his person." . . .

Of even broader import, but arising from the same regard for human dignity and self-determination, is the unwritten constitutional right of privacy found in the penumbra of specific guarantees of the Bill of Rights.

373 Mass. at 738-39, 370 N.E.2d at 424 (citations omitted); *accord Brophy*, 398 Mass. at 430-31, 497 N.E.2d at 633-34; *Conroy*, 98 N.J. at 346-48, 486 A.2d at 1221-23.

79. 211 N.Y. 125, 105 N.E. 92 (1914).

80. 224 Ill. 300, 79 N.E. 562 (1906).

81. In ringing language, Judge Cardozo declared that: "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." 211 N.Y. at 129-30, 105 N.E. at 93. Unfortunately for the plaintiff *Schloendorff*, her suit against the defendant hospital was barred

recognition under the doctrine of informed consent. This doctrine requires that the physician, as part of her fiduciary duty of providing good medical care, inform her patient both as to what a particular proposed treatment and its alternatives (including non-treatment) entail, and the risks and benefits of each.⁸² The central tenet of the informed consent doctrine is that because of our respect for individual autonomy and self-determination, each patient has the right to receive all the information necessary for him to make a knowledgeable decision concerning the most appropriate form of treatment.⁸³ The failure to provide such information may give rise to a cause of action for medical malpractice.⁸⁴

In the case of incurably ill patients, virtually every state or lower federal court that has addressed the issue has found that the competent, incurably ill adult does have a right to refuse unwanted medical treatment unless the state can demonstrate a compelling countervailing interest.⁸⁵ The only question that has provoked controversy is whether this right to privacy may be invoked by an incompetent individual, and if so, how, and by whom.⁸⁶

Classically, there are four distinct state interests, flowing generally from the state's role as *parens patriae*, which have been weighed against the individual's privacy right. These are: the interest in preserving life, the interest in preventing suicide, the interest in promoting the ethical integrity of the medical profession, and the

by the fact that the trespassing physician was not an employee of the hospital, but rather an independent contractor rendering his services there.

In *Pratt v. Davis*, the Illinois Supreme Court held that, as a general proposition, a mentally competent patient's consent is required as a prerequisite to surgery. 224 Ill. 300, 305, 79 N.E. 562, 564 (1906).

82. *Canterbury v. Spence*, 464 F.2d 772, 780-81 (D.C. Cir.), *cert. denied*, 409 U.S. 1064 (1972); *Truman v. Thomas*, 27 Cal. 3d 285, 291-92, 165 Cal. Rptr. 308, 311-12, 611 P.2d 902, 905-06 (1980); *Natanson v. Kline*, 186 Kan. 393, 400-12, 350 P.2d 1093, 1099-1108 (1960).

83. *Canterbury*, 464 F.2d at 780-81; *Natanson*, 186 Kan. at 407, 350 P.2d at 1104. For an intriguing and unconventional account of the psychodynamics of the doctor-patient relationship as they relate to informed consent, see R. BURT, *TAKING CARE OF STRANGERS* 102-04, 107, 119-20 (1979).

84. *Canterbury*, 464 F.2d at 782. There is continuing controversy as to whether the doctrine of informed consent sounds in negligence or in battery. *Sidaway v. Bethlehem Royal Hosp. Governors*, 1 All E.R. 643 (House of Lords 1985); Katz, *Informed Consent—A Fairy Tale?* *Law's Vision*, 39 U. PITT L. REV. 137, 165 (1977).

85. *E.g.*, *Quinlan*, 70 N.J. 10, 355 A.2d 647; *Brophy*, 398 Mass. 417, 497 N.E.2d 626; *In re Conservatorship of Torres*, 357 N.W.2d 332, 339 (Minn. 1984); *Satz v. Perlmutter*, 379 So. 2d 359 (Fla. 1980).

86. *See, e.g.*, *Brophy*, 398 Mass. 417, 497 N.E.2d 626 (permitting a guardian ad litem to assert constitutional rights for an incompetent person); *In re Storar*, 52 N.Y.2d 363, 420 N.E.2d 64, 438 N.Y.S.2d 266 (discussing a parent's ability to terminate medical care for an adult incompetent child), *cert. denied*, 454 U.S. 858 (1981); *Quinlan*, 70 N.J. 10, 355 A.2d 647 (allowing the father, as legal guardian, to assert his incompetent daughter's right to refuse treatment).

interest in protecting innocent third parties.⁸⁷ Although these interests would appear to be substantial, in virtually every case in which a guardian or family member of an incurably ill, incompetent patient has asserted that individual's right to privacy, these four countervailing state interests have not been found compelling.⁸⁸ As the New Jersey Supreme Court declared in *In re Quinlan*, "as the degree of bodily invasion increases and the prognosis [for eventual recovery to a cognitive, sapient existence] dims," the state's interests wane.⁸⁹ This has been the holding not only in cases in which the incompetent adult is terminally ill, such as a patient dying of cancer or of a progressively debilitating neurological disease,⁹⁰ but also in the case of individuals like Karen Ann Quinlan and Paul Brophy, who although unconscious, were not in immediate peril of death.⁹¹

B. *Consequences of the Autonomy Model*

Reflecting the high priority our society places upon respect for individual autonomy and self-determination, in the last dozen years, courts and legislatures that have grappled with the problem of decisionmaking for the incompetent incurably ill have developed a variety of substitute decisionmaking alternatives that seek to effectuate the right of personal choice. These include two vehicles by which a competent adult can elect in advance the desired treatment approach should she become incurably ill and incompetent—the living will and the designated treatment agent—as well as several forms of judicial and less formal decisionmaking that provide for a substitute decisionmaker to act on the patient's behalf if he becomes incompetent. Each of these alternatives will be explored below.

1. *Living Wills*

By far the most well-known of the advance directives for substitute decisionmaking are "living wills." Originally proposed by Doctor Louis Kutner in the late 1960s,⁹² and popularized by such groups as the Society for the Right to Die and Concern for Dying, a living will provides a mechanism by which a competent adult can designate in a legally binding manner the particular treatment or

87. See *Saikewicz*, 373 Mass. at 741, 370 N.E.2d at 424-26; *Quinlan*, 70 N.J. at 40-41, 355 A.2d at 663-64.

88. E.g., *Gray v. Romeo*, 697 F. Supp. 580 (D.R.I. 1988); *Brophy*, 398 Mass. 417, 497 N.E.2d 626 (1986); *John F. Kennedy Memorial Hosp. v. Bludworth*, 452 So. 2d 921 (Fla. 1984); *Torres*, 357 N.W.2d 332 (Minn. 1984); *Saikewicz*, 373 Mass. 728, 370 N.E.2d 417; *Quinlan*, 70 N.J. 10, 355 A.2d 647. But see *Cruzan v. Harmon*, 760 S.W.2d 408, 424 (Mo. 1988) (en banc) (finding that the state interest in preserving life outweighed the privacy interests of a patient who was in a persistent vegetative state but not incurably ill).

89. *Quinlan*, 70 N.J. at 41, 355 A.2d at 664.

90. *Leach v. Akron Gen. Medical Center*, 68 Ohio Misc. 1, 3, 426 N.E.2d 809, 810 (C.P. 1980) (involving a patient suffering from amyotrophic lateral sclerosis).

91. *Quinlan*, 70 N.J. at 18, 355 A.2d at 655; *Brophy*, 398 Mass. at 425, 497 N.E.2d at 630.

92. Martyn & Jacobs, *Legislating Advance Directives for the Terminally Ill: The Living Will and Durable Power of Attorney*, 63 NEB. L. REV. 779, 787 (1984); see Kutner, *Due Process of Euthanasia: The Living Will, A Proposal*, 44 IND. L. J. 539, 550-54 (1969), cited in Garrard, *Right to Forego Medical Treatment*, 30 RES GESTAE 113 (1986).

non-treatment that he wishes to receive should he become terminally ill and incompetent. To date thirty-eight states and the District of Columbia have enacted "living will," "death with dignity," or "natural death" statutes,⁹³ in part because of the deficiencies of the judicial model of substitute decisionmaking, discussed below. These statutes build on the constitutional and common law right to privacy and individual autonomy, often declaring in a formal preamble that each individual has a right to choose for himself the appropriate form of treatment or non-treatment,⁹⁴ and that a directive made in advance by a competent adult shall be binding on her physician and family if she later becomes incompetent.

Under a typical living will statute, a competent, non-pregnant⁹⁵

93. These states are: ALA. CODE §§ 22-8A-1 to -10 (1984); ALASKA STAT. §§ 18.12.010 to -.100 (1986); ARIZ. REV. STAT. ANN. §§ 36-3201 to -3210 (1986); ARK. STAT. ANN. §§ 20-17-201 to -218 (Supp. 1987); CAL. HEALTH & SAFETY CODE §§ 7185-7195 (Deering Supp. 1988); COLO. REV. STAT. §§ 15-18-101 to -113 (1987); CONN. GEN. STAT. ANN. §§ 19a-570 to -575 (West Supp. 1988); DEL. CODE ANN. tit. 16, §§ 2501-2509 (1983); D.C. CODE ANN. §§ 6-2421 to -2430 (Supp. 1988); FLA. STAT. ANN. §§ 765.01-765.15 (West 1986); GA. CODE ANN. §§ 31-32-1 to -12 (1985 & Supp. 1988); HAW. REV. STAT. §§ 327D-1 to -27 (Supp. 1987); IDAHO CODE §§ 39-4501 to -4508 (1986 & Supp. 1988); ILL. ANN. STAT. ch. 110 1/2, 701-710 (Smith-Hurd 1988); IND. CODE ANN. §§ 16-8-11-1 to -22 (West 1988); IOWA CODE ANN. §§ 144A.1 to -.11 (West Supp. 1988); KAN. STAT. ANN. §§ 65-3209 to -3218 (1985 & Supp. 1987); LA. REV. STAT. ANN. §§ 40:1299.58.1 to -.10 (West Supp. 1988); ME. REV. STAT. ANN. tit. 22, §§ 2921-2931 (Supp. 1988); MD. HEALTH-GEN. CODE ANN., §§ 5-601 to -614 (Supp. 1988); MISS. CODE ANN. §§ 41-41-101 to -121 (Supp. 1988); MO. ANN. STAT. §§ 459.010 to -.055 (Vernon Supp. 1989); MONT. CODE ANN. §§ 50-9-101 to -206 (1987); NEV. REV. STAT. ANN. 449.540 to -.690 (Michie 1986 & Supp. 1987); N.H. REV. STAT. ANN. §§ 137-H:1 to -:16 (Supp. 1988); N.M. STAT. ANN. §§ 24-7-1 to -10 (1986); N.C. GEN. STAT. §§ 90-320 to -323 (1985); OKLA. STAT. ANN. tit. 63, §§ 3101-3111 (West Supp. 1989); OR. REV. STAT. §§ 97.050 to -.090 (1987); S.C. CODE ANN. §§ 44-77-10 to -110 (Law. Co-op. Supp. 1988); TENN. CODE ANN. §§ 32-11-101 to -110 (Supp. 1988); TEX. REV. CIV. STAT. ANN. art. 4590h (Vernon Supp. 1989); UTAH CODE ANN. §§ 75-2-1101 to -1118 (Supp. 1988); VT. STAT. ANN. tit. 18, §§ 5251-5262 (1987); VA. CODE ANN. §§ 54.1-2981 to -2992 (1988); WASH. REV. CODE ANN. §§ 70.122.010 to -.905 (Supp. 1989); W. VA. CODE §§ 16-30-1 to -10 (1985); WIS. STAT. ANN. §§ 154.01 to -.15 (West Supp. 1988); WYO. STAT. §§ 35-22-101 to -109 (1988).

Even in jurisdictions that have not enacted a living will statute, such a document will often be considered persuasive evidence of the now incompetent patient's wishes. *See, e.g., John F. Kennedy Hosp. v. Bludworth*, 452 So. 2d 921, 926 (Fla. 1984) (stating that a living will, if executed while an individual was competent, would be persuasive evidence of the incompetent individual's intention).

94. A number of living will statutes emphasize that the statute itself does not create this right to privacy and self-determination, but merely recognizes its existence and makes it easier to be effectuated. ALA. CODE § 22-8A-2 (1984); ARIZ. REV. STAT. ANN. §§ 49-701 to -704 (Supp. 1988); CAL. HEALTH & SAFETY CODE § 7186 (Deering Supp. 1987); COLO. REV. STAT. § 15-18-102(a) (1987); DEL. CODE ANN. tit. 16, § 2502 (1983); FLA. STAT. ANN. § 765.02 (West 1986); GA. CODE ANN. § 31-32-1(d) (1985); HAW. REV. STAT. § 327D-1 (Supp. 1987); IDAHO CODE § 39-4502 (Supp. 1988); IND. CODE ANN. § 16-8-11-1 (West Supp. 1988); IOWA CODE ANN. § 144A.1 (West Supp. 1988); LA. REV. STAT. ANN. § 40:1299.58.1(A)(1) (West Supp. 1988); N.H. REV. STAT. ANN. § 137-H:1 (Supp. 1988); N.C. GEN. STAT. § 90-320(a) (1985); S.C. CODE ANN. 44-77-10 (Law Co-op. Supp. 1988); UTAH CODE ANN. § 75-2-1102(2) (Supp. 1988); VT. STAT. ANN. tit. 18, § 5251 (1987); WASH. REV. CODE ANN. § 70.122.010 (Supp. 1989).

95. The question of the extent to which the state may properly place limitations

adult may execute a written document, witnessed by two disinterested persons,⁹⁶ which states that should the declarant later become terminally ill⁹⁷ and incompetent, sustained only by "artificial" life support systems, he wishes not to receive further medical treatment.⁹⁸ The declarant may indicate a particular form or forms of treatment which he chooses not to receive, or he may make a more general statement that he wishes no medical treatment whatsoever.⁹⁹ The statutes in many jurisdictions provide a form for the living will,¹⁰⁰ but jurisdictions differ as to whether this form is

upon a pregnant woman's right to control her own body in order to protect the health of the fetus is a complex and controversial one that is receiving increasing judicial scrutiny today. *See* *Jefferson v. Griffin Spaulding County Hosp. Auth.*, 247 Ga. 86, 86-90, 274 S.E.2d 457, 458-62 (1981).

96. *See, e.g.*, IND. CODE ANN. §§ 16-8-11-11 to -12 (West Supp. 1988) (providing that a person who is at least 18 years of age and of sound mind may execute a written living will, witnessed by two disinterested persons).

97. Only two states—Arkansas and New Mexico—provide for a living will to become effective in circumstances other than terminal illness. New Mexico provides that a living will be effective if the declarant is either terminally ill or in an "irreversible coma," defined as "that state in which brainstem functions remain but the major components of the cerebrum are irreversibly destroyed." N.M. STAT. ANN. § 24-7-2(B) (1986). The Arkansas statute articulates somewhat broad definitions of "life sustaining treatment" and "terminal condition," which make it possible for a competent adult to execute a declaration to become effective if he either "should have an incurable or irreversible condition that will cause [his] death within a relatively short time" or if he should become "permanently unconscious," defined as "a lasting condition, indefinitely without change in which thought, feeling, sensations, and awareness of self and environment are absent." ARK. STAT. ANN. §§ 20-17-201(4)(a), 20-17-201(ii), 20-17-202 (Supp. 1987).

Most statutes define "terminally ill" or "terminal condition"; however, others do not. *Compare* ALASKA STAT. § 18.12.100 (1986) ("terminal condition" means a progressive incurable or irreversible condition that, without the administration of life-sustaining procedures, will, in the opinion of two physicians, when available, who have personally examined the patient, one of whom must be the attending physician, result in death within a relatively short time") with D.C. CODE ANN. § 6-2421(6) (Supp. 1988) ("Terminal condition" means an incurable condition caused by injury, disease, or illness which, regardless of the application of life-sustaining procedures, would, within reasonable medical judgment, produce death, and where the application of life-sustaining procedures serve only to postpone the moment of death . . .").

98. Many of the statutory definitions of "terminal condition," "imminent death," and "artificial life-sustaining treatment" are interdependent, if not circular. *See, e.g.*, DEL. CODE ANN. tit. 16, § 2501(e) (1983) ("Terminal condition" shall mean any disease, illness or condition sustained by any human being from which there is no reasonable medical expectation of recovery and which, as a medical probability, will result in the death of such human being regardless of the use or discontinuance of medical treatment implemented for the purpose of sustaining life or the life processes.").

99. *See, e.g.*, UTAH CODE ANN. § 75-2-1104 (Supp. 1988) (providing a standard directive form in which the declarant may direct that all life-sustaining procedures be withheld or withdrawn if he is terminally ill, but that life-sustaining treatment does not include the provision of medication, sustenance, or comfort care, unless specifically so indicated by the declarant).

100. *See, e.g.*, CAL. HEALTH & SAFETY CODE § 7188 (Deering Supp. 1988), which provides the following mandatory form:

DIRECTIVE TO PHYSICIANS Directive made this ____ day of ____ (month, year).

I _____, being of sound mind, willfully, and voluntarily make known my desire that my life shall not be artificially prolonged under the circumstances set forth below, do hereby declare:

1. If at any time I should have an incurable injury, disease, or illness certified to be a terminal condition by two physicians, and where the application of life-sustaining procedures would serve only to artificially prolong the moment of my death and where my physician determines that my death is imminent whether or not life-sustaining procedures are utilized, I direct that such

mandatory or suggested.¹⁰¹ Some statutes specifically exclude nutrition and hydration or medication, or both, from the definition of

procedures be withheld or withdrawn, and that I be permitted to die naturally.

2. In the absence of my ability to give directions regarding the use of such life-sustaining procedures, it is my intention that this directive shall be honored by my family and physician(s) as the final expression of my legal right to refuse medical or surgical treatment and accept the consequences from such refusal.

3. If I have been diagnosed as pregnant and that diagnosis is known to my physician, this directive shall have no force or effect during the course of my pregnancy.

4. I have been diagnosed and notified at least 14 days ago as having a terminal condition by _____, M.D., whose address is _____, and whose telephone number is _____. I understand that if I have not filled in the physician's name and address, it shall be presumed that I did not have a terminal condition when I made out this directive.

5. This directive shall have no force or effect five years from the date filled in above.

6. I understand the full import of this directive and I am emotionally and mentally competent to make this directive.

Signed _____

City, County and State of Residence _____

The declarant has been personally known to me and I believe him or her to be of sound mind.

Witness _____

Witness _____

101. See, e.g., Colorado's suggested, but non-mandatory form:

DECLARATION AS TO MEDICAL OR SURGICAL TREATMENT

I, (name of declarant), being of sound mind and at least eighteen years of age, direct that my life shall not be artificially prolonged under the circumstances set forth below and hereby declare that:

1. If at any time my attending physician and one other physician certify in writing that:

a. I have an injury, disease, or illness which is not curable or reversible and which, in their judgment, is a terminal condition; and

b. For a period of forty-eight consecutive hours or more, I have been unconscious, comatose, or otherwise incompetent so as to be unable to make or communicate responsible decisions concerning my person; then

I direct that life-sustaining procedures shall be withdrawn and withheld, it being understood that life-sustaining procedures shall not include any medical procedure or intervention for nourishment or considered necessary by the attending physician to provide comfort or alleviate pain.

2. I execute this declaration, as my free and voluntary act, this _____ day of _____, 19____.

By _____

Declarant

The foregoing instrument was signed and declared by _____ to be his declaration, in the presence of us, who, in his presence, in the presence of each other, and at his request, have signed our names below as witnesses, and we declare that, at the time of the execution of this instrument, the declarant, according to our best knowledge and belief, was of sound mind and under no constraint or undue influence.

life-sustaining treatment;¹⁰² others are silent on this point.¹⁰³ Florida, Indiana, and Maryland are the only jurisdictions that provide for the alternative of a binding life *prolonging* declaration, under which a competent adult may indicate that should he become terminally ill, he wishes to receive all possible treatment.¹⁰⁴ Florida, Louisiana, and Virginia also recognize the validity of an oral living will declaration.¹⁰⁵

To ensure that a living will is not used inappropriately, legislative drafters have provided a number of safeguards. Many jurisdictions require that the document be witnessed by two disinterested persons, who may not be relatives, potential beneficiaries, persons financially responsible for the declarant's medical care, or health care providers to the declarant.¹⁰⁶ All living will statutes require that at least one, and usually two, physicians certify that the declarant is terminally ill.¹⁰⁷ As an additional precaution, all living will statutes provide for the easy revocation of a living will, either by a written or oral statement to that effect, or by defacing or obliterating the will.¹⁰⁸ Although living will statutes are premised on the declarant's competence at the time the living will is executed, many statutes fail to require competency at the time of revocation, either implicitly or explicitly disregarding competency as an issue.¹⁰⁹

To provide physicians and other health care providers with an

Dated at _____, Colorado, this _____ day of _____, 19____.

Name and Address _____

 Name and Address _____

COL. REV. STAT. § 15-18-104 (1987).

For a helpful discussion of the pros and cons of mandatory versus recommended living will forms, see Marsh, *Living Will Legislation in Colorado: An Analysis of the Colorado Medical Treatment Decision Act in Relation to Similar Developments in Other Jurisdictions*, 64 DENVER U.L. REV. 5, 10-11 (1987).

102. See, e.g., UTAH CODE ANN. § 75-2-1103(6)(b) (Supp. 1988) (expressly excluding medication, sustenance or any procedure that provides comfort or alleviates pain from the definition of life-sustaining procedure, unless the declarant indicates otherwise); see also AMA COUNCIL, *supra* note 15, at § 2.18 (defining life prolonging medical treatment to include the provision of food and hydration).

103. See, e.g., N.M. STAT. ANN. § 24-7-2(C) (1978) (defining "maintenance medical treatment" as "medical treatment designed solely to sustain the life processes" without further explanation).

104. FLA. STAT. ANN. § 765.02 (West 1986); IND. CODE §§ 16-8-11-11(g), 16-8-11-12 (1984); MD. HEALTH-GEN. CODE ANN. § 5-611 (1988).

105. FLA. STAT. ANN. § 765.02 (West 1986); LA. REV. STAT. ANN. § 40:1299.58.3(A)(3) (West 1977); VA. CODE ANN. § 54.1-2982 (1988).

106. E.g., ALA. CODE § 22-8A-4(a) (1984).

107. E.g., ALASKA STAT. §§ 18.12.010(a), 18.12.030 (1986); ARIZ. CODE § 36-3202(C) (1986).

108. E.g., FLA. STAT. ANN. § 765.06 (West 1986); see also TEX. REV. CIV. STAT. ANN. art. 4590h § 4A (Vernon 1987) (providing that a competent patient's present desire shall always supersede a directive).

109. See, e.g., COLO. REV. STAT. § 15-18-109 (1987) ("A declaration may be revoked by the declarant orally, in writing, or by burning, tearing, cancelling, obliterating, or destroying said declaration."); DEL. CODE ANN. tit. 16, § 2504(a) (1983) ("A declarant

incentive to comply with a living will, all living will and natural death statutes exempt the complying health care provider from criminal and civil liability for her actions.¹¹⁰ A physician who feels it ethically or professionally inappropriate to comply with a patient's living will must transfer the patient to another physician who will comply.¹¹¹ Most statutes, however, provide no sanction for a physician's failure to comply with an advance directive.¹¹² Only a few states punish a willful failure to transfer either as a minor crime or an occasion for professional censure.¹¹³

Living wills have been widely criticized as inadequate to achieve their laudable goal of promoting individual autonomy and permitting hopelessly ill patients to free themselves from a prolonged and painful dying. Many patients are unable to take advantage of a living will statute, either because they do not know about it or because its provisions do not encompass their situation.

Significantly, many physicians are uncomfortable about discussing death, and may even be reluctant to tell a patient that he is terminally ill. Thus, numerous patients are unlikely to recognize the need to make a living will, or to have the time to execute it before they lapse into unconsciousness.¹¹⁴ This is obviously so with accident victims, but it is also so with many people whose chronic degenerative disease takes a sudden turn for the worse.

Further, even if a patient desires to execute an advance treatment directive, few physicians have living will forms available. Nor do many physicians either know, or understand, the requirements of the living will act in their jurisdiction.¹¹⁵ Consequently, they are unable to advise their patients appropriately.

In addition, a number of incurably ill patients are not terminally ill.¹¹⁶ These include those in a persistent vegetative state, those

may revoke his declaration at any time, without regard to his mental state or competency.").

110. *E.g.*, ME. REV. STAT. ANN. tit. 22, § 2927 (Supp. 1985). Some statutes state explicitly that the physician must be acting in good faith in order to invoke this exemption. *E.g.*, ILL. ANN. STAT. ch. 110-1/2 para. 707 (Smith-Hurd Supp. 1988).

111. *E.g.*, HAW. REV. STAT. § 327D-11(b) (Supp. 1988).

112. *E.g.*, N.H. REV. STAT. ANN. 137-H:1-16 (Supp. 1985).

113. *See, e.g.*, ME. REV. STAT. ANN. tit. 22, § 2928(1) (Supp. 1985) (providing that a physician who fails to transfer is guilty of a "Class E crime"); IND. CODE ANN. § 16-8-11-22 (West Supp. 1988) (providing that a physician who knowingly violates his patient's wishes will be subject to disciplinary sanctions by the state medical licensing board).

114. Note, *The California Natural Death Act: An Empirical Study of Physicians' Practices*, 31 STAN. L. REV. 913, 928, 938 (1979). Only the District of Columbia requires a physician to inform a patient of his terminal illness, and then only if the patient is alert and communicative. D.C. CODE ANN. § 6-2425(b) (Supp. 1983); Martyn & Jacobs, *supra* note 92, at 790.

115. Note, *supra* note 114, at 930-33.

116. At least one commentator has noted the irony that those who fall within the typical living will statute are the least in need of its benefits. Referring to the California Natural Death Act, Alexander Capron writes:

suffering from a chronic degenerative disease, and those suffering from a condition that is hopeless but not expected to produce death in the near future.¹¹⁷ Further, because of the pervasive use in the living will statutes of vague and sometimes circular definitions of such crucial terms as “terminally ill,” “imminent death,” “‘artificial’ life sustaining treatment,” many physicians lack guidance about whether a particular living will is effective.¹¹⁸ Thus, they may be disinclined to honor it, or honor it only at the eleventh hour.¹¹⁹ In a leading survey of physician practices in California, researchers found that many physicians defined “imminent death” to mean death within the relatively short time periods of forty-eight hours, one week or one month. Although such a definition may be appropriate clinically, reflecting the need for certainty in prognosis, it may make the beneficial effects of a natural death act illusory to all but a few terminally ill patients.¹²⁰

But perhaps the key drawback of the living will is its inherent inflexibility. The essence of a living will is the function it serves as an *advance* directive for medical treatment decisions. Yet, it is difficult, if not virtually impossible, for any adult to indicate with specificity the types of medical treatment she might wish to forego should she become incurably ill or incompetent. This is so both because what seems like a grave imposition on the quality of life to a thirty year old might appear to be an entirely reasonable restriction at the age of seventy,¹²¹ and also because it is difficult to foresee precisely the type of incompetency and incurable illness that might occur.¹²²

If the declarant deals with this uncertainty by drawing a sweeping living will that refuses all forms of treatment under any circumstances, he takes the chance that this will turn out to be medically inappropriate, and either dishonored by the physician under a kind of medical “void for overbreadth” principle, or *honored* by the physician out of deference to the declarant’s autonomy.¹²³ Alternatively, if the declarant tailors her advance directive to a particular situation, she runs the risk either that the predicted illness will not materialize, thus rendering the living will inapplicable, or that her individualiza-

[T]he only patients covered by this statute are those who are on the edge of death *despite the doctors’ efforts*. The very people for whom the greatest concern is expressed about a prolonged and undignified dying process are unaffected by the statute because their deaths are not imminent.

Capron, *The Development of Law on Human Death*, 315 ANNALS N.Y. ACAD. SCI. 45, 55 (1978), cited in COMM’N REPORT, *supra* note 8, at 143.

117. This group includes those whose prognosis is hopeless but who will not die soon unless mechanically supplied food and hydration or antibiotics are withdrawn. It is thus critical to have a clear definition of “artificial” medical treatment.

118. Note, *supra* note 114, at 920-21.

119. *Id.* at 920 n.31.

120. *Id.* at 921 n.38, 932.

121. *In re Conroy*, 98 N.J. 321, 362-63, 486 A.2d 1209, 1230 (1985); see also Hilfiker, *supra* note 24, at 718 (comparing different views of what constitutes a reasonable physical limitation on life activities of a person at different life stages).

122. *In re Westchester County Medical Center*, 72 N.Y.2d 517, 524, 531 N.E.2d 607, 625, 534 N.Y.S.2d 886, 904 (1988) (Simons, J., dissenting).

123. *Id.* at 537, 531 N.E.2d at 617, 534 N.Y.S.2d at 896 (Hancock, J., concurring).

tion of the living will renders it unenforceable in her jurisdiction.¹²⁴

Other procedural safeguards, designed to minimize the risks of an inappropriate termination of medical treatment in reliance on a living will, often result in preventing the advance declaration from becoming effective when it should. For example, California's fourteen-day waiting period¹²⁵ after the diagnosis of a terminal illness means that the living wills of persons who become incompetent before the fourteen days have passed are not binding, but are advisory only. Automatic expiration periods, like that in California,¹²⁶ mean that many people who forget to "renew" their living wills will find them of no use. And unusual filing requirements, like that of Mississippi, which requires that all living wills be filed with the Mississippi Board of Health's Bureau of Vital Statistics,¹²⁷ mean that the advance directives of many individuals will be rendered nugatory.¹²⁸

Other criticisms of living will statutes come from quite a different perspective. Some commentators suggest that the blanket elimination of civil and criminal liability may encourage physicians to be negligent in the diagnosis or prognosis of terminal illnesses, or in their treatment of the elderly and incompetent.¹²⁹ Given the difficulty that many patients and physicians have in communicating with each other, which may lead to the withholding of important information relevant to diagnosis and prognosis,¹³⁰ there is some ground for concern about a blanket exemption.

124. Four states—California, Idaho, North Carolina, and Oregon—have mandatory living will forms, while thirty-three others have permissive statutes, which only suggest a standard form of declaration. Two other states—Delaware, and New Mexico—provide no form at all.

Some statutes directly address the question of the severability of the invalid portions of a living will from the valid ones, e.g., FLA. STAT. ANN. § 765.05(2) (West 1986) ("Should any . . . specific direction [other than the designation of a medical treatment agent] be held to be invalid, such invalidity will not affect the declaration."), although others are silent on this issue. See, e.g., IOWA CODE ANN. § 144A.3(3) (West Supp. 1988) (providing for a living will, but silent as to severability of invalid directions).

125. CAL. HEALTH & SAFETY CODE §§ 7188, 7191 (Deering Supp. 1988).

126. In California, a living will automatically expires after five years. *Id.* § 7188.

127. Vitiello, *Death with Dignity in Mississippi? An Analysis of Mississippi's Natural Death Act*, 54 MISS. L.J. 459, 472 (1984) (citing MISS. CODE ANN. § 41-41-107(2) (Supp. 1984)).

128. That such an apparently simple procedural requirement can become a substantial obstacle was demonstrated by a survey of attorneys attending a seminar on the Mississippi Natural Death Act. Of the twenty-two lawyers responding to the seminar survey, only three were aware of the filing requirement, even immediately after the presentation. *Id.* at 486 n.193.

129. Relman, *The Saikewicz Decision: A Medical Viewpoint*, 4 AM. J. L. AND MED. 233, 241-42 (1978); Note, *The Virginia Natural Death Act—A Critical Analysis*, 17 U. RICH. L. REV. 863, 872-73 (1983).

130. See Branch, *Doctors as "Healers": Striving to Reach Our Potential*, 2 J. GEN. INTERNAL MED. 356, 358-59 (1987) (suggesting that difficulties in patient-physician communication often impair physicians' abilities to be accurate in diagnosis and prognosis).

2. Designating a Medical Treatment Agent

Acknowledging that living wills are in many ways inadequate, thirteen states have enacted laws that authorize a competent adult to designate someone to make treatment decisions on her behalf should she become incompetent¹³¹ and, in some cases, terminally ill.¹³² Eight of these states authorize this designation to be made in the same document that the patient would use to make a living will.¹³³ However, Alaska, California, Nevada, Rhode Island and Vermont, perhaps recognizing the rigidity that inevitably attends the advance direction of either a blanket refusal of all medical treatment or of specific medical practices, provide for the designation of a medical treatment agent to be made in a separate document, providing for a durable power of attorney for health care decisionmaking.¹³⁴

States have adopted a variety of different approaches. Alaska's unusual statutory scheme permits a competent adult to nominate a substitute decisionmaker to make medical treatment decisions on her behalf should she become incompetent, but does not authorize the treatment agent to seek the *termination* of medical treatment unless the patient has also executed a living will specifically directing the refusal of such treatment.¹³⁵ Both Colorado and Pennsylvania have enacted durable power of attorney statutes that expressly authorize a principal to designate an agent who can consent to medical treatment, but appear to preclude the agent from *refusing* treatment on the principal's behalf.¹³⁶ Maine's durable power of attorney statute expressly permits a designated agent to consent to *or* to refuse treatment for the principal, but is silent as to whether such a refusal could be made when the consequence would be the principal's death.¹³⁷ Finally, an additional thirty-three states have enacted

131. ALASKA STAT. §§ 13.26.332-.356 (Supp. 1988); CAL. CIV. CODE § 2410-43 (Deering 1986); DEL. CODE ANN. tit. 16, § 2502 (1983); FLA. STAT. ANN. §§ 765.02, 765.05(2) (West 1986); IOWA CODE ANN. § 144A.7 (West Supp. 1988); LA. REV. STAT. ANN. § 40:1299.58.1(A)(3)(a) (West Supp. 1988); NEV. REV. STAT. ANN. §§ 449.800-.860 (Michie Supp. 1987); R.I. GEN. LAWS §§ 23.4.10-1 to -2 (Supp. 1988); TEX. REV. CIV. STAT. ANN. art. 4509h (Vernon Supp. 1989); UTAH CODE ANN. § 75-2-1106 (Supp. 1988); VA. CODE § 54.1-2984 (1988); VT. STAT. ANN. tit. 14, §§ 3451-3467 (Supp. 1988); and WYO. STAT. ANN. § 35-22-102(d) (1988).

132. The Florida, Iowa, Louisiana, Texas, Virginia, and Wyoming statutes provide that the designation of a medical treatment agent is effective only when the declarant becomes "terminally ill." To the extent that this excludes patients who are incurably, but not terminally ill (see *supra* notes 97, 107, 114-120, and accompanying text), the advance designation of a treatment agent suffers from the same weakness as a living will.

133. DEL. CODE ANN. tit. 16, § 2502 (1983); FLA. STAT. ANN. §§ 765.02, 765.05(2) (West 1986); IOWA CODE ANN. § 144A.7 (West Supp. 1988); LA. REV. STAT. ANN. § 40:1299.58.1(A)(3)(a) (West Supp. 1988); TEX. REV. CIV. STAT. ANN. art. 4590h § 3(e) (Vernon Supp. 1989); UTAH CODE ANN. § 75-2-1106 (Supp. 1988); VA. CODE ANN. § 54.1-2984 (1988); and WYO. STAT. ANN. § 35-22-102(d) (1988).

134. ALASKA STAT. §§ 13.26.332-.356 (Supp. 1988); CAL. CIV. CODE §§ 2410-2443 (Deering 1986); NEV. REV. STAT. ANN. §§ 449.800-.860 (Michie 1986); R.I. GEN. LAWS §§ 23.4.10-1 to -2 (Supp. 1988); VT. STAT. ANN. tit. 14, §§ 3451-3467 (Supp. 1988).

135. ALASKA STAT. §§ 13.26.332, .335, .344(j)(2) and (i) (Supp. 1988).

136. COLO. REV. STAT. § 15-14-501 (1987); 20 PA. CONS. STAT. ANN. § 5603(h) (Supp. 1988).

137. ME. REV. STAT. ANN. tit. 18-A, § 5-501 (Supp. 1988).

durable power of attorney acts that are silent about whether the principal may appoint an agent to make health care decisions on her behalf, as opposed to a myriad of other issues affecting the principal's person or property.¹³⁸ Of these states, only New Jersey has, through its supreme court, recognized the existing durable power of attorney statute as an appropriate vehicle for designating a medical treatment agent.¹³⁹

State statutes permitting the advance designation of a medical treatment agent grow out of the same desire to protect the patient's right to autonomy and personal choice in the making of medical treatment that underlies the living will, but they achieve their goal much more effectively. Utah explicitly recognizes this principle of self-determination, providing that the competent patient will select a treatment agent "with confidence in the belief that this person's familiarity with my desires, beliefs, and attitudes will result in directions to attending physicians and providers of medical services which would probably be the same as I would give if able to do so."¹⁴⁰ Similarly, the Florida and Iowa statutes expressly state that in making their decision, the treatment agent and physician are to

138. ALA. CODE § 26-1-2 (1986); ARIZ. REV. STAT. ANN. §§ 14-5501 to -5502 (1975); ARK. STAT. ANN. §§ 28-68-201 to -203, -301 to -313 (1987); D.C. CODE ANN. §§ 21-2081 to -2085 (Supp. 1988); GA. CODE ANN. § 10-6-36 (1982); HAW. REV. STAT. §§ 560:5-501 to -502 (1982); IDAHO CODE §§ 15-5-501 to -507 (Supp. 1988); IND. CODE ANN. §§ 30-2-11-1 to -7 (West Supp. 1988); KAN. STAT. ANN. §§ 58-610 to -617 (1983); KY. REV. STAT. ANN. § 386.093 (Baldwin 1983); LA. CIV. CODE ANN. art. 3002 (West 1973); MD. EST. & TRUSTS CODE ANN. §§ 13-601 to -603 (1987 & Supp. 1988); MASS. ANN. LAWS ch. 201B, § 1-7 (Law. Co-op. Supp. 1988); MICH. COMP. LAWS § 565.631 (West 1988); MISS. CODE ANN. §§ 87-3-1 to -17 (1972 & Supp. 1988); MO. ANN. STAT. §§ 486.550 to .595 (Vernon 1987); NEB. REV. STAT. §§ 30-2664 to -2672 (1985); N.H. REV. STAT. ANN. §§ 506:5 to :7 (1983 & Supp. 1988); N.J. STAT. ANN. § 46:2B-8 (West Supp. 1988); N.M. STAT. ANN. §§ 45-5-501 to -502 (1978); N.Y. GEN. OBLIG. LAW §§ 5-1501 to -1601 (Consol. 1987); N.C. GEN. STAT. §§ 32A-1 to -14 (1987); N.D. CENT. CODE §§ 30.1-30-01 to -05 (Supp. 1987); OHIO REV. CODE ANN. §§ 1337.01 to .10 (Anderson 1987); OKLA. STAT. ANN. tit. 58, §§ 1051-1062 (West Supp. 1988); OR. REV. STAT. §§ 126.407, 413 (1987); S.C. CODE ANN. § 62-5-501 to -502 (Law. Co-op. 1976); S.D. CODIFIED LAWS ANN. §§ 59-7-2.1 to .4 (1978); TENN. CODE ANN. §§ 34-6-101 to -107 (1984); WASH. REV. CODE ANN. §§ 11.94.010 to .060 (1987); W. VA. CODE §§ 39-4-1 to -7 (Supp. 1988); WIS. STAT. ANN. § 243.07 (West 1987).

139. *In re Peter*, 108 N.J. 365, 378-79, 529 A.2d 419, 426 (1987); see *infra* notes 201-06 and accompanying text.

The New York Attorney General has expressed uncertainty as to whether New York's durable power of attorney could be used to confer broad medical decisionmaking power on a designated treatment agent. Noting that "section 5-1601 [of the New York General Obligations Law] and its history do not reflect a legislative intent either to grant or to deny an agent the power to make health care decisions for an incompetent principal," 1984 Op. Att'y Gen. N.Y. 58, 59 (1984), the Attorney General suggested that a durable power of attorney could best be used in a more limited way, like a living will, to "specifically delegate to an agent the responsibility to communicate the principal's decision to decline medical treatment under certain circumstances." *Id.* at 60.

140. UTAH CODE ANN. § 75-2-1106 (Supp. 1988).

be "guided by the express or implied intentions of the patient."¹⁴¹ Indeed, the very fact of designating a treatment agent enhances the patient's rights of self-determination and privacy in decisionmaking. Because the competent adult can nominate in advance a person whom he trusts, and who knows him well, he is given the peace of mind that comes from knowing that the ultimate treatment decision will be one that is both consonant with his moral and religious beliefs, and as close as possible to the one that he would have made himself, because it will be based upon accurate, up-to-date medical information.¹⁴²

The designation of a treatment agent is a significant advance over the living will, because it provides for intelligent and informed discussion between the treatment agent and the patient's physician. Because the treatment agent can both provide the attending physician with important background information concerning the patient's health and life habits, increasing the accuracy of the diagnosis and prognosis made, and can also consider the medical information conveyed by the physician in light of the totality of the patient's life, values, and beliefs, she can carefully tailor a treatment decision to be consistent with the patient's medical *and* moral needs. The designation of a medical treatment agent eliminates the risk that the physician will either refuse to comply with an advance treatment directive that he believes to be too sweeping in scope, or that he *will* honor it, no matter what the circumstances.

The designation of a treatment agent is thus an alternative that promotes conversation, compassion, and caring.¹⁴³ The attending physician is not bound to follow reflexively the advance directive of a living will, but must consult with the patient's designated treatment agent so that the agent may determine a course that is both medically appropriate and consistent with the patient's values and desires.

3. *Judicial and Less Formal Decisionmaking*

A dozen years ago, resort to the judiciary to seek prior authorization to terminate medical treatment of an incompetent, incurably ill adult was virtually unknown. In many cases, physicians made these decisions alone,¹⁴⁴ and frequently doctors and family members made these decisions together.¹⁴⁵ It was not until the late 1970s,

141. FLA. STAT. ANN. § 765-07(1) (West 1986); IOWA CODE ANN. § 144A.7(1) (West Supp. 1988).

142. See Cantor, *supra* note 44, at 547-48, 555-56. Yet even then the decision that is made can only be an approximation, a "best guess" as to what the person whose death is near would choose if he were now competent. See Beschle, *supra* note 39, at 360.

143. See *infra* discussion in Section III of text.

144. See *In re Quinlan*, 70 N.J. 10, 47, 355 A.2d 647, 667 (discussing testimonial and other evidence "that humane decisions against resuscitative or maintenance therapy are frequently a recognized *de facto* response in the medical world to the irreversible, terminal, pain-ridden patient"), *cert. denied*, 429 U.S. 922 (1976).

145. *In re Westchester County Medical Center*, 72 N.Y.2d 517, 524, 531 N.E.2d 607, 626, 539 N.Y.S.2d 886, 905 (1988) (Simons, J., dissenting); *In re Conroy*, 98 N.J. 321, 345, 486 A.2d 1209, 1227-28 (1985).

and the paradigmatic cases of *In re Quinlan*¹⁴⁶ and *Superintendent of Belchertown State School v. Saikewicz*,¹⁴⁷ that the judiciary became actively involved in the disposition of such cases.

The New Jersey Supreme Court in *Quinlan*, and the Massachusetts Supreme Judicial Court in *Saikewicz*, acted on the basis of a shared constitutional and common law view of the right to privacy.¹⁴⁸ They also agreed on the important state interests that must be balanced against the patient's right to privacy in determining whether, in a particular case, the patient may elect to terminate medical treatment when that will lead her to death: the state's interest in preserving human life, preventing suicide, maintaining the ethical integrity of the medical profession, and protecting the interests of innocent third parties.¹⁴⁹ Yet, despite their common starting point, the thinking of these two state courts has evolved very differently, so that the two courts currently assert conflicting views of the appropriate means of protecting a person's right to choose the course of his medical treatment when he is incapable of exercising it personally.

a. The Massachusetts Model

The Massachusetts substituted judgment model has evolved in a series of decisions, beginning with the landmark case of *Superintendent of Belchertown State School v. Saikewicz*¹⁵⁰ and continuing through *Brophy v. New England Sinai Hospital*.¹⁵¹ In these decisions, the Massachusetts Supreme Judicial Court has taken as its central precept the fundamental constitutional and common law right to privacy and self-determination, which it has held must be balanced against the state interests in the preservation of life, the prevention of suicide, the promotion of the ethical integrity of the medical profession, and the protection of innocent third parties. The court has consistently rejected the possibility of a nonjudicial substitute decisionmaker, and accordingly, has devised a highly formalized and complex set of procedures for substitute decisionmaking on behalf of incompetent, incurably ill adults.

In *Saikewicz*, the patient was a severely retarded sixty-seven-year-old man who had been diagnosed with incurable leukemia.

146. 70 N.J. 10, 355 A.2d 647, *cert. denied*, 429 U.S. 922 (1976).

147. 373 Mass. 728, 370 N.E.2d 417 (1977).

148. *Saikewicz*, 373 Mass. at 739-45, 370 N.E.2d at 424-27; *Quinlan*, 70 N.J. at 38-42, 355 A.2d at 662-64.

149. *Saikewicz*, 373 Mass. at 740-45, 370 N.E.2d at 424-27; *Quinlan*, 70 N.J. at 40-43, 355 A.2d at 663-65. The *Quinlan* court did not mention the state interest in protecting innocent parties, presumably because none were involved in that case, but the New Jersey Supreme Court subsequently recognized all four state interests noted here. *In re Farrell*, 108 N.J. 335, 348-49, 529 A.2d 404, 410-11 (1987).

150. 373 Mass. 728, 370 N.E.2d 417 (1977).

151. 398 Mass. 417, 497 N.E.2d 626 (1986).

Although chemotherapy would normally have been prescribed as a temporary ameliorative treatment, it would not significantly lengthen his life. Saikewicz's physicians were concerned that because of his retardation, he would only perceive the pain of the treatment, without understanding its purpose.¹⁵² Because of Saikewicz's incompetence, a guardian *ad litem* was appointed to represent him in proceedings brought before the probate court to determine whether treatment should be required. The probate court determined that treatment should not be ordered, and on appeal, the Massachusetts Supreme Judicial Court affirmed, articulating detailed procedures for making medical treatment decisions for the incompetent.

The court found that the fundamental constitutional and common law right for a person to be "free from nonconsensual invasion of his bodily integrity"¹⁵³ included the right to refuse medical treatment. Because this right is held equally by competent and incompetent people, courts must appoint a guardian to effectuate the incompetent person's privacy right by clearly articulating the position the guardian believes the incompetent would take if he *were* competent.¹⁵⁴ After a hearing, the trial court must undertake a substituted judgment on the patient's behalf, "attempt[ing] to ascertain the incompetent person's actual interests and preferences. . . . 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."¹⁵⁵

The *Saikewicz* court strenuously rejected any possibility of a non-judicial decisionmaker. Although the trial judge might consider the views of the patient's family, physicians, and any institutional review committee that might exist, the court stated:

We take a dim view of any attempt to shift the ultimate decision-making responsibility away from the duly established courts of proper jurisdiction to any committee, panel or group, ad hoc or permanent. . . .

We do not view the judicial resolution of this most difficult and awesome question . . . as constituting a "gratuitous encroachment" on the domain of medical expertise. Rather, such questions of life and death seem to us to require the process of detached but passionate investigation and decision that forms the ideal on which the judicial branch of government was created. Achieving this ideal is our responsibility and that of the lower court, and is not to be entrusted to any other group purporting to represent the "morality and conscience of our society," no matter how highly motivated or impressively constituted.¹⁵⁶

In *In re Spring*,¹⁵⁷ a case involving a seventy-nine-year-old senile

152. *Saikewicz*, 373 Mass. at 734 & n.5, 370 N.E.2d at 421 & n.5.

153. *Id.* at 739, 370 N.E.2d at 424.

154. *Id.* at 745, 756, 370 N.E.2d at 427, 433.

155. *Id.* at 752-53, 370 N.E.2d at 431.

156. *Id.* at 758-59, 370 N.E.2d at 434-35.

157. 380 Mass. 629, 405 N.E.2d 115 (1980).

incompetent who was receiving life-prolonging kidney dialysis, the Massachusetts Supreme Judicial Court again emphasized the superiority of the judicial model for substitute decisionmaking for incompetent, incurably ill patients. The court held that "it was error to delegate the decision [to terminate treatment] to the attending physician and the ward's wife and son."¹⁵⁸ Although ostensibly declaring that resort to the judiciary was not *necessarily* required in every case,¹⁵⁹ the court enumerated such a lengthy list of factors to be considered in determining whether judicial authorization to terminate life-sustaining medical treatment was required¹⁶⁰ that it virtually ensured that no Massachusetts physician would ever terminate such medical treatment without a judicial imprimatur.

Spring was followed by *In re Roe*¹⁶¹ and *Rogers v. Commissioner of the Department of Mental Health*,¹⁶² both decisions addressing the right of an incompetent mentally ill individual to refuse psychotropic medication.¹⁶³ In each, the Massachusetts Supreme Judicial Court relied upon the fundamental right of privacy to hold that before someone can be forcibly medicated with antipsychotic drugs, he must first be adjudicated incompetent and have a guardian appointed on his behalf. Then, a court will make a substituted judgment for him, considering six factors from the perspective of the incompetent if he could be temporarily rendered competent: (1) the patient's "expressed preferences regarding treatment," (2) the "strength of the incompetent patient's religious convictions, to the extent that they may contribute to his refusal of treatment," (3) "the impact of the decision on the ward's family," (4) "the probability of adverse side effects," (5) "the prognosis without treatment," and (6) "the prognosis with treatment."¹⁶⁴

158. *Id.* at 630, 405 N.E.2d at 117.

159. *Id.* at 636, 405 N.E.2d at 120.

160. The court declared that there are:

a variety of circumstances to be taken into account in deciding whether there should be an application for a prior court order with respect to medical treatment of an incompetent patient. Among them are *at least* the following: the extent of impairment of the patient's mental faculties, whether the patient is in the custody of a State institution, the prognosis without the proposed treatment, the prognosis with the proposed treatment, the complexity, risk and novelty of the proposed treatment, its possible side effects, the patient's level of understanding and probable reaction, the urgency of decision, the consent of the patient, spouse, or guardian, the good faith of those who participate in the decision, the clarity of professional opinion as to what is good medical practice, the interests of third persons, and the administrative requirements of any institution involved.

Id. at 636-37, 405 N.E.2d at 120-21 (emphasis added).

161. 383 Mass. 415, 421 N.E.2d 40 (1981).

162. 390 Mass. 489, 458 N.E.2d 308 (1983).

163. In *Rogers*, the incompetent individuals were civilly committed mental patients at a state hospital. In *Roe*, the incompetent was mentally ill and living at home.

164. *Rogers*, 390 Mass. at 506, 458 N.E.2d at 318-19.

Most recently, in *Brophy v. New England Sinai Hospital*,¹⁶⁵ the Massachusetts Supreme Judicial Court rendered a substituted judgment decision on behalf of Paul Brophy, a fire fighter who was in a persistent vegetative state following a stroke. As a result of this condition, Brophy was unable to swallow, and received food and water through a gastrostomy tube surgically implanted in his stomach. His death was not imminent because he could be maintained indefinitely in that condition.

Brophy's guardian, his wife, sought to exercise Brophy's right to refuse all life-sustaining treatment, including artificial nutrition and hydration. When his physicians and the hospital objected, Brophy's wife brought suit. Relying on Brophy's repeated but general statements that he would never want to be maintained on life-support systems, which were made while he was competent, the Massachusetts Supreme Judicial Court held that Brophy's right to self-determination outweighed any competing state interest, even though it meant that he would die of starvation.¹⁶⁶ Although the court disclaimed any intention to make decisions based on the quality of the incompetent's life,¹⁶⁷ it repeatedly emphasized the invasiveness of the gastrostomy tube and Brophy's helpless and demeaning condition. Finessing the question of whether the state's interest in preserving life was paramount to Brophy's autonomy interest, the court declared:

[W]e must recognize that the State's interest in life encompasses a broader interest than mere corporeal existence. In certain, thankfully rare, circumstances the burden of maintaining the corporeal existence degrades the very humanity it was meant to serve. . . .

The duty of the State to preserve life must encompass a recognition of an individual's right to avoid circumstances in which the individual himself would feel that efforts to sustain life demean or degrade his humanity.¹⁶⁸

Notwithstanding its decision that Brophy had a right to refuse life-sustaining treatment under these circumstances, the court held that his physicians should not be forced to remove his life-support system when they believed it ethically inappropriate to do so. Accordingly, the court held that the treating physicians should be ordered to assist in Brophy's transfer to another institution or his home, so that he could be allowed to die there.¹⁶⁹

In sum, the Massachusetts substituted judgment approach takes as its first precept the principle that an individual's right to privacy and autonomy can only be protected by the "detached but passionate" judgment of a court.¹⁷⁰ The underlying assumption of this preference for judicial decisionmaking—that judges, unlike other mortals, have a direct line to God—represents judicial hubris in the

165. 398 Mass. 417, 497 N.E.2d 626 (1986).

166. *Id.* at 439, 497 N.E.2d at 638.

167. *Id.* at 434, 497 N.E.2d at 635.

168. *Id.*

169. *Id.* at 439-42, 497 N.E.2d at 638-40.

170. *Saikewicz*, 373 Mass. at 759, 370 N.E.2d at 435.

extreme. A substituted judgment is just that, no matter who makes it: a best guess as to what the incompetent patient would have chosen if he were able to discuss his condition with his doctor and voice his own treatment preference.¹⁷¹ Any substitute decision must inevitably reflect the biases of the decisionmaker, no matter how hard she tries to remain "objective" and "detached," or to eschew decisions based upon the "quality of life."¹⁷²

To elevate the substituted judgment to a higher, sacrosanct plane simply because it is a judge, rather than a family member or physician, who is making the decision, is both presumptuous and ultimately destructive of the very autonomy interest that its advocates seek to preserve. Judicial proceedings are cumbersome and time-consuming. They also subject the incompetent and his family to the glare of the media spotlight, providing an opportunity for this most intimate of life's dramas to be played out daily in the newspapers and on the nightly news. In addition, rather than letting the incompetent's family—those persons who are best suited to assess the patient's wishes—deal with the tragedy of a difficult death privately, with the support of physicians and other health care personnel, the insistence on a judicial substituted judgment exacerbates the family's emotional upheaval. When resort to the courts is the preferred, if not the only, means of resolving differences of opinion within the family or between the family and physicians, it promotes distrust and the "fracture of human relationship,"¹⁷³ rather than dialogue, understanding, and mutual respect.

b. The New Jersey Model

From the outset of its involvement in decisionmaking for the incurably ill adult, the New Jersey Supreme Court has expressed a preference that close family members act as substitute decisionmakers for the incompetent patient. In the landmark case of *In re Quinlan*,¹⁷⁴ the court recognized that the competent adult has a fundamental constitutional right to privacy and self-determination. Concerned that this right should not be lost merely because the adult became incompetent, the court declared that this right could be exercised by a guardian in such cases.¹⁷⁵ Further, the court held specifically that the right to privacy encompassed the right to refuse

171. Substituted judgment has been criticized as a legal fiction, *United States v. Charters*, 829 F.2d 479, 498 (4th Cir. 1987), *vacated en banc on other grounds*, 863 F.2d 302 (1988), *stay granted*, 57 U.S.L.W. 3545 (1989), inappropriately transferred from one legal context to another. *Cruzan v. Harmon*, 760 S.W.2d 408, 425-26 (Mo. 1988) (en banc).

172. See *Brophy*, 398 Mass. at 434, 497 N.E.2d at 635; *Conroy*, 98 N.J. at 367, 486 A.2d at 1232-33.

173. See C. GILLIGAN, *IN A DIFFERENT VOICE* 31 (1982).

174. 70 N.J. 10, 355 A.2d 647, *cert. denied*, 429 U.S. 922 (1976).

175. *Id.* at 41-42, 355 A.2d at 664.

life-sustaining medical treatment when there was no chance of returning to a cognitive and sapient existence.¹⁷⁶ Although the court found that under these circumstances no countervailing state interest could outweigh the patient's right to privacy,¹⁷⁷ it was concerned that a decision to withdraw or withhold medical treatment not be reached hastily. Therefore, to guard against the risk of an erroneous diagnosis or prognosis, and to ensure the preservation of medical ethics, the guardian would be permitted to exercise the patient's right to privacy only after her hopeless diagnosis and prognosis had been confirmed by what the court termed an "ethics committee"—in reality a medical prognosis committee.¹⁷⁸ If the committee concurred in the attending physician's diagnosis and prognosis, no criminal or civil liability would attach to the physician's conduct in discontinuing treatment.¹⁷⁹ As long as this procedure was followed, the court emphasized, it would not be necessary to seek prior judicial authorization for decisions to terminate treatment.¹⁸⁰

Eight years later, in *In re Conroy*,¹⁸¹ the New Jersey Supreme Court reexamined the question of substitute decisionmaking for the incompetent in the case of an elderly patient confined to a nursing home. Claire Conroy was an eighty-four-year-old woman who was conscious, but senile, displaying extremely limited interaction with her environment. She suffered from a variety of debilitating illnesses, and, because she had extreme difficulty in swallowing, was receiving food and water through a nasogastric tube.¹⁸² Conroy's nephew, who was also her guardian, sought to have her feeding tube removed, believing that his aunt would not have chosen to receive life-sustaining treatment under such circumstances,¹⁸³ although she had never made an explicit statement to that effect.¹⁸⁴

In *Conroy*, the New Jersey Supreme Court reiterated its recognition of a fundamental right to privacy that encompassed the right of an incompetent, as well as a competent, patient to refuse life-sustaining treatment.¹⁸⁵ Although the court stressed that this right

176. *Id.* at 39, 355 A.2d at 663.

177. *Id.* at 39-41, 355 A.2d at 663-64. The court declared that, "no external compelling interest of the State could compel Karen to endure the unendurable, only to vegetate a few measurable months with no realistic possibility of returning to any semblance of cognitive or sapient life." *Id.* at 39, 355 A.2d at 663.

178. *Id.* at 49-51, 355 A.2d at 668-69.

179. This would eliminate any possible conflict of interest or concern about professional liability, which, the court suggested, might be unconsciously influencing the physician's decision to refuse to discontinue medical treatment. *Id.* at 49-51, 355 A.2d at 668-70.

180. *Id.* at 50-51, 355 A.2d at 669.

181. 98 N.J. 321, 486 A.2d 1209 (1985).

182. *Id.* at 336-37, 486 A.2d at 1216-17.

183. *Id.* at 340, 486 A.2d at 1218. Conroy's nephew stated that: "[a]ll [Ms. Conroy and her sisters] wanted was to . . . have their bills paid and die in their own house." *Id.* (quoting Ms. Conroy's nephew (alterations by the court)).

184. *Id.* at 389, 486 A.2d at 1244 (Handler, J., concurring in part and dissenting in part).

185. *Id.* at 346-50, 486 A.2d at 1221-23. Expanding upon its explication of the sources of the right to privacy in *Quinlan*, this time the court grounded the right to privacy in both the federal and New Jersey constitutions and the common law doctrine of informed consent. *Id.*

is not absolute, and may be outweighed by countervailing state interests,¹⁸⁶ the court also declared that when the interests of third parties were not implicated, "the state's indirect and abstract interest in preserving the life of the competent patient generally gives way to the patient's much stronger personal interest in directing the course of his own life."¹⁸⁷

The *Conroy* court then confronted squarely the question of how decisions should be made on behalf of an incompetent but conscious patient who is hopelessly ill yet not facing imminent death.¹⁸⁸ Reiterating its concern, expressed in *Quinlan*, that this matter was one most appropriate for legislative action, but feeling impelled to provide authoritative guidance in its absence, the court articulated three separate tests to be applied in the case of such an incompetent nursing home patient.

The first, a subjective test, is consonant with the personal right of self-determination sought to be effectuated. This test can be satisfied by clear and convincing evidence that the incompetent patient, while competent, expressed a desire not to receive life-sustaining medical treatment under the circumstances now existing.¹⁸⁹ Such evidence may be provided by detailed and specific statements to that effect, either written or verbal, a formal living will,¹⁹⁰ or a durable power of attorney or other proxy designation of a medical treatment agent.¹⁹¹

For situations in which there is inadequate evidence of the incompetent patient's wishes, the court invoked the *parens patriae* authority of the state to act humanely to end medical treatment that only prolongs a painful dying.¹⁹² The court articulated two standards for determining whether treatment should end absent evidence of the patient's wishes: the "limited-objective" test¹⁹³ and the "pure-

186. *Id.* at 348-49, 486 A.2d at 1223. Here the court referred to the four state interests traditionally recognized: "preserving life, preventing suicide, safeguarding the integrity of the medical profession, and protecting innocent third parties." *Id.*

187. *Id.* at 350, 486 A.2d at 1223.

188. The court limited its holding to the incompetent elderly nursing home patient who is expected to die within one year even if life-sustaining treatment is continued. *Id.* at 342, 486 A.2d at 1219. For a discussion of the particular risks of erroneous decision-making for nursing home patients, see *supra* notes 56-58, *infra* notes 198-200, and accompanying text.

189. *Id.* at 361, 486 A.2d at 1229.

190. The court recognized the evidentiary value of living wills despite the fact that they were not legislatively authorized. *Id.* at 361 n.5, 486 A.2d at 1229 n.5.

191. *Id.* at 361, 486 A.2d at 1229-30.

192. *Id.* at 364-65, 486 A.2d at 1231.

193. The "limited-objective" test is satisfied, and life-sustaining treatment may be terminated or withheld,

when there is some trustworthy evidence that the patient would have refused the treatment, and the decision-maker is satisfied that it is clear that the burdens of the patient's continued life with the treatment outweigh the benefits of that life for him. [That is,] that the patient is suffering, and will continue

objective" test.¹⁹⁴ Under these explicitly "best interests" tests, the substituted decisionmaker may authorize the termination of medical treatment if the prognosis for the patient's continued existence is one of extreme pain, not outweighed by any benefits of pleasureable or satisfying interaction with the environment.¹⁹⁵

In so holding, the court took great pains to eschew the notion that either of these tests would function as a substituted judgment for the incompetent patient. The court stated that: "[I]n the absence of adequate proof of the patient's wishes, it is naive to pretend that the right to self-determination serves as the basis for substituted decision-making."¹⁹⁶ Rather, the court viewed the *parens patriae* justification for state involvement as permitting a decision to end medical treatment that merely prolongs suffering, as long as all doubts were resolved in favor of continuing life, and no decisions were based on the patient's "quality of life."¹⁹⁷

Recognizing the social and medical isolation of many nursing home patients, and the concomitant risks of erroneous diagnosis and prognosis, the court devised safeguards against abuse. Under the *Conroy* framework, if a guardian wishes to make a treatment decision on his patient's behalf, he must first seek a judicial determination of the patient's incompetency to make a treatment decision, offering the clear and convincing evidence of at least two physicians who have personally examined the patient.¹⁹⁸ Each situation in which a guardian petitions for the termination of life-sustaining treatment must be treated as a potential case of abuse, to be investigated by the Ombudsman for the Institutionalized Elderly.¹⁹⁹

to suffer throughout the expected duration of his life, unavoidable pain, and that the net burdens of his prolonged life (the pain and suffering of his life with the treatment less the amount and duration of pain that the patient would likely experience if the treatment were withdrawn) markedly outweigh any physical pleasure, emotional enjoyment, or intellectual satisfaction that the patient may still be able to derive from life.

Id. at 365, 486 A.2d at 1232.

194. The "pure-objective" test applies in a case where there is no trustworthy evidence of the patient's wishes and

the net burdens of the patient's life with the treatment . . . clearly and markedly outweigh the benefits that the patient derives from life [and] the recurring, unavoidable and severe pain of the patient's life with the treatment [is] such that the effect of administering life-sustaining treatment would be inhumane. . . . Nevertheless, even in the context of severe pain, life-sustaining treatment should not be withdrawn from an incompetent patient who had previously expressed a wish to be kept alive in spite of any pain that he might experience.

Id. at 366-67, 486 A.2d at 1232.

195. Concurring Justice Handler took issue with the majority's selection of significant and recurring pain as the decisive factor in evaluating the relative benefits and burdens of prolonging life. He argued that different individuals may place a higher value on not being dependent on others or avoiding intrusive medical treatment or other intrusions on one's privacy and dignity, and that these are also important burdens that should be balanced against the benefit of continued existence. *Id.* at 392-99, 486 A.2d at 1246-50.

196. *Id.* at 364, 486 A.2d at 1231.

197. *Id.* at 354, 367, 486 A.2d at 1226, 1232-33.

198. *Id.* at 381-82, 486 A.2d at 1240-41.

199. *Id.* at 374-85, 486 A.2d at 1237-42. The office of the Ombudsman for the Institutionalized Elderly had previously been created by the New Jersey legislature. N.J. STAT. ANN. § 52:27G-3 (1986).

Further, the Ombudsman must gather evidence from two disinterested physicians, as well as from the patient's attending physician, all of whom must agree that the patient's diagnosis and prognosis are hopeless. Then, if the guardian, ombudsman, attending physician and, in a case in which either the limited-objective or pure-objective test is used, the family of the patient, concur, the guardian may order that the life-sustaining treatment be removed. Unless bad faith is shown, no participant in the decisionmaking process will be subject to civil or criminal liability.²⁰⁰

Most recently, in two cases decided in 1987, the New Jersey Supreme Court refined the substitute decisionmaking process for incompetent nursing home patients in a persistent vegetative state. In the cases of *In re Peter*²⁰¹ and *In re Jobes*,²⁰² the court declared that such patients, regardless of their life expectancy, would be governed by its decision in *Quinlan* rather than *Conroy*. Recognizing the possibility of neglect and abandonment of nursing home patients, and thus the need for safeguards against abuse, the court sought to devise a procedure that promoted the patients' well-being and protected them against a hasty or medically incorrect decision to terminate treatment, "without unduly burdening their rights to self-determination and privacy."²⁰³

Under this process, if there is clear and convincing evidence of an incompetent patient's actual treatment choice, made while competent, derived either from a living will, a durable power of attorney,²⁰⁴ or formal and unequivocal statements to that effect, the substitute decisionmaker²⁰⁵ is permitted to authorize the discontinuance of life-sustaining treatment, provided that two neurologists and the patient's attending physician agree that the patient is in a persistent vegetative state with no possibility of return to a cognitive, sapient existence. If the nursing home patient is elderly as well, the Ombudsman for the Institutionalized Elderly must also concur, after undertaking an independent investigation for possible abuse.²⁰⁶

If there is no clear and convincing evidence of the patient's wishes, as was the case in *Jobes*,²⁰⁷ then a substitute decisionmaker,

200. *Conroy*, 98 N.J. at 385, 486 A.2d at 1242.

201. 108 N.J. 365, 529 A.2d 419 (1987).

202. 108 N.J. 394, 529 A.2d 434 (1987).

203. *Id.* at 427, 529 A.2d at 451.

204. The court found that New Jersey's durable power of attorney statute could be used as a vehicle for substitute health care decisionmaking, although the statute did not expressly authorize such a use. *Peter*, 108 N.J. at 378-79, 529 A.2d at 426.

205. This decisionmaker could be either a person designated by the patient, a close family member, or a guardian appointed by the court. *Id.* at 384, 529 A.2d at 429.

206. *Id.*

207. Mary-Ellen Jobes was a thirty-one-year-old woman who had spent seven years in a persistent vegetative state following a surgical accident. *Jobes*, 108 N.J. at 401,

who may be a close family member²⁰⁸ or a court-appointed guardian, may nonetheless make a treatment decision on the patient's behalf, based on his evaluation of what the patient would have wished to be done under these circumstances.²⁰⁹

The New Jersey Supreme Court emphasized its strong preference that family members, rather than strangers, be the decisionmakers. Because they "treat the patient as a person, rather than a symbol of a cause,"²¹⁰ and because they are "'most familiar with [the patient's] entire life context,' " "including his or her philosophical, religious and moral views, life goals, values about the purpose of life and the way it should be lived, and attitudes toward sickness, medical procedures, suffering and death,' " they are in the best position to act as substitute decisionmakers.²¹¹ As in *Peter*, the court insisted on the safeguards of an independent medical examination by two neurologists and the attending physician's concurrence in the patient's diagnosis and prognosis.²¹²

Finally, the court emphasized that judicial review of a decision to discontinue life-sustaining treatment was ordinarily neither necessary nor desirable:²¹³

"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. The mere prospect of a cumbersome, intrusive and expensive court proceeding, during such an emotional and upsetting period in the lives of a patient and his or her loved ones, would undoubtedly deter many persons from deciding to discontinue treatment. And even if the patient or the family were willing to submit to such a proceeding, it is likely that the patient's rights would nevertheless be frustrated by judicial deliberation. Too many patients have died before their right to reject treatment was vindicated in court."²¹⁴

c. *Statutes Authorizing Less Formal Decisionmaking*

In addition to the judicially developed models for substitute decisionmaking, ten states have, by statute, authorized informal

529 A.2d at 436-38. Although she had made some casual statements over the years indicating that she would not want to be maintained in a condition like Karen Ann Quinlan, the court found them insufficiently probative of her preferences to meet the "subjective" test of substituted judgment. *Id.* at 409-13, 529 A.2d at 442-43.

208. The court indicated that a near relative, including a spouse, parent, child, or sibling, would be presumed to be a close relative, interested in the patient's well-being, although a physician might also recognize a more distant relative as having a sufficiently close personal relationship with the patient to act as her substitute decisionmaker. *Id.* at 419, 529 A.2d at 447.

209. *Id.* at 399, 529 A.2d at 436-37.

210. *Id.* at 416, 529 A.2d at 445.

211. *Id.* (quoting Newman, *Treatment Refusals for the Critically Ill: Proposed Rules for the Family, the Physician and the State*, III N.Y.L. SCH. HUM. RIGHTS ANN. 45-46 (1985)).

212. *Id.* at 422, 529 A.2d at 448.

213. The court stated that judicial intervention would be necessary only "[i]f a disagreement arises among the patient, family, guardian, or doctors, or if there is evidence of improper motives or malpractice." *Id.* at 427-28, 529 A.2d at 451.

214. *Id.* at 423, 529 A.2d at 449 (citations omitted) (quoting *In re Farrell*, 108 N.J. 335, 357, 529 A.2d 404, 415 (1987)).

substitute decisionmaking for incompetent, terminally ill adults²¹⁵ as part of their "living will" or "natural death" acts. Recognizing that competent adults have the right to "a peaceful and natural death,"²¹⁶ and "to control the decisions relating to their own medical care, including the decision to have life-sustaining procedures withheld or withdrawn in instances where such persons are diagnosed as having a terminal and irreversible condition,"²¹⁷ these statutes permit a substitute medical treatment decision to be made even if the patient has not executed a living will or designated a medical treatment agent. Each of the statutes provides that the patient's attending physician and at least one other person, usually chosen from a statutory list in order of priority, shall make the decision to end treatment. The Florida statute is typical.²¹⁸ It provides that life-sustaining treatment may be withheld or withdrawn from an incompetent, terminally ill adult following

consultation and a written agreement for the withholding or withdrawal of life-prolonging procedures between the attending physician and any of the following individuals, who shall be guided by the express or implied intentions of the patient, in the following order of priority if no individual in a prior class is reasonably available, willing, and competent to act:

(a) The judicially appointed guardian of the person of the patient if such guardian has been appointed. This paragraph shall not be construed to require such appointment before a treatment decision can be made under this section.

215. ARK. CODE ANN. § 20-17-214 (Supp. 1987); CONN. GEN. STAT. ANN. § 19a-571 (West Supp. 1988); FLA. STAT. ANN. § 765.07 (West 1986); IOWA CODE ANN. § 144A.7 (West Supp. 1988); LA. REV. STAT. ANN. § 40:1299.58.5(A) (West Supp. 1988); N.M. STAT. ANN. § 24-7-8.1 (1986); N.C. GEN. STAT. § 90-322 (1985); TEX. REV. CIV. STAT. ANN. art. 4590h § 4C (Vernon Supp. 1989); UTAH CODE ANN. § 75-2-1105 (Supp. 1988); VA. CODE ANN. § 54.1-2986 (1988). Of these, both Arkansas and New Mexico provide that a substitute decision to forego treatment may be made on behalf of a patient who is either terminally ill or in an "irreversible coma," N.M. STAT. ANN. § 24-7-2(B) (1986), or "permanently unconscious," ARK. STAT. ANN. § 20-17-201(ii) (Supp. 1987).

216. N.C. GEN. STAT. § 90-320(a) (1985).

217. LA. REV. STAT. ANN. § 40:1299.58.1(A)(1) (West Supp. 1988).

218. FLA. STAT. ANN. § 765.07 (West 1986).

The Connecticut statute is atypical, providing almost casually for the physician to discontinue life support after consultation with the patient's family. The statute declares that any licensed physician or medical facility

which removes or causes the removal of a life support system of an incompetent patient shall not be liable for damages in any civil action or subject to prosecution in any criminal proceeding for such removal, provided (1) the decision to remove such life support system is based on the best medical judgment of the attending physician; (2) the attending physician deems the patient to be in a terminal condition; (3) the attending physician has obtained the informed consent of the next of kin, if known, or legal guardian, if any, of the patient prior to removal; and (4) the attending physician 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 [living will declaration].

CONN. GEN. STAT. ANN. § 19a-571 (West Supp. 1988).

- (b) The person or persons designated by the patient in writing to make the treatment decision for him should he be diagnosed as suffering from a terminal condition.
- (c) The patient's spouse.
- (d) An adult child of the patient or, if the patient has more than one adult child, a majority of the adult children who are reasonably available for consultation.
- (e) The parents of the patient.
- (f) The nearest living relative of the patient.²¹⁹

A physician who withholds or withdraws treatment after such consultation will not be subject to civil or criminal liability or to censure for unprofessional conduct.²²⁰ As a precaution against inappropriate discontinuance of medical treatment, nine of the ten statutes require at least one physician in addition to the patient's own doctor to certify that the patient is suffering from a terminal condition or irreversible coma, or is being kept alive only by extraordinary medical means.²²¹

III. *Proposal for Conversation in Decisionmaking*

The autonomy model of substitute decisionmaking for the incurably ill, incompetent adult, as reflected in both the living will statutes and the decisions upholding the judicial model for substituted judgment, evidences a one-dimensional mode of analysis. In the grand vision of the autonomy model it is the individual, armed with her rights to privacy and self-determination, who is pitted against the state and her physician. Girded with a Lockean view of government as a social contract, in which only limited powers are ceded to the state, and wrapped with the magnificent garb of the constitutional right to privacy, these incompetent, incurably ill individuals are now ready to do battle, to insist that they be able to die "with their rights on."²²²

As has been shown, the consequences of this autonomy model are often devastating. Whether it is the judicial model of decisionmaking, exemplified by Massachusetts, which sanctifies the massive

219. FLA. STAT. ANN. § 765.07(1) (West 1986).

220. *E.g.*, FLA. STAT. ANN. § 765.10(1) (West 1986); LA. REV. STAT. ANN. § 40:1299.58.8(A) (West Supp. 1988).

221. Six of the states—Arkansas, Louisiana, New Mexico, North Carolina, Texas, and Utah—provide explicitly for at least two physicians to concur in judgment of the particular medical condition which triggers the operation of the statute. ARK. CODE ANN. § 20-17-203 (Supp. 1987); LA. REV. STAT. ANN. § 40:1299.58.2(7) (West Supp. 1988); N.M. STAT. ANN. § 24-7-5 (1986); N.C. GEN. STAT. § 90-322(a) (1985); TEX. REV. CIV. STAT. ANN. art. 4590h § 2(6) (Vernon Supp. 1989); UTAH CODE ANN. § 75-2-1104 (Supp. 1988). Three states—Florida, Iowa, and Virginia—require such physician concurrence in the cases of patients who have executed a living will, and one might argue that principles of statutory construction would require at least the same safeguards in the case of the patient who had not made an advance directive. FLA. STAT. ANN. § 765.03(5) (West 1986); IOWA CODE ANN. § 144A.5 (West Supp. 1988); VA. CODE ANN. § 54.1-2982 (1988). Only one state—Connecticut—has no requirement of physician concurrence. CONN. GEN. STAT. ANN. § 19a-571 (West Supp. 1988).

222. Treffert, *Dying with Their Rights On*, 130 AM. J. PSYCHIATRY 1041 (1973) (letter to the editor), reprinted in A. BROOKS, LAW, PSYCHIATRY & THE MENTAL HEALTH SYSTEM 690 (1974).

invasion of courts and the media into the private grief and despair of families, all in the name of respecting individual freedom, or the living will statutes, which purport to respect the right to individual autonomy but often render an attempt to exercise that right illusory, the autonomy model, with its exclusive emphasis on individual rights, is fatally flawed. Thus, one must ask if, in addition to individual autonomy, there is not another fundamental aspect of human personhood that the law must respect and promote: namely, the fact that we are all persons in community, in a network of connection and human interaction.²²³ Rather than seeing each person as a bundle of rights, it is much more appropriate to view each of us as a member of the human family, and to rely upon principles of familial decisionmaking for our moral reference point.

It is axiomatic that in a family, individuals have responsibilities as well as rights. Family members take care of one another, and in particular, adult family members care for both the young and the very old. In short, in a family, there is the notion of beneficent paternalism and maternalism. In addition, in many families, it is discussion and conversation, rather than the authoritarian principle, which is the preferred mode for reaching decisions and resolving difficulties.²²⁴ So too in the area of substitute decisionmaking for incompetent, incurably ill adults, the law must provide a structure for *conversations* about the treatment choice the incompetent individual would make if he were able to communicate with us. In the next section, I propose a model for substitute decisionmaking that takes into account the need for human connection and compassion, as well as the rights of privacy and self-determination.

A. Sources of the Conversation Model

The sources of this model are several. Foremost among them is Carol Gilligan's book, *In a Different Voice*, a path-breaking reexamination of moral development in American culture. In her book, Gilligan argues that mature morality is evidenced not only by an understanding of rights and rules, and the ability to choose among them according to an established hierarchy, but also by the understanding of responsibility and relationships and the ability to act out of care and compassion.²²⁵

Gilligan urges that difficult ethical dilemmas should be resolved

223. See C. GILLIGAN, *supra* note 173, at 19.

224. One would of course be naive to assert that in families all is always sweetness and light, that individual family members invariably act out of altruism and love, rather than self interest, or that there is never oppression and dominance, be it economic, sexual, or physical. For an excellent analysis of how one's conception of the family is inextricably linked to one's view of the appropriateness of different types of state involvement in medical treatment decisions, see Minow, *supra* note 59, at 946-50.

225. See C. GILLIGAN, *supra* note 173, at 19.

not through the rigid application of pre-ordained formulae and rules—treating them as “a math problem with humans”²²⁶—but rather through a response that will “sustain rather than sever connection.”²²⁷ She articulates an alternative structure for conflict resolution in which the “awareness of the connection between people gives rise to a recognition of responsibility for one another.”²²⁸ Thus conversation *itself* is the answer to the “fracture of human relationship,” because it sustains and continues “a narrative of relationships that extend over time.”²²⁹ In this light, autonomy must be seen not as the ultimate virtue, the paramount right, but rather as the source of an “illusory and dangerous quest,”²³⁰ an obstacle that must be overcome, or at least bypassed, if the goal of communal caring and compassion is to be attained.²³¹

From a distinct, but related perspective, Dr. Jay Katz writes in *The Silent World of Doctor and Patient* about the need for physicians to engage in conversation with their patients as the only way that the legal doctrine of informed consent can be rendered meaningful.²³² In Katz’s view, if doctors discuss with their patients the risks and benefits of alternative treatment, it will both enhance patient autonomy and yield better medical results, because the more information the physician has from the patient, the better the diagnosis and prognosis he will be able to reach.²³³ Thus, the practice of conversation with patients, seeing them not only as the physical embodiment of a collection of vital signs and symptoms, but as fellow beings, both enhances individual self-determination and minimizes the risk of an erroneous medical decision.²³⁴

Katz’s work in this area finds support in the Society of General Internal Medicine’s Task Force for the Medical Interview and Related Skills. Researchers have found that when physicians are trained to ask open-ended questions and to listen attentively, rather than subjecting the patient to a verbal diagnostic check list, the result is likely to be both better health and a happier relationship between the doctor and patient. This happens, first, because in the “art” of medicine, “[s]ome . . . healing . . . derives from the simple communication of understanding, of positive regard, and of caring.”²³⁵ Second, an attentive, open-ended interview leads both to greater physician understanding of the patient’s illness, desires, and expectations, and to increased patient compliance with the physi-

226. *Id.* at 28.

227. *Id.*

228. *Id.* at 30.

229. *See id.* at 28.

230. *See id.* at 48.

231. *Cf. id.* at 17-19, 23, 48 (stressing the need to both develop and value the ability to care for, and attach to, other human beings).

232. J. KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* 84 (1984); *see also* Katz, *supra* note 84, at 142-43, 147, 160.

233. J. KATZ, *supra* note 232, at 86.

234. *Id.* at 84.

235. Lipkin, *The Medical Interview and Related Skills*, in *OFFICE PRACTICE OF MEDICINE* 1287, 1293 (W. Branch 2d ed. 1987).

cian's recommended course of treatment, because the physician takes the time to explain the underlying reasons for her recommendations, and can tailor those recommendations to fit the particular needs and habits of her patient.²³⁶

The Task Force also found that an emphasis on conversation is critical not only for dying patients, but for their families as well. Being candid and concrete with the family about the dying process, while "[f]raming what is being done as 'care' rather than as 'giving up' can transform the experience from a nightmare to a final act of love, caring, and courage."²³⁷

Substantial support for a conversation-based model of substitute decisionmaking for incompetent patients is also found in the writings of Dr. Elizabeth Kübler-Ross, who has emphasized that dying is a process. Kübler-Ross has found that the dying process consists of stages through which an individual patient will often pass, including denial, anger, bargaining, depression, acceptance, and eventual peace.²³⁸ Each of these stages is an aspect of the conversation in which a patient engages with her family, friends, and physicians in regard to her impending death. In the case of an incompetent patient who cannot communicate with physicians and loved ones, it is the process of discussion among the family and doctors, of taking time for mutual and caring interaction, that will lead to a better, more humane, decision being made, as well as greater acceptance and peace of mind among the participants.

Finally, the conversation model of substitute decisionmaking finds support in the rapidly expanding literature on alternative dispute resolution. Alternative dispute resolution, which includes negotiation, arbitration, and mediation, along with many hybrid forms,²³⁹ is seen by its proponents as providing many advantages over litigation as a means of resolving controversies. These include: (1) the strengthening of ongoing relationships;²⁴⁰ (2) the increased sense of self-determination that comes from the disputants working out a resolution of a difficult problem together,²⁴¹ rather than having it imposed from outside, as in adjudication; (3) the enhanced understanding of the other person's situation;²⁴² and (4) the ability to vent emotions and to discuss issues not directly related to the dispute at hand.²⁴³ Each of these advantages supports the conversation model

236. Branch, *supra* note 130, at 359.

237. Lipkin, *supra* note 235, at 1303.

238. See E. KÜBLER-ROSS, ON DEATH AND DYING 38-137 (1970).

239. S. GOLDBERG, E. GREEN & F. SANDER, DISPUTE RESOLUTION 7-10 (1985).

240. *Id.* at 10.

241. See *id.* at 7.

242. McEwen & Maiman, *Small Claims Mediation in Maine: An Empirical Assessment*, 33 ME. L. REV. 237, 238-39 (1981).

243. *Id.*

of substitute decisionmaking.

First, when the parties to a controversy have an ongoing relationship, as is almost always so with family members, and is frequently the case with the family and the physician,

it is important to have the parties seek to work out their own solution, for such a solution is more likely to be acceptable to them than an imposed solution and hence more long-lasting. . . . [M]ediation [in particular] encourages a restructuring of the underlying relationship so as to eliminate or mitigate the source of conflict, rather than simply addressing each manifestation of conflict as an isolated event.²⁴⁴

Second, the enhanced sense of self-determination that can result from the participant-controlled give-and-take of alternative dispute resolution has a twofold virtue: it comports with the autonomy model's goal of achieving individual self-actualization and it also leads to greater satisfaction on the part of all participants with the resolution that is ultimately reached.

A recent study of small claims court mediation in Maine found that those persons who participated in mediation, and thus played an active part in the decisionmaking process, were much more satisfied with the ultimate result and more likely to adhere to the decision reached than were traditional litigants, who often viewed themselves as the mere *object* of the judge's decisionmaking.²⁴⁵ The authors of the study suggested that, in part, this enhanced participant support for a decision reached via alternative dispute resolution may stem from the opportunities that mediation provides for gaining insight into the other party's situation and the validity of his viewpoint. In addition, because it is a less structured process than adjudication, mediation gives the parties the chance to air important emotional concerns and to discuss other issues which might not be considered legally relevant.²⁴⁶ Hence, although mediation took slightly more time than adjudication, it also led to increased satisfaction with the decisionmaking process, greater compliance with the settlement eventually reached, and the continuation of the parties' long-term, ongoing relationship when one existed.²⁴⁷

B. The Conversation Model in Practice

In the case of substitute decisionmaking for the incompetent, incurably ill adult, an alternative dispute resolution process holds out the same potential for continuing and strengthening the relationship of the participants, increasing satisfaction and compliance with the resolution reached, and helping the parties deal with the sadness and emotional upheaval that inevitably attends a decision to withhold or withdraw life-sustaining treatment from a hopelessly ill individual. These advantages are present in the procedure

244. S. GOLDBERG, E. GREEN, & F. SANDER, *supra* note 239, at 10.

245. McEwen & Maiman, *supra* note 242, at 263-64.

246. *Id.* at 239, 256.

247. *Id.* at 263-64.

envisioned by the New Jersey Supreme Court in *Conroy*,²⁴⁸ *Peter*,²⁴⁹ and *Jobes*,²⁵⁰ in the process by which a designated treatment agent discusses the patient's condition and prognosis with the attending physician,²⁵¹ and, to a limited extent, in the provisions for less formal decisionmaking enacted by ten states in their natural death acts.²⁵²

In order to achieve a viable process of decisionmaking for the incurably ill, incompetent patient based on conversation, mutual respect, and responsibility, a number of changes—legal and medical—must occur. First and foremost, state legislatures must be persuaded to enact statutes permitting competent adults to designate a medical treatment agent to make decisions on their behalf should they become incompetent and incurably ill. Such laws promote individual self-determination and autonomy by permitting the competent adult to nominate in advance of illness and incompetency a treatment agent whom she trusts to make decisions for her based on the agent's knowledge of her life, moral values, and preferences. The advance designation of such a treatment agent leads both to peace of mind on the part of the competent adult, and at the same time enhances the accuracy of the treatment decision that is made. Because the treatment agent must engage in conversation with the patient's physician concerning the patient's present condition and long-run prognosis, all relevant information can be brought to bear in the decisionmaking process. The treatment decision that the physician and the treatment agent ultimately make can therefore be tailored both to the patient's medical situation and her moral value system.

It is critical that the designated treatment agent be authorized to act on the patient's behalf whenever he is incompetent and incurably ill. As noted earlier,²⁵³ to require that a patient be terminally ill before his living will or other advance treatment directive can become operative deprives many hopelessly ill people of the salutary effects of an advance directive, condemning them to a prolonged and often painful dying process.

At the same time, legislatures should enact substitute decision-making procedures for those patients who have not executed an advance treatment directive. Such procedures should be simple and informal, as in those states whose natural death acts currently provide for such a procedure.²⁵⁴ However, these procedures should

248. 98 N.J. 321, 486 A.2d 1209 (1985).

249. 108 N.J. 365, 529 A.2d 419 (1987).

250. 108 N.J. 394, 529 A.2d 434 (1987).

251. See *supra* notes 131-43 and accompanying text.

252. See *supra* notes 215-21 and accompanying text.

253. See *supra* notes 117-20 and accompanying text.

254. See *supra* notes 215-21 and accompanying text.

also be accompanied by safeguards, like those enunciated by the New Jersey Supreme Court in *Conroy*²⁵⁵ and *Jobes*,²⁵⁶ that will ensure that an accurate diagnosis and prognosis has been made, that the family is truly representing the patient's interests, and that those patients without close family members or friends to act on their behalf are not abandoned.²⁵⁷ At the same time, these procedures, like the statutes authorizing the designation of a medical treatment agent, should be broad enough to include all incurably ill patients, not only those whose conditions meet a strict definition of "terminal illness."

Such a comprehensive, informal substitute decisionmaking procedure, with adequate safeguards against ill-advised, uninformed, or improperly motivated substitute decisions, serves all the goals of the conversation model. It is private, it is capable of a speedier and yet more complete resolution of the issue, and it permits more give-and-take, more development of understanding in reaching a decision. Because each member of the decisionmaking group is better informed about the ingredients of the decision, the risk of erroneous decisionmaking is significantly reduced.²⁵⁸ This in turn leaves the participants more satisfied, and thus, more likely to comply with the decision that is reached. One can only wonder what would have happened in the *Brophy* case if Patricia Brophy and her husband's physicians had spent more time talking and less time litigating. Would not the precise result the Massachusetts Supreme Judicial Court reached—recognition of Brophy's right to refuse treatment and his transfer to the care of physicians who were willing to remove his gastrostomy tube—have been achieved earlier, and at much less financial and emotional cost to all persons involved?

As a result of a shared decisionmaking process, individual participants are able to view each other not as adversaries, but as partners in reaching the resolution of a difficult problem. Then, after a decision is made, there is not enmity, but connection. This paves the way for future relations of mutual respect, rather than malpractice litigation, or rifts within the family. Accordingly, just as is the case with alternative dispute resolution, the process of conversation, of structuring a decisionmaking model on the basis of human connection rather than on a hierarchy of rights and rules, enhances both the quality of the decision made and the participants' acceptance of it.

In addition to legislative changes permitting conversational decisionmaking, medical education also must become more sensitive to the ethical issues involved in making decisions for the incurably ill, and more responsive to the need for *conversation* in the process of

255. 98 N.J. 321, 486 A.2d 1209 (1985).

256. 108 N.J. 394, 529 A.2d 434 (1987).

257. *Conroy*, 98 N.J. at 374-85, 486 A.2d at 1237-42; see also *supra* notes 198-209 and accompanying text. However, it would not seem necessary to appoint a guardian in the ordinary case. See e.g., *In re Barry*, 445 So. 2d 365, 372 (Fla. Dist. Ct. App. 1984) (stating that in the case of a young child, the parents need not always qualify as legal guardians; the parents' decision, supported by competent medical advice, is ordinarily sufficient).

258. See Branch, *supra* note 130, at 359.

reaching those decisions. In particular, medical schools must confront directly the difficulties that inhere in our classical hierarchical relationship between doctor and patient. Just as the doctrine of informed consent has as its goal greater participation by the patient in his own medical care as a means of achieving more medically correct and more personally satisfying decisions, so too we must instill in medical students and practicing physicians the need to be open in discussing the difficult issues of death and dying, to take time with the incurably ill patient and his family, and to actively involve them in the decisionmaking process.²⁵⁹

Instead of relegating medical ethics, psychosocial aspects of patient care, and the art and science of the medical interview to a minor, elective place in the curriculum, medical schools must give these subjects a place in student studies commensurate with their importance in the practice of medicine, integrating them fully into the curriculum.²⁶⁰ Exemplifying the type of curricular change that is both necessary and possible, in 1988 Harvard University Medical School introduced a mandatory, comprehensive first-year course addressing numerous issues in the doctor-patient relationship, including informed consent, the patient interview, and ethical issues in death and dying.²⁶¹

Concomitantly with this new emphasis on the psychosocial aspects of climate practice, medical schools must also inform their students about the legal aspects of substitute decisionmaking for the incurably ill. Both students and practicing physicians must be taught about living wills, advance designations of medical treatment agents, and other legal tools available to enhance the patient's control over his own dying whenever possible.²⁶²

259. This is but one of many reasons why it is appropriate to rethink our private and state financial mechanisms for physician reimbursement, so that doctors are able to charge a reasonable fee for the time involved in making decisions to withdraw or withhold life-sustaining treatment. In addition, Dr. William T. Branch, one of the leading proponents of the attentive, open-ended interview, argues that not only must physicians find the time to engage in real conversation with patients and their families, but that such time is actually cost-effective. He notes

[O]nce these skills are practiced—and become truly integrated into the doctor's repertoire—enhanced interest in and ability to deal with patients' feelings saves time in the long run, because patients talk to their doctors more freely and cooperatively, their expectations are more fully met, compliance improves, and misunderstandings and disagreements lessen.

Branch, *supra* note 130, at 358-59.

260. Since the early 1980s, the impetus for reform of American medical education has grown. Critics generally agree on what is wrong with modern medical education, although they often have disparate views on how best to remedy these deficiencies. See Bok, *supra* note 32, at 32, 34-45, 70.

261. Telephone interview with Dr. William Branch, Harvard University Medical School (July 25, 1988). This new course accounts for 66 hours in the reformed medical school curriculum, compared with one hour previously.

262. Nursing educators must make similar curricular changes, as nurses are the pri-

It is also necessary for members of the public, as well as lawyers and health care professionals, to educate themselves about the advantages of designating a treatment agent to make health care decisions. Competent adults need to plan for their dying and discuss their treatment preferences openly, in advance of illness and incompetency, with close friends and family. By encouraging such conversation, we can also foster both individual dignity and human connection and caring.

Finally, and most important, the judiciary must take a hands-off approach. Our zeal for error-free decisionmaking should not lead us to believe that judicial intrusion in this area is either inevitable, infallible, or desirable. Ultimately, we must recognize that the courts are simply not the place for resolution of these most intimate and personal issues. It is not judges but family members, acting out of compassion, not dispassion, who are the most appropriate persons to ease their loved ones' passage from life to death.

many caregivers in the hospital setting, almost always having much more contact with the patient and his family than the physician.