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Someone to Watch Over Me: Medical Decision-Making for Hopelessly Ill Incompetent Adult Patients

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SOMEONE TO WATCH OVER ME: MEDICAL DECISION-MAKING FOR HOPELESSLY ILL INCOMPETENT ADULT PATIENTS

INTRODUCTION: SILENT CONVERSATIONS IN THE DARK

Every day, as I have for several years now, I talk to a man who does not respond to me. He is oblivious to my presence as I enter his world of unknowns. He appears equally oblivious to his own presence: I don’t know if he knows where he is, or even who he is.

On tip-toe, I peer curiously into the window of his mind. I don’t know if he feels the touch of my hand as I stroke his face, or if he hears the sound of my voice as I speak to him. I don’t know if he comprehends the music and meaning in my words when I tell him that I love him. I doubt that he understands what has become of him: his beautiful, well-educated brain and once-athletic body have been severely damaged by his nearly twenty-year battle with multiple sclerosis. Squinting my eyes and hoping to see what I suspect is not there, I wonder if he even remembers that I am his daughter.

His face is expressionless; his body motionless, except for an occasional reflexive cough or yawn. As I look at him, I am reminded momentarily of the time in my life when he was strong and I was dependent upon him. Now, I find a strange irony in his helplessness. He is wholly dependent upon the continuous loving care of my mother, and the proper functioning of a myriad of tubes and machines.

As I prepare to leave his bedside, a host of gnawing unknowns remain. Were those tears I saw, or were his eyes simply watering? Did his eyes move to follow my voice, or was that just a twitch? Does he feel pain, or are his occasional grimaces merely the product of uncontrollable reflexes? And then, the most burning, awesome question: would he want to live like this, or would he rather be allowed to die?

My father is among the hopelessly ill: those who are precariously poised on the line that separates life from death. Some, like my father, are in what has been

NOTE: This comment is dedicated in loving memory to my father, who passed away after this comment was written, and as this issue of the AKRON LAW REVIEW was being prepared for publication.

1 Someone To Watch Over Me (song written by George Gershwin and Ira Gershwin, sung by Willie Nelson on Stardust Album, Columbia Records).

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termed a "persistent vegetative state". Others are comatose. By virtue of their brain-damaged condition, all are incompetent. Although patients who are terminally ill are often incompetent, hopelessly ill patients are distinguished from terminally ill patients in that hopelessly ill patients do not face imminent death. Quite often, the contrary is true; hopelessly ill patients may "exist" on the brink of death for years.

This comment focuses on the predicament of the hopelessly ill incompetent adult patient. The comment first discusses the legal framework for medical decision-making in general. Next, it examines the legal and medical distinctions between competent and incompetent patients, and the implications of those distinctions. The comment then explores the options in caring for hopelessly ill incompetent adult patients, and the persons who may or should be responsible for exercising those options. The comment also considers the bases upon which the options may be exercised. Finally, the comment contains an examination of the current state of opinion and the law on medical decision-making for hopelessly ill incompetent adult patients, and a proposal for change.

LEGAL FRAMEWORK FOR MEDICAL DECISION-MAKING

In general, medical decision-making is governed by a well-established legal framework, the paramount principle of which is informed consent to treatment. Within that principle are implicated several other fundamental concepts, including informed refusal of treatment, and the rights of self-determination and privacy. A discussion of this framework is an essential preface to an exploration and analysis of the narrower subject of this comment.

2 Generally, "[t]he persistent vegetative state is a form of eyes-open unconsciousness in which the patient has periods of wakefulness and physiological sleep/wake cycles, but at no time is the patient aware of him- or herself or the environment. [This condition] is the result of a functioning brain stem and the total loss of cerebral cortical functioning." Am. Acad. of Neurology, Position of the American Academy of Neurology on Certain Aspects of the Care and Management of the Persistent Vegetative State Patient, 39 NEUROLOGY 125, 125 (1989) [hereinafter Position].

3 The comatose patient is defined as one who is in "[a]n abnormal deep stupor [which occurs] in illness, as a result of it, or due to an injury. The patient cannot be aroused by external stimuli." TABER'S CYCLOPEDIC MEDICAL DICTIONARY 390 (16th ed. 1989).

4 Incompetent patients have been variously defined as those who are "legally unable to execute a contract, such as a brain-damaged individual," Id. at 901; those "[lacking the] ability, legal qualification, or fitness to discharge [a] required duty," BLACK'S LAW DICTIONARY 390 (abr. 5th ed. 1983); and those who are "[i]ncapable." TABER'S CYCLOPEDIC MEDICAL DICTIONARY 901 (16th ed. 1989).

5 Terminally ill patients are those with "[i]llnesses that because of [their] nature can be expected to cause, [death]." Id. at 1836.
Informed Consent

Every patient upon whom a medical or surgical procedure is to be performed must first consent to that procedure. Consent is an authorization, by the patient, that changes a touching from nonconsensual to consensual. Unauthorized touching of another, as occurs where a procedure is performed upon a patient without his consent, constitutes the tort of battery. Once a battery has been committed upon a patient, neither absence of negligence, nor strict compliance with the standards of medical practice in the performance of the procedure is a valid defense. The nonconsensual touching, in and of itself, constitutes the tort.

Because the patient is viewed at law as the master of his own person, he must give informed consent to medical treatment. A patient must fully understand the treatment to which he is consenting in order to give informed consent. Accordingly, a physician may not treat a patient without first explaining to the patient "the risks and material facts" of the proposed treatment, as well as alternatives which may include non-treatment. Physicians must provide their patients with adequate information to permit them to choose intelligently from among the available options.

Two legal standards have been developed to determine the adequacy of information that physicians disclose to their patients. The first of these, the objective test, measures the adequacy of a physician's disclosure to his patient against the level of information that other physicians in the community usually disclose. Unfortunately, this test fails to account for the human element present in the patient. More flexible is the second standard: the subjective test. This test defines the adequacy of disclosure based upon several factors: the proposed treatment and its probable consequences, the patient's mental and physical condition, and the patient's understanding of the physician's explanation.

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6 For purposes of this prefatory discussion, the patient will be presumed to be competent and capable of making his own medical decisions.
8 Id.
9 Id.
10 Id.
12 G. POZGAR, supra note 7, at 100.
14 G. POZGAR, supra note 7, at 100.
15 Id.
16 Id.
of the risks posed by the treatment. Regardless of which test is applied, the physician should chiefly be guided by the welfare and needs of the patient.

There are modifications and exceptions to the doctrine of informed consent which fit well within the parameters of the law. For example, courts recognize the privilege of a physician to selectively disclose or withhold information for "sound therapeutic reasons." Courts have further recognized the need to imply consent where it is impossible to obtain informed consent and an emergency situation requires immediate action to save a patient’s life or to prevent permanent injury.

Informed Refusal

A logical extension of the doctrine of informed consent is that a conscious, mentally competent adult patient has the legal right to refuse any medical or surgical procedure. This right exists even when such a refusal is counter to the best medical opinion about the necessity of the treatment and despite the treatment’s life-saving or life-sustaining potential.

When a patient refuses treatment, the treating facility is obligated to ensure that no member of its staff performs the treatment. However, the treating facility is also obligated to ensure that the physician and other members of the medical staff continue to treat the patient within the limits of his refusal.

Courts usually will not intervene to order treatment which has been refused by a conscious, legally competent adult patient. To do so would be to violate the patient’s common law right of self-determination.

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17 Id. at 101.
18 A. SOUTHWICK, supra note 11, at 228.
19 A. SOUTHWICK, supra note 11, at 226. "Sound therapeutic reasons" include complication or hindrance of treatment of the patient if his emotional state or personality is such that he could not deal properly with full disclosure. Id.
20 G. POZAR, supra note 7, at 107; A. SOUTHWICK, supra note 11, at 228.
21 G. POZAR, supra note 7, at 108; G. ANNAS, supra note 13, at 79.
22 G. POZAR, supra note 7, at 108; G. ANNAS, supra note 13, at 81.
23 G. POZAR, supra note 7, at 108.
24 G. ANNAS, supra note 13, at 81.
25 Id.
26 A. SOUTHWICK, supra note 11 at 229. Exceptions to this rule include cases in which the patient’s right to refuse treatment is outweighed by one of the state’s compelling interests. Id. at 231.
The Right of Self-Determination

One century ago, the United States Supreme Court enunciated what has today become an oft-quoted legal principle. "No right is held more sacred, or is more carefully guarded, by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law." The Court continued, "[t]he right to one's person may be said to be a right of complete immunity: to be let alone."

The right of self-determination has been elaborated upon over the years, but the key concept has remained unchanged. That is, in the words of Justice Cardozo, that "[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body * * *." This concern for an individual's dignity is the cornerstone of court decisions that recognize patients' constitutional right to control fundamental medical decisions that affect them.

Thus, "[t]he right to be free of unwanted physical invasions has been recognized as an integral part of the individual's constitutional freedoms, whether termed a liberty interest protected by the Due Process Clause, or an aspect of the right to privacy contained in the notions of personal freedom which underwrote the Bill of Rights." The common law right of self-determination is grounded in the concept of individual dignity and bodily integrity, and is closely tied to the constitutionally-based right of privacy.

The Right of Privacy

The right of privacy, although not expressly set forth in the law of this country, has been recognized to exist by virtue of the "penumbra" of the specific

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29 Id. at 251.
30 Id. (quoting COOLEY ON TORTS 29).
33 United States v. Charters, 829 F.2d 479, 491 (4th Cir. 1987). See also Bradley, Does Autonomy Require Informed and Specific Refusal of Life-Sustaining Medical Treatment?, 5 ISSUES IN L. & MED. 301 (1989); Rouse, Does Autonomy Require Informed and Specific Refusal of Life-Sustaining Medical Treatment?, 5 ISSUES IN L. & MED. 321 (1989).
34 Gray, 697 F. Supp. at 583.
guarantees of the Bill of Rights. Specifically, the United States Supreme Court has grounded a constitutional right of privacy in the protections of the first, third, fourth, fifth, ninth and fourteenth amendments, recognizing "that a right of personal privacy, or a guarantee of certain areas or zones of privacy, does exist under the Constitution."

One such zone of privacy has been found to encompass the making of medical decisions. Because decisions to consent to or refuse medical treatment are so fundamentally important and utterly personal, "it is virtually inconceivable that the right of privacy would not apply to [them]." This is consistent with the Supreme Court's holdings that personal rights that are "implicit in the concept of ordered liberty" or "deeply rooted in this nation's history and tradition" are encompassed by the constitutional right of privacy.

The right of privacy, however broadly construed, is not absolute. Rather, it must be balanced against certain state interests. In the context of medical decision-making, the state's interests include the preservation of life, the protection of innocent third parties, the prevention of suicide, and the maintenance of the ethical integrity of the medical profession.

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35 Griswold v. Conn., 381 U.S. 479, 484 (1965). But see separate concurring opinions of Justices Goldberg and Harlan at 486-501. Justice Goldberg wrote that the ninth amendment established the existence of a number of rights despite the fact that they are not enumerated in the Constitution. One of these rights, according to Justice Goldberg, is the right of privacy. Id. at 486-99. Justice Harlan wrote that the right of privacy is grounded not in the ninth amendment, but rather in the concept of liberty promoted in the fifth and fourteenth amendments. Id. at 499-501. See also Cruzan v. Director, Mo. Dept. of Health, 110 S. Ct. 2841, 2851, 2851 n.7 (1990), discussed, infra note 250.

36 Id.


41 Id. at 192 (quoting Moore v. E. Cleveland, 431 U.S. 494, 503 (1977)).

42 Gray, 697 F. Supp. at 588.

43 Id.

44 SAIKIEWICZ, 373 Mass. at 741, 370 N.E.2d at 425.
Of the four interests which may be asserted to override the right of privacy, the state’s interest in the preservation of life is the most significant.\(^{45}\) This interest is strongest when the state seeks to protect an individual who is incapable of protecting himself and may thus be abused.\(^{46}\) However, in the case of a patient refusing treatment, the interest weakens greatly as the degree of bodily invasion inherent in the proposed treatment increases, and the benefit to be derived from that invasion diminishes.\(^{47}\) The state’s interest in preserving a patient’s life is greatest where the patient’s affliction is curable, and weakest where the patient is hopelessly or terminally ill.\(^{48}\)

Courts are in agreement that, in the case of a hopelessly or terminally ill patient, a point is reached at which the state’s interest is no longer significant enough to override the patient’s right of privacy.\(^{49}\) In the words of the Saikewicz Court:

> The constitutional right to privacy, as we conceive it, is an expression of the sanctity of individual free choice and self-determination as fundamental constituents of life. The value of life as so perceived is lessened not by a decision to refuse treatment, but by the failure to allow a competent human being the right of choice.\(^{50}\)

Accordingly, the state’s interest in preserving life must encompass the recognition of an individual’s right to avoid degrading and futile life-sustaining efforts.\(^{51}\)

Because deference to the state’s interest in the preservation of life has yielded to the concept of respect for the patient as a person, the state’s interest in preserving life has only rarely been cited as an explicit rationale for overriding a patient’s right of privacy.\(^{52}\)

\(^{45}\) Id. One commentator points out that despite its significance, “both the basis for and meaning of this state interest are elusive.” Oberman, Withdrawal of Life Support: Individual Autonomy Against Alleged State Interests in Preserving Life, 20 LOY. U. CHI. L. J. 797, 806-07 (1989).

\(^{46}\) Gray, 697 F. Supp. at 589.

\(^{47}\) Severns, 425 A.2d at 159.

\(^{48}\) Saikewicz, 373 Mass. at 742, 370 N.E.2d at 426.

\(^{49}\) Severns, 425 A.2d at 159.

\(^{50}\) Saikewicz, 373 Mass. at 742, 370 N.E.2d at 426.

\(^{51}\) Gray, 697 F. Supp. at 588.

\(^{52}\) Peters, The State’s Interest in the Preservation of Life: From Quinlan to Cruzan, 50 OHIO ST. L. J. 891, 891 (1989). In this excellent in-depth examination of the state’s interest in preserving life, the author discusses four possible bases for the interest: “(1) protecting patient wishes; (2) protecting patient welfare; (3) enforcing community beliefs about the inherent value or "sanctity" of life; and (4) fashioning a legal doctrine that is not susceptible to undesirable erosion (the 'slippery slope' danger).” Id. at 893. The author determines that the state’s interest in the preservation of life as presently constituted is unworkable and suggests several ways to resolve conflicts between the many hidden meanings of the state’s interest and the interests of patients as individuals. Id. at 893-977.
Closely tied to the state's interest in the preservation of life is its interest in preventing suicide. Theoretically, the latter interest becomes relevant whenever a patient's refusal of medical treatment would cause his death. However, courts wisely distinguish between purposefully causing one's own death, and resigning oneself to the hastened arrival of a death which is inevitable due to a hopeless underlying condition. Hence, the act of a competent adult in refusing medical treatment does not necessarily constitute suicide.

Only slightly more successful in overriding patients' right of privacy has been the state's interest in protecting innocent third parties. This interest is usually asserted by the state as parens patriae to protect the dependents of a patient refusing treatment. Clearly, by its very nature, this interest fails to focus upon the interests of the patient in question. For that and other reasons, the assertion of this interest as a basis for state intervention is not easily justified.

The fourth state interest, maintenance of the ethical integrity of the medical profession, was traditionally a decisive factor in judicial decisions to override a patient's right of privacy. However, the power of this interest has been tempered by changes in the law and in the attitudes of medical professionals.

"Prevailing medical ethical practice does not, without exception, demand that all efforts toward life prolongation be made in all circumstances." To the contrary, the prevalent medical ethical practice now recognizes that the dying, especially those for whom death drags its feet, are frequently less in need of medical treatment than they are of understanding and comfort. The Massachu-
Recognition of the right to refuse necessary treatment in appropriate circumstances is consistent with existing medical mores; such a doctrine does not threaten either the integrity of the medical profession, the proper role of hospitals in caring for such patients or the State's interest in protecting the same. It is not necessary to deny a right of self-determination to a patient in order to recognize the interests of doctors, hospitals, and medical personnel in attendance on the patient. Also, if the doctrines of informed consent and right of privacy have as their foundations the right to bodily integrity, [cites omitted] and control of one's own fate, then those rights are superior to the [interests of the medical profession].

**Competence: The Ability to be Autonomous**

From the foregoing discussion, it is clear that a competent adult patient has the right, in most cases, to be the master of his own destiny insofar as medical decision-making is concerned. This concept is underscored by several recent cases.

In *Bouvia v. Superior Court*, California's Second District Court of Appeal cited a plethora of legal authority in support of its order which allowed a competent quadriplegic woman to remove the nasogastric feeding tube that had been inserted and maintained in her against her will. The Court reasoned that "a person of adult years and in sound mind" has a legal right to determine the course of his medical treatment, that right must certainly encompass a right to...
refuse even medical treatment that may prolong or sustain his life. "The right to refuse medical treatment is basic and fundamental. . . . Its exercise requires no one's approval. It is not merely one vote subject to being overridden by medical opinion."  

The Court analogized Elizabeth Bouvia's situation to that of William Bartling in the earlier case of Bartling v. Superior Court. Bartling was a competent adult who suffered from an array of incurable, but not terminal health problems. During a physical examination, a tumor was discovered in his lung and was subsequently biopsied by inserting a needle into the lung. The lung deflated, and efforts to reinflate it were unsuccessful. Consequently, Bartling underwent an emergency tracheostomy, and was placed on a ventilator. His hands were restrained to prevent him from removing the ventilator tube.

Bartling and his family repeatedly asked the treating physicians to discontinue the ventilation and to remove the restraints. When the physicians did not honor their requests, Bartling executed documents which stated that he found "intolerable the living conditions forced upon him . . . and . . . [his] being continuously connected to [a] ventilator." Bartling wrote that his wish was to have the ventilator removed; that he was aware that doing so would ultimately cause his death; and that he was "willing to accept that risk rather than continue the burden of [an] artificial existence which [he found] unbearable, degrading and dehumanizing."

The California Court of Appeal held that the right to have life-support systems removed is not limited to comatose or terminally ill patients. The

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68 Bouvia, 179 Cal. App. 3d 1127, 225 Cal. Rptr. 297 (quoting Cobbs, 8 Cal. 3d at 242, 502 P.2d at 9, 104 Cal. Rptr. at 516, and citing Barber, 147 Cal. App. 3d 1006, 195 Cal. Rptr. 484; Bartling, 163 Cal. App. 3d 186, 209 Cal. Rptr. 220.

69 Bouvia, 179 Cal. App. 3d 1131, 225 Cal. Rptr. at 301.

70 Bartling, 163 Cal. App. 3d 186, 209 Cal. Rptr. 220.

71 Id. at 187, 209 Cal. Rptr. at 221.

72 Id.

73 Id.

74 A tracheostomy is a surgical incision of the skin on the neck over the trachea which creates an airway into which a tracheostomy tube may be inserted and attached to a mechanical ventilator. TABER'S CYCLOPEDIC MEDICAL DICTIONARY 1887-88 (16th ed. 1989).

75 Bartling, 163 Cal. App. 3d at 187, 209 Cal. Rptr. at 221.

76 Id.

77 Id.

78 Id. at 188, 209 Cal. Rptr. at 222.

79 Id.

80 Id. at 189, 209 Cal. Rptr. at 223. Unfortunately, Bartling died the day before the Court heard his case. Id. at 187, 209 Cal. Rptr. at 221.
MEDICAL DECISION-MAKING

Court stated that the "right of a competent adult patient to refuse medical treatment has its origins in the constitutional right of privacy . . . [which] guarantees to the individual the freedom to choose to reject, or refuse to consent to, intrusions of his bodily integrity." Moreover, judicial approval is not a prerequisite to a patient's ability to exercise his right to refuse life-sustaining medical treatment. In fact, prior judicial approval of such decisions may not only be "unnecessary", but "unwise".

Subsequent decisions have proven that the right of a competent adult patient to refuse medical treatment - even that which sustains life - is far from illusory.

In 1989, Larry McAfee, a young civil engineer who was rendered quadriplegic in a 1985 motorcycle accident, received permission from the Supreme Court of Georgia to disconnect the ventilator that sustains him. The Court held that a competent adult patient has the right to refuse medical treatment, provided the right is not outweighed by conflicting state interests. McAfee was unquestionably competent, having gone so far as to design the device that he hoped would enable him to disconnect the ventilator himself. The Court found, and the state conceded, that no state interests outweighed McAfee's right to disconnect his life-support equipment.

Another recent decision eloquently summarized the relationship between a competent adult patient's right to refuse treatment and the state interests against which it is balanced. The Nevada Supreme Court stated:

The state's interest in the preservation of life relates to meaningful life. . . . [T]he state has no . . . interest in interfering with the natural

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1 Id. at 191, 209 Cal. Rptr. at 225.
2 Id. at 192, 209 Cal. Rptr. at 226.
3 Id.
6 McAfee, 259 Ga. 579, 385 S.E.2d at 651.
7 Id.
8 Id.
9 McKay v. Bergstedt, 106 Nev. 808, 801 P.2d 617 (1990). The 31-year-old patient-plaintiff in this case had been a quadriplegic since a swimming accident at age ten. He had been cared for by his parents, but his mother had passed away and his father was near death at the time the action was filed. He feared for his well-being in their absence and he preferred death.
processes of dying among citizens whose lives are irreparably devastated by injury or illness to the point where life may be sustained only by contrivance or radical intervention. In such situations as [here], only the competent adult patient can determine the extent to which his or her artificially extended life has meaning and value in excess of the death value.90

Emerging from all of these decisions is the key concept that the right to determine one's own course of medical treatment is firmly vested in competent adult patients. Accordingly, for a court considering such a case, the threshold issue is whether the patient is competent91 to make his own medical decisions.

However, a finding of incompetence does not mean that the patient's right is lost, for equally clear is the pronouncement of the courts that a patient’s right of privacy "should not be discarded solely on the basis that [his] condition prevents [his] conscious exercise of [it]."92 Courts have consistently permitted the right of privacy of incompetent patients to be asserted on their behalf by a surrogate.93 "An incompetent patient’s right to refuse treatment should be equal to a competent patient’s right to do so.94 "The recognition of [a right to refuse medical treatment in certain circumstances] must extend to . . . an incompetent, as well as a competent, patient because the value of human dignity extends to both."95

I DON'T THINK, THEREFORE I AM NOT?:
THE PARADOXICAL INCOMPETENT PATIENT

One's right to determine his own course of treatment does not divest with the onset of incompetence. It is this concept which preserves the rights of self-
determination and privacy in the hopelessly ill incompetent adult patients upon whom this comment is focused. These people include those who are comatose, those who are in a persistent vegetative state, those who are brain dead, and those who suffer from terminal illnesses which have impaired their cognitive functioning. Each condition is slightly different from the others, and each thereby presents slightly different legal nuances.

The Comatose Patient

Ronald E. Cranford, one of the nation’s foremost authorities on neurology and medical ethics, has defined coma as a "state of sleeplike (eyes-closed) unarousability." Coma results from extensive damage to that part of the brain which is essential in initiating and maintaining wakefulness and in directing attention. Therefore, comatose patients are permanently unconscious. They have no cerebral cortical functions which would indicate consciousness or behavioral interaction with their environments.

However permanent their condition, though, such patients cannot be said to be chronically unconscious. Because of their impaired gag, cough and swallowing reflexes and resultant inability to clear the throat and lungs of secretions, comatose patients typically suffer frequent - and often fatal - respiratory infections. In that respect, they may be labeled terminally ill, as death generally occurs within six to twelve months. The absence of chronicity of coma as opposed to the extreme chronicity of the persistent vegetative state is but one important distinction between the two conditions.

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98 Id.; TABER'S CYCLOPEDIC MEDICAL DICTIONARY 1591 (16th ed. 1989).
99 TABER'S CYCLOPEDIC MEDICAL DICTIONARY, supra note 98.
100 "The cerebrum is concerned with sensations or the interpretation of sensory impulses; and all voluntary muscular activities. It is the seat of consciousness and the center of the higher mental faculties such as memory, learning, reasoning, judgment, intelligence, and the emotions." TABER'S CYCLOPEDIC MEDICAL DICTIONARY 326 (16th ed. 1989). The cerebral cortex is the thin fibrous neuron layer that covers the cerebrum. Id. at 420.
101 Cranford, supra note 97, at 28.
The Persistent Vegetative State (PVS) Patient

Cranford contrasts the persistent vegetative state (PVS) with coma by defining PVS as a form of "eyes-open" permanent unconsciousness.\(^{106}\) In PVS patients, the brain stem\(^ {107}\) remains largely intact; however, there is an absence of cerebral cortical functioning.\(^ {108}\) PVS patients are amnestic; they have completely lost their mental functions.\(^ {109}\)

Awake, but unaware, PVS patients are not cognizant of themselves or their surroundings, although their eyes may wander and appear to be "observing" events about them.\(^ {110}\) Voluntary reactions are absent,\(^ {111}\) as is the capacity to experience pain and suffering.\(^ {112}\) PVS patients do, however, experience sleep-wake cycles, and also maintain primitive protective gag, cough, and respiratory reflexes.\(^ {113}\) Their ability to rely upon these reflexes further distinguishes PVS patients from comatose patients, in that they are not as susceptible to respiratory infections and thus usually live longer.\(^ {114}\)

PVS patients are not brain dead,\(^ {115}\) nor are they terminally ill.\(^ {116}\) Although the prospect of recovery from PVS is almost nonexistent, there have been a few documented cases in which PVS patients have fully recovered cognitive

\(^{106}\) Id.

\(^{107}\) Id.

\(^{108}\) The brain stem maintains the body’s "most primitive protective reflexes, such as the cough, gag, ... swallowing, and spontaneous respiration." Id. at 27.

\(^{109}\) Id. at 28.

\(^{110}\) Id. PVS is usually precipitated by a cardiac or respiratory arrest and the resultant ischemia (lack of blood flow) and/or hypoxia (lack of oxygen) to the brain. Id. Although the brain stem is fairly resistant to ischemia and hypoxia and is generally resilient enough to continue functioning, the cerebral cortex is less able to withstand such trauma and will be essentially destroyed after four to six minutes in either condition. Id. The post-hypoxic or post-ischemic patient will frequently be in a transient coma for several days or even several weeks. Id. During this period, mechanical ventilation is often required. Id. Afterward, the patient will lapse from the eyes-closed unconscious state of coma into the eyes-open unconscious PVS state. Id.

\(^{111}\) Id.

\(^{112}\) Position, supra note 2.

\(^{113}\) Id.; Cranford, supra note 97, at 28.

\(^{114}\) Id. Such patients may survive for "five, ten, and twenty years" provided that artificial nutrition and hydration are continued. Cranford, supra note 97, at 31; Position, supra note 2. PVS patients cannot chew or swallow and must be fed a liquid diet through either a nasogastric tube or an endogastric tube. Id. Without nutrition and hydration, PVS patients will usually die in less than thirty days. Cranford, supra note 97, at 31.

\(^{115}\) Cranford, supra note 97.

\(^{116}\) Position, supra note 2.
functioning after prolonged periods in PVS. Invariably, however, these patients are left severely and permanently paralyzed.

The Brain Dead Patient

The significant difference between PVS or comatose patients and brain dead patients is that when brain death occurs, the entire brain, including the brain stem, is destroyed. These patients are in the "deepest possible coma", and have experienced total and irreversible brain damage. There are no voluntary or involuntary movements, although spinal-based reflexes (those not dependent upon the brain stem) may be present.

Brain death occurs when a primary injury or trauma to the brain causes a secondary injury in the form of brain swelling. The pressure inside the skull, caused by the swelling, quickly exceeds the systolic blood pressure and halts the blood flow to the entire brain. Brain dead patients require total respiratory support; however, vegetative homeostatic functions such as the circulatory and digestive processes are able to continue.

An accurate determination of brain death may be made in a period of hours to days. As with coma, brain death is not a chronic condition and usually does not last more than six to eight weeks.

117 Id. at 30; Snyder, Cranford, Rubens, Bundlie & Rockswold, Delayed Recovery from Postanoxic Persistent Vegetative State, 14 ANNALS OF NEUROLOGY 152 (1983).
118 Cranford, supra note 97, at 30. This condition is known as "locked-in syndrome". Id.
120 Id. at 66.
121 Cranford, supra note 97, at 28.
122 Cranford, supra note 119, at 66.
123 Id. at 65.
124 Id. at 65-66.
125 Id. at 66.
126 Cranford, supra note 97, at 27.
127 Cranford, supra note 119 at 66.
128 Id. Whole brain death has been an accepted criterion for human death since the Harvard criteria were published in 1968. Id. at 69 (citing Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death, A Definition of Irreversible Coma, 205 J.A.M.A. 337 (1968)). Nonetheless, there are some who would blur the distinction between PVS, comatose, and brain dead patients and essentially pronounce them all dead. Youngner & Bartlett, Human Death and High Technology: The Failure of the Whole-Brain Death Formulations, 99 ANNALS OF INTERNAL MEDICINE 252 (1983). See also Wikler, Not Dead, Not Dying?: Ethical Categories and Persistent Vegetative State, 18 HASTINGS CENTER REP. 41 (1988). They propose that loss of consciousness and cognition constitutes the death of a human, and that persons who are sustained in such a condition are mere "mindless organisms". Id. at 256. Thus, when cerebral and brain stem functions are irreversibly lost, the proponents of this definition would pronounce the patient dead. Id. As yet, this controversial definition of death remains unpopular.
The Terminally Ill Incompetent Patient

At this point, several distinctions can be drawn between terminally ill incompetent patients and the three categories of incompetent patients previously discussed. Of the three, the situation of the terminally ill patient most closely parallels that of the comatose patient. The PVS patient may linger indefinitely, and the brain dead patient is, for all intents and purposes, dead. But for the comatose or terminally ill patient, death is an imminent, though not immediate, reality.

Terminally ill patients are those with incurable or irreversible conditions that have a high probability of causing death within one year despite treatment. The term "terminally ill" is somewhat more restrictive than the term "incurably ill". Therefore, the two should be distinguished. Incurable illness will ultimately cause death, but, in contrast to terminal illness, no maximum life expectancy is set. A determination of terminal illness, once the decisive factor in refusal of treatment cases, is now viewed as a poor criterion for deciding whether treatment may be foregone. It has become clear that "classification as terminally ill is not a sine qua non for application of the right to [refuse treatment]."

TO TREAT OR NOT TO TREAT?: TESTING THE LIMITS OF THE RIGHT TO REFUSE TREATMENT

While decisions to treat or not to treat a medical condition arise in even the most benign contexts, the import of such decisions is most substantial when made at or near the end of a patient's life. The term "life", as used here, denotes meaningful life, for, although certain permanently unconscious patients may "live" in the sense that they may exist for years, their meaningful, productive, interactive lives have ended.

and unaccepted. Id. at 252.

129 HASTINGS CENTER, GUIDELINES ON THE TERMINATION OF LIFE-SUSTAINING TREATMENT AND THE CARE OF THE DYING 141 (1987). Not all terminally ill patients are incompetent. However, this comment will focus upon only those who are incompetent.


131 Id.

132 Id. at § 4.8.

133 Id.

134 Id.
When a hopelessly ill incompetent adult patient's life hangs in the medical balance, whether by virtue of terminal illness, brain death, or permanent unconsciousness, what are his options? Who exercises those options, and on what bases?

**Treatment Options**

Essentially, three treatment options for patients at or near the end of life exist: treatment may be withheld altogether; treatment may be initiated and either continued or withdrawn; or, in the most controversial scenario, active euthanasia may be pursued.

1. **Withholding Treatment**

   In medical-ethical circles, withholding treatment is tacitly favored over withdrawing treatment, because of an ethereal distinction between acts of omission and acts of commission. More specifically, in the context of end-of-life medical decision-making, merely omitting or withholding life-sustaining treatment is viewed as allowing the patient to die. Conversely, committing the act of withdrawing such treatment is viewed by some as killing.

However, court decisions have somewhat blurred the line on the basis of the fiduciary doctor-patient relationship. Thus, withholding and withdrawing treatment have come to be judged equally against the singular standard of "professional norms". Cases such as Barber v. Superior Court, In re Conroy, and Satz v. Perlmutter have borne out the theory that, right or wrong, failing to institute artificial nutrition, hydration or ventilation is equivalent to withdrawing such measures once instituted.

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135 See Brock, Forgoing Life-Sustaining Food and Water: Is It Killing?, in BY NO EXTRAORDINARY MEANS: THE CHOICE TO FORGO LIFE-SUSTAINING FOOD AND WATER 117, 118-19 (J. Lynn ed. 1986);

136 Brock, supra note 135, at 118. This author draws an analogy to illustrate the point: "Suppose you consciously omit to send food to persons whom you know are starving in a famine in some distant land. The famine victims die. No one would say that you killed them by not sending food, but rather that you allowed them to die. . . ." Id. at 123.

137 Id.

138 N. CANTOR, supra note 135, at 32-33.

139 Id. at 33.

140 Barber, 147 Cal. App. 3d 1006, 195 Cal. Rptr. 484.

141 Conroy, 98 N.J. 321, 486 A.2d 1209. The New Jersey Supreme Court observed that "[w]hether necessary treatment is withheld at the outset or withdrawn later on, the consequence - the patient's death - is the same." Id. at 352, 486 A.2d at 1234.

142 362 So. 2d 160 (1978), aff'd. 379 So. 2d 359 (1980).

143 Barber, 147 Cal. App. 3d 1006, 195 Cal. Rptr. at 490; Conroy, 98 N.J. 321, 486 A.2d 1209; Satz, 362 So. 2d at 163.
The issue of withholding life-sustaining treatment arises with respect to primarily two types of treatment: artificial nutrition and hydration, and mechanical ventilation. It is generally accepted that artificial nutrition and hydration may be foregone in three situations. In the first, the provision of nutrition and hydration is futile because of an innate problem which disallows either the introduction or absorption of the food. In the second situation, provision of artificial nutrition and hydration does not benefit the patient because he is in a permanent state of unconsciousness and is oblivious to even his own artificially-sustained existence. Finally, artificial nutrition and hydration may appropriately be withheld where the introduction of such measures would be more burdensome than beneficial to the patient.

The answers are not as clear-cut in cases that involve mechanical ventilation. The dilemma is exacerbated by the immediacy of the situation. Obviously, the question of whether to initiate mechanical ventilation demands a more instantaneous answer than does the question of whether to introduce artificial nutrition and hydration. Moreover, in cases where the initiation of mechanical ventilation implicates resuscitative rather than merely supportive efforts, the patient has lapsed from the living to the dead, and may as easily be brought back to the living. This raises numerous ethical and legal issues. One of the most troubling issues pertaining to the withholding of mechanical ventilation from hopelessly ill incompetent adult patients is the appropriateness of Do Not Resuscitate (DNR) orders.

Because resuscitative efforts must be initiated immediately, the consequences of a DNR order that has been issued to prevent resuscitation and initiation of mechanical ventilation are dramatic and irreversible.
2. Initiating Treatment With The Option To Continue Or Withdraw

"It is good medical practice to initiate the artificial provision of fluids and nutrition when the patient's prognosis is uncertain, and to allow for the termination of treatment at a later date when the patient's condition becomes hopeless. The artificial provision of nutrition and hydration is analogous to other forms of life-sustaining treatment, such as the use of [a ventilator]. The decision to discontinue [either of these types] of treatment should be . . . based on a careful evaluation of the patient's diagnosis and prognosis, the prospective benefits and burdens of the treatment, and the stated preferences of the patient and family."

Continuing treatment once it has been initiated is a decision frequently made by an incompetent patient's family in consultation with the patient's treating physicians. Few issues are raised by such a decision. However, a point is often reached at which withdrawing treatment becomes the more humane choice for a hopelessly ill incompetent patient. Treatment may be ethically withdrawn in any situation in which it could ethically be withheld. Rather than withhold treatment altogether for fear it can never be terminated, it is generally preferable to initiate treatment with a provision for its termination at some point. For that reason, the majority of court cases involving medical decisions at the end of life consider the withdrawal, rather than the withholding, of treatment.
The seminal case which addresses the issue of withdrawing treatment from a hopelessly ill incompetent adult patient is *In re Quinlan*. On April 15, 1975, 21-year-old Karen Quinlan ceased breathing for at least two fifteen-minute periods. She was taken to a hospital, placed on a ventilator, and examined by a neurologist who found her to be comatose. Over a course of several weeks, Karen lapsed from the coma into a persistent vegetative state.

The Supreme Court of New Jersey considered whether Karen’s father could authorize the withdrawal of her ventilator. In resolving this question "... of transcendent importance", the Court carefully considered the positions of the Quinlan family, the state, the treating physicians, and the Catholic Church. The Court found that the eighth amendment’s protection against cruel and unusual punishment was wholly inapplicable to the case. It further refused to recognize an independent parental right either of religious freedom or of privacy to support the relief that Karen’s father requested.

However, the Court did determine that Karen Quinlan had a constitutional right of privacy which encompassed a right to withdraw the ventilator, and that such right could be exercised on her behalf by her father as the legal guardian of her person. Thus began a litany of cases in which judicial approval to withdraw life-sustaining treatment was sought, based upon the constitutional right of privacy.

While only a minority of jurisdictions have addressed the issue of withholding life-sustaining treatment from hopelessly ill incompetent adults, nearly every court that has considered the issue has taken a different approach. Appearing only to agree that the right to withdraw life-sustaining treatment is grounded in

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155 *Quinlan*, 70 N.J. 10, 355 A.2d 647.
156 *Id.* at 23, 355 A.2d at 653-54.
157 *Id.*
158 *Id.*
159 *Id.* at 24, 355 A.2d at 654.
160 *Id.* at 19, 355 A.2d at 652.
161 *Id.* at 37, 355 A.2d at 662.
162 *Id.* at 37, 355 A.2d at 661-62.
163 *Id.* at 39-41, 355 A.2d at 663-64.
164 But see Armstrong & Calen, *From Quinlan to Jobes: The Courts and the PVS Patient*, 18 HASTINGS CENTER REP. 37 (1988) (arguing that it should not be necessary for families of incompetent hopelessly ill patients to continually seek court approval for withdrawal of life-sustaining treatment when a right to withdrawal has been consistently upheld by the courts).
165 R. WEIR, *supra* note 151, at 144.
the constitutional right of privacy, courts have contributed to the Quinlan\textsuperscript{166} legacy by setting forth standards in a wide variety of areas.

Several jurisdictions have shunned the artificial distinction between ordinary and extraordinary treatment. While the issue was briefly discussed by the Storar\textsuperscript{167} Court, the Severns Court offered the clearest treatment of the distinction between ordinary and extraordinary treatment.\textsuperscript{168} The Court noted that in the case of an incompetent, hopelessly ill patient, the line between the two types of treatment greatly blurs.\textsuperscript{169} Thus, the Court said, it is futile to argue over such an artificial distinction when any type of treatment, be it ordinary or extraordinary, cannot cure such a patient but can only indefinitely prolong his existence.\textsuperscript{170}

Similarly, other courts have reasoned that as the prognosis of a hopelessly ill incompetent patient dims, as the treatment becomes more futile, and as the degree of bodily invasion required to administer that treatment grows, the patient’s right to refuse all medical treatment increases.\textsuperscript{171} Accordingly, one court stated:

\begin{quote}
[T]he state’s interest in life encompasses a broader interest than mere corporeal existence. In certain circumstances, the burden of maintaining the corporeal existence degrades the very humanity it was meant to serve. The law recognizes the individual’s right to preserve his humanity, even if to preserve his humanity means to allow the natural processes of a disease or affliction to bring about a death with dignity. * * * 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.\textsuperscript{172}
\end{quote}

Most courts have required a high degree of certainty that a hopelessly ill incompetent patient would want life-sustaining treatment withdrawn before such action will be ordered. The standard was clearly enunciated when the Court of

\begin{footnotes}
\footnote{166} Quinlan, 70 N.J. 10, 355 A.2d 647.
\footnote{167} Storar, 52 N.Y.2d 363, 420 N.E.2d 64, 438 N.Y.S.2d 266.
\footnote{168} Severns, 425 A.2d 156.
\footnote{169} Id. at 159.
\footnote{170} Id. See also Note, Someone Make Up My Mind: The Troubling Right to Die Issues Presented by Incompetent Patients with No Prior Expression of a Treatment Preference, 64 Notre Dame L. Rev. 394, 401-03 (1989) (discussing the ordinary/extraordinary distinction and its evolution into the more workable proportionate/disproportionate test set forth in Barber, 147 Cal. App. 3d 1006, 195 Cal. Rptr. 484); Harris & Bostrum, supra note 152, at 426-28 (arguing that feeding by tube is ordinary care and not medical treatment).
\footnote{172} Brophy, 398 Mass. at 434, 497 N.E.2d at 380, 529 A.2d at 426, 439.
\end{footnotes}
Common Pleas of Summit County, Ohio, considered the case of Edna Leach, a 70-year-old victim of amyotrophic lateral sclerosis. After Mrs. Leach became unable to breathe on her own, mechanical ventilation was initiated. A nasogastric tube was also inserted. Some months after life-sustaining treatment was begun, Mrs. Leach's husband sought a court order for discontinuance of the treatment.

Before it could order the withdrawal of Mrs. Leach's life-sustaining treatment, the Court required clear and convincing evidence that such would be her choice if she were competent to decide. Flatly rejecting the use of a "beyond a reasonable doubt" standard, the Court granted the petition for discontinuance of mechanical ventilation, but not the artificial nutrition and hydration.

While the clear and convincing evidence standard has appeared in all the withdrawal of life-sustaining treatment decisions, one issue has consistently divided courts and commentators alike. This highly divisive issue involves the proper level of court involvement in these cases. Among those who have considered this issue, three distinct points of view have come to the forefront.

The first court to grapple with the issue was the New Jersey Supreme Court in Quinlan. There, the Court urged judicial overview of, but not direct judicial involvement in, the decision-making process. This middle-ground position seeks to strike a balance between the protection of patient interests and

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173 Leach, 68 Ohio Misc. 1, 426 N.E.2d 809. Amyotrophic lateral sclerosis is a "progressively deteriorating, disabling disease of the nervous system." Id. at 2.

174 Id. at 2-3, 426 N.E.2d at 810.

175 Id. at 3, 426 N.E.2d at 811.

176 Id. at 11, 426 N.E.2d at 815. The Court held that there was clear and convincing evidence of Edna Leach's wishes. Id. See also In re O'Connor, 72 N.Y.2d 517, 531 N.E.2d 607, 534 N.Y.S.2d 886 (1989) (defining "clear and convincing evidence" as "proof sufficient to persuade the trier of fact that the patient held a firm and settled commitment to the termination of life-supports under the circumstances like those presented"). Id. at 523, 531 N.E.2d at 613, 534 N.Y.S.2d at 892. The standard was not met in O'Connor. Id. at 524, 531 N.E.2d at 614, 534 N.Y.S.2d at 893.

177 Leach, 68 Ohio Misc. at 11, 426 N.E.2d at 815. Courts' use of the clear and convincing evidence standard in cases involving withdrawal of life-sustaining treatment was recently upheld by the United States Supreme Court. Cruzan v. Director, Mo. Dept. of Health, 760 S.W.2d 408 (Mo. 1988). Cruzan stands for the proposition that "informally expressed reactions to other people's medical condition and treatment do not constitute clear proof of a patient's intent." Cruzan, id. at 424.

178 Id. at 12, 426 N.E.2d at 816.

179 Id. at 12, 426 N.E.2d at 816. Courts' use of the clear and convincing evidence standard in cases involving withdrawal of life-sustaining treatment was recently upheld by the United States Supreme Court. Cruzan v. Director, Mo. Dept. of Health, 110 S. Ct. 2841 (1990). There, the Court sanctioned the Missouri Supreme Court's use of the standard in its Cruzan v. Harmon decision, 760 S.W.2d 408 (Mo. 1988). Cruzan stands for the proposition that "informally expressed reactions to other people's medical condition and treatment do not constitute clear proof of a patient's intent." Cruzan, id. at 424.

180 R. Weir, supra note 151, at 153.

181 Quinlan, 70 N.J. 10, 355 A.2d 647.

182 Id.
the minimization of judicial involvement. Thus, courts which have taken this position have limited the role of judicial involvement to a determination of incompetency and the appointment of a guardian.

Several years after Quinlan, the Supreme Court of Washington held in In re Colyer that when the family of a hopelessly ill incompetent patient is familiar with the beliefs the patient held while he was competent, a decision to withdraw life-sustaining treatment does not require prior judicial approval. Judicial intervention should only be used as a safeguard in cases where family members disagree about the patient's wishes, where the patient was never competent to express his wishes, where no family member or guardian exists to speak for the patient, or where ill motives are suspected.

Polarized on either side of the "middle ground" position are those who have called for total judicial intervention and those who abhor even the slightest intervention. The court best known for favoring complete judicial intervention is the Supreme Judicial Court of Massachusetts, which resolutely stated in Saikewicz:

We take a dim view of any attempt to shift the ultimate decision-making responsibility away from the duly established courts of proper jurisdiction.

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183 R. Weir, supra note 151, at 153.
184 Id.
185 Quinlan, 70 N.J. 10, 355 A.2d 647.
186 Colyer, 99 Wash. 2d 114, 660 P.2d 738.
187 Id. at 127-28, 660 P.2d at 746.
188 See In re L.H.R., 253 Ga. 439, 321 S.E.2d 716 (1984) (adding that no ethics committee need be consulted either. The Court stated that "[t]he decision whether to end the dying process is a personal decision for family members or those who bear a legal responsibility for the patient. We do not consider this conclusion an abdication of responsibility by the judiciary." Id. at 446, 321 S.E.2d at 723.)
189 But see, In re Hamlin, 102 Wash. 2d 810, 689 P.2d 1372 (1984) (stating that although court involvement may be required in such a case to appoint a guardian for the incompetent patient, once the guardian has been appointed, no further judicial intervention is required). See also Note, In re Gardner: Withdrawing Medical Care from Persistently Vegetative Patients, 41 Md. L. Rev. 447, 464 (1989) (noting that numerous reasons have been cited to justify judicial deference to family decision-making for incompetent patients); Comment, The Role of the Family in Medical Decision-making for Incompetent Adult Patients: A Historical Perspective and Case Analysis, 48 U. PITT. L. Rev. 539, 555 (1987) (citing five reasons why family ought to decide for hopelessly ill incompetent adult patients).
190 Colyer, 99 Wash.2d at 127-28, 660 P.2d at 746. See also Rasmussen v. Fleming, 154 Ariz. 207, 741 P.2d 674 (1987). The Rasmussen Court stated, "One need only look to the plethora of cases... where arguments were heard or opinions were issued long after the patient had died, to conclude that judicial intervention in decisions of this nature can indeed be unduly cumbersome... Once the court resolves the matters of guardianship and incompetence... its encroachment into the substantive decisions concerning medical treatment should be limited to resolving disputes among the patient's family, the attending physician, and independent physician, the health care facility, the guardian, and the guardian ad litem." Id. at 224, 741 P.2d at 691.
We do not view the judicial resolution of this most difficult and awesome question whether potentially life-prolonging treatment should be withheld from a person incapable of making his own decision 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.\textsuperscript{192} This position mandates prior court approval of all decisions to withdraw treatment that involve both the patient's death and potential physician liability.\textsuperscript{193}

Diametrically opposed is the position of courts such as the California Court of Appeals, which held in \textit{Barber v. Superior Court}\textsuperscript{194} that judicial involvement, either in the form of oversight or intervention, is wholly misplaced in the context of medical decision-making for hopelessly ill incompetent patients. The Court stated:

\begin{quote}
* * * in the absence of legislative guidance, we find no legal requirement that prior judicial approval is necessary before any decision to withdraw treatment can be made. * * * [W]e agree with [the courts] which have held that requiring judicial intervention in all cases is unnecessary and may be unwise.\textsuperscript{195} * * * [A] practice of applying to a court to confirm such decisions * * * would be impossibly cumbersome'.\textsuperscript{196}
\end{quote}

Similarly, the Supreme Court of Florida stated, in \textit{John F. Kennedy Memorial Hosp. v. Bludworth}\textsuperscript{197} that prior court approval is "too burdensome, is not necessary to protect the state's interests or the interests of the patient, and could render the right of the incompetent a nullity."\textsuperscript{198}

The courts that espouse this view disfavor judicial involvement at any level,\textsuperscript{199} except in the most unusual or problematic situations.\textsuperscript{200} Under this

\textsuperscript{192} \textit{Id.} at 758-59, 370 N.E.2d at 434-35. For an argument that the decision-making power properly rests with the courts and a theory of how that power should be exercised, see P. Riga, \textit{Right to Die or Right to Live?: Legal Aspects of Dying and Death} 1-12 (1981).

\textsuperscript{193} R. Weir, supra note 151, at 153.

\textsuperscript{194} \textit{Barber,} 147 Cal. App. 3d 1006, 195 Cal. Rptr. 484.

\textsuperscript{195} \textit{Id.} at 1014, 195 Cal. Rptr. at 493.

\textsuperscript{196} \textit{Id.} (quoting \textit{Quinlan,} 70 N.J. at 50, 355 A.2d at 669).

\textsuperscript{197} Bludworth, 452 So. 2d 921.

\textsuperscript{198} \textit{Id.} at 925.

\textsuperscript{199} R. Weir, supra note 151, at 154.

\textsuperscript{200} \textit{Id.}
view, treatment withdrawal decisions for hopelessly ill incompetent patients are to be the private collaborative effort of the patient's family and physicians.\(^{201}\)

3. Active Euthanasia

"Euthanasia" is derived from the Greek language and, literally, means "good death".\(^{202}\) Accepted and even encouraged by many early religions under certain circumstances, euthanasia in the form of suicide was viewed as an appropriate and merciful release from incurable suffering.\(^{203}\) Today, although no American jurisdiction considers suicide to be a crime, most consider rendering assistance to commit suicide to be a crime.\(^{204}\) All modern legal jurisdictions consider active euthanasia to be a crime.\(^{205}\)

Active euthanasia is largely condemned under the theory that one who deliberately acts to cause the death of another does so with malice, even if he intends no ill will and believes that his act is morally justified.\(^{206}\) Nonetheless, courts have sympathized with an accused whose act of euthanasia was motivated by mercy for the victim.\(^{207}\)

Although laymen have traditionally gone unpunished for committing acts of euthanasia,\(^{208}\) the weight of opinion dictates that physicians ought not engage in such acts.\(^{209}\) The American Medical Association Judicial Council posits that a physician "...should not intentionally cause death."\(^{210}\) Arthur Caplan, Director of the Center for Biomedical Ethics at the University of Minnesota in

\(^{201}\) Id.

\(^{202}\) G. POZGAR, supra note 7, at 233.

\(^{203}\) Id. at 233-34.

\(^{204}\) P. RIGA, supra note 192, at 91.

\(^{205}\) Id.

\(^{206}\) Id.

\(^{207}\) Id. at 96. See Glantz, Withholding and Withdrawing Treatment: The Role of the Criminal Law, 15 LAW, MED. & HEALTH CARE 231, 232-34 (1987/88); Molenda, Active Euthanasia: Can It Be Justified?, 24 U. TULSA L. REV. 165 (1988) (both citing to numerous instances of unpunished acts of euthanasia). See also Fadiman, The Liberation of Lolly & Gronky, LIFE, Dec., 1986, at 71 (a moving account of an elderly couple's choice to free themselves from the trap of incurable chronic illnesses that plagued them both. Sharing a single glass, they drank together the mixture of whiskey and crushed tranquilizer tablets that killed them. Id.)

\(^{208}\) But see Ubell, When a Life is in Your Hands, PARADE MAGAZINE, March 5, 1989, at 16 (noting that in the Florida case of Roswell Gilbert, who shot to death his incurably sick wife in 1985, a life sentence was imposed. Gilbert served several years of the sentence before being released from prison in 1990.)

\(^{209}\) But see Haney, Doctors Condone Helping the Dying Commit Suicide, Akron Beacon J., March 30, 1989, at A-1, col. 5 (citing a report of a twelve-member panel of physicians which concluded that it is ethical for physicians to assist terminally or hopelessly ill patients in ending their lives by prescribing lethal doses of certain drugs).

\(^{210}\) Devettere, Reconceptualizing the Euthanasia Debate, 17 LAW MED. & HEALTH CARE 145 (1989) (citing the Current Opinion of the Judicial Council of the American Medical Association (1984)).
Minneapolis, does not believe physicians should kill because "[a]ctive euthanasia is easy to abuse and misuse. It sows distrust between doctor and patient."\textsuperscript{211}

The recent case of Michigan physician Jack Kevorkian underscores the widespread disapproval of physician-assisted suicides or active euthanasia.\textsuperscript{212} Although murder charges against the doctor were dismissed,\textsuperscript{213} Kevorkian has been ordered never to use his "suicide machine" again.\textsuperscript{214} The outcome of Dr. Kevorkian's case is consistent with the view expressed by Rita Marker, Director of the International Anti-Euthanasia Task Force.\textsuperscript{215} She believes that if physicians are permitted to aid in causing the deaths of terminally ill or hopelessly ill patients, "the professional healer and care-giver will take on [the] role [of] hired killer."\textsuperscript{216}

**Autonomy by Proxy:**

**Who Decides for the Hopelessly Ill Incompetent Adult Patient and How**

**Options**

There are limited means by which a hopelessly ill incompetent adult patient's right to have medical treatment withdrawn or withheld can be exercised. Obviously, the patient can no longer exercise the right by himself. If the patient had the foresight to prepare some type of advance directive, his wishes regarding treatment are more easily honored. Even in that event, a surrogate decision-maker will need to effectuate the patient's choice(s).

\textsuperscript{211} Ubell, supra note 208, at 16-17. The author builds on Caplan's comments and cites the rampant practice of active euthanasia in Holland as evidence of the fostering of distrust in the physician-patient relationship. The author claims that in many of the 5000 annual cases of active euthanasia in Holland, the patients do not want to die but are killed by their physicians "for their own good". \textit{Id.} at 17.

\textsuperscript{212} Suicide Machine's Use Is Prohibited, Akron Beacon J., Feb. 6, 1991, at D-7, col. 1. Kevorkian helped a victim of Alzheimer's disease commit suicide by using a machine that he invented. \textit{Id.}

\textsuperscript{213} Levin, Doctor Who Aided in Suicide is Cleared, Akron Beacon J., Dec. 14, 1990, at A-10, col. 4. The charges were dismissed because Michigan has no specific law against assisting suicide. \textit{Id.}

\textsuperscript{214} Suicide Machine's Use Is Prohibited, supra note 212. The opinion rendered in the Circuit Court of Oakland County, Michigan scolded Dr. Kevorkian for his "bizarre behavior". \textit{Id.} The court stated, "As a physician, Dr. Kevorkian was morally, ethically, professionally, and legally obligated to adhere to the current standards of medical practice." \textit{Id.} The Court stated that assisting suicides is a clear violation of those obligations. \textit{Id.}

\textsuperscript{215} "Aid-In-Dying": The Right to Die or the Right to Kill?: A Public Forum, INT'L REV., Spring, 1988, at 54, 61.

\textsuperscript{216} \textit{Id.} For arguments for and against active euthanasia as an option for hopelessly ill patients, see Comment, The Right to Voluntary Euthanasia, 10 WHITTIER L. REV. 489 (1988); Gelfand, Euthanasia and the Terminally Ill Patient, 63 NEB. L. REV., 741 (1984); Kuhse, The Case for Active Voluntary Euthanasia, 14 LAW MED. & HEALTH CARE 143 (1986).
MEDICAL DECISION-MAKING

Where no advance directive exists, the patient’s family and physician may jointly determine the course of the patient’s treatment. In some cases, a guardian or conservator will decide for the patient. In all cases in which a surrogate makes a medical decision on behalf of an incompetent patient, the decision must rest upon well-established rules of law that are designed to protect the patient’s interests.

1. Advance Directives

Various forms of advance directives are recognized in this country. Generally, they include the living will, the durable power of attorney, and the health care agent or proxy. The durable power of attorney and health care agent or proxy work to ensure reliance by third parties upon a surrogate decision-maker’s authority, so as to protect the patient’s interests. Through such a directive, a competent individual may delegate to a surrogate the authority to make medical decisions on his behalf should he become incompetent.

The most common statutorily authorized form of advance directive is the living will. Through this document, a legally competent adult writes an affirmative directive to medical personnel to withhold or withdraw certain medical treatment in certain circumstances. Individuals creating a living will are

218 Id. See also Moore, The Durable Power of Attorney as an Alternative to the Improper Use of Conservatorship for Health Care Decisionmaking, 60 St. John’s L. Rev. 631 (1986). Currently, nine states have adopted durable power of attorney statutes that make no mention of medical decisions, while nine others have adopted statutes that do not mention medical decisions but have been either judicially or legislatively interpreted to cover such decisions. Society for the Right to Die, State Law Governing Durable Power of Attorney, Health Care Agents, Proxy Appointments (Oct. 29, 1990). Twenty states and the District of Columbia have adopted durable power of attorney statutes that specifically authorize surrogates to make medical decisions, including decisions to withhold or withdraw life support, while seven states allow all surrogate medical decision-making except that which would authorize withholding or withdrawal of life support. Id. Finally, twelve states have enacted statutes that permit individuals to appoint proxies to make decisions authorized under the particular statute when the patient is in a medical condition covered by the statute. Id.
219 Comment, supra note 217, at 660.
220 Id. at 655. The directive will generally resemble the following document, prepared by the Society for the Right to Die:

LIVING WILL DECLARATION
To my Family, Doctors, and All Those Concerned with My Care
I, __________, being of sound mind, make this statement as a directive to be followed if I become unable to participate in decisions regarding my medical care.
If I should be in an incurable or irreversible mental or physical condition with no reasonable expectation of recovery, I direct my attending physician to withhold or withdraw treatment that merely prolongs my dying. I further direct that treatment be limited to measures to keep me comfortable and to relieve pain.
These directions express my legal right to refuse treatment. Therefore I expect my family, doctors, and everyone concerned with my care to regard themselves as legally and morally bound to act in accordance with my wishes, and in so doing to be free of any legal lia-
advised to keep the signed original in a safe place at home, and to review, initial and date the document periodically to indicate continued intent. Copies of the document are to be provided to the individual’s family, doctors and proxy.

2. The Surrogate Decision-Maker

In most cases, treatment decisions for the incompetent patient are intensely private and made by the patient’s family and physicians. The family members normally considered close enough to make such a decision include the patient’s spouse, parents, adult children, or siblings. If another relative acts as a member of the patient’s nuclear family, he may also be a suitable surrogate decision-maker.

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Comment, supra note 217, at 455.

221 Id. At present, living will laws are in effect in all but eight of the states in the United States. Society for the Right to Die, Living Will Legislation in the United States (April 9, 1990). All but one of the states without living will legislation have living will bills pending in their state legislatures. Id. South Dakota is the only state which has shown no movement toward any type of living will law. Id. Although living wills have come to be recognized as important documents, they are not without shortcomings. Arthur Caplan notes that "they may not exactly fit the situation when the time comes, ... [the family and the doctor may not know about [a patient’s] will, ... [and in] many instances, family members may disregard [a patient’s] will and order the doctor to follow their wishes rather than [the patient’s]." Ubell, supra note 208, at 17. Dr. Robert White, Head of Neurosurgery at Cleveland’s Metro Health Medical Center, dislikes the finality and rigidity of the living will. Morning Exchange (ABC television broadcast, local affiliate WEWS, Cleveland, Jan. 2, 1991). He believes the documents are binding and leave little leeway for the changes of mind patients often experience. Id. For a discussion on how advance directives can be created to best reflect the wishes of the patient, see Gibson, Reflecting on Values, 50 OHIO ST. L. J. 451 (1990). For an argument that advance directives do not adequately preserve patients’ personal identity, see, Buchanan, Advance Directives and the Personal Identity Problem, 17 PHIL. & PUB. AFF. 277 (1988). See also UNIFORM RIGHTS OF THE TERMINALLY ILL ACT (Draft 1990), which, as amended, offers a new approach to advance directives by combining the concepts behind the living will and the appointment of a health care surrogate. However, the Act applies only to those patients who are terminally ill (facing imminent death). Id. at 1, 4.


decision-maker for the incompetent patient. However, absent such a close degree of kinship, a guardian must usually be appointed.\textsuperscript{225}

Unless a patient has executed an advance directive while competent, or there is irrefutable evidence of the patient’s beliefs and wishes, the surrogate must act upon his own intuition. Essentially, this destroys, rather than protects, the patient’s fundamental rights of self-determination and privacy.\textsuperscript{226} Judicial standards that have sought to protect the rights and interests of hopelessly ill incompetent adult patients include the substituted judgment (subjective) standard, and the best interests (objective) standard.\textsuperscript{227}

\textbf{a. The Substituted Judgment Standard}

Most courts that have addressed the issue of medical decision-making for hopelessly ill incompetent patients have adopted the substituted judgment standard.\textsuperscript{228} This standard treats the incompetent patient as if he were competent and requires an inquiry into what the patient would choose for himself.\textsuperscript{229} The standard considers the patient’s incompetence, as well as a variety of proof, including advance directives and oral testimony about the patient’s beliefs and wishes.\textsuperscript{230} Clearly, this standard is most useful when the patient has manifested his intent while competent.\textsuperscript{231}

\begin{itemize}
  \item \textsuperscript{225} \textit{Id.} See also Hamlin, 102 Wash. 2d 810, 689 P.2d 1372 (patient had no family, relatives, or close friends to speak on his behalf, and a guardian was thus appointed to make his medical decisions); Drabick v. Drabick, 200 Cal. App. 3d 185, 245 Cal. Rptr. 840 (1988) (conservator sought court approval to remove patient’s nasogastric feeding tube). For more on conservatorship as an alternative to guardianship, see Federman, \textit{Conservatorship: A Viable Alternative to Incompetency}, 14 FORDHAM L. REV. 815 (1986). A guardian may be either someone who knows the patient, or a stranger, depending upon the situation. Veatch, \textit{Limits of Guardian Treatment Refusal: A Reasonableness Standard}, 9 AM. J. L. & MED. 427, 428 (1984). This commentator takes a very common-sense approach to the issue of guardianship. He categorizes guardians as either "bonded" or "non-bonded", depending upon whether they have a bond or a tie with the patient prior to the guardianship. \textit{Id.} He prefers bonded guardians over non-bonded guardians because they are better able to stand in the stead of the patient when representing him/her. \textit{Id.}
  \item \textsuperscript{227} For an exhaustive debate on these standards, see Rhoden, \textit{Litigating Life and Death}, 102 HARV. L. REV. 375 (1988); Dresser, \textit{Relitigating Life and Death}, 51 OHIO ST. L. J. 425 (1990).
  \item \textsuperscript{228} \textit{Id.;} Schultz, \textit{Procedures and Limitations for Removal of Life-Sustaining Treatment from Incompetent Patients}, 34 ST. T. LOUIS U.L.J. 277, 289 (1990).
  \item \textsuperscript{230} Comment, \textit{Termination of Life-Sustaining Treatment: Who and How to Decide}, 33 N.Y.L. SCH. L. REV. 469, 486 (1988).
  \item \textsuperscript{231} \textit{Rasmussen, 154 Ariz. 207, 741 P.2d 674.} The standard was first applied in \textit{Quinlan, supra note 38, although the patient had not clearly expressed her intent while competent. It was more properly applied in Brophy, 398 Mass. 417, 497 N.E.2d 365, 529 A.2d 419.}
\end{itemize}
b. The Best Interests Standard

Where the substituted judgment standard is inapplicable or inappropriate, courts will apply the best interests standard. This standard does not consider the patient’s presumed wishes, but rather, the patient’s best interests in his current state. The question becomes whether the treatment, in light of the extended life and the burden of that extended life, serves the patient’s best interests.

LEGAL LIABILITY OF THE MEDICAL PROFESSION IN CARING FOR HOPELESSLY ILL INCOMPETENT ADULT PATIENTS: IS THE BARK WORSE THAN THE BITE?

Despite the fact that courts have consistently ruled against liability for medical professionals who honor a patient’s treatment refusal, looming ominously over this country’s hospitals is the somewhat contrived specter of incarceration or civil damages. However, in the only reported case in which physicians were charged with homicide for withdrawing life-sustaining treatment from a hopelessly ill incompetent adult patient at his family’s request, the charges were ultimately dismissed on the ground that the patient’s family could legally exercise the patient’s right to refuse treatment. Ironically, while fears of civil or criminal liability for withholding or withdrawing treatment are largely unfounded, failing to withhold or withdraw treatment on the request of a hopelessly ill incompetent adult patient’s surrogate decision-maker may result in the very legal entanglement which is sought to be avoided.


233 Id.; Saikewicz, 373 Mass. at 790, 370 N.E.2d 417.

234 Comment, supra note 228, at 379.

235 Note, supra note 228, at 379. In reaching a determination under the best interests standard, several factors are considered. These include the extent of bodily invasion caused by the life-sustaining treatment, the dignity of the patient, the amount of suffering, the quality and duration of life sustained with or without treatment, expressions of the patient, and the amount of emotional and financial suffering of those closest to the patient. Schultz, supra note 229, at 290. Most closely aligned with the best interests standard are Saikewicz, 373 Mass. 728, 370 N.E.2d 417 and Conroy, 98 N.J. 321, 486 A.2d 1209.


Comment, supra note 235.
While a number of plaintiffs have sought to recover in actions for wrongfully instituting and maintaining life-sustaining treatment, only one reported case exists in which the plaintiff was successful.

In *Leach v. Shapiro*, the Court conceded that "doctors must be free to exercise their best medical judgment in treating a life threatening emergency." However, the Court also warned that, "[c]arried to its extreme, . . . the doctrine of implied consent could effectively nullify . . . privacy rights . . ." On that basis, the Court held the defendant physician and other medical professionals involved liable for instituting mechanical ventilation in the hopelessly ill incompetent patient, over the express prior refusal of the patient herself and without the consent of the patient’s family.

In a case in which the plaintiff is successful, the treating facility itself may be held liable under the theory of corporate liability. Corporate liability differs from vicarious liability in that the lack of an employment relationship will not necessarily protect a facility from liability for the negligent acts of its medical staff. Accordingly, where a treating facility negligently violates its duty of reasonable care to the patient and thereby contributes to the patient’s injury, the facility will be liable. However, courts are split on whether the hospital’s duty extends broadly to supervising the quality of the ongoing treatment rendered by independent staff physicians, or only to the exercise of reasonable care in screening the competency of independent staff members prior to granting them medical privileges at the facility.

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240 Id.

241 Id. at 396, 469 N.E.2d at 1053.

242 Id.

243 Id.

244 See Darling v. Charleston Community Memorial Hosp., 33 Ill. 2d 326, 211 N.E.2d 253 (1965).


246 Id.

247 Id. at 160-161.
HEALING AND HOLINESS: MEDICAL AND RELIGIOUS VIEWPOINTS ON MEDICAL DECISION-MAKING FOR HOPELESSLY ILL INCOMPETENT ADULT PATIENTS

Medical Viewpoints

"I do not favor besetting the last few minutes of a person's life with pumping on the chest, intubation, and all that sort of useless drama," says one oncologist. He urges physicians to remember that they ultimately owe their allegiance to their patients, and whatever the patient's decision is, it ought to be followed. A nurse agrees, saying that the patient should be allowed to choose his/her own medical course of treatment if possible, but where the patient is incompetent, those closest to the patient should decide whether measures will be employed to prolong a hopeless life.

Codes governing both nursing in particular and medicine in general address the issue as well. The American Nurses' Association Code of Ethics for Nurses (Code for Professional Nurses) states that a nurse is responsible for affirming and maintaining a patient's right to privacy and self-determination. Addressing the issue more broadly, the American Medical Association's Council on Ethical and Judicial Affairs adopted the following statement on March 15, 1986:

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.

For humane reasons, with informed consent, a physician may do what is medically necessary to alleviate severe pain, or cease or omit treatment to permit a terminally ill patient whose death is imminent to die. However, he should not intentionally cause death. In deciding whether


249 Id. at 17. Physicians appear to have mixed feelings on the use of advance directives. See Zinberg, Decisions for the Dying: An Empirical Study of Physicians' Responses to Advance Directives, 13 VT. L. REV. 445, 468-484 (1989); but see Van Scoy-Mosher, supra note 248, at 17, stating that an incompetent patient's prior expression of wishes is merely a legal convenience for the courts but is not really valid. Id. He believes people make statements that purport to express their desires upon reaching a certain point in life, but that when they actually reach that point, they feel differently. Id.

the administration of potentially life-prolonging medical treatment is in
the best interest of the patient who is incompetent to act in his own
behalf, the physician should determine what the possibility is for
extending life under humane and comfortable conditions and what are the
prior expressed wishes of the patient and attitudes of the family or those
who have responsibility for custody of the patient.

Even if death is not imminent but a patient’s coma is beyond doubt
irreversible and there are adequate safeguards to confirm the accuracy of
the diagnosis and with the concurrence of those who have responsibility
for the care of the patient it is not unethical to discontinue all means of

Life-prolonging medical treatment includes medication and artificially or
technologically supplied respiration, nutrition or hydration. In treating a
terminally ill or irreversibly comatose patient, the physician should deter-
mine whether the benefits of treatment outweigh its burdens. At all
times, the dignity of the patient should be maintained.252

"We must give those patients a way out. There comes a time that the
physician must step back and, at the patient’s or the family’s request, allow the
patient to die with dignity."253

Religious Viewpoints

The consensus among religions which have spoken on the issue is much the
same as that of the medical profession. The fundamental principle of doing unto
others as we would want done to ourselves is common to the major religions of
the world.254 Applying that principle to the issue of medical decision-making
for hopelessly ill incompetent adult patients, a Methodist minister stated that "the
medical and moral duty of all of us is to keep the patient comfortable until
death."255 Agreeing is a professor of theology at the University of Notre Dame,
who believes that, "[g]iven a reasonably certain diagnosis that the person won’t

252 American Medical Association Council on Ethical and Judicial Affairs, Withholding or Withdrawing
Life-Prolonging Medical Treatment (March 15, 1986).
253 Ubell, supra note 208, at 16 (quoting Dr. James H. Sammons, then-executive vice president of the
American Medical Association). See also Koop, Decisions at the End of Life, 5 ISSUES IN L & MED.
225 (1989). Some physicians argue that this obligation to let patients die with dignity encompasses the
act of euthanasia, as well. See Caplan, It’s Time We Helped Patients Die, MED. ECON., June 8, 1987, at
214.
254 M. Heifetz, THE RIGHT TO DIE ix-x (1975) (citing to the existence of the principle in Judaism, Hindu-
ism, Buddhism, Confucianism, Zoroastrianism, Christianity, and Islam).
255 Ubell, supra note 208, at 17 (quoting Rev. J. Robert Nelson, Director of the Institute of Religion at
the Texas Medical Center in Houston).
return to a cognitive state, . . . [life-sustaining] treatment can be withheld, because the patient cannot get any benefit.\textsuperscript{256}

Well-known for its pro-life stance, the Catholic Church has spoken out most clearly on the issue of medical decision-making for hopelessly ill incompetent adult patients. The Catholic Church has long taught that life is a fundamental good for which we are obliged to care and show respect.\textsuperscript{257} However, life is not viewed as the ultimate or absolute good, and the limit to our duty to preserve life is reached when the effort to sustain it becomes an overwhelming burden for a patient whose prognosis is hopeless.\textsuperscript{258} Sometimes, it is more consistent with the concept of respect for life to let it go, than to cling to it.\textsuperscript{259}

In \textit{Delio v. Westchester Cty. Med. Center},\textsuperscript{260} a Jesuit priest was called to testify as an expert witness on the ethics of withdrawing life-sustaining treatment from hopelessly ill incompetent adult patients.\textsuperscript{261} He testified that

\begin{quote}
* * * a Vatican document published in 1980 rejected the distinction between ordinary and extraordinary means of life support as a measure of when it would be ethical to discontinue those means of support; rather, the Vatican adopted a test of proportionality under which the measure of whether to discontinue life-sustaining mechanisms was whether those mechanisms would provide benefits to the patient greater that the burdens imposed on the patient, the family and others as a result.\textsuperscript{262}
\end{quote}

It is clear, however, that the position of the Catholic Church stops short of sanctioning active euthanasia.\textsuperscript{263}

\begin{itemize}
\item \textsuperscript{258} Id. at 4-5.
\item \textsuperscript{259} Id. at 5.
\item \textsuperscript{260} 516 N.Y.S.2d 677, 129 A.D.2d 1 (1987).
\item \textsuperscript{261} Id. at 683, 129 A.D.2d at 9.
\item \textsuperscript{262} Id.
\item \textsuperscript{263} \textit{See, Molenda, supra} note 207, at 18-19; Pilla, \textit{All Human Life Deserves Respect, Justice and Love}, Catholic Universe Bull., Sept. 28, 1990, at 1C, col. 1.
\end{itemize}
MEDICAL DECISION-MAKING FOR HOPELESSLY ILL INCOMPETENT ADULT PATIENTS: RECENT DEVELOPMENTS IN THE LAW

Two unprecedented developments in the area of medical decision-making for hopelessly ill incompetent patients occurred in 1990: the United States Supreme Court decided *Cruzan v. Director, Mo. Dept. of Health*, and Congress enacted what has come to be called the "Patient Self-Determination Act". These developments symbolize the recent recognition, at the federal level, of the difficulty of medical decision-making for hopelessly ill incompetent adult patients. Both have already begun to leave their mark on the state of the law.

*Cruzan v. Director, Mo. Dept. of Health*

In *Cruzan*, the plaintiffs appealed from a decision of the Missouri Supreme Court denying them the authority to remove the feeding tube that sustained their daughter, who had been in a persistent vegetative state since a 1983 car accident. Nancy Cruzan suffered severe brain damage after she was thrown from her car and lay face-down in a ditch for about fifteen minutes before paramedics arrived. Detecting no cardiac or respiratory function, the paramedics resuscitated Nancy and took her to a hospital, where she remained unconscious. After three weeks in a coma, Nancy lapsed into a persistent vegetative state. She was able to breathe on her own; however, a gastrostomy tube was implanted in her abdomen to allow her to obtain nutrition and hydration.

Realizing that Nancy would never regain cognitive functioning, her parents requested the hospital medical staff to withdraw nutrition and hydration. The staff refused to do so without a court order; accordingly, the Cruzans obtained such an order from the state trial court. That decision was reversed by the

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266 110 S. Ct. 2841.
267 Id.
268 Cruzan v. Harmon, 760 S.W.2d 408 (Mo. 1988).
269 Cruzan, 110 S. Ct. at 2845.
270 Id.
271 Id.
272 Id.
273 Id. at 2846.
274 Id.
Supreme Court of Missouri,\textsuperscript{275} and Nancy continued to exist in a persistent vegetative state, sustained by artificial nutrition and hydration.\textsuperscript{276}

The United States Supreme Court engaged in a lengthy review of relevant judicial precedent before addressing the issue, as stated by the Court: "Whether the United States Constitution grants what is in common parlance referred to as a 'right to die'.\textsuperscript{277}" The Court found that a competent person does have a right to refuse any medical treatment, but grounded that right in the constitutional guarantee of liberty under the fourteenth amendment, rather than the right of privacy espoused by \textit{Quinlan}\textsuperscript{278} and its progeny.\textsuperscript{279}

The Court cautioned that while a \textit{competent} patient has a right to refuse medical treatment, to claim that an incompetent patient has the same right is to beg the question.\textsuperscript{280} The Court stated that "an incompetent person is not able to make an informed and voluntary choice to exercise a hypothetical right to refuse treatment or any other right. Such a 'right' must be exercised for her, if at all, by some sort of surrogate."\textsuperscript{281} Accordingly, the Court held, states' establishment of procedural safeguards to ensure that the surrogate effectuates the patient's wishes is wholly proper.\textsuperscript{282}

The Court commented that while a surrogate decision-maker may have the noblest of motives in attempting to assert a patient's right to refuse treatment, the surrogate's choice may not be the same choice that the patient would have

\begin{itemize}
\item \textsuperscript{275} \textit{Cruzan}, 760 S.W.2d 408 (Mo. 1988).
\item \textsuperscript{276} \textit{Cruzan}, 110 S. Ct. at 2846.
\item \textsuperscript{277} Id.
\item \textsuperscript{278} 70 N.J. 10, 355 A.2d 647.
\item \textsuperscript{279} \textit{Cruzan}, 110 S. Ct. at 2851, 2851 n.7. The Court affirmed the decision of the Supreme Court of Missouri in \textit{Cruzan} v. Harmon, 760 S.W.2d 408 (Mo. 1988), and agreed with that decision's conclusion that the Quinlan Court was presumptuous in its finding that the right to refuse medical treatment was encompassed by the right of privacy. \textit{Cruzan}, 760 S.W.2d at 418. The Supreme Court of Missouri stated that the Quinlan Court had cited to the United States Supreme Court decision in Griswold v. Conn., 381 U.S. 479 (1965), as authority for the proposition that the right of privacy exists, and "without further analysis" presumed that the right encompassed the right to refuse medical treatment. \textit{Cruzan}, 760 S.W.2d at 418. The Missouri Court had "grave doubts as to the applicability of privacy rights to decisions to terminate the provision of food and water to an incompetent patient," in light of the narrow construction of the right in Bowers v. Hardwick, 478 U.S. 186 (1986). The United States Supreme Court agreed, and stated that "[a]lthough many state courts have held that a right to refuse treatment is encompassed by a generalized right of privacy, we have never so held. We believe this issue is more properly analyzed in terms of a Fourteenth Amendment liberty interest." \textit{Cruzan}, 110 S. Ct. at 2851 n.7.
\item \textsuperscript{280} Id. at 2852.
\item \textsuperscript{281} Id.
\item \textsuperscript{282} Id. The Court endorsed the use of the clear and convincing evidence standard by which to judge the evidence of an incompetent's wishes expressed while competent. Id. The Court determined that such a standard properly advances both the state's legitimate interest in preserving life and the patient's interest in refusing life-sustaining treatment. \textit{Id.} at 2852-54.
\end{itemize}
The best way to guard against such situations and to truly protect the patient's right to self-determination is to require clear and convincing evidence of the patient's wishes. That standard was not met in *Cruzan*, and the judgment of the Missouri Supreme Court was affirmed.

The "Patient Self-Determination Act"

The essence of the Supreme Court's ruling in *Cruzan* is that while individuals have a constitutionally-protected right to refuse life-sustaining treatment, states may prevent family members from withdrawing the life-sustaining treatment of hopelessly ill incompetent adult patients about whose wishes there is no clear and convincing evidence. Obviously, the clearest and most convincing evidence is that which is memorialized in a writing, such as an advance directive.

Accordingly, in November, 1990, Congress passed what has become known as the "Patient Self-Determination Act," the intent of which is to enhance awareness of the availability of the option to create such documents. The Act requires that all Medicare and Medicaid participating health care institutions maintain written policies and procedures on advance directives "with respect to all adult individuals receiving medical care by or through the provider or organization." The law, effective December 1, 1991, defines "advance directive" as "... a written instruction, such as a living will or durable power of attorney for health care, recognized under State law (whether statutory or as recognized by the courts of the State) and relating to the provision of such care when the individual is incapacitated."

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283 *Id.* at 2855-56.
284 *Id.* at 2856.
286 § 4206(c)(1).
289 *Id.* at 2855-56. Specifically, the law requires Medicare and Medicaid participating health care facilities to do the following:

* * * [1] provide written information to each adult receiving care concerning
* * * [a] an individual's rights under State law (whether statutory or as recognized by the courts of the State) to make decisions concerning such medical care, including the right to
According to Fenella Rouse, executive director of the Society for the Right to Die, "[p]assage of this bill represents a real breakthrough and a significant step forward toward recognition of individuals’ rights at the end of life. [It is a signal] that this is serious and must be talked about. It’s going to change the whole world."\footnote{\textit{New Law}, supra note 288.}

A PROPOSAL FOR CHANGE

Not all state statutes governing advance directives are created equal. The effect of the Patient Self-Determination Act is partially lessened by lack of national uniformity as to the scope of citizens’ rights when creating advance directives.\footnote{Consider the quandary of a person who makes a legally valid and binding advance directive in one state and subsequently moves to another state where he becomes incompetent before creating an advance directive in conformity with the laws of that state. Worse yet, consider the possibility that the second state may have no workable laws governing advance directives. This point raises doubt as to whether these issues should be considered on the state level. \textit{McNeil/Lehrer News Hour: Focus on Cruzan Case} (PBS television broadcast, Dec. 31, 1990).} Moreover, in states with no living will laws, the clear and convincing evidence standard set forth in \textit{Cruzan} becomes an insurmountable obstacle.

Given the \textit{Cruzan} decision and the Patient Self-Determination Act, states should not be permitted to govern the legal aspects of medical decision-making for hopelessly ill incompetent adult patients in such a random manner. A more workable plan would either regulate medical decision-making for hopelessly ill incompetent adult patients on the federal level, or, more feasibly, set minimum standards at the federal level to which each state must adhere in promulgating its

\begin{itemize}
\item accept or refuse medical or surgical treatment and the right to formulate advance directives
\item \[\textit{[2]}\] document in the individual’s medical record whether or not the individual has
declared an advance directive;
\item \[\textit{[3]}\] not \[\textit{[4]}\] condition the provision of care or otherwise discriminate against an
individual based on whether or not the individual has declared an advance directive \[\textit{[4]}\] to be
construed as requiring the provision of care which conflicts with an advance directive;
\item \[\textit{[5]}\] provide (individually or with others) for education for staff and the community on
issues concerning advance directives. \textit{Id.}
\end{itemize}
own laws on the issue. Such minimum standards might include the following:

1. A provision in every state allowing a competent adult individual to name a durable power of attorney for health care, or other health care proxy, to make medical decisions for the principal if he becomes incompetent, to the same extent that the principal could if he were competent, and with no expiration date. The attorney in fact or health care proxy would be authorized to refuse all life-sustaining treatment, including nutrition and hydration, provided the patient is either terminally ill (facing imminent death) or hopelessly ill (having a total loss of cerebral cortical functioning with no expectation of recovery, and is permanently, irreversibly unconscious).

2. A provision in every state that, in order for a surrogate decision-maker to exercise the right of an incompetent patient to refuse medical treatment, there must be conclusive evidence of the patient’s wishes and beliefs as expressed while he was competent. Such evidence may be measured by a standard which requires the evidence to be clear and convincing, but in no event may such evidence be measured by a standard which requires the evidence to be probative beyond a reasonable doubt.

3. A provision in every state allowing a competent adult individual to execute a living will for the purpose of establishing conclusive evidence of his intent where a surrogate decision-maker may be acting on behalf of the one executing the living will if he becomes incompetent. The executor of a living will may specify refusals of any treatment, including life-sustaining treatment, to be withheld or withdrawn in the event he becomes incompetent.

4. A provision in every state making advance directives legally valid, binding, and of full force and effect. Advance directives are to be complied with to the fullest possible extent in making medical decisions for incompetent patients who executed them prior to becoming incompetent.

5. A provision in every state absolving from all civil and criminal liability any health care professional who takes part in complying with the advance directive of a patient or the decision of an incompetent patient’s surrogate decision-maker to have treatment withheld or withdrawn. This provision will apply only to the extent that the action taken strictly complies with the advance directive or authorization of the surrogate. This provision will not supersede the laws of a particular state pertaining to assisting suicide.
6. A provision in every state that no judicial intervention is required, unless no advance directive exists, no surrogate decision-maker exists, or suspicious motives exist on the part of a surrogate decision-maker.

States would be free to add to these minimums, so long as such additions further, rather than encroach upon, the scope of patients' rights. Such a framework would truly allow maximal preservation and recognition of hopelessly ill incompetent adult patients' rights and dignity, with minimal interference in, and prolongation of, the dying process. In addition to this framework, it may be wise to implement expanded public education about medical decision-making for hopelessly ill incompetent patients. Provisions for advance directives in the law will do little good if people are unaware of or unfamiliar with them.

CONCLUSION

Medical decision-making for hopelessly ill incompetent adult patients is an area in which the disciplines of medicine, law, ethics, and religion intersect on a daily basis. Advances in technology, growth of the elderly population, and incurability of many diseases promise to continue that area of intersect well into the future. To deal effectively with the issues raised, there is a need for greater public awareness about options for what are essentially end-of-life decisions, as well as uniformity in the laws that govern those decisions. Moreover, medical professionals who comply with the advance directives of incompetent patients or the decisions made by their surrogates must not be held liable for such compliance.

Most importantly, the need for judicial involvement in the area of medical decision-making for hopelessly ill incompetent adult patients must be minimized. Incompetent patients at or near the end of life and those close to them endure a living hell unimaginable to those who haven't experienced it personally. To prolong the dying process of such patients is to prolong an existence that should be allowed to come to a natural end in the irreversible, incurable disease process, as well as to prolong the grief of loved ones who perpetually mourn the simultaneous loss and horrific existence of one suspended in the "twilight zone" between life and death.

As the shadows of evening fall eerily across my father's bed, I ponder upon that "twilight zone" in which he is now suspended. I wonder what it is like to be in such a state, and silently reaffirm my desire never to be subjected to such an
existence. My heart is torn between happiness that he is still with us, and an aching mournfulness that the best parts of him are forever lost. He is with us all the time; yet, I miss him so much. Ironically, I sometimes think his very presence makes me miss him all the more.

I have tried for years to find some good in his illness, if only to help me justify it in my own mind. Perhaps the good borne of it has been that my family has been strengthened both as a unit and as individuals. Each of us has been inspired by his courage and determination, and made more acutely aware of the beauty of life's smallest blessings. We have each become more patient and understanding of the special needs of others. And we have all been given an opportunity to evaluate for ourselves what our own wishes will be if, someday, we should be in a condition like that of my father.

As I step away from his bedside, my father's eyes gaze in a wide, child-like stare, almost as if they are looking through me. I am troubled by thoughts I want so much for us to be able to share. But for now, I know that all my questions will have to wait. I am somehow comforted by the knowledge that he cannot remain in this "twilight zone" forever, and I suspect that someday we will meet again under better circumstances. Until then, his spirit will live with me always.

As I turn out the light beside his bed, I gently kiss his cheek. Good night, Dad. I love you.

**POSTSCRIPT**

On November 7, 1991, the fragile threads which had suspended my father in the "twilight zone" snapped, and he crossed the line that separates life from death. My mother had sensed his impending passage, and had gathered all of us at his bedside. Although his last thirty-six hours with us were turbulent ones -- his body wracked with unrelenting, violent seizures -- his death came so quickly that it was several moments before we knew he was truly gone.

As the color drained from his face, the ventilator at his bedside continued momentarily to infuse him with its now-empty breaths of artificial life. The faint "whoosh-whoosh" to which we had all grown so accustomed suddenly seemed almost deafening in contrast to the stillness which had befallen the room. The moment I had feared most in life was at once here and gone, and a peaceful tranquility slowly enveloped the house.

My father's death has caused me to reflect on everything I've written on the preceding pages. In my father's case, incompetence was a sudden and unexpected development, and the onset of PVS was even more sudden. However, it is the case with many patients that their loved ones, who see them change gradually on
a daily basis, do not recognize the encroaching walls of incompetence until those walls have become firmly entrenched. Thus, whether the onset of incompetence is sudden or gradual, it is often not recognized until it has come to pass.

Accordingly, I cannot stress enough the importance of anticipating a situation in which one may become hopelessly ill and incompetent, and of discussing one’s wishes in that event with those who will ultimately be left to carry them out. I remain firmly committed to the position that each of us, while competent, has the right to pre-arrange our release from the earthly prison of hopeless illness.

Several years ago, before his mind fell prey to disease, my father wrote poetry which spoke of the pain he felt in being trapped within that prison. The following words, excerpted from one of his poems, are perhaps the most poignant:

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It is light now,
and at last
I am free
From my
Dark and cramped
Confinement.
  * * *
I can feel it now -
The happiness of
Unfettered freedom
At last, at last
I can fly.
  * * *
Forever
I yearned to
Shed the bond
And the weight
Of Earth,
  * * *
I am free,
Watch me now . . .
I am free.
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DEBRA L. DIPPEL