In July 2007, Dr Martinez was asked to evaluate a young man with high tetraplegia and permanent dependence on ventilator support. The director of the psychiatric consult service explained that the case had caused significant conflict and disagreement in the surgical intensive care unit. Because of the ethical difficulties of the case, it was felt that it would be helpful to have additional consultation.

David was a 33-year-old athlete, who strongly identified with his body’s strength and agility. Two months after his injury, David expressed the desire to be free from unwanted medical interventions, including interventions that sustained his life, and he asked to have his ventilator removed. Did David possess the “rational” capacities to make this decision? Did he understand the consequences of his decision? Was he able to consider alternatives? Was he depressed and, therefore, his judgment and decision making clouded and compromised?

As he entered David’s hospital room in the summer of 2007, little did Dr Martinez anticipate that what he believed would be a one-time competency assessment would evolve into an intimate and privileged relationship. Little did he know that he would spend the next 2 and a half months meeting with David and participating in the hospital’s decision-making process. The ventilator was finally removed and David died, but not before making a video in which he explained the reasons for his decision.

Nor did Dr Martinez anticipate that he would be tossed into the center of the significant conflict and disagreement that preceded the removal of the ventilator: disagreements about David’s decision, disagreements about the role of individual health care professionals who took care of David, and disagreements about the responsibilities and obligations of the hospital in responding to David’s request. While Dr Martinez was familiar with the legal and ethical traditions that clearly supported David’s decision, he did not anticipate the powerful emotions that required processing and discussion, both for David and the hospital staff, before David’s request could be granted.

A psychiatrist’s being asked to provide a second opinion about David’s competency became minor in retrospect. But the role of the psychiatrist in end-of-life decisions was profoundly shaped and stimulated by the relationship between David and Dr Martinez.

**Legal Precedent:** Right to Refuse Treatment

The right to refuse medical treatment and procedures is well established through case law, statutory law, and the evolution of the informed consent doctrine. Justice Benjamin N. Cardozo, while on New York State’s highest court, in a 1914 case wrote the opinion that most consider the birth of the informed consent doctrine. “Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without the patient’s consent commits an assault for which he is liable in damages.” In the 1960s, with the development of technologies that allowed for extending life, the courts were confronted with situations in which participants grappled with decisions that shaped the dying process.

In the 1970s, Karen Ann Quinlan, at age 21, after drug- and alcohol-induced brain damage, entered a persistent vegetative state in which her life was continued through mechanical ventilation and artificial nutrition and hydration. Her father petitioned the New Jersey courts to have his daughter’s ventilator removed. After a lower court denied his request, the New Jersey Supreme Court agreed with Mr Quinlan’s request. The court reasoned that since a competent patient has a constitutional entitlement to reject life-sustaining medical intervention, then an incompetent
person also is protected. The court selected a protect-
ed privacy right, citing the prior rulings by the US Su-
preme Court in Griswold v Connecticut, 381 US 479
(1965) and Roe v Wade, 410 US 113 (1973).

In Quinlan, the New Jersey court stated: “We think
that the State’s interest contra [sic] weakens and the
individual’s right to privacy grows as the degree of
bodily invasion increases and the prognosis dims. Ul-
timately there comes a point at which the individual’s
droutines overcome the State interest.” Justice Hughes
reasoned that since Ms Quinlan was not competent
and could not speak for herself, her father could be
her representative and speak on her behalf. Other-
wise, her constitutional interests would be unprotect-
ed.

The court established several principles that would
become standards of practice and understanding in
the end-of-life debates. Justice Hughes indemnified
health professionals and institutions against criminal
prosecution when withdrawing mechanical ventilation.
According to Judge Hughes, “... if there is no rea-
sonable possibility of Karen’s ever emerging from her
comatose condition ... the present life-
support system may be withdrawn and said action
shall be without any civil or criminal liability on the
part of any participant.”

The 1983 President’s Commission provided addi-
tional support for the proposition that an unconscious
patient has the same rights as a conscious patient in
the refusal of unwanted medical technologies. While
recognizing the state’s interest in preserving life, up-
holding the integrity of the medical profession, pro-
tecting vulnerable individuals, and preventing suicide,
the Commission made clear in its publication Decid-
ing to Forego Life-Sustaining Treatment that a mix-
ture of Constitutional and case law firmly established
a right of refusal for the incapacitated patient through
identified surrogates.

The American Medical Association (AMA) Council
on Ethical and Judicial Affairs updated their statement
“Withholding or Withdrawing Life-Prolonging Med-
cal Treatment” in 1994:

The social commitment of the physician is to sus-
tain life and relieve suffering. Where the perfor-
mance of one duty conflicts with the other, the
preferences of the patient should prevail. The
principle of patient autonomy requires that physi-
cians respect the decision to forego life-sustaining
treatment of a patient who possesses decision-
making capacity. Life-sustaining treatment is any

treatment that serves to prolong life without revers-
ing the underlying medical condition. Life-
sustaining treatment may include, but is not limited
to, mechanical ventilation, renal dialysis, chemother-
apy, antibiotics, and artificial nutrition and hy-
dration. ... Physicians have an obligation to relieve
pain and suffering and to promote the dignity and
autonomy of dying patients in their care. This in-
cludes providing effective palliative treatment even
though it may foreseeably hasten death.

In the case of Elizabeth Bouvia, the California Court
of Appeals overruled a lower court that had denied
Ms Bouvia’s request to have a nasogastric tube re-
moved. Ms Bouvia was born with cerebral palsy, and
she was quadriplegic and bedridden. At the time of
the California appellate decision, Ms Bouvia was 28
years old. She was in a county hospital in Los Ange-
esthe time of her petition, and all parties agreed that
she was competent to make medical decisions and did
not suffer a terminal illness.

In the lower court decision, the trial judge ruled
against Ms Bouvia’s request, reasoning that her re-
quest for the removal of the nasogastric tube involved
suicidal intent. At the trial court hearing, the hospital
argued that while it recognized a basic right to refuse
medical treatment for competent patients, Ms Bou-
via’s situation was different. The county hospital
argued that the state had an interest in preserving life,
preventing suicide, protecting third parties, and main-
taining the ethical standards of the medical profession.
The hospital argued that she was not comatose, ter-
minally ill, or in a persistent vegetative state; that she
had asked for medical treatment and could not accept
part of the treatment and refuse the rest; that she was
trying to commit suicide by starving herself to death;
and that the state could not assist in this activity.

The appellate court disagreed with all the arguments
and stated these arguments were insufficient to deny
Ms Bouvia her fundamental right to refuse treatment.
According to the court, “... the trial court mistakenly
attached undue importance to the amount of time
possibly available to petitioner, and failed to give equal
weight and consideration for the quality of that life.”
Associate Justice Beach wrote:

Here Elizabeth Bouvia’s decision to forego med-
cal treatment or life-support through a mecha-
nical means belongs to her. It is not a medical
decision for her physicians to make. Neither is it
a legal question whose soundness is to be re-
solved by lawyers and judges. It is not a conditional right subject to approval by ethics committees or courts of law. It is a moral and philosophical decision that, being a competent adult, is hers alone.7

In the case of In re Conroy, the court allowed removal of a nasogastric tube from 84-year-old Claire Conroy, who had irreversible mental and physical problems, based on her right to self-determination, and informed consent as provided by her surrogate.8 First, the court concluded that the right to self-determination of an incompetent patient survives his or her incompetence, and that a surrogate should make “the decision that the patient would have made if competent” (known as substituted judgment). However, the court qualified the use of evidence of the patient’s wishes based on the “remoteness, consistency, and thoughtfulness of the prior statements or actions and the maturity of the person at the time.”

The court also recognized that it is often not possible to know the wishes of a patient. In that case, the court allowed that acting humanely, in the best interests of a suffering patient, a surrogate could make a decision to remove life-sustaining medical treatment. The court set 2 standards for that process. The first is called a “limited-objective test,” where there is some trustworthy evidence of what the patient would want, and the burdens of continued treatment markedly outweigh the value to the patient. The second, called the “pure-objective test,” would apply if there was no trustworthy evidence of what the patient would want, and the burdens of continued treatment markedly outweigh the value to the patient. Several subsequent decisions in New Jersey upheld this reasoning and supported deference to family members as acceptable.

Contrast the Conroy ruling with that in Matter of Westchester County Medical Center on Behalf of O’Connor. In 1988 New York’s highest court refused to accept anything less than the difficult-to-meet clear and convincing evidence standard to prevent the insertion of a feeding tube in an elderly incompetent woman who had suffered several strokes. While acknowledging a common-law right to refuse treatment, the court rejected the surrogate decision to stop the insertion without explicit evidence that the family was accurately representing the intent of the incompetent patient.

The court argued: “. . . no person or court should substitute its judgment as to what would be an acceptable quality of life for another. Consequently, we adhere to the view that, despite its pitfalls and inevitable uncertainties, the inquiry must always be narrowed to the patient’s expressed intent, with every effort made to minimize the opportunity for error.”9 (Although the court used the phrase “substitute its judgment,” this is not an example of the “substituted judgment” standard where the surrogate substitutes the patient’s judgment for his own.)

Only after the passage of the Family Health Care Decisions Act, A.7729-D; S.3164-B in 2010 were surrogate decision makers able to freely make end-of-life decisions even if patients had not expressed explicit instructions. As noted by commentators afterward: “Previously, those close to the patient and health care providers faced insurmountable legal hurdles in making decisions to forgo life-sustaining treatment for patients who lacked decision-making capacity.”10

The Cases of Nancy Cruzan and Terri Schiavo

In the Cruzan decision in 1990, the US Supreme Court entered the “right to die” debate for the first time.11 Nancy Cruzan was 25 years old when on January 11, 1983, she crashed her 1962 two-toned Rambler on a narrow 2-lane blacktop road south of Carthage, Missouri.12 After the accident, she was in a persistent vegetative state and required artificial nutrition and hydration to sustain life. Her family entered into a 7-year ordeal, battling in the courts for what they believed represented the wishes of their daughter and sister.

Housed in a state facility for 7 years, Nancy Cruzan received daily liquid feedings. She became a flash point for the controversy involving the right to choose, the role of the family in deciding for incapacitated loved ones, and obligations of the state in “protecting” vulnerable persons.

Ultimately, the US Supreme Court supported the state of Missouri’s requirement that family members who are deciding for an incapacitated loved one must demonstrate that they are reflecting the wishes of the loved one by a high legal standard of proof, a clear and convincing evidence standard. This is the same standard of the law required for the termination of parental rights and the civil commitment of the mentally ill. The judges, in a split vote, ruled that the state’s interest in preserving life and protecting the
vulnerable requires such a standard of proof. This, of course, launched and stimulated the practice of advance directives and stimulated conversations about values pertaining to the balance between longevity and quality of life. This precedent would help guide the case of Terri Schiavo.

The circumstances of Ms. Schiavo and her family in Florida are legally and morally tied to the Cruzan decision. In 1990, at age 26, she had a cardiopulmonary arrest that resulted in an anoxic brain injury. She was in a coma for 2.5 months, after which she received a diagnosis of persistent vegetative state. Initially, her husband and her parents collaborated closely to arrange care. After being told that there was no possibility of recovery, her husband petitioned to have Ms. Schiavo’s feeding tube removed in 1998, a decision her parents opposed. Ms. Schiavo’s prolonged 15-year ordeal resolved with the final withdrawal of her feeding tube and death in 2005.

The reasons for such a protracted ordeal are complex. Contentious political dynamics and unprecedented media attention fueled the legal drama in Florida courts, the US Congress, and the White House. But the story ended as it did because of Ms. Schiavo’s husband’s determination to honor her wishes that she not be maintained with a feeding tube in such a state. While Ms. Cruzan’s family was united in opposition to the state of Missouri’s decision to maintain her on a feeding tube, in Ms. Schiavo’s case, there was the complicating dynamic of a family in disagreement about her condition and about what her desires might be if she were conscious and could speak for herself.

Although the case took 15 years to resolve, the legal recognition that the proper person to speak for Ms. Schiavo was her husband and that it was her right to be free from unwanted medical treatment was further established through the action (and inaction) of the courts. Ultimately, in spite of the family disagreement and the political dynamics, the legal process came to an end because the legal questions revisited in the Schiavo case had been resolved in the Cruzan decision.

### Issues at the Periphery of Withholding / Withdrawing Life-Sustaining Treatment

Those involved with the ethical dilemmas of end-of-life care know that many of these dilemmas involve the withdrawal of life-sustaining medical treatment. Although some argue that withholding treatment and withdrawing treatment are morally equal, at a social and emotional level many health care professionals involved in withdrawing life-sustaining technology report that withdrawing treatment feels different than withholding treatment. If one starts down a course of treatment, it is necessarily because of the raised hopes it entails. One does it only because it might help. Later withdrawal of treatment generates an additional level of dashed hopes. It is thus little comfort that ethically there is no difference between withdrawing and withholding life-sustaining medical treatment. The AMA’s formal position is simply this: “There is no ethical distinction between withdrawing and withholding life-sustaining treatment.” Furthermore, one can safely infer that the AMA also considers them legally equal, based on patient autonomy and informed consent.

This distinction between the ethical and the humane sometimes comes into sharp relief with brain-dead patients. If a person is brain dead, he or she is permanently unconscious, defined as dead clinically and legally. Yet patients who are brain dead may look like they are sleeping, at least at first; they are warm to the touch; and because they are completely nonresponsive to external stimuli, they do not express discomfort. They can be maintained on a ventilator for an indeterminate time. To those that love them, it is hard to believe they are not there. They do not look dead. A tragic recent example occurred in California when 13-year-old Jahi McMath died after surgery. Her family could not accept the clinical reality, obtained a court order to maintain Jahi on a ventilator, and took her from the coroner to an undisclosed location.

Patients who are in a persistent vegetative state are often even more vexing to families and caregivers. These patients are not brain dead, they may breathe on their own, their eyes may open, and they have sleep and wake cycles. The auditory region of their brains may respond to questions, and the visual cortex may respond to descriptions of places. Behaviorally, those in a vegetative state exhibit no evidence of consciousness, no interaction with their environment, and no sense of self. Both the case of Terri Schiavo and the case of Nancy Cruzan involved these behaviors, which contributed to the psychological and emotional responses of loved ones faced with these observations.

Another dramatic example of how a patient’s loved ones experience a patient in a persistent vegetative...
state is seen in the life and recent death of former Israeli Prime Minister Ariel Sharon. After a stroke, he never spoke again but lay in bed for 8 years in a persistent vegetative state. Yet to his son, Gilad Sharon, he was still with the family: “He lies in bed, looking like the lord of the manor, sleeping tranquilly. Large, strong, self-assured. His cheeks are a healthy shade of red. When he’s awake, he looks out with a penetrating stare. He hasn’t lost a single pound; on the contrary, he’s gained some.” Of course, in Judaism, considerable variability exists in end-of-life decisions and, when Jewish patients and their families seek guidance, there is an important cultural and religious dynamic in working with such families.

While it is clear that physicians rightly allow their patients to withdraw life-sustaining medical treatment, there is a strong consensus—but not unanimity—that this does not extend to physicians directly performing a life-ending procedure at a patient’s behest. Two companion US Supreme Court cases addressed this issue based on 2 theories.

In *Washington v Glucksberg*, 117 SCt 2258 (1997), the issue was framed this way: Does the Washington State ban against physicians assisting competent, terminally ill patients to die violate the Due Process Provision of the 14th Amendment of the US Constitution? Was the prohibition thus a deprivation of a fundamental liberty interest of a patient’s wish to die?

The Court held that it was not because the ban was rationally related to a legitimate governmental interest. “Rationally related” is the lowest threshold test to uphold the constitutionality of a statute. The Court reasoned that Washington State has an “unqualified interest in the preservation of human life;” it has an interest in protecting “vulnerable groups” in end-of-life situations; and making a quintessential slippery slope argument, Washington has an interest in avoiding going “down the path to voluntary and perhaps even involuntary euthanasia.”

In *Vacco v Quill*, the issue was framed somewhat differently and drew on the Equal Protection Clause of the US Constitution. Does the New York State prohibition against physicians assisting competent, terminally ill patients to die violate the Equal Protection Clause, by treating terminally ill patients on respirators, who are allowed to stop artificial respiration and die, differently from those who need affirmative help to die?

Again, the Court held that the distinction was valid because the ban was “rationally related” to a legitimate governmental interest. The justifications they cited included “prohibiting intentional killing and preserving life; preventing suicide; maintaining physicians’ role as their patients’ healers; protecting vulnerable people from indifference, prejudice, and psychological and financial pressure to end their lives; and avoiding a possible slide towards euthanasia.”

Perhaps the most significant reactions to the barriers erected by *Glucksberg and Quill* are found in the Death with Dignity laws of Oregon and Washington State. Both states allow physicians to indirectly aid a terminally ill patient to die. In Oregon, a request for a lethal prescription by a terminally ill patient must be made twice, approved by 2 physicians, and witnessed by 2 independent persons. There also is a 17-day waiting period between the patient’s first request and receiving the prescription. The physicians must assure themselves that the patient is not impaired by depression or a mental disorder. If he or she is, the physician must refer the patient for counseling and cannot prescribe for the patient unless the impairment is successfully treated. The role of psychiatry in these situations is undefined, since the statutes refer only to attending and consulting physicians and do not define the status of the counselor.

**Role of Psychiatry in End-of-Life Decisions**

While the *Cruzan* decision and subsequent cases did not have a direct effect on the practice of psychiatry, these cases have dramatically shaped decision making in end-of-life care, helped in the development of palliative care medicine, and promoted the practice of advance care planning. Psychiatrists with expertise in hospital-based medical and surgical consultation, and psychiatrists who work with palliative care services, should be familiar with legal decisions and the developments in end-of-life decision making following these court cases.

Not only are psychiatrists considered medical experts in the determination of capacity or competency to make medical decisions, often they are asked to participate in family meetings involving such decisions; sometimes these meetings involve conflict and disagreement. On some occasions, psychiatrists may be asked to consult in complex cases in which questions of suicidal intent must be evaluated before decisions to withdraw life-sustaining technologies can be concluded.
With *Cruzan*, the doctrine of informed consent and informed refusal was extended to include a mechanism for the incompetent patient in a persistent vegetative state to exercise “choice.” While some were disappointed with the Court’s position in *Cruzan*, what was made clear is that incompetent persons retain their liberty interests in refusing life-sustaining treatments through their surrogates and loved ones. The informed consent and informed refusal doctrine further evolved and was strengthened by *Cruzan* and other end-of-life legal decisions. Advance directives and conversations about one’s values pertaining to the balance between longevity and quality of one’s life moved from the shadows and low lighting of the back-stage, to center stage.

The societal consensus as to what level of autonomy patients can exercise over their end-of-life decisions continues to evolve. As it does, the courts will reflect that new reality. As Louis Brandeis and Samuel Warren put it: “Political, social, and economic changes entail the recognition of new rights, and the common law, in its eternal youth, grows to meet the demands of society.”

Yet, overarching recognition and compassion for the suffering of patients and their families, and the way in which they experience the end of life—regardless of the clinical, ethical, and legal principles involved—must remain the moral imperative. Psychiatrists involved in these dramatic moments with families should be familiar with the clinical, legal, and ethical principles but can act as guides, maintaining an eye on the patient and family, and guiding the drama toward the proper end.

**David’s Lesson**

David asked to make a video recording of his decision-making process before his death and requested that the video be shared with health care professionals and the public (see the video). He wanted to teach and leave a lesson for those willing to learn. David’s care team took 2.5 months, continually joined in conversation with him, to achieve the correct and morally sound outcome. During these months, numerous meetings were required, involving members of the treatment team, the legal department, the ethics committee and, on one occasion, the executive committee of the hospital. Genuine disagreement was aired.

The leadership of the hospital cautiously considered the legal precedents and legal advice supportive of patient autonomy, while also taking into account the clinical and scientific evidence that David’s decision involving catastrophic injury and loss could not be simply reduced to a single ethical and legal principle. Since there was no recent institutional history of a request such as David’s, no delineated procedure was in place for processing his request.

As a major trauma center, the hospital frequently manages the withdrawal of treatment from irreversibly damaged and irretrievably sick patients, but in recent memory, no one in David’s situation of consciousness and capacity for communication had requested withdrawal of treatment. Most patients in his situation are transferred to rehabilitation services or a specialty hospital. So all involved who had an interest, a concern, had become engaged in David’s situation and participated in an extended conversation and process that required numerous ad hoc meetings and discussions.

This stands in contrast to the recent case of a man in Indiana with a severe spinal cord injury who was awakened in the immediate aftermath of his injury to decide his fate; he chose to die.

Many ethicists are concerned about this case: this man was awakened from his induced coma after his injury within the first 24 hours to confirm that he wanted to be withdrawn from life support. While morally defensible on the principle of respect for autonomy, it is an approach fraught with danger, given the decision is irreversible. Clinically, it ignores the question of the reliability of the decision given the catastrophic and sudden nature of the patient’s injury. Not only was this patient awakened and thus confronted with such a devastating injury, he was likely vulnerable and compromised in his capacity to rationally consider his circumstances, while under the effects of medications and other medical interventions. The wisdom of burdening this man with such a decision in the immediate aftermath of such an injury is questionable. This is the principle of autonomous choice taken to an extreme.

In David’s situation the process required time. Many factors contributed to the ultimate decision to withdraw the ventilator, including acknowledgment of the caution offered in the medical literature dedicated to rehabilitation of those with spinal cord injuries and disabilities; processing of disagreement and conflict within the health care team; ruling out depression and suicidal intent; determining consistency in David’s decision over time and understanding how his emotional state was affecting his decisions; con-
tinuously discussing David’s decision through conversation and dialogue; providing David with education about his prognosis including offering him exposure to others with similar injuries; and establishing total transparency of the process as David and the staff worked through his decision. After numerous discussions, members of the health care team, members of the ethics consultative service, the legal department, hospital administrators, and David and his family joined in making the decision.

The human drama and complexity of each case that involves end-of-life decisions must be respected. While legal and ethical precedent recognizes the importance of autonomous choice and decision making, health care professionals in such situations, including the psychiatrist who may be called to assist, must recognize that what is legal in a literal sense must be qualified, utilized as one of many guides to decisions, and at times even subordinated to what is ethical and wise.

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Endnotes:

1. Schloendorff v Society of New York Hospital, 211 NY 125, 129–130 (1914).


23. Oregon Revised Statutes 127.815; Washington Statute 70.245.060.


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