

Comas

Karen Quinlan, Nancy Cruzan, and Terri Schiavo

The famous case of Terri Schiavo exploded across the world in 2005, but it had a pedigree, building on the previous cases of Nancy Cruzan and Karen Quinlan. The Quinlan case started in 1975 in New Jersey courts. Fifteen years later in 1990, the U.S. Supreme Court finally defined basic rights of dying patients. Fifteen years after that, the Schiavo case showed that problems still remained about treatment of incompetent patients at the end of life.

The Quinlan case sparked the public's interest in medical ethics and its many questions: Does a person die when only machines keep her body alive? Can families alone decide when medicine ceases to be treatment and becomes torture? Can physicians? Does killing patients differ from intentionally letting them die? In making decisions, what role should courts take? What should be the standard of brain death? The definition of personhood? How should we safeguard incompetent patients from overzealous families? When, if ever, should we force families to accept medical realities?

THE QUINLAN CASE

In April 1975, after just turning 21, a perky, independent young woman named Karen Quinlan became comatose from drinking alcohol after taking either barbiturates or benzodiazepines, or both.¹ Karen had also been dieting, and at admission, weighed only 115 pounds.

Benzodiazepines, antianxiety drugs such as Valium, Librium, Ativan, and Xanax, act on specific nerve receptors in the brain and are considered safer than barbiturates. The latter have been around since 1912, when physicians first used phenobarbital.

Both benzodiazepines and barbiturates intensify with alcohol, an effect called *synergism*. Alcohol *potentiates* these drugs, and an empty stomach increases the effects. Actor River Phoenix unintentionally killed himself in 1993 by mixing barbiturates, alcohol, and benzodiazepines.

Karen lost her brain from a synergistic reaction of barbiturates, benzodiazepines and alcohol, taken on an empty stomach. These drugs suppressed her

breathing, caused loss of oxygen to her brain, and after 30 minutes, destroyed her higher brain.

At St. Clare's Hospital, a Catholic institution in Denville, New Jersey, a small ventilator, also called a ventilator, kept Karen breathing. It also prevented aspiration of vomit, which could cause pneumonia.

Respirators began to be used in medicine during the 1960s and by 1975 had become common in cases of emergency and trauma. The respirator's use in this case showed that the *criteria of death* needed clarification. Because the brain must have a fresh supply of oxygenated blood to live, lack of such oxygenated blood (anoxia) quickly damages the brain and over enough time, destroys it. The traditional definition of death—where the body stops breathing and the person is declared dead—indirectly *assumed* brain death to be inevitable, but now a respirator prevented this.

Karen's appearance shocked her sister, who said:

Whenever I thought of a person in a coma, I thought they would just lie there very quietly, almost as though they were sleeping. Karen's head was moving around, as if she was trying to pull away from that tube in her throat, and she made little noises, like moans. I don't know if she was in pain, but it seemed as though she was. And I thought—if Karen could ever see herself like this, it would be the worst thing in the world for her.²

Sometimes Karen would choke, sit bolt upright with her arms flung out and her eyes wide open, appearing to be in intense pain. Eventually her breathing stabilized, but even then she didn't breathe deeply enough to sigh. Without breathing to a sigh, the lower sacs of her lungs risked infection. Hence she was put on a larger respirator for a "sigh volume." This larger respirator required a tracheotomy (a hole cut surgically in the throat or trachea) to which her mother, Julia Quinlan, reluctantly agreed.

This more powerful respirator altered her appearance. At a later hearing, her lawyer testified about Karen in September 1975 that:

Her eyes are open and move in a circular manner as she breathes; her eyes blink approximately three or four times per minute; her forehead evidences every noticeable perspiration; her mouth is open while the respirator expands to ingest oxygen, and while her mouth is open, her tongue appears to be moving in a rather random manner; her mouth closes as the oxygen is ingested into her body through the tracheotomy and she appears to be slightly convulsing or gasping as the oxygen enters the windpipe; her hands are visible in an emaciated form, facing in a praying position away from her body. Her present weight would seem to be in vicinity of 70–80 pounds.³

Karen Quinlan, of course, was in a coma, but what does that mean? The word "coma" is vague. Despite popular belief at the time, under New Jersey law in 1975 Karen was not brain-dead, which required *all* of her brain to be not functioning.

Karen Quinlan was in a serious form of coma called *persistent vegetative state* (PVS). PVS is a generic term covering a type of deep unconsciousness that, if it persists for a few months, is almost always irreversible. In this case, her eyes were *disconjugate*, i.e., they moved in different, random directions at the same time. Despite eye movements, she was thought to be *decorticate*: Karen's brain could not

receive input from her eyes. She had slow-wave—not isoelectric or “flat”—electroencephalograms (EEGs).

At one time, a patient in such a condition would simply starve to death; but in the late 1960s, crude intravenous and nasogastric feeding tubes began to be used. Initially, an intravenous tube fed Karen, but as her condition persisted, the rigidity of her muscles made it difficult to insert and reinsert such a tube into her veins. Five months after her admission, in September 1975, she required a nasogastric feeding tube.

The Quinlans never allowed a picture to be taken of Karen in PVS. So the public never saw a realistic picture of a PVS patient with a shaved head on her respirator and feeding tube.

In the fall of 1975, the Quinlan parents decided that Karen would never regain consciousness, so they decided to remove the respirator and let Karen’s body die. They had no idea that their struggle to reach this decision would be the easy part.

The Quinlans averred that Karen had twice said that if anything terrible happened to her, she did not want to be kept alive as a vegetable on machines. But was she really a “vegetable?” We now know that a rare patient may recover from PVS.

Recall that the use of respirators in the Quinlan case revealed new ethical problems about brain death. In combination with a feeding tube, the question arose of how active could ethical physicians be in *withdrawing* such devices? To physicians and family members, such withdrawals may *feel* like killing a vulnerable patient. The Catholic Church asserted such. Were such feelings justified? Isn’t it a physician’s job to look out for vulnerable patients? What if the patient’s family feels differently than the physician? How should such a conflict be resolved?

Robert Morse and Arshad Javed, a resident in internal medicine and a fellow in pulmonary medicine, were the physicians of record in this case and, when the Quinlans asked them to disconnect Karen’s respirator, they wanted to block charges of criminal misconduct. Why was that?

First, in 1975 the American Medical Association (AMA) equated withdrawing a respirator for death to occur with euthanasia, and then equated that with murder. Note that in 1975, no federal or state court had decided anything about death and dying or clarified the rights of dying patients or their families.

Second, the physicians feared that if the Quinlans later changed their minds, they could sue for malpractice. One common definition of malpractice is “departure from normal standards of medical practice in a community” and in 1975—when almost all physicians felt it their duty to continue treatment until the very last moment of life—actively assisting in the death of a comatose patient would have been such a departure.

Paul Armstrong, a Legal Aid lawyer for indigent clients, represented Karen Quinlan and her parents. Armstrong was a young, inexperienced lawyer interested in big issues of constitutional law.

Dr. Morse testified that no medical precedent allowed him to disconnect Karen’s respirator. The neurologist Julius Korein testified that he had seen about 50 patients in PVS and that all of them were better off than Karen; he described Karen as having no mental age at all and as being like “an anencephalic monster.”⁴ Famous neurologist Fred Plum confirmed Korein’s diagnosis; Plum described Karen as “lying in bed, emaciated, curled up in what is known as flexion contracture.

Every joint was bent in a flexion position and making one tight sort of fetal position. It's too grotesque, really, to describe in human terms like fetal."⁵

The lower-court judge decided that Karen's respirator should not be disconnected because her wishes had never been written down, so Karen's true wishes were unknown. He further ruled that her parents' testimony about her wishes (substituted judgment) could not be taken as final if it entailed her death. He also ruled that the right to die could not be found in the U. S. Constitution.

Several weeks later, the New Jersey State Supreme Court heard the case on direct review. These justices expressed surprise when physicians distinguished between disconnecting a respirator and not starting it. Additionally, lawyers for the physicians argued that once a physician accepted a patient, an absolute duty to pursue the patient's welfare became "attached" to the physician, such that the physician could never pursue death.

In contrast, neurologist Julius Korein testified that physicians privately used "judicious neglect" in letting terminal patients die and that this was an unwritten standard of the time in medicine. The justices pressed the hospital's lawyers about the physician-patient relationship. Why couldn't Morse and Javed allow Karen to be transferred to another hospital, where other physicians could disconnect her? The lawyers for the hospital hemmed and hawed, but finally just said that St. Clare's thought it would be immoral to do so. The justices found all these lines of reasoning "rather flimsy."

The U.S. Supreme Court in 1965 had first recognized a right to privacy in *Griswold v. Connecticut*, when it found state laws unconstitutional that banned physicians from giving contraceptives to married couples. The *Griswold* court said for a state government to say women and couples couldn't use contraception to avoid having children violated the *fundamental liberty to lead one's personal life as one saw fit* that the Constitution assumed such liberty, and that such liberty made the lives of Americans the envy of people around the world.

This decision marked the start of a split in American life about the role of the federal government enforcing quasi-religious values in family and personal life that still continues today in divisions between "red" and "blue" states and in divisions in bioethics. Under the misleading phrase "family values," social conservatives attempted to block expansion of choice at the start of life about birth control pills, intrauterine devices (which block implantation of embryos), abortion, and in vitro fertilization. At the end of life, in both the Quinlan (1975) and Schiavo (2005) cases, they tried to block choices of spouses and parents about discontinuing treatment of incompetent patients.

In January 1976, after two months of deliberation, the New Jersey Supreme Court ruled unanimously in favor of the Quinlans. The Constitution's implied right to privacy (liberty) allowed the family of a dying incompetent patient to decide to let that patient die by disconnecting life-support. Because the Supreme Court of the United States had not yet made a comparable decision, New Jersey was thus the first to apply the right to privacy in a case of letting die. The New Jersey court also allowed Joseph Quinlan to become Karen's guardian, gave legal immunity to Morse and Javed for disconnecting Karen's life-support, and suggested (though it did not require) an advisory role for ethics committees in hospitals composed mostly of laypeople to help in future cases.

This last suggestion is interesting because the ensuing decades have seen a proliferation of hospital ethics committees (HECs). But the court may have been guilty of a fantasy here in thinking that such committees could help the legal system. For consider: how many laypeople in 1975 would have understood, before all the publicity, the real issues of the Quinlan case? Moreover, some of the real issues emerged only after the legal battle.

Pulling the Plug or Weaning from a Respirator? In April 1976, four months after the higher-court decision, a respirator helped Karen Quinlan's body breathe. By then, decubitus ulcers had eaten through her flesh, exposing her hip bones. Why Karen was still alive at this point is one of the least understood and most interesting aspects of this case.

According to the Quinlans, Morse resisted implementing the decision of the New Jersey Supreme Court, because "this is something I will have to live with for the rest of my life."⁶ The head nun was more blunt: "You have to understand our position, Mrs. Quinlan. In this hospital we don't kill people."⁷ To this, Julia Quinlan replied, "Why didn't you tell me 10 months ago? I would have taken Karen out of this hospital immediately."

The administrators at St. Clare's were not alone in their position. Catholic hospitals saw the Quinlan decision as another step down a slippery slope that had started three years earlier with the American legalization of abortion in 1973. During the trial, the Vatican theologian Gino Concetti criticized the Quinlans: "A right to death does not exist. Love for life, even a life reduced to ruin, drives one to protect life with every possible care."⁸ A pulmonary specialist at Catholic University in Rome said that removal of the respirator "would be an extremely dangerous move by her doctors, and represents an indirect form of euthanasia."⁹

Instead of simply disconnecting Karen's respirator, Morse and Javed weaned her from it. "Weaned" means they gradually trained the body off the machine by building up different muscles. The tired, confused Quinlans and their inexperienced lawyer did not understand what this meant, and the real implications would become painfully clear over the next 10 years. Eventually, Javed had Karen off the respirator for four hours; then, after intensive work over many weeks, for 12 hours. By late May of 1976, Karen was off the respirator altogether.

A more experienced lawyer would have obtained a *writ of habeus corpus* ("you should have the body"), which protects Americans from false imprisonment. This writ can be issued by a local judge and works quickly. If the Quinlans had gotten one, they could have transferred Karen to a hospital where she would have been quickly allowed to die.

This weaning confused the public: Some people took it to mean that Karen had gotten better; others, that Karen's physicians had "pulled the plug," but a miracle had prevented her death. Both impressions were false.

St. Clare's hospital now wanted Karen transferred and New Jersey's Medicaid office forced a nursing home to accept Karen in June 1976. At this point, Karen had been in PVS for 14 months.

After more than 10 years in this nursing home, Karen Quinlan's body expired in June 1986. For several months before that, Karen had had pneumonia, and the Quinlans had declined antibiotics to reverse it.

Substituted Judgment and Kinds of Cases. The *Quinlan* decision ran two different kinds of cases together.¹⁰ As noted, the Court based its decision partly on the right to privacy, a right that in medical contexts would presumably apply only to competent patients. But the standard of *substituted judgment* also grounded *Quinlan*, according to which relatives or friends could substitute their judgment for that of an incompetent patient.

Consequently, this decision had at least two major problems. First, how did a family's right to exercise substituted judgment derive from *Griswold*? Critics felt that the New Jersey court had jumped too quickly from married people's right to control their own reproduction (the situation in *Griswold*) to parents' right to let an adult, comatose incompetent child die—especially because no intervening decisions had been made about whether competent adults had a right to hasten their own death by refusing medical treatment. Given that quick, big jump, critics wondered what was next. Giving parents the right to make life-or-death decisions for never-competent patients? For retarded babies?

Second, substituted judgment is a notoriously subjective criterion.¹¹ It presumes that decisions made by a patient's family will reflect what the patient herself would have wanted done. In the *Quinlan* case, like the later *Cruzan* and *Schiavo* cases, it was unclear whether these women had really expressed a wish not to have their lives prolonged or whether the families just wished it so.

Finally, the right to privacy most obviously applies to competent patients and their rights to determine their own medical destinies. Ideally, our courts would have first laid out that right and then tackled incompetent patients. But life is messy and things didn't happen that way, so the *Quinlan* decision tackled incompetent patients first. It took 15 more years before things were straightened out, when the U. S. Supreme Court finally decided the *Cruzan* case.

THE CRUZAN CASE

The *Cruzan* case led to a landmark decision by the United States Supreme Court in June 1990.¹² Before this decision, 20 states had recognized the right of competent patients to refuse medical life-support, and all these states (with the exception of New York and Missouri) had recognized the right of surrogates to make decisions for incompetent patients.¹³ The *Cruzan* decision first explicitly recognized the rights of competent dying patients.

On January 11, 1983, 24-year-old Nancy Cruzan lost control of her car at night on a lonely, icy country road in Missouri.¹⁴ Thrown 35 feet from the car, she landed face down in a water-filled ditch. Paramedics arriving on the scene found that her heart had stopped. Injecting a stimulant into her heart, they restarted it, but because her brain had been anoxic for 15 minutes, Nancy did not regain consciousness.¹⁵

For seven years, Nancy remained in this state. Over time, her body became rigid, her hands curled tightly, and her fingernails became claw-like. Like Karen *Quinlan*, Nancy could take nothing by mouth and somebody turned her every two hours to prevent ulcers. She drooled much of the time, causing her hair, pillow and sheets to be wet. Her care cost the state of Missouri \$130,000 a year.

Where the Quinlan case focused on withdrawal of a respirator, the Cruzan case, like the Schiavo case 15 years later, focused on withdrawal of a feeding tube. Because she could not swallow, Nancy could not be fed by mouth. Loss of ability to swallow signals a key decision in the care of incapacitated patients, especially those with dementia or neurological diseases. Before feeding tubes began to be used in the 1960s, the natural course for such patients was death by starvation. With a feeding tube, this natural deterioration of the body can be put on hold for years, even decades.

Legally or morally, is a PVS patient owed food and water forever? Karen Quinlan's parents thought so; they never withdrew the nutrition that kept her body alive. Nancy's parents, Joe and Joyce Cruzan, thought otherwise: they sought permission in court to disconnect her feeding tube.

In discussing the Cruzan case, it is necessary to understand standards of legal evidence. The minimum standard is *preponderance of evidence*; a more rigorous standard is *clear and convincing evidence*; the most rigorous standard—the standard used for serious felonies—is *beyond a reasonable doubt*.

Preponderance of evidence simply means that there is more evidence one way than the other; in some cases, this simply means there is some evidence rather than none. *Clear and convincing* denotes more rigorous evidence and with dying, it requires an advanced directive (living will) or durable power of attorney. Finally, *beyond a reasonable doubt* requires the most evidence and, of course, is used in trials of homicide to establish guilt and where the accused is presumed innocent.

The Cruzans won their case in probate court; but upon direct review, the Missouri Supreme Court reversed the decision, and this reversal had to do with the standard of clear and convincing evidence. Because Nancy had no advanced directive and because only her parents and a sister testified about her alleged wishes, the Cruzans did not produce enough evidence to be “clear and convincing” about Nancy's true wishes. In particular, Joe Cruzan emphasized that Nancy was a fighter and strong-willed, and therefore wanted to die, but it was hard for the Justices to see why Nancy's strong will wouldn't make her want to fight to return to life.

The Missouri Supreme Court concluded that the state had an interest in preserving life, regardless of quality of life, and no matter how strongly the family felt otherwise, that before medical support could be withdrawn from an incompetent patient, its standard of clear and convincing evidence had to be met. Missouri felt it had a duty to protect an incompetent adult child against parents who might be merely seeking financial and emotional closure.

In reviewing this Missouri decision, the United States Supreme Court did much more than adjudicate this particular case. Indeed, it made three very important declarations.

First, and most important, it recognized a right of *competent* patients to decline medical treatment, even if such refusal led directly to their death. The Supreme Court decided in *Cruzan* for the first time that the Constitution gave competent Americans freedom to refuse unwanted medical support.

Second, the Supreme Court found that withdrawing a feeding tube did not differ from withdrawing any other kind of life-sustaining medical support. Some state laws, which permitted forgoing or withdrawing respirators but not artificial nutrition, were hence unconstitutional.

Third, with regard to *incompetent* patients, the Supreme Court held in *Cruzan* that a state *could, but need not*, pass a statute requiring the clear and convincing standard of evidence about what a formerly competent patient would have wanted done. Because Missouri had such a standard, its law was constitutional. Because the *Cruzan* family had not met that standard, Nancy's feeding tube could not be removed.

Cruzan said nothing about never-competent patients, such as people with profound mental retardation. Because of past abuses, it is reasonable to expect that in these cases only state laws with the most rigorous standards of proof would pass the Supreme Court's review. For such cases, the Supreme Court will probably require the standard of beyond a reasonable doubt.

Reactions to the Supreme Court *Cruzan* decision ran along two lines: legal commentators welcomed it; medical commentators hated it.

Most legal scholars supported the new conservative position of the Rehnquist Court on its role with regard to the Constitution. The proper function of the Supreme Court, according to the law professor Charles Baron, was not as a super legislature over the states or even to promulgate uniform rules of state law. Instead, the U.S. Supreme Court should only strike down state laws that conflict with either federal law or the U.S. Constitution.¹⁶ So not every bad or undesirable state law is unconstitutional.

Texas law professor John Robertson went so far as to say that Nancy *Cruzan* could not be harmed and hence had no interests in the case. He argued that the real claim in *Cruzan* had nothing to do with Nancy *Cruzan*'s right to die or her right to privacy (her liberty interests); instead, the case was about the *Cruzan* family's right to be free of the emotional burden of maintaining her body in a state institution.¹⁷

Both Baron and Robertson agreed that the previous legal standard of *substituted judgment* was a mockery "[leading] us to pretend that we are merely complying (however reluctantly) with the wishes of the patient. The result in most states is mere lip service to substituted judgment. Almost any evidence is deemed sufficient to establish a preference for death over PVS and/or families are empowered to express patient preferences for death—with few questions asked."

In contrast, another standard used in such cases was that of *best interests* of the patient. So in the *Cruzan* case, would the best interests of Nancy be to live on in such a state and subject her family to such a burden? Most people would say no, although this judgment is not open-and-shut since the State of Missouri argued that Nancy's best interests entailed continued feeding.

A different kind of reaction came from physicians who worked with families of vegetative patients. Neurologist and bioethicist Ronald Cranford of Minnesota, who would later testify in the Schiavo case, predicted that "many families will experience the utter helplessness of the *Cruzans*." Allowing the standard of clear-and-convincing evidence would "place an enormous burden on society, which will spend hundreds of millions of dollars each year for a condition that no one in their right mind would ever want to be in."¹⁸

Hospice physician Joanne Lynn emphasized that in Missouri and New York, "the suffering of the patient and family, the costs, the kind of life that can be gained, are all to count for nothing. If life can be prolonged, then it will have to be."¹⁹

Nancy had been divorced just before her accident, and many of her friends knew her only by her married name, Nancy Davis. When her case first became widely known, her friends had not realized who she was. After the major decision, the case was reheard in a lower court and Nancy's old friends testified. In that hearing, the lower court decided that Nancy Cruzan's parents had met the clear-and-convincing standard.²⁰ So five months after the Supreme Court decided *Cruzan*, on December 14, 1990, physicians legally removed Nancy Cruzan's feeding tube, and her body died.

THE HUGH FINN CASE

Controversy erupted in 1998 when the Republican governor of Virginia disputed a wife's right to remove the feeding tube of her husband, Hugh Finn, who had been in PVS for three years.²¹ Hugh Finn, a former television anchorman in Louisville, Kentucky, had prepared a document stating that he would not want to live in a persistent vegetative state sustained by a feeding tube. Unfortunately, before he could sign it, a terrible automobile accident severed his aorta and left his brain anoxic for many minutes. His resulting coma left him unable to eat, care for himself, or communicate.

Or so it seemed, until a nurse claimed that, when she smoothed his hair, he had said "Hi" to her. So Hugh's brother, John, challenged a request by Hugh's wife, Michelle, to remove Hugh's feeding tube. Hugh's parents joined John in the suit. They lost in court, but Governor James Gilmore asked the Virginia Supreme Court to continue Finn's feeding tube. Gilmore stated that its removal would be "mercy killing or euthanasia." The high court disagreed, deciding that removal would merely "permit the natural process of dying" and would not be euthanasia.

Hugh Finn's body died shortly thereafter, but Governor Gilmore had set a precedent for escalating a private family dispute about a dying patient into a sensationalized, national debate. Seven years later, Governor Jeb Bush in Florida escalated another such dispute to a much bigger national debate.

THE TERRI SCHIAVO CASE

During the months of 1990 when the U. S. Supreme Court was deciding its *Cruzan* decision, an even bigger coma case was beginning. On February 25, 1990, Terri Schiavo, a 27-year-old, anorexic Caucasian woman went into a coma because of anoxia, a lack of oxygen to her brain, perhaps from a heart arrhythmia caused by extreme hypoalkemia (an imbalance of potassium in her body), causing severe hypoxic ischemic encephalopathy (brain damage).²²

There is evidence that Terri Schiavo suffered from anorexia before her heart attack. People with such eating disorders may suffer from an imbalance of potassium. According to documents filed in her malpractice suit, a three-stage imbalance of potassium led to Terri's heart attack, which led to anoxia and subsequent brain damage.

Many diets today contain too little potassium; the average American woman consumes less than half of the 4700 milligrams a day considered to be adequate.²³

Among other medical conditions, chronic lack of potassium can cause heart attacks and strokes. Moreover, blood tests for potassium can be normal even when real symptoms occur from chronic potassium insufficiency. As a result, physicians often fail to diagnose a chronic lack of potassium.

To keep her alive, physicians inserted a PEG (percutaneous endoscopic gastroscopy) feeding tube. When a patient lacks the reflex to swallow, a PEG tube is placed through the abdominal wall into the stomach, allowing a nutritious, slushy mixture to feed the patient. PEG tubes are sometimes inserted to buy time after an emergency, with the implicit understanding that they may be temporary and may be removed later.

Once attached, feeding tubes can be emotionally difficult for people to remove. Years later, removal of the feeding tube became the central issue of this case.

Two months later in April, her husband Michael transferred Terri from the hospital to a rehabilitation center. In May, and with no objection from her parents, Robert and Mary Schindler, he became her legal guardian. Later, her parents took her to their home to care for her, but were overwhelmed by the task and returned her to the center. Later, Michael flew Terri to California for a two-month experiment with a "thalamic stimulator implant" in her brain. Later, at the Mediplex Rehabilitation Center in Brandon, Florida, and for months 13–18 into her coma, three shifts of workers worked 24 hours a day trying to rehabilitate Terri.

In July 1991, Terri went to Sable Palms, a skilled care facility, where neurologists continued to test her and where speech, occupational, and physical therapists worked on her for another three years, from 1991 to 1994.

Michael Schiavo and Terri's parents stopped living together in May 1992. That August, Michael received a settlement from the malpractice case against Terri's obstetrician for failing to diagnose her potassium imbalance. He got \$750,000 from the hospital for a trust fund specifically for Terri's care and \$300,000 for loss of her companionship.

The three adults fought over this money. Michael owed the Schindlers \$10,000 and the Schindlers believed they were entitled to part of the \$300,000 for loss of spousal companionship. After the dispute, their relationship soured.

Based on what several physicians told Michael, at this point Terri had no chance of meaningful recovery. Michael agreed to a "Do Not Resuscitate" order for Terri, but her parents violently disagreed and he later rescinded the order.

The Schindlers then tried to remove Michael as Terri's guardian, but a court-appointed special guardian investigated and determined that Michael had acted appropriately toward Terri, which the court accepted.

Four years passed, during which Terri's condition did not improve. During this time, and in order to help care for Terri, Michael became certified as a licensed respiratory therapist.²⁴

In May 1998, eight years after Terri's heart attack, Michael asked a court to allow removal of the PEG tube so that Terri could die. Michael testified that, while watching television many years before, Terri had once remarked that she wouldn't want to live in a vegetative state. The Schindlers responded that their daughter wanted to live and that they didn't want the money for themselves but to be set aside for Terri's care.

Nearly two years after Michael Schiavo's request to have Terri's feeding tube removed, Judge George Greer in 2000 approved the request. He ruled that clear and convincing evidence existed that Terri would not have chosen to live under such circumstances. Legally, this ruling lacked support, because Terri's parents disputed this claim and because she had no living will.

The Schindlers appealed, which took a year, but they lost. They appealed again, this time to the Florida Supreme Court, which in April 2001 denied their appeal.

Over the next few years, the Schindlers began to allege that Michael caused Terri's condition, perhaps because of domestic abuse. An autopsy after her death proved that no such abuse occurred. Moreover, if Terri had arrived at an emergency room with this kind of trauma, surely Michael would have been reported (as required by law) to authorities for domestic violence, battery, or possible manslaughter. Nor, if such evidence existed, would the hospital and its physicians have settled a malpractice case or allowed Michael to become Terri's guardian.

The Schindlers also testified that, even if she had asked them to do so, they would not remove Terri's feeding tube under any circumstances. They said that even if she developed gangrene and all her limbs had to be amputated, they would still keep her alive.²⁵

A year later in the fall of 2003, having exhausted all appeals in Florida, the Schindlers appealed in federal court to prevent removal of Terri's feeding tube. The Schindlers appealed to the public through the media, and several physicians publicly joined their side, including a pathologist and a physician who hoped to try exotic "coma stimulation" therapies.

Lawyers for Florida Governor Jeb Bush, a Catholic, filed a brief on the side of the Schindlers; Governor Jeb Bush praised the parents in the media for defending their daughter's right to life. President George W. Bush praised his brother's stand. The Advocacy Center for Persons with Disabilities filed a lawsuit claiming that removal of Terri's PEG tube would abuse a person with disabilities. The anti-abortion group, Life Legal Defense Fund, helped the Schindlers hire lawyers, eventually paying bills of \$300,000.

Three neurologists, including distinguished neurologist Ronald Cranford, testified that Terri was in PVS (Cranford substituted "permanent" for "persistent" to emphasize the irreversibility of her condition). The Schindlers cited Terri's ability to swallow saliva as evidence that she was not in PVS; Cranford rebutted and testified that such swallowing was controlled by primitive functions of her brain stem.

Dr. William Mayfield, a pioneer in the field of medical radiology and a founder of the American College of Hyperbaric Medicine, testified that he believed that hyperbaric oxygenation therapy (HBOT) would benefit Terri. Neurologist Ronald Cranford retorted, "Increase the blood flood to dead tissue, and what do you get? Dead tissue."²⁶

Physician William Hammesfahr, a champion of HBOT, testified for the Schindlers that Terri was not in PVS and would respond well to hyperbaric treatments, which were then his primary business. Hammesfahr, who seemed eager to appear on television, presented himself as an unappreciated genius, like Semmelweis, who was far ahead of the medical community and, hence, a pariah.²⁷

The three neurologists found Hammesfahr unprofessional and noted that he required cash in advance for his hyperbaric treatments and had published no articles documenting the amazing successes he claimed from using his hyperbaric chambers.

Mayfield and Hammersfahr represented extreme, marginal positions in the medical community. The overwhelming medical consensus was that Terri had died long ago, that she had no chance of returning to any normal conscious state, and that dragging on the controversy was two steps backwards from the Cruzan case in moving towards an enlightened national policy about ending care for comatose patients.

At the last moment, a neurologist affiliated with the Mayo Clinic in Jacksonville, Florida, William Cheshire, visited Terri in her room and opined that Schiavo "may" have been in a minimally conscious state, although he did not extensively examine her.²⁸ Cheshire was director of Center for Bioethics and Human Dignity, a web-based bioethics center and passionate critic of assisted suicide.²⁹

Another disagreement among these physicians concerned what Terri's movements meant. Ability to respond to a squeeze or pinch is consistent with PVS. In the Cruzan case, when neurologist Cranford examined Nancy, her lawyer William Colby described what happened:

Cranford next grabbed hold of Nancy's stiff right leg and tried to bend it straight. Nancy grimaced. Then he reached for the soft skin on the inside of the upper part of her right arm, and held the pinch. Slowly, as if she were a robot, Nancy's head lifted off the bed and turned. Her face locked on her father's for about ten seconds, before she lowered just as slowly to the pillow.³⁰

Despite being there and witnessing this phenomenon in this case, Dr. Cranford insisted that Nancy Cruzan's biography was over, that no one was conscious within the reflexes of her body, and that further treatment was futile.

In the fall of 2003, the Florida legislature passed a special bill, *Terri's Law*, that allowed the Governor to issue a one-time stay of a judge's order to remove a feeding tube in certain cases where a patient is in PVS. After its passage, Governor Bush immediately issued such a stay.

Michael and the American Civil Liberties Union appealed in state court and won, but Governor Bush appealed to a mid-level appellate court, lost, and appealed again to the Florida Supreme Court.

On September 23, 2004, Florida's Supreme Court ruled 7-0 that Terri's Law was unconstitutional. It based its decision upon two constitutional canons: the separation of powers and the unlawful delegation of authority. "It is without question an invasion of the authority of the judicial branch for the Legislature to pass a law that allows the executive branch to interfere with the final judicial determination in a case," wrote Chief Justice Barbara Pariente.³¹

About two months later, the top U. S. court let stand without comment the decision by the Florida Supreme Court against Terri's law.³² Activists predicted Terri's imminent "brutal murder" and claimed (based on watching the widely seen videotape aired constantly on television) that she was a "purposefully interactive, alert, curious, lovely young woman who lives with a very serious disability."³³

At the end of February 2005, 15 years after the case began, the Schindlers filed a variety of desperate motions in Judge Greer's court. Judge Greer ordered the feeding tube removed. The Schindlers appealed, but a Florida appellate court again rebuffed them.

Extraordinary events, of a kind never before seen in the history of modern bioethics, then ensued. As the Schlinders lost in court, they became desperate; they turned to the media for their cause, enlisting their other son and daughter to go on television. Catholic priests dressed in robes of monastic orders appeared with them. Anti-abortion activist Randall Terry showed up. People flooded Florida legislators with email and phone calls.

Activists and the Schlinders then turned to the U. S. Congress. First, House leaders tried to compel Terri to appear before a House committee as a witness, and fall under protection of the federal program that protects such witnesses. Judge Greer ignored this subpoena.

So activists next turned to Congressional leaders and President Bush. House Speaker Tom DeLay faced an ethics scandal and indictments in his home state of Texas for getting money in illegal ways, exactly the kind of scandal that had forced previous speaker Jim Wright out of Congress in 1989. (DeLay also failed to reveal that his family had agreed to remove a respirator from his father, who had been badly injured in an accident in 1988 at his Texas home.)³⁴

In the Senate, Senator Bill Frist, the physician, may have planned to run for President in 2008 and may have wanted to align himself with the same culture-of-life constituency that had helped George W. Bush narrowly win. So the two of them worked to have Congress pass a federal version of Terri's Law, which they did, having President Bush fly back during a Congressional recess and sign a bill passed at midnight by a vote of 203 to 58.³⁵

Some critics said that Senator Frist crossed a dangerous ethical line and committed virtual malpractice by declaring—merely by watching the edited video clip and never actually visiting or examining Terri—that Terri “did not seem to be” in a persistent vegetative state. As one critic fumed, “It’s quackery. It’d be hilarious if it weren’t so grotesque, how his presidential ambition and pandering to the right wing is clashing with his life’s work.”³⁶ Congressman Dave Weldon, a physician and also a pro-life Republican, agreed with Frist. So these high-ranking politician-physicians publicly contradicted the neurologists who had actually examined Terri.

Congressmen Frist and Weldon had one problem here: the federal government cannot order a physician to insert a feeding tube. The only thing it could do is order a federal judge to review the case again, which was done. The federal judge, James Whittemore, reviewed the whole case over two days and concluded, like two dozen appellate judges before him, that nothing was amiss, that Terri had no chance of recovery, that Michael was properly motivated, and that previous courts had made no errors. An appeal to the U. S. Court of Appeals for the 11th Circuit in Atlanta, a conservative group, produced the same conclusions.

During March 2005, media exposure escalated, producing what *Newsweek* later called “a public spectacle airing nonstop on cable and playing on front pages around the world.”³⁷ Terri’s supporters traveled to Pinellas Park, Florida, to hold prayer vigils, while others threatened to kill Michael and his lawyer, George Felos.

Various members and friends of both sides went on cable television shows and endlessly discussed the family's problems.

A juggernaut for Terri ensued: soon, four Schindlers, plus recovered coma patients, some physicians, activist monks, Patrick Mahoney, director of the Christian Defense Coalition, and anti-abortion activist Randal Terry all campaigned on television, radio, and the Internet against Michael Schiavo, who was media shy and only had his brother, Scott, and lawyer George Felos to help him.

The tactics in this case showed contempt for the truth and a willingness to say anything, do anything, to win. No matter what the facts, or the law, the attitude was: "Do what it takes to win." So Barbara Weller, an attorney working for the Schindlers said that she herself had seen Terri trying to talk, and thus went from a lawyer to a witness. Protestors called Judge Greer a "judicial murderer" and Republicans blasted the "imperial judiciary." The Reverend James Kennedy urged Governor Jeb Bush to ignore the federal judges the way Alabama's Governor George Wallace did in defying federal orders to integrate.³⁸ Soon after, the FBI arrested a man offering \$250,000 to kill Michael Schiavo and \$50,000 to do the same to Judge Greer. Another two people were arrested trying to break into the hospice.

For example, Terri was said to be "suffering terribly" by starving, even though physicians in palliative care repeatedly denied first, that when feeding tubes are removed, terminal patients suffer, and second, that in this case, any person still existed to suffer.³⁹

The case again showed the limitations of the media, of television, of Internet and radio, because what made great visuals (people praying and screaming outside Terri's hospice), what made great drama (the Schindlers crying on television), and what made great tension (various people claiming that Michael was evil), distorted facts of the case. What had been a private family dispute suddenly became the War of Saints against Evil.

On March 18, the last appeal failed to the U.S. Supreme Court (which had already twice refused to review the case) and Terri's feeding tube was removed for the last time. Palliative care physicians predicted it would take about two weeks for Terri to die and emphasized that, in terminal patients such as Terri, it would not be painful. Opponents outside decried "murder by starvation." After 13 days, while protestors prayed and rallied outside, Terri's body expired, on March 31, 2005. An autopsy, ordered by Michael, showed she had not been abused.

What Schiavo's Autopsy Showed

Chief Medical Examiner for Pinellas County, Florida, Jon Thogmartin, MD, released Terri's autopsy on June 13, 2005. It answered some questions and left others as mysteries.

First, he cleared up the mysterious bone scan of 1991 introduced by the Schindlers in 1992 with the claim that Terri's coma had been caused by trauma, possibly by Michael. Here is what happened: when Mediplex admitted Terri in early 1991, her physicians there ordered a bone scan to rule out degenerative changes in her bones. The bone scan was done at nearby Manatee Memorial Hospital. There, the bone scan form *erroneously* listed Terri Schiavo as a case of "closed

head injury" and said "the patient has a history of trauma." Thogmartin writes, "It appears that with little or no knowledge of the admitting diagnosis or clinical situation of Mrs. Schiavo, Manatee Memorial staff and radiologists completed the report."⁴⁰

The coroner writes that it is true that the bone scan showed a compression fracture of the spine, but it was *due to osteoporosis*, a common condition in paralyzed patients. Moreover,

In summary, any rib fractures, leg fractures, skull fractures or spine fractures that occurred concurrent with Mrs. Schiavo's original collapse would almost certainly have been diagnosed in February, 1990, especially with the number of physical exams, radiographs, and other evaluations she received in the early evolution of her care at Humana Hospital-Northside. During her initial hospitalization, she received twenty-three chest radiographs, three brain CT scans, two abdominal radiographs, two echocardiograms, one abdominal ultrasound, one cervical spine radiograph, and one radiograph of her right knee. No fractures or trauma were reported or recorded. . . . By far the most likely explanation for the bone scan findings in Mrs. Schiavo are prolonged immobility induced osteoporosis and complicating H.O. [hypertopic ossification⁴¹] in an environment of intense physical therapy.⁴²

In sum, there was no evidence of trauma or abuse by anyone. Michael was wrongly accused of killing Terri. Everyone misunderstood what the 1991 bone scan revealed and how it had originally been mistakenly labeled.

The big surprise of the autopsy was that "Mrs. Schiavo's heart was anatomically normal without any areas of recent or remote myocardial infarction. Her heart (including the cardiac valves, conduction system and myocardium) was essentially unremarkable. . . ." That was a big surprise because, although the cause of her heart attack was debatable, few of Michael's supporters doubted that she had had one.

We cannot prove that either trauma or a heart attack caused Terri's coma. Probably, we will never know exactly what happened to her. Two crucial pieces of evidence are that she may have consumed as much as one gram of caffeine a day and that she had hypoalkemia. Perhaps this combination, after the extreme weight loss, stressed her heart too much that night.

According to reports filed by paramedics or police the night of her original collapse, no other drugs were found in her system.

Another surprise was that the autopsy showed no clinical evidence of bulimia, especially the kind of wear on the enamel of the back teeth that is often caused by this condition. Despite the fact that the malpractice suit was settled on the assertion that Terri had an undiagnosed eating disorder, the coroner's report showed no evidence of this disorder.

However, it still could be true that 15 years before, she was anorexic. Certainly her low potassium level, and the fact that her weight dropped in a few months over 100 pounds, combined with her drinking large amounts of iced tea, are evidence for this hypothesis.

The autopsy also revealed that Terri Schiavo was not in a minimally conscious state. In fact, she had massive brain damage. "Mrs. Schiavo's brain showed global anoxic-ischemic encephalopathy resulting in massive cerebral atrophy. Her brain

weight was approximately half of the expected weight. Of particular importance was the hypoxic damage and neuronal loss in her occipital lobes, which indicates cortical blindness. Her remaining brain regions show severe hypoxic injury and neuronal atrophy/loss. No areas of recent or remote traumatic injury were found."⁴³

Finally, without the PEG feeding tube, she would have died. "Oral feedings in quantities sufficient to sustain life would have certainly resulted in aspiration." Aspiration of food in such patients is a serious, even lethal, complication, causing infection, choking, and possible suffocation.

ETHICAL ISSUES

Standards of Brain Death

People have always feared that they might be declared dead prematurely and buried alive. In the eighteenth century, gruesome stories circulated about exhumations that found frantic scratches on the inside lids of coffins. In the nineteenth century, some legislatures required a delay before burial, and in 1882 an undertaker named Kirchbaum attached periscopes to coffins so that a person who woke up after being buried might signal for help.⁴⁴ Many people were buried with cowbells which they could ring if they awakened underground.

This whole-body standard became inappropriate when respirators allowed respiration of brain-damaged patients. Before them, heart-lung machines could maintain immobilized patients. As early as 1967, when surgeon Christiaan Barnard transplanted Denise Darvall's heart into a dying patient named Louis Washkansky (discussed in a later chapter), the question arose whether Denise Darvall had really been dead before her heart was removed. She obviously hadn't been declared dead by the whole-body standard since her healthy heart was exactly what was wanted for transplantation. Medicine needed a new standard of death, specifically of *brain death*, to determine when organs could be removed from a still-living body.

Although first described in the medical literature in 1959, brain death did not really become operational until Barnard transplanted a heart in late 1967.⁴⁵

Shortly after that event, an ad hoc committee at Harvard Medical School developed the Harvard criteria of brain death.⁴⁶ The Harvard criteria operationally defined brain death as behavior that indicated unawareness of external stimuli, lack of bodily movements, no spontaneous breathing, lack of reflexes, and two isoelectric (nearly flat) electroencephalogram (EEG) readings 24 hours apart. These criteria required loss of virtually all brain activity (including the brain stem, and hence breathing).

The Harvard criteria embody caution: no one declared dead by these criteria has ever regained consciousness. (One could truly say, "If you're Harvard dead, you're really dead.") The extreme conservatism of the Harvard standard disappoints people waiting for organ transplants from donors: during the last 25 years, the standard has covered relatively few patients.

Another standard of brain death is the *cognitive criterion*. This criterion identifies a philosophical core of properties of persons and assumes that without such a

core, a human body is no longer a person; the core properties commonly include reason, memory, agency, and self-awareness. For example, neurological disorders such as Alzheimer's or Lewy body disease destroy brain cells at a high rate, so that over a decade, none of the higher person remains.

The cognitive criterion has the greatest potential to generate organs for transplantation. So far, however, this criterion has been too controversial and too vague to be adopted by any state, although countless families in fact act on it when they use it to agree to reduce treatment to speed a patient's death.⁴⁷

A third standard of brain death, the *irreversibility standard*, falls between the Harvard and cognitive criteria. According to this standard, death occurs simply when unconsciousness is irreversible. Operationally, this judgment would be made by a neurologist and by another physician. The irreversibility standard would allow PVS patients to be declared dead after several years (perhaps, in some cases of anoxia, after several months). At the time of the first heart transplant in 1968, this standard was thought to be too broad.

In popular culture, some people believe that a uniform, metaphysical event with physical manifestations, and perhaps as the counterpart of a similar event at the beginning of life, marks death. Some people would have described these metaphysical events as the entrance and departure of a soul. The occurrence of such metaphysical events of course cannot be proven, and even if they do occur, they seem to have no physical manifestations. In medical reality, the definition of death is not so much a discovery as a decision that families and their physicians make. It is not an event, but a process.⁴⁸

As it turns out, the phrase "brain death" misleads us in many ways. Newspapers commonly refer to someone as being "brain dead" for months until "life-support" is removed, after which the patient is said to "expire." Reformers such as North Carolina medical ethicist Lance Stell believe that such terms incorrectly imply that a patient could be dead in two different ways and that there are degrees of being dead. Such equivocation creates confusion about the epistemological criteria for declaring death, and implies that someone might die more than once. Stell thinks a more accurate phrase would be "death by neurological criteria." A being that meets these criteria, he says, "is not a patient but a cadaver."⁴⁹

Proposals to redefine brain death create controversy. On the one hand, reformers want to end public uncertainty over brain death, expand the number of organs available for transplantation, save the medical system money by not maintaining comatose patients, and help families move on after the death of a relative by having a universally accepted, practical definition of brain death. On the other hand, advocates for vulnerable patients want to give them every chance of recovery.

CHANCES OF AWAKENING FROM PVS

Although most patients who have been in PVS for over a year never wake up, on rare occasions, some do. In one well-known study, 7 of 434 adults with traumatic head injuries who were in PVS for more than a year made good recoveries and regained consciousness, some with normal quality of life.⁵⁰ These seven recoveries warn against any quick judgment that a patient's condition is irreversible.

Classic Cases in Medical Ethics

*Accounts of the Cases
and Issues that Define
Medical Ethics*

FIFTH EDITION

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