Case Presentation

Terri Schiavo

Michael Schiavo claimed that around four in the morning on February 26, 1990, he was awakened by a dull thud. Startled, he jumped out of bed, and it was then that he discovered his wife Terri sprawled on the floor. Michael knelt down and spoke to her, but she was obviously unconscious. He called 911, but by the time the paramedics arrived and resuscitated Terri, she had suffered damage from which she would never recover.

Teresa Marie Schindler was born on December 31, 1963, in Huntingdon Valley, Pennsylvania. Although overweight during her childhood, she lost fifty pounds in her senior year in high school, and most of the rest of her life she struggled to keep her weight down. She and Michael Schiavo met when she was in her second semester at Bucks County Community College. They married in 1984 and soon moved to St. Petersburg, Florida. Michael worked as a restaurant manager, and Terri got a job as a clerk with an insurance company. Terri's parents, Robert and Mary Schindler, also moved to Florida to be near their daughter and son-in-law. Relations between the parents and the young couple were friendly.

After Terri collapsed at home, she was rushed to the nearest hospital and treated for an apparent heart attack. A blood assay done at the hospital showed she was suffering from a potassium imbalance, and her doctors thought that this had probably triggered the heart attack. The potassium imbalance, some physicians later suggested, might have been the result of bulimia, the eating disorder that had troubled her life since high school. The cycle of overeating, purging, and dieting characteristic of the disorder can produce a change in the electrolytes in the blood. Because this change disrupts the electrical signals controlling the heart, it may produce cardiac arrest. Terri had continued to work at losing weight in Florida, and at the time of her collapse she weighed only 120 pounds.

Diagnosis

Whatever the reason for Terri's collapse, she failed to regain consciousness. Once she was out of immediate danger, the hospital neurologists performed a series of tests and examinations: Did she respond to a simple command like "Squeeze my hand"? Did her eyes track moving objects? Did her pupils respond to light? Did she show any sign of recognizing Michael or her parents? The answers to these questions were always no.

Terri's neurological responses were distinctly abnormal, and she showed no signs of cognitive functioning. In addition, CT scans of her brain revealed that the disruption of the oxygen supply to her brain caused by the cardiac arrest had damaged the cerebral cortex. The more primitive parts of her brain were undamaged, but the parts responsible for even the most basic forms of thinking and self-awareness had been destroyed.

The neurologists, after reviewing all the evidence, reached the conclusion that Terri Schiavo had suffered damage to her brain that was both severe and irreversible. She was diagnosed as being in a persistent vegetative state.

Persistent Vegetative State

Persistent vegetative state (PVS) is a specific diagnosis, not to be confused with brain death. People diagnosed with PVS have damaged or dysfunctional cerebral hemispheres, and this results in their not being aware of themselves or their surroundings. They are incapable of thinking and of deliberate or intentional movement. When the brain stem is undamaged, as it was in Terri's case, the autonomic nervous system and a range of bodily reflexes remain intact.

PVS patents are still able to breathe and excrete; their hearts beat, and their muscles behave reflexively. The patients cycle through regular sleep–wake patterns, but although their eyelids may blink and their eyes move, they lack the brain capacity to see. (They resemble a digital camera with a functioning optical system but no microprocessor—information is supplied, but it can't be used.) Some PVS patients may [illegible] tears may run down their cheeks, but these events are reflexive and thus are connected with circumstances in which smiling or crying would be appropriate only in an accidental way.

If a patient's brain is injured but not substantially destroyed, the patient may remain in a vegetative state for only a short time. Such a recovery is unusual, however. After a vegetative state lasts four weeks, neurologists consider it *persistent.* In most cases of PVS, if a change for the better has not occurred after three months, it's not likely to occur at all. When PVS lasts for six months, only about half of those with the diagnosis ever acquire any sort of interactive consciousness. Even then, it is only interactive consciousness of the "Squeeze my hand" variety. Such higher functions as talking or answering questions do not occur. (A study by Cambridge University scientists in September 2006 showed that MRI images might be used to make more reliable diagnoses. The study obtained images of conscious people asked to imagine walking around a room in their house or watching a tennis match, then compared them with the images of a brain of a patient who was given the same instructions. The same areas of the patient's brain lighted up. This suggested her brain was responding to the command, but whether she was having any subjective experience can't be known. Nor is it clear whether the patient or others like her are likely to recover any interactive abilities.)

After six months, PVS patients virtually never recover even the most rudimentary form of consciousness. They remain vegetative as long as they live, which may be for decades. (Karen Quinlan lived almost ten years after lapsing into unconsciousness. See the Case Presentation later in this chapter.) PVS patients require complete care, including feeding through a gastric tube surgically implanted in the stomach and hydration through an IV line, for the remainder of their lives. Because they are prone to infections, they must be carefully monitored and given IV antibiotics prophylactically. They must be kept on special mattresses and moved regularly to prevent the development of bedsores, ulcers caused by the breakdown of the skin and underlying tissue from the constant pressure of the body's weight on the same area.

Neither Brain Dead nor Minimally Conscious

PVS patients have no higher-level brain functioning, but they are not brain dead. To be considered brain dead, a patient must be diagnosed as completely lacking in any detectable brain activity. This means that even the brain stem (which keeps the heart beating and the lungs functioning) must show no functional or electrical activity.

PVS patients are also not in a *minimally conscious state*. Those who fit into this diagnostic category show at least some episodes of awareness. Their eyes may track movement from time to time, though not always. They may respond to commands like "Squeeze my hand for yes" by squeezing for no.

Neurologists consider this category an appropriate diagnosis when the available evidence supports the idea that the patient displays some glimmer of consciousness at least some of the time. Brain scans of minimally conscious patients, for example, show that their language areas respond when a loved one speaks to them. PVS patients display none of these characteristics. Also, minimally conscious patients, have a much higher expectation of recovering more consciousness than do PVS patients. Even so, the expectation of any recovery is low, and if any recovery does occur, it is likely to be only slight.

Michael as Guardian

Michael Schiavo, as Terri's husband, became her legal guardian as soon as she was diagnosed as mentally incompetent. In 1992, he sued his wife's gynecologists for malpractice to get the money to pay for her private care. The theory behind the suit was that they had failed to detect the potassium imbalance that led to her heart attack, which, in turn, led to the loss of oxygen that caused her brain damage. (After Terri Schiavo died, an autopsy showed no evidence that she had suffered a heart attack.) Michael won the suit. He was awarded $750,000 earmarked for Terri's extended care and another $300,000 to compensate him for his loss and suffering.

In 1993, a year later, Michael and his wife's parents, Robert and Mary Schindler, had a disagreement over the care Terri was receiving. Michael later claimed that the disagreement was really over money and that the Schindlers wanted to force him to give them a share of his $300,000 malpractice award. They filed a suit asking the court to remove Michael as Terri's guardian and appoint them in his place. The court found no reason to hold that the care Michael was providing Terri was inadequate, and the suit against him was dismissed.

Treatment Decisions: The Legal Battles

The course of events involving the struggle over the fate of Terri Schiavo became intricate and confusing after the falling out between Michael and the Schindlers. The clearest way to follow the dispute is to consider the events in chronological order.

1994

Four years after Terri's PVS diagnosis, Michael met with the doctors taking care of her to ask about the likelihood of her ever regaining consciousness. He learned from them that this was unlikely ever to happen. Michael then told the long-term care facility where she was a patient that he didn't want her to be resuscitated if she suffered a heart attack or if some other life-threatening event occurred. (This is known as a "do not resuscitate" or DNR order.)

The relations between Michael and the Schindlers continued to deteriorate, particularly after Michael and his girlfriend Jodi Centonze had two children together. (The Schindlers had originally encouraged Michael to move on with his life, and he started a relationship with Centonze only after Terri had been a nursing home for four years.) Supporters of the Schindlers denounced Michael as an adulterer who was not fit to act as Terri's guardian.

1998

Four years after Michael had authorized the DNR order and eight years after Terri was diagnosed as in a PVS, Michael, in his role as Terri's guardian, filed a petition asking Florida's Pinellas–Pasco Circuit Court to authorize him to order the removal of her gastric tube and allow her to die. Michael argued that, even though Terri had left no written instructions, several times she had expressed to him the view that she would not want to be kept alive in her present condition. Robert and Mary Schindler opposed Michael's petition, claiming that Terri was capable of recovering consciousness.

2000

Circuit Court Judge George Greer found that Terri was in a persistent vegetative state and that there was "clear and convincing evidence" that if she were able to make her own decisions, she would discontinue the life-sustaining measures. (See Case Presentation: The Cruzan Case later in this chapter for a discussion of the relevant U.S. Supreme Court decision.)

Ruling in favor of Michael's petition, Judge Greer ordered the doctors at the nursing facility where Terri was a patient to remove her gastric tube. Under Florida law, the execution of a judge's order is automatically stayed to allow opponents to appeal. The Schindlers filed an appeal.

2001

The Florida Supreme Court refused to consider the Schindlers' appeal. The Schindlers immediately appealed to the U.S. Supreme Court, but the Supreme Court also refused to hear the case. Judge Greer's order was executed, and on April 24, 2001, Terri's feeding tube was removed.

Two days later, however, the tube was reinserted. The Schindlers had quickly filed a civil suit against Michael, claiming that he lied when he said that Terri had told him she wouldn't want to have her life prolonged in her present state. Judge Greer ordered the tube to be replaced so that the Schindlers' case could be heard. He also appointed five doctors to consider whether Terri's condition was likely to improve. Each side chose two of the physicians, and the court chose the fifth. The physicians were allowed to examine Terri and given access to all her medical records.

Starting in 2001, the Schindlers began to file accusations of abuse against Michael. From 2001 to 2004 they made nine accusations that included neglect of hygiene, denial of dental care, poisoning, and physical harm. All were investigated by the Florida Department of Children and Families. (Agency reports released in 2005 concluded that there were no indications of any harm, abuse, or neglect.)

2002

The doctors testified in court about Terri's condition. Judge Greer decided that there was no substantial evidence supporting the notion that Terri was likely to improve. He once again ordered the feeding tube removed, but the execution of the order was once again automatically postponed to permit appeal.

2003

The Schindlers filed a federal suit against Michael. They also asked pro-life groups and members of the religious right to support them by appealing to elected officials to act to keep Terri alive. Responding to the plea, the governor of Florida, Jeb Bush (who identified himself as a pro-life Catholic), filed a friend-of-the-court brief in support of the Schindlers.

The Schindlers, in violation of a court order, showed a videotape of Terri to their supporters. On the tape, she was shown smiling, moving her body, and groaning from time to time. The tape convinced many lay observers that she still had some cognitive functioning and was capable of improvement. Rand Terry, the former head of the antiabortion group Operation Rescue, set up a vigil at the hospital. "Thi is someone who is cognitive," he said. "This is not a person in a vegetative state." Others saw the Terri Schiavo case as one in which the rights of the disabled were at stake. "This is just a precipice," said one advocate for the disabled. "If they pull the plug on this woman, do you then take other disabled people who can't feed themselves?" Conservative Christian leader Pat Robertson called the decision "judicial murder."

The Schindlers continued to make clear their opinion that Terri's condition was not the result of a heart attack. In their view, Michael had tried to strangle her but failed to kill her. They offered no evidence for this view, other than their speculation that Michael eventually established a relationship with another woman.

Terri's feeding tube was removed on October 15, but the Florida State Legislature quickly passed a piece of legislation referred to as "Terri's Law" that allowed the governor to order the tube reinserted. The Schindlers met with Governor Bush by invitation, and he signed the reinsertion order. His brother, President George Bush, made a public statement praising the action. Michael Schiavo's attorney filed a suit in state court challenging the constitutionality of Terri's Law.

Religious conservatives claimed that Terri's Law was the result of their prayer vigils, broadcasts on Christian radio, and thousands of e-mail messages to Florida legislators. Some saw the result as a model for an approach they might take to get laws passed in other states to forbid removing feeding tubes, allow prayer in school, and post the Ten Commandments in courts and other public places. Terri's Law, some said, was a victory for conservatives nationally, for it showed that it was possible to use legislation to take away much of the power of the courts.

Vigils and demonstrations continued around Woodside Hospice where Terri was a patient. Fundamentalist religious conservatives, both Catholic and Protestant, vied for media attention. Most had special agendas, some connected with promoting religious values, others with promoting disability rights. Others seemed to focus only on Terri and the prospect of her death. Very few counterdemonstrators appeared in what was often a hostile, angry environment. Michael Schiavo was compared to Hitler and called a murderer.

2004

ge W. Douglas Baird ruled that Terri's Law was onstitutional, thus finding in favor of Michael's request that Terri's feeding tube be removed. Robert Schindler denounced the ruling at a press conference. "These Pinellas County judges are aiding and abetting Michael Schiavo in his continuing crime against Terri," he said. "This current order is nothing more than an unjust killing of a young woman who has demonstrated time and again that she very much wants to live."

The Florida state attorney general appealed the decision. The seven-member Florida Supreme Court unanimously upheld the lower-court decision that Terri's Law violated the Constitution. The law, according to the court's opinion, is "an unconstitutional encroachment on the power that has been reserved for an independent judiciary." Governor Bush appeared to accept the ruling.

2005

January. The Schindlers appealed the Florida Supreme Court decision to the U.S. Supreme Court, but the Supreme Court refused to hear the case.

February. The Florida legislature tried to fashion a second law that would be constitutional, yet block Michael's efforts to have his wife's feeding tube removed. Because of the court rebukes over Terri's Law, Governor Bush and the legislature became more guarded in their efforts. "I am not going to do something that would be inappropriate and completely disrespectful of the laws of the State of Florida," the Governor said.

The Florida Department of Children and Families, however, filed a petition with the court to take legal charge of Terri's care and prevent her tube from being removed. Judge George Greer of the Florida Circuit Court rejected the petition. He ordered that the tube be removed on March 18.

Various members of the United States Congress were approached by a number of members of the religious right and asked to intervene in the Florida case. Speaker of the House Tom DeLay, a Texas Republican, said that removal of Terri's feeding tube would be "an act of medical terrorism." One of the Schindlers' spiritual advisors said, "We pray that this modern-day crucifixion will not happen."

March 16. Congress initiated a debate over what could be done to allow the Schindlers to prevent Terri's feeding tube from being removed. The White House indicated that if Congress passed such a bill, the president would sign it.

March 18. While the debate was proceeding, Terri's feeding tube was removed, for the third time, in accordance with Judge Greer's order. The Schindlers visited Terri in the hospice afterward. They were accompanied by one of their spiritual advisors, Father Malinowski, who later said he had taken a scrap from a robe worn by Mother Teresa and touched Terri's throat, forehead, and cheek with it.

March 21. The House and Senate passed a bill that allowed the Schindlers' case against removing Terri's feeding tube to be heard in a federal court. They were thus given another opportunity to achieve what they had failed to accomplish in the state courts. "Every hour is incredibly important to Terri Schiavo," said House Majority Leader DeLay.

Senator Bill Frist, Republican of Tennessee, the Senate majority leader, said that Congress had to act on the bill because "These are extraordinary circumstances that center on the most fundamental of human values and virtues: the sanctity of human life." Frist, a transplant surgeon as well as a senator, had earlier claimed to be able to tell from the videotape of Terri that she was not in a persistent vegetative state. He received much criticism from the medical community for making a diagnosis without examining the patient or the medical records.

A number of legislators denounced the legislation. Representative Christopher Shays of Connecticut, one of four Republicans in the House to vote against it, objected that "this Republican party of Lincoln has become a party of theocracy."

President Bush signed the bill into law at his ranch in Texas around one in the morning. The next day, at a public appearance in Tucson, he praised Congress for "voting to give Terri's parents another chance to save their daughter's life." The statement was met with a roar of approval from the crowd of Republican supporters.

March 23–26. The bill passed by Congress and signed into law permitted the Schindlers to file a sequence of petitions and appeals in the federal courts. On Wednesday, March 23, they filed an emergency request with the U.S. Supreme Court to replace Terri's feeding tube. Republican leaders of the House and the Senate filed briefs in support of the Schindlers. The brief signed by Senator Frist argued that "the Court cannot permit Mrs. Schiavo to die" before the claims of her parents are reviewed by federal courts. But on Thursday, March 24, the Supreme Court rejected the Schindlers' petition.

In Florida, Governor Bush suggested on Wednesday, March 23, that he might send state agents to forcibly replace Terri's gastric tube. Judge Greer issued an emergency order barring the state from "taking possession of Theresa Marie Schiavo."

On Thursday, March 24, Governor Bush appealed the ruling. In court documents, he charged that Terri's medical condition might be due to abuse by her husband and filed an affidavit by a neurologist claiming she had been misdiagnosed as being in a persistent vegetative state. The Schindlers also filed a petition on the same grounds.

The court-appointed neurologist who examined Terri rejected the possibility of a misdiagnosis. Judge Greer then turned down the petitions of both Governor Bush and the Schindlers. On the same day, a higher state court and the Florida Supreme Court also rejected appeals of the rulings.

A federal 11th Circuit Court of Appeal panel in Atlanta refused to reconsider the case. Further, Chief Judge J. L. Edmundson, a conservative Republican, wrote that federal courts had no jurisdiction in the case and that the law enacted by Congress and signed by President Bush allowing the Schindlers to seek a federal court review was unconstitutional. "If sacrifices to the independence of the judiciary are permitted today," Judge Edmundson wrote, "precedent is established for the constitutional transgressions of tomorrow." Having been turned down by the Appeals Court, the Schindlers made another emergency appeal to the U.S. Supreme Court. For the fifth time, however, the Supreme Court refused to intervene in the case. The Schindlers had reached the end of the legal line.

March 27–30. Reporter Rick Lyman described the mood of the protesters who maintained their post across the street from Woodside Hospice as one that was more somber and subdued than it had been earlier. Not Dead Yet, a disability rights organization that focuses on end-of-life issues, blocked the driveway leading to the hospice. A member of the group said that it hoped to make society change its view that a life with a severe disability is not worth living. One man at the scene blew a ram's horn from time to time another chanted, and a young woman prayed into he cupped hands, then released the prayer toward the hospice.

Signs expressed in shorthand the views that protesters had often spelled out in interviews and speeches: *Hey, Judge. Who Made You God? Murder Is Legal in America, Hospice or Auschwitz?* Even Gove

Bush wasn't immune from criticism, because he had said there was nothing else he could do within the law: *Where's Jeb?* Some protestors became angry, shouting "Nazi!" and "Murder!" but the Schindlers made it known that they wanted the crowd to remain calm.

Several protesters tried to carry cups of water into the hospice to give to Terri, but they were turned back by the police. Because Terri was unable to swallow, the attempts were symbolic. Some protesters continued to hold prayer vigils.

The End

On the morning of Thursday, March 31, 2005, just after nine o'clock, Terri Schiavo died at Woodside Hospice. Michael was at her bedside and cradled her head as life slipped away and she stopped breathing. At Michael's request, neither her parents nor her brother or sister were present, although all of them had paid her a last visit at the hospice. Thirteen days had passed since Terri's feeding tube had been withdrawn. The end came, as is typical in such cases, as a result of dehydration.

The acrimony toward Michael by the Schindlers and their supporters did not end with Terri's death. "After these recent years of neglect at the hands of those who were supposed to care for her, she is finally at peace with God for eternity," Terri's sister, Suzzane Vitadamo, said in a public statement. "His [Michael's] heartless cruelty continued until the very last moment," said a priest who had sided with the Schindlers.

Michael Schiavo neither appeared in public nor made any statement. His lawyer, speaking on his behalf, said that "Mr. Schiavo's overriding concern here was to provide for Terri a peaceful death with dignity. This death was not for the siblings and not for the spouse and not for the parents. This was for Terri."

Autopsy

hree months after Terri Schiavo's death, on June 15, 005, the results of the extensive autopsy that was rformed on her body were made public. The results vealed that her brain had shrunk to less than half its mal weight due to the destruction caused by a loss of ygen ("anoxic-ischemic encephalopathy"). No treat-nt nor the passage of time could ever have restored i to even the lowest level of awareness or motor trol. Her brain had shriveled and forever lost those cities. The autopsy *showed that the original diagnosis* rsistent vegetative state had been correct.

The autopsy failed to find any signs of trauma or strangulation, undercutting the assertion by the Schindlers that Michael had abused Terri and thus was responsible for her condition. Also, no evidence was found suggesting that she had been neglected or received inadequate or inappropriate care.

What the autopsy could not establish, however, was the cause of the cardiac arrest that resulted in the oxygen deprivation that caused Terri's brain damage. "No one observed her taking diet pills, binging and purging or consuming laxatives," the autopsy report observes, "and she apparently never confessed to her family or friends about having an eating disorder." What is more, says the report, her potassium level was measured only after she had been treated with a number of drugs known to lower potassium in the blood, and this makes suspect the main piece of evidence supporting the idea that she suffered from bulimia." Thus, the evidence that Terri suffered "a severe anoxic brain injury" is certain, but what caused it is not. " The manner of death will therefore be certified as undetermined," the report concludes.

The Battles Continue

Incredibly, the conflict over Terri Schiavo did not end with her death. The Schindlers attempted to have independent experts witness the autopsy, but the Pinellas County Medical Examiner refused their request. Videotapes, photographs, and tissue samples from the autopsy were made available by the agency's office, however.

The Schindlers also petitioned a court for the right to determine the disposition of their daughter's body. They said that they wanted her to be buried in Pinellas County so that they could visit her grave. The court rejected the petition, holding that Michael Schiavo had the right to make such decisions.

Terri Schiavo's body was cremated on April 1, 2005. Michael's lawyer announced that Michael's plan was to bury Terri's ashes in Huntingdon Valley, Pennsylvania, where she had grown up and where they had met so many years earlier. In January 2006, Michael married Jodi Centonze, the woman he had met in 1994, four years after Terri had been placed in a nursing home. The newly married couple and their two children continued to live in Florida.

Briefing Session

Death comes to us all. We hope that when it comes it will be swift and allow us to depart without prolonged suffering, our dignity intact. We also hope that it will not force burdens on our family and friends, making them pay both financially and emotionally by our lingering and hopeless condition.

Such considerations give euthanasia a strong appeal. Should we not be able to snip the thread of life when the weight of suffering and hopelessness grows too heavy to bear? The answer to this question is not as easy as it may seem, for hidden within it are a number of complicated moral issues.

Just what is euthanasia? The word comes from the Greek for "good death," and in English it has come to have the meaning "easy death." But this does little to help us understand the concept. For consider this: If we give ourselves an easy death, are we committing suicide? If we assist someone else to an easy death (with or without that person's permission), are we committing murder? Anyone who opposed killing (either of oneself or of others) on moral grounds might also consider it necessary to object to euthanasia.

It may be, however, that the answer to both of these questions is no. But if it is, then it is necessary to specify the conditions that distinguish euthanasia from both suicide and murder. Only then would it be possible to argue, without contradiction, that euthanasia is morally acceptable but the other two forms of killing are not.

Someone who believes that suicide is morally legitimate would not object to euthanasia carried out by the person herself, but he would still have to deal with the problem posed by the euthanasia/murder issue.

Active and Passive Euthanasia

We have talked of euthanasia as though it involved directly taking the life of a person, either one's own life or the life of another. However, some philosophers distinguish between "active euthanasia" and "passive euthanasia," which in turn rests on a distinction between killing and letting die.

To kill someone (including oneself) is to take a definite action to end his or her life (administering a lethal injection, for example). To allow someone to die, by contrast, is to take no steps to prolong a person's life when those steps seem called for—failing to give a needed injection of antibiotics, for example. Active euthanasia, then, is direct killing and is an act of commission. Passive euthanasia is an act of omission.

This distinction is used in most contemporary codes of medical ethics (for example, the American Medical Association's Code of Ethics) and is also recognized in the Anglo-American tradition of law. Except in special circumstances, it is illegal to deliberately cause the death of another person. It is not, however, illegal (except in special circumstances) to allow a person to die. Clearly, one might consider active euthanasia morally wrong, while recognizing passive euthanasia as morally legitimate.

Some philosophers, however, have argued that the active–passive distinction is morally irrelevant with respect to euthanasia. Both are cases of causing death, and it is the circumstances in which death is caused, not the manner of causing it, that is of moral importance.

Furthermore, the active–passive distinction is not always clear-cut. If a person dies after special life-sustaining equipment has been withdrawn, is this a case of active or passive euthanasia? Or is it a case of euthanasia at all?

Voluntary, Involuntary, and Nonvoluntary Euthanasia

Writers on euthanasia have often thought it important to distinguish among voluntary, inv untary, and nonvoluntary euthanasia. ***Volunta*** *euthanasia* includes cases in which a person takes his or her own life, either directly or by refusing treatment. But it also includes cases in which a person deputizes another to act in accordance with his wishes.

Thus, someone might instruct her family not to permit the use of artificial support systems should she become unconscious, suffer from brain damage, and be unable to speak for herself. Or someone might request that he be given a lethal injection, after suffering third-degree burns over most of his body, suffering uncontrollable pain, and being told he has little hope of recovery.

Finally, assisted suicide, in which the individual requests the direct help of someone else in ending his life, falls into this category. (Some may think that one or more of the earlier examples are also cases of assisted suicide. What counts as assisted suicide is both conceptually and legally unclear.) That the individual explicitly consents to death is a necessary feature of voluntary euthanasia.

Involuntary euthanasia consists in ending the life of someone contrary to that person's wish. The person killed not only fails to give consent, but expresses the desire not to be killed. No one arguing in favor of nonvoluntary euthanasia holds that involuntary euthanasia is justifiable. Those who oppose both voluntary and nonvoluntary euthanasia often argue that to permit either runs the risk of opening the way for involuntary euthanasia.

Nonvoluntary euthanasia includes those cases in which the decision about death is not made by the person who is to die. Here the person gives no specific consent or instructions, and the decision is made by family, friends, or physicians. The distinction between voluntary and nonvoluntary uthanasia is not always a clear one. Physicians ometimes assume that people are "asking" to , even when no explicit request has been made. so, the wishes and attitudes that people express en they are not in extreme life-threatening dical situations may be too vague for us to ertain that they would choose death when are in such a situation. Is "I never want to be ked up to one of those machines" an adequate indication that the person who says this does not want to be put on a respirator should she meet with an accident and fall into a comatose state?

If the distinctions made here are accepted as legitimate and relevant, we can distinguish eight cases in which euthanasia becomes a moral decision:

1. Self-administered euthanasia
   a. active
   b. passive
2. Other-administered euthanasia
   a. active and voluntary
   b. active and involuntary
   c. active and nonvoluntary
   d. passive and voluntary
   e. passive and involuntary
   f. passive and nonvoluntary

Even these possibilities don't exhaust the cases euthanasia presents us with. For example, notice that the voluntary–nonvoluntary distinction doesn't appear in connection with self-administered euthanasia in our scheme. Yet it might be argued that it should, for a person's decision to end his life (actively or passively) may well not be a wholly voluntary or free decision. People who are severely depressed by their illness and decide to end their lives, for example, might be thought of as not having made a voluntary choice.

Hence, one might approve of self-administered voluntary euthanasia, yet think that the nonvoluntary form should not be permitted. It should not be allowed not because it is necessarily morally wrong, but because it would not be a genuine decision by the person. The person might be thought to be suffering from a psychiatric disability. Indeed, the current debate about physician-assisted suicide turns, in part, on just this issue.

Defining "Death"

The advent of new medical technologies, pharmaceutical agents, and modes of treatment raises the question of when we should consider someone dead. Suppose someone's heartbeat, blood pressure, respiration, and liver and kidney functions can be maintained within the normal range of values by medical intervention. Should we still include this individual among living persons, even though she is in an irreversible coma or a chronic vegetative state?

If we consider the individual to be a living person, we need to decide how she ought to be treated. Should she be allowed to die or be maintained by medical means? This is the kind of question faced by families, physicians, and the courts in the *Quinlan* and *Cruzan* cases (see the Case Presentations in this chapter), and it is one faced every day in dozens of unpublicized, though no less agonizing, cases.

But what if an unconscious individual lacking higher cortical functioning is no longer a living person? Could a physician who disconnected a respirator or failed to give an antibiotic be said to have killed a person? If nutrition and hydration are withheld from a "brain dead" individual or even if the individual is given a lethal injection, is it reasonable to say that this is a case of killing? Perhaps the person died when her brain stopped functioning at a certain level. Or perhaps she died when she lapsed into coma.

A practical question that advances in medicine have made even more pressing is when or whether a comatose individual may be regarded as a source of transplant organs. If the individual remains a living person, it may be morally wrong (at least prima facie) to kill him to obtain organs for transplant. But what if the comatose individual is not really alive? What if he is dead already and no longer a person? Then there seem to be no reasonable grounds for objecting to removing his organs and using them to save the lives of those who need them. (See Chapter 7 for a discussion of organ donation.)

Questions like the ones raised here have prompted various attempts to define the notion of death. In the view of many commentators, the traditional notion of death is no longer adequate to serve as a guide to resolving issues about the treatment of individuals who, through disease or accident, have fallen into states in which many of their basic physiological functions can be maintained by medical means, although they remain comatose or lacking in higher-brain function.

Until recently, the traditional notion of death has been enshrined in laws defining crimes such as homicide and manslaughter. Given the change in medical technology, actions like removing a respirator, which might once have been regarded as criminal for causing the death of a person, perhaps should now be viewed in a different way. Perhaps a person may be dead already, even though major physiological systems are still functioning.

Four major notions or concepts of death have emerged during the last two decades. We'll list each of them, but it's important to keep in mind that there is a difference between specifying the concept of death (or, as it is sometimes put, defining "death") and the criteria for determining that the concept fits in particular cases. This is analogous to defining "the best team" as the one winning the most games, then providing criteria for determining what counts as winning a game.

The concepts are merely sketched and the criteria for applying them only hinted at.

1. *Traditional.* A person is dead when he is no longer breathing and his heart is not beating. Hence, death may be defined as the permanent cessation of breathing and blood flow. This notion is sometimes known as the "cardiopulmonary" or "heart–lung criterion" for death.
2. *Whole-brain.* Death is regarded as the irreversible cessation of all brain functions. Essentially, this means that there is no electrical activity in the brain, and even the brain stem is not functioning. Application of the concept depends on the use of electroencephalographic or imaging data.
3. *Higher-brain.* Death is considered to involve the permanent loss of consciousness. Hence, someone in an irreversible coma or chronic vegetative state would considered dead, even though the brain stem continued to regulate breathing heartbeat. Clinical, electroencephalograp

and imaging data are relevant to applying the concept. So, too, are statistics concerning the likelihood of the individual's regaining consciousness.

4. *Personhood.* Death occurs when an individual ceases to be a person. This may mean the loss of features that are essential to personal identity or (in some statements) the loss of what is essential to being a person. Criteria for personal identity or for being a person are typically taken to include a complex of such activities as reasoning, remembering, feeling emotion, possessing a sense of the future, interacting with others, and so on. The criteria for applying this concept have more to do with the way an individual functions than with data about his brain.

Technology makes it necessary to take a fresh look at the traditional notion of death, but technology also provides data that have allowed for the development of new notions. It would be pointless, for example, to talk about brain death without having some means to determine when the concept might be satisfied.

The whole-brain concept of death was proposed by the 1981 *Report of the President's Commission for the Study of Ethical Problems in Medicine* and included in the Uniform Death Act. As a consequence, state laws employing the traditional concept of death generally have been modified in keeping with the whole-brain concept.

The whole-brain concept has the advantage of being relatively clear-cut in application. However, applying the concept is not without difficulty and controversy. In the view of some, the concept is too restrictive and so fails to esolve some of the difficulties that prompted e need for a new concept. For example, both ren Quinlan and Nancy Cruzan (see the e Presentations in this chapter), would have n considered alive by the whole-brain ria. However, those who favor concepts of n based on the loss of higher-brain function e loss of personhood might argue that both cases were ones in which the affected individuals were, in the respective technical senses, dead.

Furthermore, critics charge, the whole-brain concept is not really as straightforward in its application as it might seem. Even when there appears to be a complete lack of cognitive functioning and even when basic brain-stem functions appear to have disappeared, a brain may remain electrically active to some degree. Isolated cells or groups of cells continue to be alive, and monitoring of the brain yields data that are open to conflicting interpretations.

The higher-brain and personhood concepts face even greater difficulties. Each must formulate criteria that are accepted as nonarbitrary and as sufficient grounds for deciding that an individual is dead. No one has yet solved either of these problems for either of these concepts. The fact that there can be controversy over whole-brain death indicates how much harder it is to get agreement about when higher-brain functions are lost. Also, securing agreement on criteria for determining when an entity either becomes or ceases to be a person is a conceptual difficulty far from being resolved to the satisfaction of most philosophers. (For more on this topic, see the discussion of persons in connection with abortion in Chapter 9.)

Advance Directives

Like so many issues in bioethics, euthanasia has traditionally been discussed only in the back rooms of medicine. Often decisions about whether to allow a patient to die are made by physicians acting on their own authority. Such decisions do not represent so much an arrogant claim to godlike wisdom as an acknowledgment of the physician's obligation to do what is best for the patient.

Most physicians admit that allowing or helping a patient to die is sometimes the best assistance that can be given. Decisions made in this fashion depend on the beliefs and judgment of particular physicians. Because these may differ from those of the patient concerned, it is quite possible that the physician's decision may not reflect the wishes of the patient.

But covert decisions made by a physician acting alone are becoming practices of the past as euthanasia is discussed more widely and openly. Court cases, such as *Quinlan* and *Cruzan*, have both widened the scope of legally permissible actions and reinforced the notion that an individual has a right to refuse or discontinue life-sustaining medical treatment. Such cases have also made it clear that there are limits to the benefits that can be derived from medicine—that, under some conditions, individuals may be better off if everything that technologically can be done is not done. Increasingly, people want to be sure that they have some say in what happens to them should they fall victim to hopeless injury or illness.

One indication of this interest is that the number of states permitting individuals to sign "living wills" or advance directives has now increased to include all fifty states. The first living-will legislation was the "Natural Death Act," passed by the California legislature on August 30, 1977. The act is generally representative of all such legislation. It permits a competent adult to sign a directive that will authorize physicians to withhold or discontinue "mechanical" or "artificial" life-support equipment if the person is judged to be "terminal" and if "death is imminent."

The strength of advance directives is that they allow a person to express in an explicit manner how he or she wishes to be treated before treatment is needed. In this way, the autonomy of the individual is recognized. Even though unconscious or comatose, a person can continue to exert control over his or her life. This, in turn, means that physicians need not and should not be the decisive voice in determining the continuation or use of special medical equipment.

Critics of advance-directive legislation have claimed that it does not go far enough in protecting autonomy and making death easier (where this is what is wanted). They point out that the directive specified in the California bill and most others would have made no difference in the case of Karen Quinlan. She had not been diagnosed as having a "terminal condition" at least two weeks prior to being put on a respirator, yet this is one of the requirements of the act. Consequently, the directive would have been irrelevant to her condition.

Whose Life Is It Anyway?

A study published in the March 2002 issue of the *Journal of the American Geriatric Society* found that 60 percent of the 1185 Medicare patients surveyed at five teaching hospitals told their doctors to focus on making them comfortable rather than on extending their lives. Yet evidence indicated that more than one-third of the people expressing this wish had it ignored. They were treated more and lived longer than the two-thirds whose wishes were respected. Either their doctors forgot about their preferences, or they deliberately ignored them.

Nor, for that matter, would those people be allowed to die who wish to, if their disease or injury does not involve treatment by "artificial" or "mechanical" means. Thus, a person suffering from throat cancer would simply have to bear the pain and wait for a "natural" death. Finally, at the moment, some states explicitly exclude nutrition and hydration as medical treatments that can be discontinued. The Supreme Court in the *Cruzan* case accepted the notion that the nutrition received by Nancy Cruzan through a feeding tube implanted in her stomach was a form of medical treatment that could be withdrawn. However, the Court did not rule on the Missouri law that forbids withdrawal. Until this law or some other like it is successfully challenged in court, an advance directive does not necessarily guarantee that such treatment will be discontinued, even when requested.

Limitations of such kinds on living wills have led some writers to recommend that individuals sign a legal instrument known as a durable power of attorney. In such a docume an individual can name someone to act on h behalf should he become legally incompeten act. Hence, unlike the advance directive, a durable power of attorney allows a surrogate to exercise control over novel and unanticipated situations. For example, the surrogate may order the discontinuation of artificial feeding, something that an advance directive might not permit.

The widespread wish to have some control over the end of one's life is reflected in a federal law that took effect in 1991. The Patient Self-Determination Act is sometimes referred to as a "medical Miranda warning."

It requires that hospitals, nursing homes, and other health-care facilities receiving federal funding provide patients at the time of admission with written information about relevant state laws and the rights of citizens under those laws to refuse or discontinue treatment. Patients must also be told about the practices and policies at that particular institution so they can choose a facility willing to abide by their decisions. The institutions must also record whether a patient has provided a written "advance directive" (e.g., a living will or power of attorney for health care) that will take effect should the patient become incapacitated.

Another sign of change is the recent concern with the medical circumstances in which people die. The medical ideal of a "hospital death," one in which the patient's temperature, pulse rate, and respiration are brought within normal limits by medication and machinery, is being severely challenged. This is reflected in the policy of the AMA that holds that it may be morally appropriate to withhold "all means of life prolonging medical treatment," including artificial feeding, from patients in irreversible comas.

A new ideal of natural death also seems to be emerging. In this view, the kind of support a dying patient needs is psychological counseling and contact with family and friends rather than eroic medical efforts. An acceptance of death as normal end of life and the development of new eans of caring for the dying may ease the prob- n of euthanasia. If those who face imminent ath are offered an alternative to either eu- nasia or an all-out medical effort to preserve r lives, they may choose that alternative. ath with dignity" need not always mean osing a lethal injection.

Ethical Theories and Euthanasia

Roman Catholicism explicitly rejects all forms of euthanasia as being against the natural law duty to preserve life. It considers euthanasia as morally identical with either suicide or murder. This position is not so rigid as it may seem, however. The principle of double effect (see Part V: Foundations of Bioethics) makes it morally acceptable to give medication for the relief of pain—even if the indirect result of the medication will be to shorten the life of the recipient. The intended result is not the death of the person but the relief of suffering. The difference in intention is thus considered to be a morally significant one. Those not accepting the principle of double effect would be likely to classify the administration of a substance that would relieve pain but would also cause death as a case of euthanasia.

Furthermore, on the Catholic view there is no moral obligation to continue treatment when a person is medically hopeless. It is legitimate to allow people to die as a result of their illness or injury, even though their lives might be lengthened by the use of extraordinary means. Additionally, we may legitimately make the same decisions about ourselves that we make about others who are in no condition to decide. Thus, without intending to kill ourselves, we may choose measures for the relief of pain that may secondarily hasten our end. Or we may refuse extraordinary treatment and let "nature" take its course, let "God's will" determine the outcome. (See Part V: Foundations of Bioethics for a fuller discussion of the Roman Catholic position on euthanasia and extraordinary means of sustaining life.)

At first sight, utilitarianism would seem to endorse euthanasia in all of its forms. Whenever suffering is great and the condition of the person is one without legitimate medical hope, then the principle of utility might be invoked to approve putting the person to death. After all, in such a case we seem to be acting to end suffering and to bring about a state of affairs in which happiness exceeds unhappiness. Thus, whether the person concerned is ourself or another, euthanasia would seem to be a morally right action.

Public Views on Euthanasia

	Agree	Disagree	Neither
1. If a person has a fatal illness, that person should have the right to have all life-sustaining devices removed, including feeding tubes.	79%	12%	9%
2. If a person is in a coma that cannot be reversed, relatives should be allowed to tell doctors to remove all life-sustaining devices, including feeding tubes.	81%	11%	8%
3. In case of fatal illness, doctors should be allowed to help that person end his or her life.	49%	35%	16%
4. If a person has been diagnosed as having a fatal illness, he or she should be allowed to take his or her own life.	39%	45%	16%

Source: Parade Magazine (9 February 1992) mail survey of 3750 people aged twenty-one or older; 2203 respondents. Reprinted with permission from *Parade,* copyright © 1992.

A utilitarian might argue in this way, but this is not the only way in which the principle of utility could be applied. It could be argued, for example, that since life is a necessary condition for happiness, it is wrong to destroy that condition because by doing so the possibility of all future happiness is lost. Furthermore, a rule utilitarian might well argue that a rule like "The taking of a human life is permissible when suffering is intense and the condition of the person permits no legitimate hope" would be open to abuse. Consequently, in the long run the rule would actually work to increase the amount of unhappiness in the world. Obviously, it is not possible to say there is such a thing as "the utilitarian view of euthanasia." The principle of utility supplies a guide for an answer, but it is not itself an answer.

Euthanasia presents a considerable difficulty for Kant's ethics. For Kant, an autonomous rational being has a duty to preserve his or her life. Thus, one cannot rightly refuse needed medical care or commit suicide. Yet our status as autonomous rational beings also endows us with an inherent dignity. If that status is destroyed or severely compromised, as it is when people become comatose and unknowing because of illness or injury, then it is not certain that we have a duty to maintain our lives under such conditions. It may be more in keeping with our freedom and dignity for us to instruct others either to put us to death or to take no steps to keep us alive should we ever be in such a state. Voluntary euthanasia may be compatible with (if not required by) Kant's ethics.

By a similar line of reasoning, it may be that nonvoluntary euthanasia might be seen as a duty that we have to others. We might argue that by putting to death a comatose and hopeless person we are recognizing the dignity that person possessed in his or her previous state. It might also be argued that a human being in a vegetative state is not a person in the relevant moral sense Thus, our ordinary duty to preserve life does no hold.

According to Ross, we have a strong prim facie obligation not to kill a person except in j tifiable self-defense—unless we have an even stronger prima facie moral obligation to do something that cannot be done without killi Since active euthanasia typically requires tak the life of an innocent person, there is a mo presumption against it. However, another of Ross's prima facie obligations is that we keep promises made to others. Accordingly, if someone who is now in an irreversible coma with no hope of recovery has left instructions that in case of such an event she wishes her life to be ended, then we are under a prima facie obligation to follow her instructions. Thus, in such a case we may be justified in overriding the presumption against taking an innocent life.

What if there are no such instructions? It could be argued that our prima facie obligation of acting beneficently toward others requires us to attempt to determine what someone's wishes would be from what we know about him as a person. We would then treat him the way that we believe that he would want us to. In the absence of any relevant information, we might make the decision on the basis of how a rational person would want to be treated in similar circumstances. Of course, if anyone has left instructions that his life is to be maintained, if possible, under any circumstances, then we have a prima facie obligation to respect this preference also.

Case Presentation

Karen Quinlan: The Debate Begins

At two in the morning on Tuesday, April 14, 1975, Mrs. Julie Quinlan was awakened by a telephone call. When she hung up she was crying. "Karen is very sick," Mrs. Quinlan said to her husband, Joseph. "She's unconscious, and we have to go to Newton Hospital right away."

The Quinlans thought their twenty-one-year-old adopted daughter might have been in an automobile accident. But the doctor in the intensive-care unit told them that wasn't so. Karen was in a critical comatose state of unknown cause and was being given oxygen through a mask taped over her nose and mouth. She had been brought to the hospital by two friends who had been with her at a birthday party. After a few drinks, she had started to pass out, and her friends decided she must be drunk and put her to bed. Then someone checked on her later in the evening and found that Karen wasn't breathing. Her friends gave her mouth-to-mouth resuscitation and rushed her to the nearest hospital.

Blood and urine tests showed that Karen had not consumed a dangerous amount of alcohol. They also showed the presence of .6 milligram of aspirin and the tranquilizer Valium. Two milligrams would have been toxic, and five lethal. Why Karen stopped breathing was mysterious. But it was during that time that part of her brain died from oxygen depletion.

After Karen had been unconscious for about a week, she was moved to St. Clare's Hospital in nearby Denville, where testing and life-support facilities were better. Dr. Robert J. Morse, a neurologist, and Dr. Arshad Javed, a pulmonary internist, became her physicians. Additional tests were made. Extensive brain damage was confirmed, and several possible causes of the coma were ruled out.

No Longer the Same

During the early days, the Quinlans were hopeful. Karen's eyes opened and closed, and her mother and her nineteen-year-old sister, Mary Ellen, thought that they detected signs Karen recognized them. But Karen's condition began to deteriorate. Her weight gradually dropped from 120 pounds to 70 pounds. Her body began to contract into a rigid fetal position, until her five-foot-two-inch frame was bent into a shape hardly longer than three feet. She was now breathing mechanically, by means of an MA-1 respirator that pumped air through a tube in her throat. By early July, Karen's physicians and her mother, sister, and brother had come to believe it was hopeless to expect her ever to regain consciousness.

Only her father continued to believe it might be possible. But when he told Dr. Morse about some encouraging sign he had noticed, Dr. Morse said to him "Even if God did perform a miracle so that Karen would live, her damage is so extensive she would spend the rest of her life in an institution." Mr. Quinlan then realized that Karen would never again be as he remembered her. He now agreed with Karen's sister: "Karen would never want to be kept alive on machines like this. She would hate this."

Need to Go to Court

The Quinlans' parish priest, Father Thomas Trapasso, had also assured them that the moral doctrines of the Roman Catholic Church did not require the continuation of extraordinary measures to support a hopeless life. Before making his decision, Mr. Quinlan asked the priest, "Am I playing God?" Father Thomas said "God has made the decision that Karen is going to die. You're just agreeing with God's decision, that's all."

On July 31, after Karen had been unconscious for three and a half months, the Quinlans gave Drs. Morse and Jared their permission to take Karen off the respirator. The Quinlans signed a letter authorizing the discontinuance of extraordinary procedures and absolving the hospital from all legal liability. "I think you have come to the right decision," Dr. Morse said to Mr. Quinlan.

But the next morning Dr. Morse called Mr. Quinlan. "I have a moral problem about what we agreed on last night," he said. "I feel I have to consult somebody else and see how he feels about it." The next day, Dr. Morse called again. "I find I will not do it," he said. "And I've informed the administrator at the hospital that I will not do it."

The Quinlans were upset and bewildered by the change in Dr. Morse. Later they talked with the hospital attorney and were told by him that, because Karen was over twenty-one, they were no longer her legal guardians. The Quinlans would have to go to court and be appointed to guardianship. After that, the hospital might or might not remove Karen from the respirator.

Mr. Quinlan consulted attorney Paul Armstrong. Because Karen was an adult without income, Mr. Quinlan explained, Medicaid was paying the $450 a day it cost to keep her alive. The Quinlans thus had no financial motive in asking that the respirator be taken away. Mr. Quinlan said that his belief that Karen should be allowed to die rested on his conviction that it was God's will, and it was for this reason that he wanted to be appointed Karen's guardian.

Legal Arguments

Mr. Armstrong filed a plea with Judge Robert Muir of the New Jersey Superior Court on September 12, 1975. He explicitly requested that Mr. Quinlan be appointed Karen's guardian so that he would have "the express power of authorizing the discontinuance of all extraordinary means of sustaining her life."

Later, on October 20, Mr. Armstrong argued the case on three constitutional grounds. First, he claimed that there is an implicit right to privacy guaranteed by the Constitution and that this right permits individuals or others acting for them to terminate the use of extraordinary medical measures, even when death may result. This right holds, Armstrong said, unless there are compelling state interests that set it aside.

Second, Armstrong argued that the First Amendment guarantee of religious freedom extended to the Quinlan case. If the court did not allow them to act in accordance with the doctrines of their church, their religious liberty would be infringed. Finally, Armstrong appealed to the "cruel and unusual punishment" clause of the Eighth Amendment. He claimed that "for the state to require that Karen Quinlan be kept alive, against her will and the will of her family, after the dignity, beauty, promise, and meaning of earthly life have vanished, is cruel and unusual punishment."

Karen's mother, sister, and a friend testified that Karen had often talked about not wanting to be kept alive by machines. An expert witness, a neurologist, testified that Karen was in a "chronic vegetative state" and that it was unlikely that she would ever regain consciousness. Doctors testifying for St. Clare's Hospital and Karen's physicians agreed with this. But, they argued, her brain still showed patterns of electrical activity, and she still had a discernible pulse. Thus, she could not be considered dead by legal or medical criteria.

On November 10, Judge Muir ruled against Joseph Quinlan. He praised Mr. Quinlan's character and concern, but he decided that Mr. Quinlan's anguish over his daughter might cloud his judgment about her welfare so he should not be made her guardian. Furthermore, Judge Muir said, because Karen is still medically and legally alive, "the Court should not authorize termination of the respirator. To do so would be homicide and an act of euthanasia."

Appeal

Mr. Armstrong appealed the decision to the New Jersey Supreme Court. On January 26, 1976, the court convened to hear arguments, and Mr. Armstrong argued substantially as before. But this time the court's ruling was favorable. The court agreed that Mr. Quinlan could assert a right of privacy on Karen's behalf and that whatever he decided for her should be accepted by society. It also set aside any criminal liability for removing the respirator, claiming that if death result it would not be homicide and that, even if it were ho cide, it would not be unlawful. Finally, the court stat that, if Karen's physicians believed that she would n emerge from her coma, they should consult an eth committee to be established by St. Clare's Hospital. If the committee accepted their prognosis, then the respirator could be removed. If Karen's present physicians were then unwilling to take her off the respirator, Mr. Quinlan was free to find a physician who would.

Six weeks after the court decision, the respirator still had not been turned off. In fact, another machine, one for controlling body temperature, had been added. Mr. Quinlan met with Morse and Jared and demanded that they remove the respirator. They agreed to "wean" Karen from the machine, and soon she was breathing without mechanical assistance. Dr. Morse and St. Clare's Hospital were determined that Karen would not die while under their care. Although she was moved to a private room, it was next door to the intensive-care unit. They intended to put her back on the respirator at the first sign of breathing difficulty.

Because Karen was still alive, the Quinlans began a long search for a chronic-care hospital. Twenty or more institutions turned them away, and physicians expressed great reluctance to become involved in the case. Finally, Dr. Joseph Fennelly volunteered to treat Karen, and on June 9 she was moved from St. Clare's to the MorrisView Nursing Home.

The End—After Ten Years

Karen Quinlan continued to breathe. She received high-nutrient feedings and regular doses of antibiotics to ward off infections. During some periods she was more active than at others, making reflexive responses to touch and sound.

On June 11, 1985, at 7:01 in the evening, ten years after she lapsed into a coma, Karen Quinlan finally died. She was thirty-one years old.

Her father died of cancer on December 10, 1996, at the Karen Quinlan Center of Hope, a hospice Joseph and Julia Quinlan had founded in 1980 with money they received from the film and book rights to their daughter's story. Joseph Quinlan continued to support the right of patients and their families to discontinue the use of life-sustaining technologies, but he opposed all forms of physician-assisted suicide.

Case Presentation

The Cruzan Case: The Supreme Court Upholds the Right to Die

In the early morning of January 11, 1983, twenty-five-year-old Nancy Cruzan was driving on a deserted county road in Missouri. The road was icy and the car skidded, then flipped over and crashed. Nancy was thrown from the driver's seat and landed face down in a ditch by the side of the road.

An ambulance arrived quickly, but not quickly enough to save her from suffering irreversible brain damage. Nancy never regained consciousness, and her physicians eventually concluded that she had entered into what is known medically as a persistent vegetative state, awake but unaware. The higher brain functions responsible for recognition, memory, comprehension, anticipation, and other cognitive functions had all been lost.

Her arms and legs were drawn into a fetal position, her knees against her chest, and her body stiff and contracted. Only loud sounds and painful stimuli oked responses, but even those were no more than urological reflexes.

"We've literally cried over Nancy's body, and ve never seen anything," her father, Joe Cruzan, "She has no awareness of herself."

Nancy was incapable of eating, but her body was sustained by a feeding tube surgically implanted in her stomach. She was a patient at the Missouri Rehabilitation Center, but no one expected her to be rehabilitated. She could only be kept alive.

"If only the ambulance had arrived five minutes earlier—or five minutes later," her father lamented.

The cost of Nancy Cruzan's care was $130,000 a year. The bill was paid by the state. Because she was a legal adult when her accident occurred, her family was not responsible for her medical care. Had she been under twenty-one, the Cruzans would have been responsible for her medical bills, as long as they had any financial resources to pay them.

Eight Years Later

In 1991, eight years after her accident, Nancy was almost thirty-three years old, and her physicians estimated she might live another thirty years. She was like some 10,000 other Americans who are lost in the dark, dimensionless limbo lying between living and dying.

Those who love them can think of them only with sadness and despair. Given a choice between lingering in this twilight world and dying, most people find it difficult to imagine anyone would choose not to die.

Hope eventually faded even for Nancy Cruzan's parents. They faced the fact she would never recover her awareness, and the time came when they wanted their daughter to die, rather than be kept alive in her hopeless condition. They asked that the feeding tube used to keep her alive be withdrawn. Officials at the Missouri Rehabilitation Center refused, and Joe and Louise Cruzan were forced to go to court.

Lower Court Decisions

During the court hearings, the family testified that Nancy would not have wanted to be kept alive in her present condition. Her sister Christy said Nancy had told her that she never wanted to be kept alive "just as a vegetable." A friend testified that Nancy had said that if she were injured or sick she wouldn't want to continue her life, unless she could live "half-way normally." Family and friends spoke in general terms of Nancy's vigor and her sense of independence.

In July 1988, Judge Charles E. Teel of the Jasper County Circuit Court ruled that artificially prolonging the life of Nancy Cruzan violated her constitutional right. As he wrote, "There is a fundamental right expressed in our Constitution as 'the right to liberty,' which permits an individual to refuse or direct the withholding or withdrawal of artificial death-prolonging procedures when the person has no cognitive brain function."

Missouri Attorney General William Webster said Judge Teel's interpretation of the Missouri living-will law was much broader than the legislature intended and appealed the ruling. In November 1988, the Missouri Supreme Court in a 4-to-3 decision overruled the decision of the lower court—Nancy Cruzan's parents would not be allowed to disconnect the feeding tube.

The court focused on the state's living-will statute. The law permits the withdrawing of artificial life-support systems in cases in which individuals are hopelessly ill or injured and there is "clear and convincing evidence" this is what they would want done. The act specifically forbids the withholding of food and water. Judge Teel's reasoning in the lower court decision was that the surgically implanted tube was an invasive medical treatment and that the Missouri law permitted her parents, as guardians, to order it withdrawn.

The Missouri Supreme Court held that the evidence as to what Nancy Cruzan would have wanted did not meet the "clear and convincing" standard required by the law. Also, the evidence did not show that the implanted feeding tube was "heroically invasive" or "burdensome." In the circumstance, then, the state's interest in preserving life should override other considerations.

The court found "no principled legal basis" to permit the Cruzans "to choose the death of their ward." Thus, "in the face of the state's strongly stated policy in favor of life, we choose to err on the side of life, respecting the right of incompetent persons who may wish to live despite a severely diminished quality of life." William Colby, the Cruzans' attorney, appealed the ruling to the United States Supreme Court, and for the first time the Court agreed to hear a case involving "right to die" issues.

Supreme Court Decision

On June 25, 1990, the Supreme Court issued a landmark ruling. In a 5-to-4 decision, it rejected Colby's argument that the Court should overturn as unconstitutional the State of Missouri's stringent standard requiring "clear and convincing evidence" as to a comatose patient's wishes. The decision came as a cruel disappointment to Nancy Cruzan's parents, because it meant they had lost their case.

Yet for the first time in U.S. judicial history, the Court recognized a strong constitutional basis for living wills and for the designation of another person to act as a surrogate in making medical decisions on behalf of another. Unlike the decisions in *Roe v. Wade* and *Quinlan*, which found a right of privacy in the Constitution, the Court decision in *Cruzan* appealed to a Fourteenth Amendment "liberty interest." The interest involves being free to reject unwanted medical treatment. The Court found grounds for this interest in the common-law tradition, according to which, if one person even touches another without consent or legal justification, then battery is committed.

The Court regarded this as the basis for requiring that a patient give informed consent to medical treatment. The "logical corollary" of informed consent, the Court held, is that the patient also possesses the right to withhold consent. A difficulty arises, though, whe a patient is in no condition to give consent. The pro lem becomes one of knowing what the patient's wishes would be.

Justice Rehnquist, in the majority opinion, he that the Constitution permits states to decide on standard that must be met in determining the wishes of a comatose patient. Hence, Missouri's rigorous standard that requires "clear and convincing proof" of the wishes of the patient was allowed to stand. The Court held that it was legitimate for the state to err on the side of caution, "because an erroneous decision not to terminate treatment results in the maintenance of the status quo," while an erroneous decision to end treatment "is not susceptible of correction."

Justice William Brennan dissented strongly from this line of reasoning. He pointed out that making a mistake about a comatose patient's wishes and continuing treatment also has a serious consequence. Maintaining the status quo "robs a patient of the very qualities protected by the right to avoid unwanted medical treatment."

Justice Stevens, in another dissent, argued that the Court's focus on how much weight to give previous statements by the patient missed the point. The Court should have focused on the issue of the best interest of the patient. Otherwise, the only people eligible to exercise their constitutional right to be free of unwanted medical treatment are those "who had the foresight to make an unambiguous statement of their wishes while competent."

One of the more significant aspects of the decision was that the Court made no distinction between providing nutrition and hydration and other forms of medical treatment. One argument on behalf of the state was that providing food and water was not medical treatment. However, briefs filed by medical associations made it clear that determining the formula required by a person in Nancy Cruzan's condition and regulating her feeding are medically complex procedures. The situation is more comparable to determining the contents of an intravenous drip than to giving someone food and water.

The Missouri living-will statute explicitly forbids the withdrawal of food and water. However, the law was not directly at issue in the *Cruzan* case, because Nancy Cruzan's accident occurred before the law was passed. The Court's treatment of nutrition and hydration as just another form of medical treatment has since served as a basis for challenging the constitutionality of the Missouri law, as well as laws in other states containing a similar provision.

The Supreme Court decision placed much emphasis on the wishes of the individual in accepting or rejecting medical treatment. In doing so, it underscored the importance of the living will as a way of indicating our wishes, if something should happen to render us incapable of making them known directly. In some states, though, living wills have a legal force only when the individual has a terminal illness (Nancy Cruzan did not) or when the individual has been quite specific about what treatments are unwanted. Because of such limitations, some legal observers recommend that individuals sign a durable power of attorney designating someone to make medical decisions for them if they become legally incompetent.

The Court decision left undecided the question of the constitutionality of assisted suicide. Some state courts have held that, although individuals have a right to die, they do not have a right to the assistance of others in killing themselves. While more than twenty states have passed laws against assisted suicide, only Oregon has made it legal for physicians to prescribe drugs to help patients end their lives.

A Final Court Ruling

What of Nancy Cruzan? The State of Missouri withdrew from the case, and both the family's attorney and the state-appointed guardian filed separate briefs with the Jasper County Circuit Court asking that the implanted feeding tube be removed. A hearing was held to consider both her medical condition and evidence from family and friends about what Nancy Cruzan would wish to be done. On December 14, 1990, Judge Charles Teel ruled that there was evidence to show that her intent, "if mentally able, would be to terminate her nutrition and hydration," and he authorized the request to remove the feeding tube.

Even after the tube was removed, controversy did not end. About twenty-five protesters tried to force their way into Nancy Cruzan's hospital room to reconnect the feeding tube. "The best we can do is not cooperate with anyone trying to starve an innocent person to death," one of the protest leaders said.

Twelve days after the tube was removed, on December 26, 1990, Nancy Cruzan died. Her parents, sisters, and grandparents were at her bedside. Almost eight years had passed since the accident that destroyed her brain and made the remainder of her life a matter of debate.

"We all feel good that Nancy is free at last," her father said at her graveside.

The *Cruzan* decision, by acknowledging a "right to die" and by finding a basis for it in the Constitution, provides states with new opportunities to resolve the issues surrounding the thousands of cases as tragic as Nancy Cruzan's.

Social Context

Physician-Assisted Suicide in Oregon

On March 24, 1998, an anonymous woman in her mid-eighties became the first person known to choose physician-assisted suicide under an Oregon law authorizing physicians to prescribe drugs that terminally ill patients can use to end their lives.

The woman, who lived in Portland, died shortly after swallowing a lethal dose of barbiturates, which she washed down with a glass of brandy. She was suffering from metastatic breast cancer and had been given less than two months to live. In an audiotape she made two days before her death, she said she "looked forward" to her coming suicide, because "I will be relieved of all the stress I have." She said she had grown tired of fighting cancer and had trouble breathing and walking. "I can't see myself living a few more months like this," she said. She died about half an hour after taking the prescribed drugs.

She may not have been the first person to commit suicide under the provisions of the law. The law allows for strict privacy, and the woman's death was made public, with her consent, by an advocacy group that supports the law.

The Law

Oregon's 1994 "Written Request for Medication to End One's Life in a Humane and Dignified Manner" or Death With Dignity Act is the first (and so far only) physician-assisted suicide measure passed by any state. The law does not permit a physician to play an active role in ending a patient's life. The major provision of the measure is that it allows physicians to prescribe lethal drugs for terminally ill patients without risking criminal prosecution.

The law spells out a set of conditions that must be met by patients and physicians:

1. A primary-care physician and a consulting physician must both agree that the patient has six months or less to live.
2. The patient must make two oral requests (at least forty-eight hours apart) for drugs to use to terminate his or her life.
3. The patient must wait at least fifteen days after the initial oral request, then make a written request to the physician.
4. If either physician thinks the patient has a mental disorder or is suffering from impaired judgment from depression, they must recommend the patient for counseling.
5. The patient can terminate the request at any time during the process.

Under the law, a physician is not permitted to assist a patient to die by any means more active than prescribing a drug that can cause death and indicating the manner in which the drug can be used. Hence, such practices as lethal injections remain as illegal as before.

A Long Time Coming

In 1994 the Oregon law was approved by the slight margin of 52 to 48 percent of voters. Opponents of the law immediately challenged it in court. The legal wrangles took three years, then in 1997 the opponents mounted an effort through a voter initiative to have it repealed. The effort failed, and the law was approved once more—this time by 60 percent of the voters.

Despite voter approval, physicians were uncertain about what might happen to them if they acted in accordance with the law and assisted a patient in killing himself. Thomas Constantine, then the head of the Drug Enforcement Administration, responding to pressure by two conservative members of Congress, announced that the agency would impose severe sanctions on any physician who prescribed lethal doses of drugs Constantine claimed that prescribing drugs fo use in suicide wasn't a legitimate medical use under the federal drug laws. The DEA canno cancel a physician's license to practice medicine, but it can withdraw a physician's license to prescribe drugs. Thus the DEA threat to physicians was very real.

The DEA warning kept the law from being implemented until June 1998. Attorney General Janet Reno said that the DEA threat to prosecute physicians had been issued without her knowledge or consent. Because the DEA is a branch of the Justice Department, Reno's statement thus removed a legal roadblock. Overruling Constantine, Reno said that the drug laws were intended to block illicit drug dealing and that there was no evidence that Congress ever meant for the DEA to play a role in resolving the moral problems presented by the Oregon law.

The law explicitly protects only physicians from prosecution. Hence, it leaves in doubt the legal status of nurses. Many terminally ill patients are paralyzed or too weak to take prescribed medications without assistance. Nurses typically help patients take prescribed medications, but what if they help the patient take a lethal dose of drugs? Does this make them liable for legal prosecution?

Also, from a moral point of view, if a nurse is opposed to euthanasia or suicide, does the general responsibility he has to assist a patient require him to help the patient take a lethal drug? Nurses in Oregon are facing these questions, although few (if any) have had to deal with them in a practical way.

Some Oregon pharmacists also have trouble with the physician-assisted suicide law. Because they must fill the prescriptions written by physi- ians, the law makes them, to an extent, partici- ants in the suicide. Some have argued that drugs rescribed for potential use in a suicide should be beled as such on the prescription. That way harmacists who object to assisted suicide can oid becoming involved in one. The prescription uld be filled by some other pharmacist.

Physicians object to this proposal, though. ey point out that if prescriptions were labeled potential suicide agents, the patient's confi- tiality would be violated. Particularly in small ns, if word got out, the families of those who chose assisted suicide might become the targets of criticism or demonstrations by opponents of assisted suicide.

In March 1998, Oregon state officials decided to make physician-assisted suicide available to low-income residents under the state's Medicaid program. The state will have to bear the full cost, however, because by law federal funds cannot be used to pay for physician-assisted suicide.

Critics claim that this use of state funds is a tacit endorsement of suicide, but supporters claim it is only an extension of the "comfort care" already covered by Medicaid. Many who believe state mental-health services are underfunded think that supporting physician-assisted suicide is a serious mistake. It suggests to patients that death is the only help available to them.

Is the Law Needed?

Proponents of the Oregon law would like to see other states pass similar legislation. They point out that terminally ill people who decide to end their lives are often frustrated in carrying out their wishes, even though the society has endorsed in principle a "right to die."

The federal Patient Self-Determination Act requires hospitals to inform patients that they have the right to refuse or discontinue treatment and that by means of living wills and powers of attorney for health care, they can put their decisions into practice. The Supreme Court in the *Cruzan* decision (see the Case Presentation) implicitly acknowledged a "right to die," by allowing the withdrawal of life-sustaining treatment when "clear and compelling evidence" shows that this reflects an individual's wish. Yet despite the legal possibility of exercising control over medical care during the last stages of one's life, various barriers stand in the way of actual control.

Right to Discontinue Care. Surveys of physicians and health-care workers show that many are not aware of laws allowing them to withhold or discontinue such care as mechanical ventilation, kidney dialysis, and even feeding tubes. Many believe that once a treatment has been started, it is illegal to discontinue it. Courts have repeatedly upheld the right of individuals to decide that, at a certain point in their treatment, they do not want to be provided with food or water, yet in one survey 42 percent of health-care workers rejected this as an option patients could choose.

Oral Instructions. Many physicians and hospitals simply ignore the oral instructions patients give them about discontinuing their care. In one study of more than 4000 seriously ill patients, researchers found that although a third of the patients asked not to be revived by cardiopulmonary resuscitation, 50 percent of the time "Do not resuscitate" was never written in their charts.

Advance Directives. The living wills or powers of attorney made out by patients may not be followed. In a 1997 study of 4804 terminally ill patients, only 688 had written directives, and only 22 of these contained instructions explicit enough to guide the care they received. Even these instructions were ignored about half the time, and physicians knew about the patient's instructions only about a quarter of the time.

Also, advance directives are sometimes not included among the documents constituting a patient's medical chart. In another study, when 71 patients were moved to a nursing home, 25 of them had living wills that were not sent with them.

As a result, despite the efforts patients may make to control what happens to them at the end of their lives, they may be forced to accept decisions about their care made by physicians or nurses in accordance with their own values or institutional policies.

Patient vs. Family. Families may override the wishes expressed by patients in their living wills. Even though the views of the patient take legal precedence over those of a relative, in practice a physician or hospital may do as the relative wishes. Families never sue because of the overtreatment of a patient, but they do because of withholding or discontinuing treatment.

Physician-Assisted Suicide

"If a person has a disease that will ultimately destroy their mind or body and they want to take their own life, should a doctor be allowed to assist the person in taking their own life, or not?"

	Yes	No
2004	46%	45%
1998	52%	48%
1993	58%	36%

n = 885

Source: CBS News Poll, 24 November 2004

Laws like the one in Oregon are viewed by many as the only way patients can be sure that in the final days of their lives they can exercise control. Many fear that if they enter a hospital, they cannot trust nurses and physicians to know their wishes and to respect them.

Various polls suggest that a majority of the American people favor a policy of voluntary physician-assisted suicide. When physicians have been charged with aiding the death of a terminally ill patient at the patient's request, they have typically been found not guilty or been given suspended sentences. People who cannot control their illness often take some comfort in being able to control their escape from it.

How Many Cases?

The Oregon law is written so that only Oregon residents can ask physicians to assist them in suicide under the stipulated conditions. Thus, sick people have not migrated to the state with the idea of getting a physician's help in killing themselves.

Although the way is clear for any terminally ill Oregon resident to seek help in dying, relative few people have done so. State officials reporte that in 1998, the first year under the new law, fifteen people ended their lives with drugs le prescribed for that purpose. (There were 29, deaths in Oregon that year.) The average ag the eight men and seven women was seven

Thirteen had cancer, one congestive heart failure, and the other chronic lung disease. Fourteen had lived in the state at least six months, and one had come to be with family members.

Eight other people in 1998 were certified as terminally ill and had received authorization to receive lethal doses of drugs. Six died of their diseases without taking the medications, and the other two were still alive at the end of the year. For the fifteen who acted under the law, the cause of death was listed as "Drug overdose, legally prescribed." In 2001, forty-four people obtained drugs under the Death With Dignity legislation, but only twenty-one used them. This was down from twenty-seven people the previous year, the same figure as for 1999.

The most recent figures available show that from 1998 to 2003 only 171 people ended their lives with assistance. The average age was seventy, but the range was from twenty-five to ninety-four. According to a state report, those choosing physician-assisted suicide were "not disproportionately poor, uneducated, uninsured, fearful of the financial consequences of their illnesses," or "lacking end-of-life care." The primary factor mentioned by individuals was "the importance of autonomy and personal control." Neither financial worries nor the pain of a long illness was mentioned by them as a decisive factor.

The average time to unconsciousness after taking the prescribed drugs was five minutes (with a range of one to thirty-eight), and the average time to death was twenty-five minutes.

That relatively few have taken advantage of the Oregon law may support the idea of those favoring it that most people simply want to know that if they are terminally ill and in pain, a way out is available to them. To this extent, then, the Oregon experience may encourage other states to allow physician-assisted suicide. So far, however, the Oregon law remains unique.

Supreme Court Rejects Federal Action

In November 2001, Attorney General John Ashcroft reversed the course taken by Janet Reno and sent a letter to the DEA authorizing agents to take legal action against physicians prescribing drugs for the purpose of ending the lives of terminally ill patients. Ashcroft held that "prescribing, dispensing or administering federally controlled substances to assist suicide" is "not a legitimate medical purpose." Ashcroft's successor, Alberto Gonzales, accepted the same view.

Oregon filed suit against the Justice Department, and eventually the case went to the United States Supreme Court. In January 2006, the Court upheld the decisions of two lower courts and ruled 6 to 3 that the Justice Department had acted without legal authority in attempting to restict the actions of Oregon physicians. The ruling was made on the narrow administrative ground that the regulation of medical practice is a state, not a federal, matter.

The ruling left open the possibility that Congress could pass a law explicitly forbidding the use of drugs by physicians who are assisting in a suicide. This encouraged those who disapprove of active euthanasia and discouraged those who believe that terminally ill people ought to have access to medical help in ending their lives.

Case Presentation

Dr. Jack Kevorkian: Activist and Convicted Felon

August 5, 1993, Thomas W. Hyde Jr., a thirty-
r-old *Michigan* construction worker with a wife
a two-year-old daughter, was taken inside a bat-
d white 1968 Volkswagen bus parked behind the
tment building in the Detroit suburb of Royal Oak where sixty-five-year-old retired pathologist Dr. Jack Kevorkian lived.

Dr. Kevorkian fitted a respiratory mask over Hyde's face and connected the plastic tubing leading from the mask to a short cylinder of carbon monoxide gas. Dr. Kevorkian placed a string in Hyde's hand. At the opposite end of the string was a paper clip crimping the plastic tubing and shutting off the flow of gas. Hyde jerked on the string, pulled loose the paper clip, then breathed in the carbon monoxide flowing into the mask. Twenty minutes later, he was dead.

Mr. Hyde suffered from amyotrophic lateral sclerosis (Lou Gehrig's disease), a degenerative and progressive neurological disorder. He was paralyzed, unable even to swallow, and, without suctioning, he would have choked to death on his own saliva. He reported that he was in great pain, and like hundreds before him, he approached Dr. Kevorkian to help him end his life.

In a videotape made on July 1, 1993, Mr. Hyde said to Dr. Kevorkian, "I want to end this. I want to die." Dr. Kevorkian agreed to help, and Mr. Hyde became the twentieth person since 1990 whom Dr. Kevorkian had assisted in committing suicide.

Trial

After the death of Thomas Hyde, Dr. Kevorkian was arrested and charged with violating the 1992 Michigan law that had been enacted specifically to stop his activities. The law applies to anyone who knows another person intends to commit suicide and either "provides the physical means" or "participates in a physical act" by which the suicide is carried out. However, the law explicitly excludes those administering medications or procedures that may cause death, "if the intent is to relieve pain or discomfort."

On May 2, 1994, a jury found Dr. Kevorkian innocent of the charge of assisting suicide. As one juror said, "He convinced us he was not a murderer, that he was really trying to help people out." According to another, Dr. Kevorkian had acted to relieve Mr. Hyde's pain, and that is allowed by the law.

Several jurors expressed skepticism and resentment at the attempt to legislate behavior falling within such a private sphere. "I don't feel it's our obligation to choose for someone else how much pain and suffering they can go through," one said. "That's between them and their God."

After the decision, Dr. Kevorkian reiterated his position that people have a right to decide when to end their lives. He acted, he said, to protect that right. "I want that option as I get older, and I want it unencumbered, unintimidated, free with my medical colleagues," he said. "So I did it for myself, too, just as any competent adult would want to do."

Kevorkian always insisted he practiced physician-assisted suicide only in accordance with stringent safeguards. "You act only after it is absolutely justifiable," he said. "The patient must be mentally competent, the disease incurable." He maintained that other physicians should determine that a candidate for assisted suicide was incurable and that a psychiatrist assess the patient's mental state and determine that he or she was competent. In practice, Kevorkian did not proceed in this fashion, because other physicians refused to cooperate with him.

Critics

Critics charged that without the safeguard of a psychiatric evaluation, patients who sought out Kevorkian to help them kill themselves were likely to be suffering from depression. Hence, they couldn't be regarded as having made an informed, rational decision to end their lives.

Other critics worried that if physicians are allowed to play a role in terminating the lives of patients, that role could expand. Physicians might begin by assisting those who ask their help, but then move on to making their own decisions about who should live. Or they might even be recruited to carry out a government policy identifying those who should be "assisted" in dying. The potential for abuse is so serious that physicians should not be associated in any way with procedures intended to end the lives of patients.

Finally, some critics, though disagreeing with Kevorkian, believed he had successfully pointed out a major flaw in the health-care system: The medical profession is so committed to preserving life it has not developed ways of dealing with death in cases in which it is inevitable. Rather than help people kill themselves, critics said, physicians ought to surrender the idea of treatment and concentrate on making those with terminal illnesses pain free so they can spend their remaining time enjoying the comfort of their families and friends.

It was in keeping with such an aim that hospitals and other institutions set up hospices to provide nursing care and support for the dying. Even after decades, however, hospices remain at the margins of the medical establishment, and physician associated with them are given little respect by thei colleagues.

A Charge of Murder

In 1998 the Michigan Department of Consumer a Industry Services, the state agency responsible fo licensing physicians, charged that Jack Kevorkian was practicing medicine without a license by assisting forty-two people in committing suicide. (Kevorkian said he assisted about 120 people.)

Although the agency had issued a cease-and-desist order, Kevorkian continued to help terminally ill people die. The Michigan legislature, that same year, passed a law making assisting in suicide a crime, but Kevorkian announced he would continue his activities despite the law.

In September 1998, Dr. Kevorkian administered a lethal injection to Thomas Youk, a fifty-two-year-old man in an advanced stage of the motor neuron disease ALS (amyotrophic lateral sclerosis). For the first time, Kevorkian by his own direct action caused the death of a person, thus moving from physician-assisted suicide to active euthanasia.

Kevorkian videotaped the event and offered the tape to the CBS program *Sixty Minutes,* which broadcast excerpts from the tape on national television on November 22. About 15.6 million households watched the program.

Kevorkian said he had given the tape to CBS in the hope that it would lead to his arrest and become a test case for assisted suicide and active euthanasia.

"I want a showdown," Kevorkian told a reporter. "I want to be prosecuted for euthanasia. I am going to prove that this is not a crime, ever, regardless of what words are written on paper."

On November 25, the prosecutor of Oakland County, Michigan, filed first-degree murder charges against Jack Kevorkian. David G. Gorcyca, the prosecutor, said that Dr. Kevorkian's actions clearly fit the definition of premeditated murder and that the consent of the man killed was no legal defense.

On April 13, 1999, Jack Kevorkian was found guilty of second-degree murder and sentenced to a prison term of ten to twenty-five years. "This trial was not an opportunity for a referendum," Judge Jessica Cooper said at the sentencing.

Those sympathetic to Jack Kevorkian believe he did more than anyone else to force society to face an issue it has chosen to ignore. His critics believe he made a circus of what should be a serious and deliberative discussion.

Case Presentation

A Canadian Tragedy

Robert Latimer admitted that he killed his twelve-year-old daughter Tracy by putting her in the cab of his pickup truck, then rolling up the windows and letting the engine run until the cab filled up with deadly carbon monoxide gas.

But he said he did it because he loved her.

Tracy was born with cerebral palsy, a birth disorder involving physical and sometimes mental mpairments of varying degrees of severity. A year before she died, Tracy's father said she had been "a happy little girl," living with her parents and three iblings on a 1280-acre wheat and canola farm in askatchewan, Canada. Then she had surgery that as supposed to improve her condition. Instead, it rned her into a child who was in constant agony nd who could not walk, talk, or feed herself. She lost much weight that at the time of her death she ighed only forty pounds.

Yet Tracy's doctors wanted her to have additional gery. They wanted to do extensive surgery on her to stabilize the metal rods they had inserted into back to help her stay upright. They also wanted to rt a feeding tube into her stomach, because the antiseizure medication she had to take interfered with her appetite and her digestion. That was when Bob Latimer decided Tracy would be better off dead.

Latimer was charged with second-degree murder and found guilty by a jury in 1994. The conviction was overturned on a technicality, and although he was convicted a second time, the jury made it clear they had done so reluctantly and only because they were required to consider only the facts presented in court. They took the unusual step of asking the judge to sentence Latimer to only one year in prison.

The general public was as sympathetic toward Latimer as the jury. "Bob Latimer is not a murderer, and he's no threat to society," said one of his neighbors. "It's a shame to take him away from his family and lock him up."

But advocates for the disabled did not share the jury's and public's forgiving attitude toward Latimer. In their view, he deserved to be given a stiff prison term to make it clear that the lives of severely disabled people are worth just as much as the lives of others.

"If you can make your own choice, that's a different thing," said Ron Bort, the president of the local chapter of

Voice of People with Disabilities. "For someone else to decide your life is not worth living—that's the scary part."

The point was echoed by the vice president of another advocacy group, the Canadian Association for Community Living. "Tracy Latimer did not choose to die," Diane Richler said. "She was murdered, and justice should be served."

Latimer told a reporter he had felt he had no choice. "People are saying this is a handicap issue, but they're wrong," he said. "This was a torture issue. It was about mutilation and torture for Tracy. She had bedsores, she was in pain all the time, and she wasn't eating well. With the combination of a feeding tube, rods in her back, her leg cut and flopping around, and bedsores, how can people say she was a happy little girl?"

Latimer said he and his wife were never concerned with any legal problems he might have by causing Tracy's death. "We were just concerned with Tracy," he said.

The Canadian Senate debated in 1995 the question of whether a special category should be introduced into the criminal code to cover cases of "mercy killing" like that carried out by Robert Latimer. While a recommendation for such a change was drafted, the law was never changed.

Consequently, despite the jury's wishes, Robert Latimer's conviction of second-degree murder carried with it a mandatory sentence of twenty-five years in prison, with no possibility of parole until after ten years.

Case Presentation

Rip van Winkle, for a Time: Donald Herbert

In 1995, Donald Herbert was thirty-four years old and a member of the Buffalo, New York, fire rescue squad. On the morning of December 29 of that year, he raced into a burning apartment building and began searching the attic for potential victims. The smoke was thick, but he wore a breathing apparatus.

Suddenly, without warning, the roof of the burning building collapsed. Herbert's breathing mask was knocked off, and he was buried under flaming debris. His fellow firefighters realized what had happened, but by the time they could reach him, he had been without oxygen for at least six minutes. His rescuers pulled him through a window, then rushed him to the Erie County Medical Center.

Herbert's condition was critical. In addition to oxygen deprivation, he had suffered severe head trauma. He remained in a coma for two and a half months. He regained consciousness in 1996, but his speech was slurred, he couldn't feed himself, his vision appeared to be damaged, and he was confined to a bed or wheelchair. He didn't know his age or what his job had been. He seemed unable to recognize his wife and children or his relatives and old friends. Because he could not care for himself, Herbert was removed to Baker Manor, a nursing home in a Buffalo suburb.

Awakening

On a Saturday morning in May 2005, Donald Herbert suddenly recovered his memory. "I want to talk to my wife," Herbert said to a nursing home employee. The employee called his home, but it was his thirteen-year-old son Nicholas who answered. "That can't be," Herbert said. "He can't talk, he's just a baby."

Herbert was soon surrounded by his wife Linda, his four sons, various relatives, and several old friends. For fourteen hours, they hugged and kissed him, talked to him, and rejoiced in his recovery. Herbert asked questions, especially about his sons. "He wouldn't go to sleep," his mother-in-law said. "He stayed up all night talking to his sons."

"How long have I been gone?" he asked.

"We told him almost ten years," his uncle Simon Manka, recalled. "He said, 'Holy Cow!' He thought it had been three months." While Herbert was unconscious, cell phones became common, e-mail use spread worldwide, the attack of 9/11 occurred, and the United States went to war in Iraq. His oldest son turned twenty-four, and many of his fellow firefighters retired.

Mr. Manka told reporters that Herbert recognized several family members and friends and called them by name. He was completely different than he had been. "He was asking questions, and he'd recognize a voice." He recognized the voices of the members of the rescue crew he'd served with, even though he couldn't see the people.

Hearing her husband speak was "completely overwhelming," Linda Herbert said. "We are still trying to cope with this incredible experience."

A Change

Three days after his startling recovery, Donald Herbert began to become less animated. He still engaged in conversation, but his periods of clarity became less frequent. He spent most of his time sleeping, and his family and friends made an effort not to tire him.

His doctor, Jamil Ahmed, said that Herbert's condition had been close to a persistent vegetative state, one in which he appeared to be awake but was unaware of what was going on around him. He seemed to have laid down some memories during this period, however, because he was able to recognize the names of some of the nursing home staff. The big change in Herbert took place three months after his medication was changed. The drug combination that he took had shown beneficial results in patients with more recent brain injuries. The drugs combined are more often used individually to treat patients with Parkinson's disease, attention deficit disorder, and depression.

On February 22, 2006, Donald Herbert died. He never left the nursing home, but he continued to interact to a limited degree with his family and friends until the end of his life. As recently as the week before his death, he was playing catch with his youngest son. Herbert developed pneumonia that weekend, and although he was treated with antibiotics, he failed to recover.

"He was never as good as he was when he first woke up," Michael Lombardo said. "But he was pretty good right up to the end."

Cases of people with severe brain damage making what seem to be miraculous recoveries of self-consciousness and memory occur from time to time, but they are extremely rare. When such cases are publicized, they encourage people who love someone diagnosed with a severe brain injury to believe that recovery is likely. Sadly, these hopes are almost never realized.

Social Context

Physician-Assisted Suicide: The Dutch Experience

In 2000 the Dutch Parliament passed a law establishing specific rules to allow physicians to assist in the suicide of a terminally ill patient or to kill the patient at the patient's explicit request without risking criminal prosecution. The new law gave a legal status to a practice that had already been followed in the Netherlands for almost fifteen years.

Under a 1993 act, ending a patient's life or assisting in suicide remained illegal, although the law provided physicians with protection from prosecution if they followed the provisions of the law. The Dutch criminal code previously provided as much as twelve years in prison for anyone who "takes the life of another at his or her explicit and erious request."

In a 1972 case involving a physician who put er mother to death at the mother's request, owever, a court refused to impose a penalty. nce then and with the reenforcement of a ma- court decision in 1984, the extralegal practice voluntary, active, physician-administered eu- nasia became established in the Netherlands. The new legislation made the Netherlands the first nation to legalize assisted suicide.

Conditions

The 2000 law, following the provisions of the 1993 legislation, requires that a physician follow an extensive checklist to avoid prosecution. The safeguards built into the law include the following:

1. *Patient-initiated request.* The physician must be convinced that the patient's request for euthanasia is "voluntary and well-considered." The request must be made entirely of the patient's own free will and not under pressure from others, including family, friends, or physicians. The patient must make the request personally; relatives cannot make a request on behalf of a patient.
2. *Patient competence.* At the time of the decision, the patient must be in a rational state of mind and able to make informed

decisions. Those who suffer from dementia or are in a coma are not candidates for euthanasia.

3. *Patient understanding.* The patient must have a correct and clear understanding of his or her situation and prognosis.
4. *Informed as to alternatives.* The patient must be informed about alternatives to assisted-suicide or euthanasia. The patient should then be encouraged to discuss them with physicians, family, and advisors.
5. *Enduring decision.* Requests to physicians made on impulse or ones that may be the result of depression cannot be regarded as legitimate.
6. *Unbearable suffering.* "The patient must experience his or her suffering as perpetual, unbearable, and hopeless." The physician must be able to make the reasonable judgment that the suffering the patient is experiencing is unendurable. The patient's condition does not have to be terminal.
7. *Professional consultation.* The physician must consult with at least one other physician who has had experience in dealing with patients requesting euthanasia or help in dying.
8. *Medically appropriate.* The physician must end the patient's life in a medically appropriate manner.
9. *Government report.* The physician must submit a report to the government in which the patient's medical history is presented and the physician declares that all the conditions required for assisting in suicide or performing euthanasia have been observed.

The patient must also sign a witnessed explicit authorization for the act to be carried out. Typically, the physician then injects a barbiturate to induce sleep, combined with curare to produce death.

Minors Excluded

Part of the initial bill would make it possible, in exceptional cases, for minors between the ages of twelve and sixteen to request euthanasia against the wishes of their parents. This provision of the bill was strongly criticized and was eventually withdrawn. Critics have since charged that by omitting the provision, young children and infants have been denied a way to end suffering that is open to people above the age of sixteen. Some physicians have pressed, in particular, for making active, physician-assisted euthanasia legally possible for newborns with a hopeless prognosis who suffer from severe pain. (See Chapter 10 for a discussion.)

Statistics

Two studies published in 2003 (the most recent) suggested that the demand for euthanasia and physician-assisted suicide is stabilizing in the Netherlands. One study involved reviewing patient records from sixty general medical practices, the same sixty that had been reviewed yearly from 1977 to 2001. (The 2000 law legalizing assisted suicide didn't take effect until 2001.)

The data suggested that in the late 1970s about 1500 terminally ill patients each year asked for an assisted death. By 1985, the number had increased to 4000. The rise then slowed, and after 1995, the number leveled off. By 2001, about 5000 people a year asked for assistance, and most of these were people with metastatic cancer. These figures were confirmed by a survey of 400 general-practice physicians, specialists, and nursing-home physicians. Requests for euthanasia, the survey suggested, rose by 30 percent from 1990 to 1995, then barely altered by 2001.

The second 2003 study found that only about 5000 deaths a year in the Netherlands result from a physician's administering a drug, at the patient's request, with the deliberate intention of killing the patient. The number of deaths per year in Holland is about 140,000, so this amounts to only 3.5 percent of the total deaths.

Rather than physician-assisted suicide, Dut citizens appear to be choosing different approach The second study found that in 40 percent of deaths in 2001 physicians either gave a pain that might shorten a patient's life or ceased active treatment and allowed the patient to

Despite the fears of many people critical of physician-assisted suicide, the Dutch law has not proved to be a slippery slope leading to involuntary euthanasia. Indeed, almost paradoxically, the legalization of physician-assisted suicide seems to have reduced the demand for it.

No Right

Although the Dutch law decriminalized euthanasia, it does not recognize a right to euthanasia. Physicians have a right to refuse to cooperate if asked to assist in a suicide, even if the conditions required by the law are satisfied. Surveys suggest that as many as two-thirds of the people who ask physicians to end their lives are turned down.

One difficulty with the new law is that it is unclear about how to deal with cases in which someone has made a request for assisted suicide while of sound mind, then comes to suffer dementia. Should the request be honored? The Dutch Ministry of Health has explicitly stated that dementia itself cannot be ground for assisted suicide. The patient would have to be suffering from intolerable pain and a very early stage of dementia for a request to be acted on.

Model for the United States?

Dutch practice and laws are often mentioned in the United States as an example of what a reasonable euthanasia policy might include. In particular, the practice is offered as a model for providing an option to continuing treatment of individuals suffering from a lingering terminal illness. People suffering from the intractable pain of terminal cancer or the steady physical deterioration of ALS, for example, have often expressed a wish for a social and legal policy that would permit active, voluntary euthanasia or assisted suicide. These are just the sort of people the Dutch practice has evolved to deal with.

The medical-care situation in the United States, however, is different in what may be considered a relevant and important way. Dutch citizens are almost universally participants in health plans that cover their medical costs. Hence, individuals are not under economic pressures to make decisions about ending their lives. They need not worry that they are running out of insurance coverage or may be bankrupting their families by remaining alive.

Furthermore, the Dutch practice does not deal with the type of cases that have caused much concern and controversy in this country. Until recently, the proper treatment of individuals in irreversible comas or persistent vegetative states, as in the Quinlan, Cruzan, and Schiavo cases, has been at the focus of dispute. Since the practice in Holland requires that individuals be conscious and intellectually competent, it embodies no principles that could be appealed to for resolving the troublesome issues involved in dealing with those in persistent vegetative states.

Nevertheless, the Dutch experience may still be valuable in showing whether it is possible to have a social policy permitting assisted suicide and voluntary euthanasia without the abuses or corruption of medical power feared by critics.

READINGS

Section 1: The Case Against Allowing Euthanasia and Physician-Assisted Suicide

he Wrongfulness of Euthanasia

Gay-Williams

Gay-Williams defines *euthanasia* as intentionally taking the life of a person
o is believed to be suffering from some illness or injury from which recovery
not reasonably be expected. Gay-Williams rejects passive euthanasia as a