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PHYSICIAN-ASSISTED SUICIDE AND EUTHANASIA

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Physician-Assisted Suicide and Euthanasia

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CHAPTER 1

INTRODUCTION TO EUTHANASIA

Supporters call it the ultimate civil right. Opponents link it with the Holocaust. As the 21st century dawns, euthanasia (from Greek words meaning "good death") has joined abortion as one of the most painfully divisive issues in the developed world. The ethical issues raised by the debate about euthanasia reach to the very roots of human mortality and compassion. Federal Ninth Circuit Court judge Stephen Reinhardt, in his historic 1996 decision on the right-to-die case *Compassion in Dying et al. v. State of Washington*, said that this debate

> *requires us to confront the most basic of human concerns—the mortality of self and loved ones—and to balance the interest in preserving human life against the desire to die peacefully and with dignity. . . . [This] controversy . . . may touch more people more profoundly than any other issue the courts will face in the foreseeable future.*[1]

The movement to legalize some form of euthanasia has often been called the right-to-die movement. The name seems strange, since nothing is more unquestionably guaranteed to everyone than death. What the movement's supporters want to protect is not really the right to die but the right to have some degree of control over the time and manner of one's death—as one group puts it, "the right to choose to die." They believe that competent adults with less than six months to live should be legally permitted not only to refuse life-sustaining medical treatment but also to receive a physician's help in ending their lives if they request it. Some right-to-die supporters feel that people who have an incurable degenerative or disabling condition should also be allowed to ask for aid in dying, even though their illness is not terminal.

People who oppose the movement, on the other hand, say that no individual's right outweighs the state's duty to protect life and the physician's duty not to harm patients. They fear that if physician-assisted suicide or euthanasia is legalized, society will slide down a "slippery slope" toward coercing and even perhaps forcing vulnerable members—the elderly, chronically ill, disabled, poor, and minorities—to die against their will. The so-called right to die, they say, will become a duty to die.

Aid in dying can take several forms. Distinguishing among them is important because some individuals or groups support some forms but not others, and state and national laws also often make such distinctions. One form is passive euthanasia, or "letting die": ceasing or not starting medical treatment that keeps a person alive, such as attachment to a respirator or provision of food and water through a tube. Another is assisted suicide, in which a physician or, sometimes, a family member or friend provides the means for a person with a terminal or incurable illness to end life, but the patient is still the one who performs the final act. The third is active euthanasia, in which someone (usually a physician) causes the death of a sick person without that person's participation. Active euthanasia can be either voluntary (done at the sick person's request) or involuntary (done without the person's concurrent request or permission). Some groups also distinguish between nonvoluntary and involuntary euthanasia, using *nonvoluntary euthanasia* to refer to euthanasia of people incompetent to consent to the act (though they may have given permission for it or requested it at an earlier time, when they were when competent) and *involuntary euthanasia* to refer to the "mercy killing" of competent adults who are suffering but have not requested death.

The right of competent adults to refuse medical treatment, including medical treatment that sustains life, is legally recognized today in all states of the United States and in most other Western countries. The right of designated surrogates to refuse such treatment on behalf of incompetent but formerly competent adults who left prior instructions to do so in the form of living wills or other advance directives is also widely recognized. Some states allow surrogates to refuse life-sustaining treatment on behalf of never-competent individuals as well. Physician-assisted suicide, on the other hand, is legal in only one state (Oregon) and legal or openly practiced in only a few other countries, chiefly the Netherlands. Active euthanasia, even if voluntary, is even more rarely legalized. It is not legal anywhere in the United States.

Even though they seldom have an explicit legal right to do so, survey after survey makes clear that, under certain circumstances, physicians regularly if clandestinely do assist death, just as they surely have throughout history. Of 355 American oncologists (cancer specialists) interviewed in 1998, for example, 56 (15.8 percent) admitted having carried out physician-assisted suicide or euthanasia. *New England Journal of Medicine* executive editor Marcia Angell claimed in March 1999 that at least 15,000 physician-assisted deaths take place in the United States each year, and the Death with Dignity Education Center places the number at 7,000 a month. Many of these assisted deaths take the form of terminal sedation or what is often called the "double effect," in which a physician gives high doses of narcotics primarily for the purpose of controlling pain but knows that such doses will also shorten or perhaps even end a terminally ill patient's life. "This is the dirty little secret of medicine," says internist Howard Grossman of the St. Lukes-Roosevelt Hospital at Columbia University. "This is the tremendous burden that physicians have carried with them for a long, long time, the fact that they already help people [to die]."[2]

HISTORICAL ATTITUDES TOWARD SUICIDE AND EUTHANASIA

Feelings and laws about euthanasia, especially in the form of physician-assisted suicide, are closely related to those concerning suicide in general. Both have changed considerably throughout history. The ancient Greeks, for example, believed that suicide could be acceptable or even honorable under certain conditions, one of which was escaping the pain of an untreatable illness. In some Greek city-states, including Athens, people could even request government help in killing themselves. The state could also order suicide as a punishment for crimes, as happened most notably in the case of the philosopher Socrates, whom Athenian magistrates commanded to drink poison hemlock in 399 B.C. after convicting him of corrupting the city's youth with his teachings. Socrates accepted his death sentence calmly; indeed, in *Phaedo*, the account his student Plato wrote of Socrates' death, the philosopher is quoted as saying, "True philosophers make dying their profession."[3]

In spite of such statements, neither Socrates nor Plato encouraged people to seek death. They disapproved of suicide under most circumstances, although they agreed that it might be forgiven as a kind of temporary insanity if it was a response to "intolerable . . . misfortune" such as incurable illness.[4] Plato's student Aristotle spoke out even more strongly against suicide, calling it an act of cowardice in his *Ethics*.

On the other hand, a school of Greek and Roman philosophers called the Stoics offered eight different motives for which suicide was acceptable, including terminal or degenerative illness. Seneca, a Roman Stoic philosopher, wrote, "I will not relish old age unless it leaves my mind intact. . . . If

I know when I will suffer forever, I will depart. . . . Just as I choose a ship to sail in or a house to live in, so I choose a death for my passage from life."[5] Even the Stoics, however, considered only a few motives for suicide to be heroic, and the desire to escape painful illness was not one of them.

This relative tolerance for suicide ended when Christianity became the dominant religion of the Western world. Although nothing in the Bible explicitly forbids suicide, Judaism condemns it (as does Islam), and such condemnation became part of the doctrine of the early Christians as well. St. Augustine, bishop of Hippo in the early fifth century, expressed the Church's attitude very plainly when he called suicide a "detestable and damnable wickedness."[6] Unless done at the specific command of God, Augustine wrote, self-murder violated the sixth commandment, "Thou shalt not kill."

St. Thomas Aquinas, drawing on the writings of Aristotle as well as Augustine, expanded on this position in the 13th century by claiming that suicide was a sin against God because only God had the right to take back the gift of life that He had given. Indeed, he wrote, suicide was the worst of sins because it left no time for repentance. Aquinas said that suicide was also a sin against society because it deprived the community of useful people. The writings of Aquinas, along with those of Augustine and other church leaders, defined the prevailing Western view of suicide for hundreds of years. They still underlie most Christian objections to assisted suicide and euthanasia.

The Renaissance, with its reemphasis on the culture of the ancient world and on the importance of human beings and earthly life, brought the first stirrings of a return to the idea that people might be entitled to exert some control over the manner of their death. The ideal society described in Sir Thomas More's *Utopia* (1516), for example, encouraged assisted suicide to end painful and incurable illness. Ethicist Michael M. Uhlmann points out, however, that *Utopia* was partly satirical, so statements in the book may not have represented the personal feelings of More, who was a devout Catholic and thus unlikely to favor an action of which the Catholic Church so strongly disapproved.

Some Enlightenment intellectuals also accepted suicide, at least under some circumstances. The 16th-century French essayist Michel de Montaigne and the 17th-century English poet John Donne are among those whose writings suggest that they condoned suicide. In *Biathanatos*, Donne offered an explicit defense of suicide and a refutation of the reasoning behind the Christian prohibition of the act.

In an essay published in 1777, a year after his death, Scottish philosopher David Hume stated even more clearly than Donne that suicide "is no transgression of our duty to God," especially in the case of people who are already dying. Regarding Aquinas's claim that suicide shirked one's duty to the community, Hume wrote, "I am not obliged to do a small good to society at the expense of a great harm to myself: when then should I prolong a miserable existence because of some frivolous advantage which the public may perhaps receive from me?"[7] According to Hume, suicide to end a life of severe illness or disability, in which one can contribute little or nothing to society and is enduring intolerable suffering, not only is acceptable but may even confer a net social benefit.

On the other hand, Hume's contemporary, German philosopher Immanuel Kant, opposed suicide because, he said, its motive was self-interest, which he did not consider a justifiable reason for an action. Kant also believed that suicide showed a disrespect for life. He agreed with Aquinas that the act usurped a power that belonged only to God and violated one's duty as a created being: "Human beings are sentinels on earth and may not leave their posts until relieved by another beneficent hand. God is our owner; we are His property."[8]

For centuries, suicide was against the law in most countries as well as proscribed by religion. Antisuicide laws usually required the heirs of a suicide to forfeit some or all of the person's property to the state. Such laws began to be withdrawn in the 19th century, not because people found suicide any more morally acceptable than before, but because they came to feel that punishing the suicide's family was unfair. Suicide was further decriminalized in the 20th century because the act came to be seen primarily as a result of mental illness. Suicide and attempted suicide are no longer against the law in any state of the United States.

On the other hand, assisting in a suicide, even that of a terminally or incurably ill person, has always been illegal in most states. In 1872, for example, the Ohio Supreme Court ruled in the case of a man who had made poison available to such a person:

> *It is immaterial whether the party taking the poison took it willingly . . . or was overcome by force. . . . The life of those to whom life has become a burden—of those who are hopelessly diseased or fatally wounded . . . are under the protection of the law equally as the lives of those who are in the full tide of life's enjoyment.*[9]

Euthanasia, in its modern meaning of "mercy killing," was even more surely illegal: technically, it was simply a form of murder. The term was coined by the English philosopher and statesman Sir Francis Bacon in the early 17th century, but Bacon used it only to describe the painless, peaceful natural death that people hoped to have. Its meaning changed in the 20th century.

Illegal and nameless though it might have been, euthanasia in its present meaning has no doubt always existed. Although family members or friends might occasionally have killed sick people to end their suffering, that unhappy task, in ancient times as well as today, was most likely to be performed by a physician. Physicians are uniquely well placed to assist suicide or perform euthanasia for their patients because of their medical skills and access to painlessly lethal drugs. Whether doing so is an extension of the physician's role as healer and comforter or the ultimate violation of it has been hotly debated.

By far the best known ancient statement about such activity is found in the Hippocratic Oath, which many doctors still take when they graduate from medical school. Part of the oath reads, "I will [not] give a deadly drug to anybody if asked for it, nor will I make a suggestion to that effect."[10] Although this oath is often considered to be the ultimate statement of the physician's moral creed, Michael Uhlmann points out that Hippocrates, the Greek physician of the fourth century B.C. to whom the oath is credited, was not expressing the common medical viewpoint of his time. Hippocrates' views were probably derived from those of the philosopher Pythagoras, who held (as Christian theologians also later would) that human souls contained sparks of divinity and thus should not be wantonly destroyed.

During the Christian era, physicians probably were as repelled as anyone else by the idea of deliberately hastening death under most circumstances. Nonetheless, despite the official disapproval of church, law, and their profession, some doctors—perhaps even a majority—once in a while quietly speeded a suffering patient's dying process by drugs or other means. Beginning in the late 19th century and increasingly as the 20th century progressed, a few physicians dared to mention this hidden practice in print and even to demand that it be given legal sanction.

ASSISTED SUICIDE AND EUTHANASIA IN THE 20TH CENTURY

The first attempt to legalize voluntary euthanasia performed by physicians in the United States was a bill introduced into the Ohio legislature in 1906. According to a contemporary newspaper, the bill proposed that

> *when an adult of sound mind has been fatally hurt and is so ill that recovery is impossible or is suffering extreme physical pain without hope of relief, his physician, if not a relative and if not interested in any way in the person's es-*

> *tate, may ask his patient in the presence of three witnesses if he or she is ready to die. . . . Three other physicians are to be consulted.*[11]

If the patient acquiesced and the other physicians agreed about the person's medical condition, the doctor could provide a painless death. The bill called this act *euthanasia*, applying the term, perhaps for the first time, to the deliberate causing of death in order to relieve suffering.

The bill met powerful opposition. An editorial warned of many of the same dangers that opponents bring up in connection with physician-assisted suicide and euthanasia today, including the possibility that people would use such a law to rid themselves of burdensome relatives or gain inheritances. It also claimed that such a law would destroy the trusting relationship between patient and doctor, so that "the patient would look forward to the visit of the physician with dread."[12] When the bill was sent to the legislature's Committee on Medical Jurisprudence, it failed by a vote of 78 to 22.

Another important effort to legalize voluntary euthanasia was made in Great Britain in the 1930s. C. Killick Millard, health officer for the city of Leicester, drew up a draft bill for this purpose in 1931, and the British Voluntary Euthanasia Society was formed in 1935 to promote the bill. Although it did not use the term, the society was essentially the world's first right-to-die organization. Its members included such prominent figures as H. G. Wells, George Bernard Shaw, and Bertrand Russell. Nonetheless, when the bill was introduced into Parliament in 1936, the House of Lords voted it down by 35 to 14. The society continued its advocacy efforts but was unable to bring another euthanasia bill into Parliament until 1950.

Charles Potter, a Unitarian minister, formed a similar group, the Euthanasia Society of America, in the United States in 1938. Some of its members proposed legalizing euthanasia not only for terminally or incurably ill people who requested it but also for infants with severe mental and physical defects ("nature's mistakes") and even "criminals and hopeless lunatics."[13] The society tried to introduce a bill legalizing voluntary euthanasia for terminally ill adults into the New York legislature in 1939 but could find no legislator to sponsor it. Later attempts, continuing until about 1960, met with similar failure.

In opinion polls taken in the 1930s, about 40 percent of Americans and as much as 69 percent of Britons favored euthanasia for the terminally or incurably ill under at least some circumstances. Even when family members were arrested for assisted suicide or euthanasia of terminally ill people, they were seldom convicted or punished. In 1938, for example, a New York grand jury refused to indict Harry C. Johnson for gassing his cancer-stricken wife (at her request, he said) after three psychiatrists testified that he had committed the act while temporarily insane. Several parents who killed children with severe mental retardation were also acquitted or given suspended sentences. Such cases lent support to the claim in a 1939 *Time* article that there were "unwritten laws condoning mercy killings," although judges invariably reminded juries that the written laws said otherwise.[14]

During World War II, however, Nazi Germany gave the word *euthanasia* a sinister connotation that it has yet to shake. Between 1939 and 1941, the Hitler government carried out a program of so-called euthanasia for people possessing what the Nazis deemed *lebensunwerten leben*, or "life unworthy of life."[15] The program started with mentally disabled children, then expanded to include mentally and physically disabled adults. The rationale behind the program was partly economic—a desire to spare the state the expense of caring for "useless" people—and partly biological, stemming from a belief in eugenics, which claimed that only the healthy should reproduce.

Between 1939 and 1941, the Nazi "euthanasia" program is estimated to have killed as many as 100,000 disabled people, all Aryan Germans. The infamous "final solution" to the problem of Jews and other minority groups, whom the Nazis also eventually dubbed unworthy of life, grew out of this program. Indeed, the euthanasia program was a sort of dress rehearsal for the Holocaust, featuring the same combination of gas-emitting fake shower stalls, ever-running crematoria, and—most tellingly, modern opponents of euthanasia say—the full cooperation of many German physicians. Leo Alexander, an investigator for the Nuremberg War Crimes Tribunal, wrote in 1949:

> *It started with the [German physicians'] acceptance of the attitude, basic in the euthanasia movement, that there is such a thing as life not worthy to be lived. This attitude in its early stages concerned itself merely with the severely and chronically sick. Gradually the sphere of those to be included in this category was enlarged to encompass the socially unproductive, the ideologically unwanted, the racially unwanted and finally all non-Germans. But it is important to realize that the infinitely small wedged-in lever from which this entire trend of mind received its impetus was the attitude toward the nonrehabilitable sick.*[16]

Needless to say, modern supporters of the right-to-die movement disavow any similarity between the Nazi program and the activities they propose to legalize. They emphasize that their programs, even at their furthest extension, would approve only euthanasia requested by competent adults or, in the case of incompetent people, by written directives made at an earlier date when the people were competent. In the case of never-competent people, family members or other legally recognized surrogates would have to request euthanasia for them. The Nazi program, by contrast, made no pretense of fulfilling sick people's requests or asking anyone's permission.

Although some details of the Nazi euthanasia program were not revealed until 20 years after it occurred, enough emerged after the war to make the American public leery of the subject. In a 1947 Gallup poll, only 37 percent of those polled answered yes when asked, "When a person has a disease that cannot be cured, do you think doctors should be allowed by law to end the patient's life by some painless means if the patient and his family request it?" By contrast, 46 percent had answered yes to a similar question in 1937 and 1939 Gallup polls.

Demand for a way to control events at the end of life began to build again in industrialized countries during the 1950s and 1960s, however, chiefly because of the unexpected effects of medical technology's success in extending life expectancy. As antibiotics and other advances did away with many infectious diseases and other formerly common causes of a relatively quick death, more people lived into old age and began to suffer from chronic conditions such as cancer, heart disease, diabetes, and Alzheimer's disease. Death from such illnesses was often preceded by years of slow and sometimes painful decline in physical or mental functions.

For the first time, too, technology became able to prolong—sometimes for years—the process of dying. Dying people began to be "rescued" by respirators or ventilators and by machines that used electric shock to restart the heart. These devices sometimes restored people to normal life, but at other times they returned them only to coma or a few extra days of pain. Tubes that carried water and nutritive solutions into the stomach could maintain the life of a comatose person for decades. A doctor noted in a *New York Times* article, "Our medical inventions have invented our own dilemma. Sometimes the machines are a blessing. And sometimes they are a curse. But we haven't invented laws or rules yet to tell the difference."[17]

An important indication of a change in feelings about some forms of euthanasia came in a statement that Pope Pius XII made in 1957. The pope continued to oppose active euthanasia, but he told a conference of anesthesiologists that Catholics and their families did not have to continue extraordinary treatments such as the use of artificial respirators in seemingly hopeless cases. He also sanctioned the "double effect," in which pain-controlling narcotics might ease someone into death. In short, the pope said that passive euthanasia was acceptable.

Another factor that encouraged public thinking about a right to die was the rise of what has been called the "rights culture" in the late 1960s and early 1970s. Students in America and Europe envisioned, and indeed tried to insist on, a society in which all people could "do their thing" without interference, so long as they did not harm others. They expressed, sometimes violently, a distrust of and resistance to all forms of authority. Women, African Americans, and other minority groups demanded an end to discrimination and unequal treatment and a recognition of their individual rights, and many of their demands were put into law. Individual liberty and autonomy, always high on the list of American values, began to be celebrated almost to the exclusion of everything else.

A combination of increasing technology and specialization, which tended to depersonalize medicine, and people's growing demand to have a say in decisions that affected them eroded the worshipful respect with which most Americans had regarded the medical profession in the 1950s. Instead, the public began to view doctors as paternalistic, greedy, and indifferent to the feelings of patients and their families. The result was the patients' rights movement of the 1970s. One of the medical rights that people demanded was the right to have a voice in end-of-life decisions involving themselves or loved ones. At very least, they wanted to be able to refuse medical treatment that they considered futile or excessively painful, even if it (after a fashion) preserved life.

THE 1970S: THE RIGHT-TO-DIE MOVEMENT BEGINS

Death had been a taboo subject in the United States during much of the century, but in the early 1970s it instead became almost an obsession. Beginning with Swiss-born psychiatrist Elisabeth Kübler-Ross's *On Death and Dying* (1969), books about death became best-sellers. The number of new books and popular magazine articles on the subject in the United States doubled each year between 1968 and 1973, then doubled again between 1973 and 1975. Some people even began to talk about the possibility of hastening death for the terminally ill. During the early 1970s, bills that would have legalized some form of voluntary euthanasia were introduced in Montana, Florida, Washington, Oregon, and Wisconsin. None came even close to passing; the time was not yet ripe.

Public concern was growing, however, as medical technology continued to change the face of death. Traditionally, most people had died at home, but by 1978, about 71 percent died in hospitals, nursing homes, or other medical institutions. The figure had risen to more than 80 percent in the late 1990s. In his 1994 best-seller *How We Die*, physician-writer Sherwin Nuland described the typical modern death scene as filled with

> *beeping and squealing monitors, the hissing of respirators and pistoned mattresses, the flashing multicolored electronic signals—the whole technological panoply is background for the tactics by which we are deprived of the tran-*

> *quillity we have every right to hope for, and separated from those few who would not let us die alone.*[18]

The 1970s saw the first appearance of an alternative to this kind of death: the hospice, an institution devoted to palliative or "comfort" care for the dying. The World Health Organization defines palliative care as care that

> *affirms life and regards dying as a normal process; neither hastens nor postpones death; provides relief from pain and other distressing symptoms; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; [and] offers a support system to help the family cope during the patient's illness and in their own bereavement.*[19]

Hospice, which has the same root as *hospital*, meant a way station for people on religious pilgrimages during the Middle Ages. Dame Cicely Saunders, a British physician, established St. Christopher's, the world's first modern hospice, in London in 1967. The first American hospice opened in New Haven, Connecticut, in 1974. Today, although some hospices are separate institutions like these, hospice has come to mean more a philosophy of end-of-life care than a set of buildings; in most cases, hospice workers help people die comfortably at home. In the 1970s, however, neither hospice organizations nor their philosophy was common.

Public concern about modern dying came to a head because of a series of events in 1975 and 1976—events that some historians place at the root of the right-to-die movement. This tragic story began on April 14, 1975, when a 21-year-old New Jersey woman named Karen Ann Quinlan went into a coma after consuming a mixture of drugs and alcohol at a party. A respirator had to be inserted in her throat to keep her breathing.

When Quinlan showed no signs of returning consciousness after a month and a half, Robert Morse, the neurologist who was acting as her physician, told Joe and Julia Quinlan, her grieving parents, that she was in a persistent vegetative state (PVS). This meant that her brain stem, which is responsible for automatic bodily functions, remained active, producing tracings on an electroencephalogram as well as causing her to open her eyes and sometimes thrash about and make sounds. Her higher brain, however, had been damaged beyond repair. Only the respirator, feeding tubes, and other medical machinery kept her alive.

After spending agonized months at their daughter's bedside, watching her weight drop from 115 to 90 pounds and her contracting muscles draw her body into a contorted posture, Joseph and Julia Quinlan concluded that, for all purposes that mattered, Karen was dead. Both Catholics, they asked their priest, Tom Trapasso, for advice. He told them about Pope Pius XII's 1957 statement that doctors did not have to employ "extraordinary means" such as respirators to keep patients alive. On July 31, therefore, the Quinlans signed a form directing Morse to remove the respirator. Morse and St. Clare's, the large Catholic hospital where Quinlan was being treated, refused. "You have to understand our position," Sister Urban, the president of the St. Clare's board of trustees, later told Julia Quinlan. "In this hospital we don't kill people."[20]

The Quinlans and their attorney, Paul W. Armstrong, appeared before Judge Robert Muir Jr., in probate court in Morristown, New Jersey, on October 20, 1975. Armstrong not only asked for Joe Quinlan to be named Karen's guardian but directly requested permission to disconnect Karen's respirator. This made the case a precedent-setting one, and it immediately attracted wide media attention. "Whatever the decision," wrote *Washington Post* reporter B. D. Colen, "it is one that will haunt us for years to come."[21] The attention was increased because the case featured an attractive young woman (Karen was usually shown staring out thoughtfully from her high school yearbook photo). The media and the public pictured her as a sort of tragic Sleeping Beauty.

In court, Julia Quinlan testified that Karen had twice, after seeing people she knew die slowly from cancer, said that she would not want to be "kept alive like that," although Mrs. Quinlan admitted that she was not using Karen's exact words. Armstrong claimed that the case was covered under the rights to medical privacy and to control over one's body that the Supreme Court had recognized in several decisions, most notably in *Roe v. Wade*, the landmark 1973 ruling that legalized abortion. On the other hand, Thomas R. Curtin, appointed by Muir as Karen's temporary guardian, said that his job was "to do every single thing that I can do as a skilled professional to keep Karen Quinlan alive."[22] He and Ralph Porzio, Morse's lawyer, insisted that what the Quinlans wanted to do was euthanasia and, as such, was both legally and morally wrong.

After hearing four days of testimony and reviewing the 745-page hearing transcript, Muir gave his decision on November 10, 1975. He refused to make Joe Quinlan Karen's guardian because, he said, doing so would not be in her best interest. He also refused permission to turn off the respirator. Although he agreed that if she had been conscious, Karen, like any competent adult, would have had the right (long recognized both in common law and in Supreme Court decisions) to refuse any medical treatment for herself, he maintained that "there is no constitutional right to die that can be asserted by a parent for his incompetent adult child."[23] Karen's wishes, he believed, were not clearly known, and he felt that in such situations physicians rather than family members should make "substituted judgments" about the health care of incompetent patients.

Armstrong and the Quinlans appealed their case to the New Jersey Supreme Court, which heard it beginning on January 26, 1976. On March 31, the state high court unanimously reversed Muir's decision. The justices ruled that the right to privacy could in fact cover situations like the Quinlans', making theirs the first state court to apply the right to a case of "letting die." The court appointed Joseph Quinlan as Karen's guardian and gave Morse and the hospital immunity from prosecution if they disconnected her respirator. In the written opinion of the court, Justice Richard J. Hughes said that whatever the Quinlans decided to do about their daughter "should be accepted by society, the overwhelming majority of whose members would, we think, in similar circumstances exercise such a choice in the same way for themselves or for those closest to them."[24]

Tragically for the Quinlans, their story by no means ended with their court victory. In spite of the justices' decision, Morse and St. Clare's still refused to remove Karen's respirator, and while the family was searching for a more cooperative long-term-care home to which she could be transferred, the hospital staff began to "wean" her from the respirator by turning it off for longer and longer periods of time. On June 9, 1976, the Quinlans transferred Karen to Morris View Nursing Home and turned the respirator off, but by then she was able to breathe on her own. Her parents refused to authorize removal of the feeding tubes and antibiotics that now sustained her ("That would be euthanasia" and therefore against his religion, Joseph Quinlan had said during the trial), so Karen lingered on in her medical twilight for another decade, finally dying of pneumonia on June 13, 1986.[25]

One of the most immediate consequences of the Quinlan case was an uprush of interest in living wills, the first type of advance health care directive to be introduced. A living will specifies which medical treatments a competent adult wishes to have or to refuse if he or she should become incompetent. Louis Kutner had coined the term in an article in the summer 1969 *Indiana Law Review*. Such a document, he wrote, would be "analogous to a revocable or conditional trust with the patient's body as the *res*, the patient as the beneficiary and grantor, and the doctor and the hospital as trustees."[26] Before the Quinlan case, however, few people knew about living wills and fewer still had filled them out.

Living wills were supposed to serve as guidelines to family and hospital staff, but they were not legally binding. For reasons ranging from paternalism to fear of lawsuits, doctors and hospitals frequently ignored them. In the early 1970s, therefore, groups who supported living wills, such as the Society for the Right to Die (originally the Euthanasia Society of America), began to work toward giving them legal standing. Barry Keene, a California assemblyman from Eureka, introduced a state bill for this purpose in 1974. The bill might have seemed destined for easy passage, since an opinion poll taken at the time showed that 87 percent of California adults supported the right of incurably ill people to refuse life-prolonging medical treatment, but three powerful groups—the California Medical Association, the California Catholic Conference, and the California Pro-Life Council—opposed the bill, and it was defeated. Similar bills were introduced in four other states that year, but they also failed.

When the California bill was reintroduced in 1976 in the wake of the Quinlan case, however, it passed, albeit narrowly and after much debate. (Ironically, the bill would not have helped the Quinlan family even if it had been in effect where they lived and Karen had made a living will, because it allowed refusal of life-prolonging medical treatment only for patients who were terminally ill, which Karen was not.) Governor Jerry Brown signed the bill, called the Natural Death Act, into law on September 30, 1976, saying, "This bill gives recognition to the human right that people have to let their life come to its natural conclusion."[27] It was the first living-will law in the country. Fifty similar bills were introduced in 38 states the following year, and they passed in seven. During the next decade, a total of 36 states followed California's lead.

The Quinlan case also increased people's knowledge of hospital ethics committees, a fairly new type of body designed to settle difficult cases such as the Quinlans' without reference to the courts. The New Jersey court required the Quinlans to consult such a committee, which is composed of physicians, social workers, attorneys, theologians, and others, before disconnecting Karen's respirator. Most hospitals would eventually establish ethics committees.

Above all, the case galvanized the public into trying to make sure that they and their loved ones would never find themselves in the horrible situation that the Quinlan family faced. Wrenched by the fact that Karen's life and her family's emotional ordeal did not end when her respirator was turned off, some people began to demand the right not only to refuse medical treatment but also to hasten an unduly prolonged death.

THE 1980S: THE MOVEMENT EXPANDS

The right-to-die movement, as it was beginning to be called, gained increasing prominence during the 1980s. To begin with, right-to-die supporters encouraged the expansion of advance health care directives to include not only living wills but also a new type of directive called a durable power of attorney for health care, or a health care proxy. This directive allowed people to specify a surrogate to make health care decisions for them if they should become incompetent. By 1986, all 50 states had made durable powers of attorney legally binding, although in some states, an appointed surrogate could not order the withholding of life-sustaining treatment without "clear and convincing" evidence, such as a living will, that the patient would have wanted such an action. The health care proxy was thus a complement to the living will, not a substitute for it.

At the same time advance directives were becoming more common and accepted, several influential groups softened their position on the withdrawal of medical treatment that such directives often mandated. In 1986 the American Medical Association revised its position on patients with PVS, stating that the group now felt that it was ethically permissible for a physician to remove both respirator and feeding tubes from someone in irreversible PVS if the person's family wished. The Catholic Church, too, abandoned attempts to distinguish between "ordinary" and "extraordinary" treatment. Pope John Paul II stated in 1980 that patients might refuse any type of medical treatment without violating church doctrine, provided that death is imminent and treatment is futile.

The chief leader in "pushing the envelope" of death rights beyond advance directives and refusal of medical treatment into active hastening of death during the 1980s was Derek Humphry, a British-born journalist. In 1973, while Humphry was living in England, his first wife, Jean, developed breast and bone cancer. Treatment failed, leaving her in tremendous pain, and she asked Humphry to help her end her life. Such an act was illegal in England, but charges could be brought only with the permission of the Director of Public Prosecutions, a man Humphry knew from his reporting work and felt would be unlikely to pursue this course. Humphry therefore consulted a physician he later identified only as "Dr. Joe" and obtained a prescription for a lethal dose of medication. In March 1975, when Jean decided that the time had come, Humphry prepared the mixture. She drank it and died about an hour later. Humphry published a book about this experience, *Jean's Way*, in 1978. It attracted considerable media attention, and the police investigated, but, as Humphry had predicted, the prosecutor declined to press charges.

In August 1980, Humphry and his second wife, Ann Wickett, then living in southern California, founded the Hemlock Society, a group whose purpose was to legalize physician-assisted suicide and voluntary euthanasia for terminally ill people. This was a much more active approach to the right to die than that taken by the existing American euthanasia societies, Concern for Dying (formerly the Euthanasia Education Council) and the Society for the Right to Die (formerly the Euthanasia Society of America), which concentrated strictly on promoting advance directives. His approach was more similar to that of Britain's Voluntary Euthanasia Society, or EXIT, as it was then called.

Humphry published a second book, *Let Me Die Before I Wake*, in early 1981. It consisted primarily of accounts by family members who had helped terminally ill people die, but drug dosages and other specific details of suicide methods were embedded in the stories. The other American right-to-die societies protested Humphry's activist approach, both because they thought that people who were not terminally ill might misuse the information he provided and because they feared that his book and campaign to legalize physician-assisted suicide would turn public opinion against their own less controversial efforts. Ann Jane Levinson, Concern for Dying's executive director, wrote to Humphry, "I only hope the backlash [caused by your activities] doesn't sink us all."[28]

Active right-to-die efforts like Humphry's gained support during the 1980s from an unexpected source: sufferers in the AIDS epidemic. After observing the often protracted and painful deaths of friends and lovers, some people infected with HIV, the virus that causes AIDS, began "saving pills" for the day when their own suffering might become unendurable. They also brought discussion of the right to die out of the shadows. "Instead of broken and weary 80-year-old citizens dealing with life-threatening diseases . . ., affluent 25- to 35-year-old men—eager and able to extend their political clout and organization—suddenly joined the debate" on assisted suicide and euthanasia, Gary Thomas noted in *Christianity Today*. "Almost immediately, prolonged deaths became a matter of public discussion."[29]

Meanwhile, by fits and starts, American courts were expanding both the range of incompetent people for whom surrogates might refuse life-sustaining treatment and the types of treatment that might be rejected. Right-to-life groups and some other critics claimed that these court decisions bore out predictions that they had made in the 1970s when they stated that seemingly harmless advance directives and the surrogate rights granted to Karen Quinlan's parents marked the first steps down the slippery slope to Nazi-style involuntary euthanasia.

A 1977 Massachusetts case involving a severely retarded man, Joseph Saikewicz, had established a precedent for the right of surrogates to refuse life-extending medical treatment on behalf of never-competent adults in some cases. That case, however, caused nothing like the stir that surrounded another in the early 1980s, in which the never-competent person was a baby. The child, a boy, was born on April 9, 1982, in Bloomington, Indiana.

Known to courts and public only as Baby Doe, the Bloomington baby had Down's syndrome, which is caused by an extra chromosome 21 and produces moderate to severe mental retardation. He also had an opening between his esophagus and his windpipe that prevented him from eating without choking. Surgery to close the opening would not have been difficult, but Walter Owens, the family's obstetrician, emphasized the extremely limited mental activity of most children with Down's syndrome (as it was understood at the time) and the high economic and emotional cost of caring for such a child. He advised the baby's parents to refuse the surgery, and they did so. They also decided against having the baby fed intravenously.

Hospital administrators and other pediatricians disagreed with Owens's prognosis set up an emergency session with a local judge, John Baker, to try to force the baby's treatment and feeding. Baker ruled that Baby Doe's parents had the right to decide its fate. The district attorney appealed the decision to the county circuit court and then, when that appeal failed, to the Indiana Supreme Court. The higher court, too, found for the parents. The district attorney even asked the U.S. Supreme Court for an emergency intervention, but the baby died before this appeal could be ruled upon.

The Baby Doe case caused far more outcry against the parents than Karen Quinlan's had. In *In the Arms of Others: A Cultural History of the Right-to-Die in America*, Peter G. Filene speculates that this may have been partly because Baby Doe's parents, unlike the Quinlans, insisted on preserving their anonymity and because they had reached their decision very quickly. Another factor may have been that many people who saw a respirator as "extraordinary" treatment did not feel the same way about provision of food. The helplessness of an infant, who obviously (unlike a formerly competent adult such as Karen Quinlan) never could have consented to withdrawal of treatment, also tugged powerfully on people's emotions. As a Virginia man wrote to the *Washington Post*, "the cries of a starving infant are apt to haunt my nightmares."[30] The uproar increased when evidence surfaced that Baby Doe's case was anything but unique. On the contrary, failing to treat severely brain-damaged infants (with the parents' consent) was a fairly common practice in neonatal intensive care units.

The publicity surrounding Baby Doe's death attracted the attention of the conservative Reagan administration. On April 30, two weeks after the child died, President Reagan directed the Justice Department and the Department of Health and Human Services (HHS) to require treatment in future cases of this type. The administration used as its justification Section 504 of the Rehabilitation Act of 1973, which stated that discrimination on the basis of disability was illegal.

A little less than a year later, HHS sent a notice to all hospitals, requiring them to post large signs in every infant care facility reading "Discriminatory failure to feed and care for handicapped infants in this facility is prohibited by federal law."[31] The signs also had to include a toll-free "Baby Doe hotline" phone number via which anyone could report instances of such discrimination. When calls were placed to this number, "Baby Doe squads" of physicians, lawyers, and government workers would fly to the offending hospitals, seize relevant medical records, and enforce the rule. Irritated pediatricians called these squads the "Baby Doe Gestapo."

The "interim final" Baby Doe rules took effect on March 21, 1983. The American Academy of Pediatrics, however, resented this interference with physicians' right to decide on treatment and sued immediately in a federal district court to have the rules blocked. Federal District judge Gerhard Gesell did so in April. Gesell said he had made his decision partly on procedural grounds, but he also had harsh words for the regulations themselves, calling them "arbitrary and capricious" and the hotline "ill-considered."[32]

After HHS made some minor modifications, the final Baby Doe rules took effect on February 12, 1984. Less than two weeks later, however, they were rendered unenforceable by the decision of the Second Circuit Court of Appeals in a second "Baby Doe" case. This ruling, confirmed by the U.S. Supreme Court in a different case (*Bowen v. American Hospital Association et al.*) in 1986, denied the government access to the medical records that it would need in order to prove discrimination.

During its year or so of existence, the Baby Doe hotline received 1,633 calls, and the government squads (which had continued to operate even while the rules mandating them were being contested and revised) investigated 49 of these. In only six of those cases did the investigations result in babies receiving medical treatment that they might not otherwise have had. Adrian Peracchio reported in *Newsday*, a Long Island, New York, newspaper, that "in some [of these six] cases, intervention has saved a baby with a fair chance of living a useful life; in others, extraordinary surgical measures have given babies no more than a few extra days of life at enormous financial and emotional costs."[33]

Despite the court defeats, the federal government did not lose its determination to protect the lives of babies born with birth defects. In 1985 it established a new set of regulations that classified refusal of treatment for such babies as a form of child abuse or neglect. The new rules required any state receiving federal funds for prevention of child abuse to make sure that all infants received life-supporting treatment unless they were clearly terminally ill, irreversibly comatose, or suffering from conditions that made life support both futile and inhumane. Even in those cases, basic nutrition and liquids had to be provided. These rules are still in place, leading to the strange legal situation that food and water can be refused on behalf of an incompetent adult but not on behalf of a baby who is expected never to be competent.

The case of Claire Conroy in 1983 further expanded the types of medical treatment that could be refused on an incompetent person's behalf. Conroy, an 82-year-old woman, had suffered from diabetes, hardening of the arteries, and other debilitating conditions before falling into an irreversible semiconscious state somewhere between dementia and coma. She could breathe on her own but could not eat or drink, so her life was maintained by nutrition delivered to her stomach through a tube. Thomas Whittemore, her nephew and guardian, asked the doctor in her nursing home to remove her feeding tube, citing her independence and fear of doctors as evidence that she would not want to go on living in her present condition. The doctor refused on ethical grounds. Whittemore then appealed to the New Jersey Superior Court on January 24, 1983, for permission to order the tube removed.

Judge Reginald Stanton concluded that, given her medical condition, Conroy's life "had become impossibly and permanently burdensome for her" and that the tube could be removed. Conroy died before the order could be carried out, but because of its importance as a precedent, her case continued on its way through the court system.[34] The New Jersey Court of Appeals reversed the lower court, but in January 1985 the New Jersey Supreme Court reversed the appeals court. The state supreme court ruled 6 to 1 that "a competent person has the right to decline any medical treatment, including artificial feeding, and should retain that right when and if he becomes incompetent."[35] At the same time, however, the court said that this general ruling would not necessarily have applied to Conroy because she had not left a living will or other written document describing her wishes, and Whittemore had not, in the justices' opinion, provided enough evidence about her beliefs and opinions to allow a judgment on the matter.

Not only right-to-life supporters but others, including famed bioethicist Daniel Callahan, protested the Conroy decision, both because starvation and dehydration seemed such an inhumane way to die and because removal of food and water tubes, far more than removal of a respirator, seemed to hover on the line between letting die and actively killing. Similarly, some states that accepted living wills did not allow the stopping of food and hydration unless death was imminent. As time went on, however, more and more ethicists, physicians, and members of the public came to see feeding tubes as being just as artificial and "extraordinary" as respirators and removal of them just as acceptable. Callahan, for instance, expressed such an opinion in 1993.

The range of conditions under which one could refuse medical treatment or even ask for help in dying was broadened by another case, that of Elizabeth Bouvia in California. Bouvia had severe cerebral palsy, which left her with only a little use of her right hand, plus some control of her face; she also had arthritis, which caused her considerable pain. Nonetheless, her request for aid in dying shocked many because she was neither in uncontrollable agony nor terminally ill. She had simply decided that she no longer found her life worth living.

Bouvia's difficulties in life had included not only severe disability but the divorce of her parents, a stint in a children's home, a miscarriage, and a failing marriage. In September 1983, when she was 26 years old, she entered the emergency room of Riverside General Hospital in California and announced that she wanted to kill herself at the hospital—"just to be left alone and not bothered by friends or family or anyone else and to ultimately starve to death."[36]

Bouvia was admitted to the hospital's psychiatric ward as a voluntary patient. When Donald Fisher, the hospital's chief of psychiatry, refused to let her carry out her plan, she called a reporter and the American Civil Liberties Union (ACLU) and asked for help in gaining legal permission to refuse medical treatment—that is, her feeding tube. Her story was publicized, and brought her a variety of visitors, including other disabled people and organizations such as Advocates for the Developmentally Disabled.

Bouvia's first court hearing was before John Hews, a probate judge. At the hearing, Fisher claimed that Bouvia would eventually change her mind about wanting to die and said he would force-feed her if necessary to keep her alive. In December 1983, Hews ruled that Fisher could carry out the force-feeding if Bouvia would not eat. The judge agreed that Bouvia was rational, sincere, and mentally competent but ruled against her because of the effect her death would have on the hospital staff and on other disabled people.

Bouvia appealed her case. Meanwhile, physicians, law professors, newspaper columnists, and others argued about it—and the force-feeding, a gruesome procedure, went on. She lost her first court appeal, and in April 1984 she left Riverside Hospital. She changed hospitals several times and eventually appeared in court again. Her second court hearing also denied her right to what the judge, Warren Deering, interpreted as assistance in suicide. In 1986, however, the California Court of Appeal reversed the second decision and affirmed Bouvia's right to refuse medical treatment, including a feeding tube, even if doing so shortened her life. "A desire to terminate one's life is probably the ultimate exercise of one's right to privacy," the judges wrote.[37]

In fact, however, Elizabeth Bouvia did not starve herself. In 1995 she was still living in a California hospital, supported by Medicaid, the combined state and federal program that pays for medical care for the poor. Morphine controlled the pain of her arthritis. She told a reporter that she spent most of her time watching television. "I wouldn't say I'm happy, but I'm physi-