CHAPTER 2

Requests to Die: Non-Terminal Patients

This chapter presents Elizabeth Bouvia and Larry McAfee, two people with non-terminal physical disabilities who tried to die, won important cases in court, and whose outcomes surprised people. It discusses depression, autonomy, disability culture, philosophers on suicide, and whether physicians should assist non-terminal, disabled adults who want to die.

THE CASE OF ELIZABETH BOUVIA

In 1983, Elizabeth Bouvia's father drove her from Oregon to Riverside General Hospital in California, where psychiatrists admitted her as a voluntary suicidal patient. Wanting "just to be left alone and not bothered by friends or family or anyone else and to ultimately starve to death," she had already attempted suicide once.[1] "Death is letting go of all burdens," she claimed. "It is being able to be free of my physical disability and mental struggle to live."

Almost totally paralyzed from cerebral palsy, Elizabeth, then 25 years old, never had the use of her legs, although her right hand could control a battery-powered wheelchair and smoke cigarettes. She could use her facial muscles to chew, swallow, and speak. She also had painful, severe degenerative arthritis. As a California resident, her medical care was paid for by Medi-Cal, a state–federal program.

She had a hard life. At age 5, her parents divorced. Afterward, her mother raised her for five years, but then abandoned her to a children's home. The following account comes from two physicians:

> For their 18th birthday, some children receive cars and gifts. When [Elizabeth] turned 18, her father, a postal inspector, told her that he would no longer be able to care for her because of her disabilities. The chief of psychiatry at Riverside says that what she did next showed great drive and promise. She gathered her requisite amount of state aid and lived on her own in an apartment with a live-in nurse. Although she earlier had dropped out of high school, she completed her general equivalency degree and went on to graduate from San Diego State University with a bachelor's degree in 1981. She even entered a master's program at the

university's School of Social Work, but left in 1982 over a disagreement about her field work placement.

For eight months, she worked as a volunteer in the San Diego placement program, but she has never been employed for salary or wages.

During the last year, Ms. Bouvia faced a series of devastating events. In August 1982, she married an ex-convict, Richard Bouvia, with whom she had been corresponding by mail. Together they conceived a child, but a few months later she suffered a miscarriage.

Her husband's part-time job did not provide enough income for the two to live decently, so they called her father to ask for help. He declined to aid them, Richard Bouvia said. They next went to Richard Bouvia's sister in Iowa to ask for help. That did not work out for long, and soon they ended up back in Oregon, where Richard Bouvia still could not find work. At that point, he abandoned her, stating—according to pleadings in the case—that he "could not accept her disabilities, a miscarriage, and rejection by her parents."

A few days later, Elizabeth Bouvia got a ride to Riverside General and wheeled herself into the emergency room, complaining that she wanted to commit suicide.[2]

During her first four months at Riverside Hospital, the chief of psychiatry, Donald Fisher, supervised her treatment. When he refused to let her starve, Elizabeth contacted the American Civil Liberties Union (ACLU) and telephoned a reporter. Richard Scott of Beverly Hills, both a physician and a lawyer, represented her free of charge.

The Legal Battle: Refusing Sustenance

In a hearing before California probate judge John Hews, Fisher testified that because Elizabeth might change her mind, he would not let her starve and would force-feed her: "The court cannot order me to be a murderer nor to conspire with my staff and employees to murder Elizabeth."[3] Elizabeth Bouvia asked the judge to block her force-feeding.

Habeeb Bacchus, associate chief of medicine at Riverside Hospital and Bouvia's second physician, argued that "being allowed to die when there's no need for her to die—this is a dangerous precedent. Patients might wonder, `Am I next slated to be allowed to die?' "[4]

Advocates for the disabled feared that if Elizabeth died, other disabled people might follow. A lawyer at the Law Institute for the Disabled asserted that Bouvia symbolized a "social problem" of disabled people who are told they cannot be productive and said, "She needs to learn to live with dignity."[5]

At this point, the case escalated into a public debate:

Disabled individuals held vigils at the hospital to convince her to change her mind. Bouvia's estranged husband hitchhiked to Riverside from Iowa, retained lawyers, and asked to be named her legal guardian. He charged the ACLU with using his wife as a "guinea pig." She filed for divorce. Columnist Jack Anderson's offer to raise funds for Bouvia's treatment was rebuffed. Richard Nixon sent a letter to Bouvia to "keep fighting." A meeting with President Reagan was discussed. Two neurosurgeons offered free surgery to help her gain the use of her arms. A convicted felon volunteered to shoot her.[6]

Judge Hews allowed the force-feeding. Admitting Elizabeth's rationality, sincerity, and competence, he decided based on the "profound effect on the medical staff, nurses, and administration of the hospital," as well as the "devastating effect on other . . . physically handicapped persons."[7] Bouvia's lawyer said Hews accepted "the Chicken Little defense that the sky would fall if Ms. Bouvia wasn't force-fed."[8] Judge Hews held that since the patient was not terminally ill and could live for decades, "there is no other reasonable option."

Columnist Arthur Hoppe thought otherwise:

> I had the feeling that the judge, the doctor, and the hospital had found Elizabeth Bouvia guilty—guilty of not playing the game. It was as though the Easter Seal Child had looked into the camera and said being crippled was a lousy deal and certainly nothing to smile about.[9]

Boston University law professor George Annas blasted Hews:

> The judge's decision begs the question: Is there a reasonable option? In the adversary proceeding played out in California, no one seemed to search for reasonable options. The county, in fact, consistently took the most extreme position. It continually threatened to eject Ms. Bouvia from the hospital by force, and leave her out on the front sidewalk, hoping someone would pick her up and take her away. Almost from the beginning, the county and hospital made it clear that they did not care whether she lived or died but, because of their own fear of potential legal liability, would not let her die at Riverside Hospital.[10]

Elizabeth appealed, but continued to be force-fed. When aides pushed plastic tubing in her mouth, she bit through it. Thereafter, three attendants held her down while another inserted tubing through her nose into her stomach, pumping in a liquid diet. Annas commented on this gruesome scene:

> I do not believe competent adults should ever be force-fed; but efforts at persuading the individual to change his or her mind, and offering oral nutrition should continue. If a court determines, however, that invasive force-feeding is required, . . . then to [prevent] hospitals from becoming the most hideous torture chambers, some reasonable limit must be placed on this "treatment."[11]

Elizabeth Bouvia lost her first appeal and left Riverside Hospital in 1984. Individual commentators interpreted differently what happened next. Two physicians wrote in a medical journal:

> The standoff continued until April 7, when Ms. Bouvia unexpectedly checked herself out of the hospital. The hospital bill for the 217 days, excluding physicians' fees, was more than $56,000, paid by Riverside County and by the State of California. Ms. Bouvia went to the Hospital del Mar at Playease de Tijuana, Mexico, known for amygdalin (Laetrile) treatments for cancer. She believed the staff would help her die. Her new physicians, however, became convinced that she wanted to live. Two weeks later, Ms. Bouvia left the hospital, hired nurses, and moved to a motel. Three days later, with friends, a reporter, and an intern from Hospital del Mar at her side, she gave up her plan to starve herself to death and took solid food. Ms. Bouvia said that she wanted treatment, including surgery to reduce muscle spasms. . . . Her case was complicated further by the revelation that the newspaper reporter who covered the case most closely had a contract with Ms. Bouvia for a book, television, and movie rights to her story.[12]

This account emphasizes Elizabeth Bouvia's unexpected departure from the hospital, her costly hospital bills at public expense, the agreement of Mexican with American physicians in refusing to allow her to die, her seemingly arbitrary decision to give up starving herself, and a contract for book and film rights to her story.

In contrast, lawyer George Annas writes:

> Two years ago this column dealt with Elizabeth Bouvia's unequal and doomed struggle. . . . After losing both in the hospital and in the courtroom, Ms. Bouvia fled to Mexico on April 7, 1984, to seek her death. She was soon persuaded that Mexican physicians and nurses would be no more sympathetic to her plan than those at Riverside, and so returned to California. Because of the brutal force-feeding she had endured at Riverside, she was afraid to return there. Since no other facility would admit her unless she agreed to eat, she resigned herself to eating and entered a "private care" location. There she remained, without incident, for more than a year.[13]

An advocate for dignified dying, the Hemlock Society's Derek Humphrey, wrote even more sympathetically:

> Her troubles multiplied. The graduate school where she had been studying refused to readmit her, and her brother was drowned in a boating accident. Not long after, Elizabeth had a miscarriage, and she learned her mother was dying of cancer. . . . Determined once again to be in charge of her fate, she asked her father to take her to the county hospital in Riverside, near Los Angeles (an area where she had friends), for an examination. She checked herself into the psychiatric ward and told physicians she wanted to die by starvation. Elizabeth specifically asked that, until she died, she be looked after normally and given painkillers when her arthritis was troublesome.[14]

Disability advocate Paul Longmore offered a very different perspective on Bouvia's case, arguing that it reflected rank prejudice against the disabled. He wrote:

> The very agencies supposedly designed to enable severely physically handicapped adults like her to achieve independence . . . become yet another massive hurdle they must surmount, an enemy they must repeatedly battle but can never finally defeat. . . .
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> [When she tried to go on internship,] the SDSU [San Diego State University] School of Social Work refused to back her up. They wanted to place her at a center where she would only work with disabled people. She refused. Reportedly, one of her employers told her she was unemployable, and that, if they had known just how disabled she was, they would never have admitted her to the program. . . .
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> The attorneys brought in three psychiatric professionals to provide an independent evaluation. None of them had experience or expertise in dealing with persons with disabilities. In fact, Elizabeth Bouvia had never been examined by a psychiatric or medical professional qualified to understand her life experience. . . .
>
> Her examiners prejudicially concluded that because of her physical condition she would never be able to achieve her life goals, that her [physical] disability was the reason she wanted to die, and that her decision for death was reasonable. . . . [Judge Hews] too declared that Ms. Bouvia's physical disability was the sole reason she wished to die.[15]

Each account appeared in scholarly journals, implying objectivity, yet the physicians portray her as irresponsible; Annas and Humphrey portray her as a heroine fighting a cold bureaucracy; and Longmore portrays her as a victim of a prejudiced system and of misguided, do-gooder lawyers. Physicians refer to her as "Bouvia," Humphrey calls her "Elizabeth," and Longmore uses "Elizabeth Bouvia" or "Ms. Bouvia." The physicians say that, "she got a ride" to Riverside, as if she had hitchhiked to some arbitrary location; Humphrey says that her father took her to a place "where she had friends." Longmore emphasizes her desire to be independent; Humphrey emphasizes her physical pain and social trauma. Longmore suggests that society is prejudiced against disabled people and thus that Elizabeth Bouvia's disability is not so much her problem as society's problem. Humphrey writes from a point of view inside Elizabeth Bouvia; the physicians write from the viewpoint of hospital staff members who deal with problematic patients. Longmore critiques an inadequate system that forces terrible, desperate decisions.

In 1985, Elizabeth entered Los Angeles County–USC Medical Center, where physicians installed a morphine pump to control pain caused by her worsening arthritis. She promised to eat, so she was not force-fed.

After two months, physicians transferred her to nearby High Desert Hospital, another public hospital. Although she ate there, her physicians decided that she wasn't eating *enough* and again force-fed her. They reasoned that, "since she is occupying our space, she must accede to the same care which we afford every other patient admitted here, care designed to improve and not detract from chances of recovery and rehabilitation."[16] Critics objected: must all patients who occupy High Desert hospital's space do as they are told? Would the hospital want to market this theme "Enter High Desert Hospital and Do As: We Say."?

Elizabeth petitioned courts to stop her forced feeding. At this time, she weighed only 70 pounds. A consultant on nutrition noted that a weight of 75 or 85 pounds "might be desirable." Her physicians wanted her to weigh about 110 pounds.

At a hearing, Judge Warren Deering interpreted her low weight as "not motivated by a bona fide right to privacy but by a desire to terminate her life."[17] He said the right to privacy did not cover suicide by starvation and ordered force-feeding because, "Saving her life is paramount."

Elizabeth appealed and the California Court of Appeal ruled in her favor: "A desire to terminate one's life is probably the ultimate exercise of one's right to privacy."[18] This Court found "no substantive evidence to support the [lower] court's decision."

Judge Deering had been concerned that Elizabeth could live for decades, but the Court dismissed that concern: "This trial court mistakenly attached undue importance to the amount of time possibly available to her, and failed to give equal weight and consideration for the quality of that life; an equal, if not more significant, consideration."

The appeals court concluded:

> This matter constitutes a perfect paradigm of the axiom: "Justice delayed is justice denied." Her mental and emotional feelings are equally entitled to respect. She has been subjected to the forced intrusion of an artificial mechanism into her body against her will. She has a right to refuse the increased dehumanizing aspect of

> her condition. . . . The right to refuse medical treatment is basic and fundamental. It is recognized as part of the right of privacy protected by both the state and federal constitutions. Its exercise requires no one's approval. It is not merely one vote subject to being overridden by medical opinion. . . .
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> [A precedent has been established that when] a doctor performs treatment in the absence of informed consent, there is an actionable battery. The obvious corollary to this principle is that a competent adult patient has the legal right to refuse medical treatment. [Moreover,] if the right of the patient to self-determination as to his own medical treatment is to have any meaning at all, it must be paramount to the interests of the patient's hospital and doctors. . . . The right of a competent adult patient to refuse medical treatment is a constitutionally guaranteed right which must not be abridged. . . .
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> In Elizabeth Bouvia's view, the quality of her life has been diminished to the point of hopelessness, uselessness, unenjoyability, and frustration. She, as the patient, lying helplessly in bed, unable to care for herself, may consider her existence meaningless. She is not to be faulted for so concluding. . . . As in all matters, lines must be drawn at some point, somewhere, but that decision must ultimately belong to the one whose life is in issue.

The state appellate court held that competent adults could refuse medical treatment: Building on prior decisions in other states,[19] this state court said that a competent adult patient had a constitutionally guaranteed right to refuse medical treatment that must not be abridged. This court also had strong words about force-feeding:

> We do not believe it is the policy of this State that all and every life must be preserved against the will of the sufferer. It is incongruous, if not monstrous, for medical practitioners to assert their right to preserve a life that someone else must live, or more accurately, endure, for "15 or 20 years." We cannot conceive it to be the policy of this State to inflict such an ordeal upon anyone.

The court concluded that, "no criminal or civil liability attaches to honoring a competent, informed patient's refusal for medical service."

If nothing else, Elizabeth Bouvia, frail, small, alone, and barely able to move, won a remarkable victory. Preceding the U.S. Supreme Court's *Cruzan* decision by five years, she wrested from the courts a victory about the right to die for competent patients.

Yet after her victory, Elizabeth did not kill herself. When some caring people offered to help her die, she changed her mind. Most important, by giving her control over her life, they gave her a reason to live.

A decade after her victory in court, she described her body as "gnarled and useless."[20] In 1994, she lived in California on Medi-Cal, in a private hospital room with 24-hour-day care at a cost of $300 a day. A morphine pump controlled her pain, and she weighed 100 pounds. She said her life was "a lot of needles and bags," and she spent her time watching television. "I wouldn't say I'm happy, but I'm physically comfortable, more comfortable than before. There is nothing really to do. I just kind of lay here."

In 1992, Richard Scott, the physician and lawyer who represented Elizabeth Bouvia, and who battled depression most of his life committed suicide. When he did, Elizabeth Bouvia said, "Jesus, I wish he could have come in and taken me with him."

In 1996, Elizabeth, appeared on *60 Minutes* on the tenth anniversary of a previous *60 Minutes* story about her. Then she lived in Riverside County Hospital, but in 1997, a new pro bono attorney Griffith Thomas, M.D., got her disability payments put into a trust fund that allowed her to live in her own apartment with 24-hour-a-day, in-home assistants. Even though this cost far less than her hospital room, it took a decade to accomplish.

Elizabeth in 1996 still had pain each day and still needed morphine. She did not intend to be alive for another story by *60 Minutes* in 2006 and felt ambivalent about her life. An obituary for a disability rights advocate in 2008 mentioned that Elizabeth was still alive.[21] In 2013, she seemed to be still alive, but no one had heard anything about her.

THE CASE OF LARRY MCAFEE

In 1985, an accident left 29-year-old Larry McAfee almost completely paralyzed (a C-2 quadriplegic). While studying mechanical engineering at Georgia State University, he fell forward over his motorcycle on a dirt road, snapped his head, and crushed his two top vertebrae. Left with use only of his eyes, mouth, and head, he could not clear his throat and sometimes choked. He needed a ventilator to breathe and could not control his bladder and bowels. He was unmarried and could feel no pleasure from sexual activity.

McAfee had a $1 million health insurance policy, and using it, remained for over a year at the expensive Shepherd Spinal Center in Atlanta, where the average stay for C-1 to C-4 patients is 19 weeks. He then moved to an apartment in Atlanta, where he insisted on certified nurses who were three times more expensive than home health aides. After 16 months of such living, he exhausted his insurance. Not wanting to be a burden, he refused his family's offer of care.

With no resources, he became eligible for Medicaid, the fund in each state that pays for medical care for the indigent. McAfee wanted Georgia Medicaid to pay for his care in an apartment and refused to enter a state nursing home. Only a small number of nursing homes in America admit ventilator-dependent patients such as Larry. Even fewer take Medicaid patients because Medicaid's reimbursement doesn't pay for the staffing needed for such patients. Georgia officials eventually transferred him to a Medicaid nursing home in Ohio that could care for respirator-dependent C-1 patients. This facility accepted McAfee on a temporary basis until Georgia could find a bed for him.

In Ohio, Larry wouldn't make appointments for vocational rehabilitation. The administrator there said, "Larry was very demanding, wanted things precisely the way he wanted them. . . . I had nurses toward the end who just couldn't work with him anymore because they were just extremely, extremely frustrated."[22] He noted that McAfee's family and friends all lived in Georgia.

McAfee claimed that he had been housed in Ohio with demented, senile, and brain-damaged patients who were being cheaply warehoused with only one or two staff for as many as 40 patients. The easiest way to warehouse such patients is to keep them heavily sedated. McAfee said that he experienced intense loneliness and received inadequate personal care. "You're just a sack of potatoes," he said.[23]

After two long years it became clear to Ohioans that McAfee had been dumped on them, so officials angrily hustled him onto a plane and left him in the emergency room at Grady Memorial Hospital in Atlanta.

There, Larry spent several miserable months in the intensive care unit. In 1989, Briarcliff Nursing Home, in a suburb of Birmingham, Alabama, accepted him as a patient, and he transferred there.

Larry one day called the radio talk show of Russ Fine, a disability advocate and director of the Injury Control Research Center at the University of Alabama at Birmingham. According to Fine, McAfee's treatment represented "everything that's wrong about the system that serves disabled people."[24]

On first meeting Larry, Fine found him lying in bed staring at the ceiling, with no voice-activated telephone and no television. All he could do was stare "at whatever happened to be in front of his face. From a quality of life standpoint, it was a devastating commentary on a society with a very advanced health-care system."[25]

A reporter once arrived to find McAfee's urinary catheter not connected to a container and spilling urine on the floor. Fine says, "These facilities were not equipped to take care of a patient such as Larry, with labor-intensive health-care requirements."[26]

In 1989, four years after Elizabeth Bouvia's victory, Larry filed suit in federal court to exercise his right to die. After a heart-wrenching 45-minute hearing in Fulton County Superior Court, Judge Edward Johnson found in McAfee's favor. Because his ventilator had once dislodged accidentally, causing him to suffocate, Larry did not want to experience such feelings again, so he asked to be sedated before disconnection. Judge Johnson granted this, declaring that no civil or criminal penalty would attach to any doctor who helped.

Everyone assumed that with his legal victory, McAfee would kill himself within days. Like Elizabeth Bouvia, he did not. Behind the scenes, Russ Fine had convinced McAfee to stay alive. But then Larry's financial problems began.

Social Security, besides financing income for Americans over 62, provides financial assistance to disabled people as Supplemental Security Income (SSI). In 2011, SSI payments averaged $700 a month and were paid to 10.6 million disabled Americans.[27] Larry qualified for SSI assistance.

In 1989, Russ Fine persuaded Birmingham's United Cerebral Palsy to let Larry live temporarily in its nine-person group home. Larry stayed there on-and-off until late 1990, but because he required expensive nurses, he then had to find somewhere else to live.

Federal regulations affecting Medicaid block using it to pay for disabled people to live in group homes. This structural discrimination forces such people to live either in public hospitals or be warehoused in huge public nursing homes. When President George Bush refused a waiver of Medicaid to help Larry, the Georgia legislature created an independent-living facility for him and for five other patients as an exception to Georgia's disability law and Medicaid plan. Larry then lived in Augusta, near its medical school.

In 1993, his accident and fight were portrayed in *The Switch*, a CBS movie. To keep his disability payments, McAfee could not accept any money from the movie.

A few months later, Georgia "forgot" to fund McAfee's group home in its state budget. Once again, Russ Fine held Georgia's feet to the fire for Larry, pointing out that the cost per person in the group home was only $52 a day. Georgia found funds to continue the home for another year.

In 1993, a kink in Larry's urinary catheter caused urine to back up. Being paralyzed, Larry could not feel what was happening; the backup caused toxicity and high blood pressure. This caused two devastating strokes.[28] Larry survived, but the strokes injured his brain and he was left with just a small amount of short-term memory.

He had planned to leave the group home for his own apartment but instead was transferred to a long-term nursing home. This was just the kind of place Larry had wanted to avoid. Ten years after his accident, Larry died in 1995. He died not by his own decision, but after being comatose for many months.

THE CASE OF DAX COWART

Another famous case in bioethics concerned 29-year-old bachelor Dax (Donald) Cowart, who suffered burns over two-thirds of his body in 1973. Physicians treated him against his will for 14 months in a burn unit in Parkland Hospital in Dallas. He was left blind, disfigured, and with only partial use of his fingers.[29]

Afterward, Dax won a million dollars from an out-of-court settlement with a gas company. He then hired a plane, flew to Mexico, and spent several hours on a landing strip with a gun in his hand, debating whether to kill himself. Like Bouvia and McAfee, once he had the power to kill himself, he changed his mind.

Instead, he graduated from law school in 1986 and later married a nurse he had known previously when both of them were students in high school. He became interested in ham radio and raising golden retrievers. Since then, he has been an active trial lawyer, winning several lawsuits.

In retrospect, Dax rejects the decision of his physicians to keep him alive. He frequently tells his story in public, emphasizing the cruelty of the physicians who made him endure 14 months of terrible pain. He argues that even though he is glad to be alive today, his physicians wrongly treated him against his wishes. As he once said to this author, "If I should be so unlucky as to be burned that way again, and if I knew what was waiting at the end, I wouldn't go through that pain to get there."[30] In 2013, Dax was still alive, although living in some pain.[31]

BACKGROUND: PERSPECTIVES ON SUICIDE

Greece and Rome

Ancient Greek aristocrats strove not simply to live, but to lead lives of nobility, honor, excellence, and beauty. Believing that "the unexamined life is not worth living," they thought the "important thing is not to live but to live well." They thought that study of philosophy would provide wisdom to approach death (*philosophy* means "love of wisdom"). Plato records Socrates as saying, "True philosophers make dying their profession, and . . . to them of all men, death is

least alarming. . . . So if you see one distressed at the prospect of dying, it will be proof that he is a lover not of wisdom but of the body."[32]

Socrates died famously. Sentenced to die for his political beliefs, he could have fled Athens, but chose instead to drink hemlock, a poison. At his end, he discussed death with a friend.

The friend argues that if one is convinced of life after death, it is easy not to fear death, but what if the soul is "dispersed and destroyed on the very day that the man himself dies [and] may be dissipated like breath or smoke, and vanish away, so that nothing is left of it anywhere. . . . No one but a fool is entitled to face death with confidence, unless he can prove that the soul is absolutely immortal and indestructible."

Socrates replies that the soul may be immortal, but if it is not, then death is like a sleep from which one never awakes. If so, we should not fear it, because no one will exist to feel pain or to miss life.

Hemlock acts as a poison by decreasing circulation at the extremities, creating distal numbness, and eventually stopping the heart. Hemlock began to work during Socrates' abstract discussion about death, moving up from his toes to his ankles. As the discussion ends, the state poisoner finds that Socrates' thighs are numb and says that, when the poison reaches the heart in minutes, Socrates will die.

As his friends begin to cry, Socrates says, "Calm yourselves and try to be brave!" He dies moments later. His admiring follower, Plato writes, "Such . . . was the end of our comrade, who was, we may fairly say, of all those whom we knew in our time, the bravest and also the wisest and most upright man."

Centuries later in Rome, emperor Marcus Aurelius wrote that suicide surpassed undignified dying. These Roman Stoics defended the argument for the open door: "If the room is smoky, if only moderately, I will stay; if there is too much smoke, I will go. Remember this, keep a firm hand on it, the door is always open."[33]

Another Stoic, Seneca, wrote about old age: "If it begins to shake my mind, if it destroys my faculties one by one, if it leaves me not life but breath, I will depart the putrid or the tottering edifice."[34]

In the twentieth century, existentialist philosopher Jean-Paul Sartre revived the argument for the open door.[35] He emphasized that choice—even the choice of staying alive each day—is inescapable. He famously wrote, "Not to choose is always still a choice."

Philosophers on Voluntary Death

The Bible does not explicitly prohibit suicide, and seems to condone the suicides of Saul and Judas. During the fourth century, Augustine condemned suicide, basing his condemnation on the sixth commandment, "Thou shalt not kill" (Exodus 20:13).

Augustine distinguished between private killing and killing endorsed by divine authority. Killing on one's own authority is never right, but when God commands it, humans should obey. So Abraham had to obey when God commanded him to kill his son, Isaac. Individuals who so kill are instruments of God.

This reasoning underlies killing in capital punishment and just wars. The worldly Ambrose had already said that Christians could kill in war, and Augustine went further by condoning war against heretics. Frederick Russell in *The Just War in the Middle Ages* says that through Augustine's interpretation, "the New Testament doctrines of love and purity were accommodated to the savagery of the Old Testament and pacifism was defeated."[36]

The thirteenth-century philosopher Thomas Aquinas held that suicide is sinful because it leaves no time for repentance; repudiates a gift from God; deprives the community of talented people; deprives children of their parents; and is unnatural, going against the instinct of self-preservation.

Michel de Montaigne in the sixteenth century concluded in "To Philosophize Is to Learn How to Die" by saying, "If we have learned how to live properly and calmly, we will know how to die in the same manner."[37] The Dutch philosopher Baruch Spinoza wrote, "A free man, that is to say, a man who lives according to the dictates of reason alone, is not led by the fear of death."[38] The English poet John Donne in the seventeenth century wrote, "When the [terminal] disease would not reduce us, [God] sent a second and worse affliction, ignorant and torturing physicians."[39]

Hume In the eighteenth century, Scottish philosopher David Hume argued that suicide "is no transgression of our duty to God." Hume hated vanity and observed, "The life of a man is of no greater importance to the universe than that of an oyster."[40]

In his "Essay on Suicide," Hume disagreed with Augustine and Aquinas. For dying patients, he argued, voluntary death is not a sin: "A house which falls by its own weight is not brought to ruin by [God's] providence."[41] Hume argued that if God made the natural world through the laws of causality—the laws of biology, medicine, and physics—then disease belonged to that world.

While Immanuel Kant argued that we have a station in life assigned to us by God that we must not give up, Hume replied, "It is a kind of blasphemy to imagine that any created being can [by taking his own life] disturb the order of the world. Any suicide is insignificant to the workings of the universe and it is blasphemy to think otherwise."

Hume disputed Aquinas's argument that suicide harms the community,

> A man who retires from life does no harm to society; he only ceases to do good; which, if it is an injury, is of the lowest kind. All our obligations to do good to society seem to imply something reciprocal. I receive benefits of society, and therefore ought to promote its interests; but when I withdraw myself altogether from society, can I be bound any longer? But [even] allowing that our obligations to do good were perpetual, they have certainly some bounds; 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?

Kant Hume's contemporary, German philosopher Immanuel Kant, opposed suicide. For Kant, an act is right if it derives from a rule that can be universalized, that is, a rule we would want everyone to act on. Everyone cannot commit suicide or humanity would end.

Suicide also cannot be universalized because its motive is self-interest (for instance, escaping pain). For Kant, self-interest can never justify moral decisions, only respect for the moral law.

Second, a person "who does not respect his life even in principle cannot be restrained from the most dreadful vices." If I do not respect my own life, I will not respect anything else. To respect the sacred value of the lives of others, I must respect the sacred value of my own.

Third, Kant wrote, "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."[42]

Finally, suicide is immoral because people should always be treated as ends in themselves, never as mere means. This entails recognizing one's free will as an absolute, rather than as a relative, value, but destroying oneself entails destroying that freedom of will. "Man's freedom cannot subsist except on a condition which is immutable. This condition is that man not use his freedom against himself to his own destruction."[43]

In other words, Kant believed that each person must treat *his body* as an "end in itself." "To deprive oneself of an integral part of organ (to mutilate oneself), for example, to give away or sell a tooth so that it can be implanted in another person, or to submit oneself to castration in order to gain an easier living as a singer, and so on, belongs to partial self-murder."[44] (For this reason, Kant seems to reject giving another person a kidney.)

John Stuart Mill In his 1859 essay, *On Liberty,* John Stuart Mill famously wrote that,

> One very simple principle [is] entitled to govern absolutely the dealings of society with the individual in the way of compulsion and control, whether the means used is physical force in the form of legal penalties, or the moral coercion of public opinion. That principle is, that the sole end for which mankind are warranted, individually or collectively, in interfering with the liberty of action of any of their number, is self-protection. That the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant. . . . The only part of the conduct of any one, for which he is amenable to society, is that which concerns others. In the part which merely concerns himself, his independence is, of right, absolute. Over himself, over his own body and mind, the individual is sovereign.[45]

According to this principle, so long as others are not harmed, we can do whatever we want with our own lives and bodies.

Mill distinguished between *self-regarding* and *other-regarding* acts, arguing that we may censure others only for other-regarding acts. Paradoxically, Mill's analysis can both support and condemn suicide. On one hand, taking one's own life is clearly self-regarding; suicide is often described as the ultimate personal issue. On the other, suicide can affect others, especially when they believe they should have prevented it. If a suicidal person desired to make others feel bad, then Mill's principle condemns the suicide.

The Modern Era American feminist Charlotte Perkins Gillman killed herself in 1935, writing that she preferred "chloroform to cancer" and that, "The record of a previously noble life is precisely what makes it sheer insult to allow death in pitiful degradation. We may not wish to 'die with our boots on,' but we may well prefer to 'die with our brains on.' "[46]

A century ago, only poor people without families went to hospitals to die. Before the Harrison Act of 1914, Americans could purchase heroin and opiates to lessen the pain of terminal cancer and to die at home. Today, physicians control such drugs, death has been medicalized, and most people die in hospitals.

The nature of deadly diseases has also changed. Before World War II, most people died of sudden-onset, acute diseases such as pneumonia and cholera. Today, people live longer and die slowly from chronic diseases such as emphysema, diabetes, dementia, cancer, and coronary artery disease. Such diseases slowly erode the quality of life, and many people want to die before such quality becomes too bad.

The Concept of Assisted Suicide

One question raised by the cases of Elizabeth Bouvia and Larry McAfee is what to call their intended action: suicide, rational suicide, assisted suicide, euthanasia, voluntary death, or self-deliverance? Let us clarify some terms here.

First, *euthanasia* usually means the killing of one person by another for merciful reasons. The preceding cases do not involve euthanasia because in each case death would be initiated by the person herself.

Second, a terminally ill patient who forgoes medical treatment doesn't really "commit suicide." We should distinguish between (1) cases where an underlying disease is incrementally leading to death, and by choosing not to do everything possible, the patient accepts death; and (2) cases where a competent adult without a terminal illness causes his own death. The second kind of case is appropriately called "suicide." The Bouvia and McAfee cases are therefore best called cases of *assisted suicide*. Neither Elizabeth Bouvia nor Larry McAfee had a terminal disease, but they also could not easily kill themselves, hence they needed *assistance*.

One reason to make this distinction is that life insurance companies do not pay benefits for suicides. Another reason is that in all states it is illegal to assist in suicides.

ETHICAL ISSUES: FOR AND AGAINST ASSISTED SUICIDE

Easy to Kill Oneself?

Why didn't Elizabeth Bouvia and Larry McAfee simply kill themselves? Surprisingly, the answer is that it's difficult to kill yourself painlessly, aesthetically, and with certainty. When you're disabled, it's almost impossible to do so by yourself.

Whenever a suicide is botched, people infer ambivalence, but this is often mistaken. Emergency medicine contains many stories of bizarre survivals.[47] The hand holding the gun wobbles a fraction of an inch and leaves the would-be

suicide a drooling zombie. Because drugs taken for courage also relax muscles and thus soften impact, some jumpers survive falls from the Golden Gate Bridge. One jumper hit a parked car, did not die, and did not lose consciousness.[48]

Although suicide attempts by teenagers increased 300 percent between 1967 and 1982, only one in 50 succeeded.[49] The elderly succeed one in three times. Women attempt suicide more than men, but succeed less. Men use violent means (such as guns); women use drugs.

Attempted suicides present a grim picture. People take lorazepam and benzodiazepines in insufficient quantities to cause death, often ending up merely comatose. In 1987, National Security Advisor Robert McFarlane took 35–45 10-mg tablets of Valium. When he didn't die, people inferred he didn't want to die. An equally plausible explanation is that he didn't know how to kill himself. Even physicians don't. In 1985, physician Robert Rosier didn't know how much morphine to give his terminally ill wife to help her die.[50]

People using other methods may not die but awake in the ER. Carbon monoxide (CO) poisoning may not work because the car can stall or run out of gas; the CO may not concentrate enough to produce death, so that the person ends up with half his former intelligence.

Slitting wrists in a warm tub is not easy: the cuts are painful and must be made deep and in the right place. Nor is this method certain: in the time between unconsciousness and death, the arm may move out of the water and the blood may coagulate. One ER physician observes, "Most slashers just get a trophy: a claw hand."

Some people who don't kill themselves wake up with a nasogastric tube down their throat, into which syrup of ipecac is pumped to induce vomiting. ER physicians then inject saline solution and start gastric lavage—alternate flooding and suctioning of the stomach—and then pump granulated charcoal to absorb remaining toxins.

If they want to spare the feelings of others or be found in a dignified state, suicides should avoid certain methods. A drug overdose not only decreases respiration, but also relaxes bowels and bladders. Jumping off a building or shooting oneself in the head leaves a crushed body. Hanging is difficult to do correctly because the neck may not break and the victim, kicking in agony as he partially asphyxiates, may not die. Men who do die this way are found with an erection and may have lost control of their bladder and bowels.

Rationality and Competence

In the movie *Whose Life Is It, Anyway?*, the quadriplegic hero, Ken Harrison, wants to die and offers rational arguments for suicide to his psychiatrist. Harrison makes a convincing case for suicide, but his psychiatrist decides he's too depressed to make the decision to die. A judge decides that Harrison is of sound mind and his psychiatrist allows him to discontinue dialysis and tells Harrison no attempt to revive him will be made if he slips into a coma.

In Elizabeth Bouvia's case, psychiatrist Nancy Mullen testified that because Elizabeth was suicidal, she could not rationally make decisions about her life. Mullen said that she could conceive of no situation where people could make

competent decisions to take their own lives.[51] Carol Gill, a clinical assistant professor of occupational therapy who used a wheelchair, criticized the ACLU for backing "a handful of medical experts" who found that Bouvia was competent.[52]

Mullen and Gill may have begged the question of rational suicide. A question is begged when the answer is assumed to be true rather than proved. In these cases, the question or point is whether a decision to die is irrational: whether it indicates misinformation or faulty reasoning. Just assuming that a decision to die is always irrational begs that question.

This is not to say that a decision to die is always rational. Elizabeth Bouvia may have been depressed, and psychological tests might have shown this. But Mullen and Gill did not base their arguments on such tests. They were not Elizabeth's therapists and were not treating her. Mullen and Gill reacted to the content of Elizabeth's decision rather than to psychological tests. Indeed, three psychiatric professionals who actually tested Elizabeth found her competent.[53]

In America a patient is legally competent until proven otherwise and proven so in a legal hearing. No patient can be held in a hospital against her will without having been proven legally incompetent. In practice, hospitals sometimes break such laws. Although physicians never legally declared Dax Cowart incompetent, they treated him against his will for 14 months in a burn unit.

Autonomy

At the start of bioethics in the 1970s, autonomy fueled the patient rights movement. Applied to the right to die, an autonomous person who has not been proved incompetent and who is terminally ill always has a right to end his life.

But not everyone glorifies autonomy in bioethics. Critics argued that Bouvia and McAfee did not want to die because they made dramatic demands on public institutions, "acting out" and pleading for attention. In such cases, critics argue, physicians must not accede to wishes of unstable patients. Only fools would assist every distraught patient who came to an ER wishing to die.

The Roman Catholic Church opposes autonomous suicide. In 1990, Father Kevin O'Rourke argued that humans are not in control of their lives.[54] O'Rourke argued that God has a plan for each person and it never includes suicide.

One problem with uncritical acceptance of autonomy is the famous SUPPORT study (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments). It discovered that competent people do not accurately predict what they will later find unacceptable as quality of life.[55] People who predicted that they would rather die than go on a ventilator most often did *not* choose to die but chose life on a ventilator. It's one thing to say abstractly that one would "rather be dead than live like that," but when actually faced with death, most people decide to live.

Moreover, in rehabilitation medicine there is the equally famous *adaptation effect*, in which after six months or so, patients like Larry McAfee or Dax Cowart, who were disabled in accidents, adapt their views about acceptable quality of life. What they once considered unacceptable then becomes acceptable. For most patients, it may take six months or more for this effect to occur.

Supporters of assisted suicide argued that providing such assistance continues good medical care, even if a patient is not terminally ill. When qualify of life

diminishes, the fact that a patient does not have a terminal disease is irrelevant. The real issue is whether a quality of life is acceptable to the person who must endure it, and that is an evaluative judgment that can be made only by that person.

If physicians ignore autonomy, patients can be flogged to death with unnecessary tubes, surgery, and radiation. Such barbaric end-of-life treatment differs little from involuntary commitment of competent people in psychiatric wards.

So the key question was not whether Elizabeth Bouvia was demonstrably competent or incompetent, but where the onus of proof should lie. For rugged individualists and Libertarians who abhor the growing powers of government and physicians, this onus should be on those who would take away autonomy.

As we shall see in Chapter 4, in 1990, the United States Supreme Court decided in its *Cruzan* decision that no state may pass a law limiting the right of competent patients to decline medical treatment, even if declining treatment would hasten death. *Cruzan* built on the *Bouvia* and *McAfee* decisions, and was a victory for the right of competent adults to control how they died.

Treating Depression, Pain, and Symptoms Well

Although every decision to die is not irrational, some suicidal people suffer from treatable depression.

This is especially true of the three patients of this chapter, who were young, non-terminal, competent adults. Although it is understandable to want to die after being horribly burned or after losing physical abilities, people in the throes of depression do not understand how much better they can later feel. Anti-depressants can lift mood and should be given to all non-terminal patients who wish to die.

A different clinical issue concerns relief of symptoms. One physician in palliative care always asks his patients, "What is the chief symptom that makes you want to die now?"[56] That answer is often not what outsiders predict. One patient suffered obviously from air hunger but most missed going to a public park in his trailer, so volunteers quickly arranged such visits. With good coverage, almost any symptom can be controlled, including pain, air hunger, itchiness, fatigue, and boredom.

End-of-life care varies considerably across developed countries. A survey by a charity ranked Britain best for such care, followed by Australia and New Zealand, then the United States.[57]

Social Prejudice and Physical Disabilities

Disability advocate Paul Longmore, whose commentary was quoted earlier and who was a ventilator-dependent person with quadriplegia, opposes voluntary death for people with disabilities. For him, Bouvia's case shows how a prejudiced system destroys the independence of disabled people.

By creating intolerable conditions, society paints people with disabilities into a corner, leaving them with only one autonomous decision consistent with their former selves: to decide to die. Professionals who keep them passive and dependent make every other decision for them. In Longmore's words:

> Given the lumping together of people with disabilities with those who are terminally ill, the blurring of voluntary assisted suicide and forced "mercy" killing, and the oppressive conditions of social devaluation and isolation, blocked opportunities, economic deprivation, and enforced social powerlessness, talk of their "rational" or "voluntary" suicide is simply Orwellian newspeak. The advocates of assisted suicide assume a nonexistent autonomy. They offer an illusory self-determination.[58]

To see Bouvia or McAfee or Cowart simply as cases of a right to die is to miss a much bigger issue. Elizabeth Bouvia wanted to die because of centuries of prejudice against people who are physically disabled—prejudice that society expresses daily—prejudice that idealizes youth, beauty, sex, athleticism, fitness, and wealth. Other values also can make life valuable, such as caring for others, erudition, creativity, and community, but our culture does not idealize them.

Longmore despises films that encourage disabled people to view killing themselves as a rational response to their miserable conditions. He cites *Annie Hall*, *Elephant Man*, and especially *Whose Life Is It, Anyway?* He claims that watching the latter depressed Elizabeth Bouvia. He could have also cited the 2004 film *Million Dollar Baby*.

Longmore sees Bouvia as one who slipped through the cracks of an impersonal system. She was tragic not because of her physical situation, but because of her *social* situation. Even as a hospitalized patient, she remained sadly alone. It was this aloneness that underlay her fierce desire to tear herself away from life.

Structural Discrimination Against the Disabled

In 1990, the Americans with Disabilities Act (ADA) became federal law. This legislation represents one of the most sweeping changes in American life and was intended to integrate Americans with disabilities into normal life. Despite it being passed over two decades ago, some institutions still do not comply with it because of lack of financial resources.

Raising the issue of inadequate resources puts physicians in an awkward place. On the one hand, they do not want to torture disabled people who want to die. On the other hand, they do not want to kill disabled people because a prejudiced society is too cheap to help such people.

The catch is that to provide such great care, the patient must be rich or have great insurance, or society must be generous. If the true measure of a society's humanity is how it treats its least well-off members, then our society is not humane toward the disabled.[59]

As a result of childhood polio, Professor Longmore's arms were paralyzed, his spine was curved, and he used a ventilator as much as 18 hours a day. As a professor of history at San Francisco State University, his success would have been impossible without his ability to live on his own, which required home health care aides. Fortunately, California's generous Medicaid program paid for his domestic aides ($15,000 a year) and Medicare disability paid for his ventilator ($12,000 a year). Had he lived in Georgia, Longmore, too, might have wanted to die, where he would not have been able to find a group home and where, as he said, he "probably would have found my life unendurable."

Longmore maintained that Elizabeth Bouvia's problems resulted in part because she did not receive her maximum payments and because her county is notorious for its stingy benefits to disabled people.

When a disabled person takes a job or marries, officials reduce her benefits. California's In-Home Supportive Services program allowed Elizabeth to manage her own life at home only while she was single; when she married, however, her husband was expected to care for her. Given these circumstances, it is no wonder that Bouvia later divorced or that she did not complete her training for a job. Longmore concludes:

> This is a woman who aimed at something more significant than mere self-sufficiency. She struggled to attain self-determination, but she was repeatedly thwarted in her efforts by discriminatory actions on the part of the government, her teachers, her employers, her parents, and her society. Contrary to the highly prejudiced view of the appeals court, what makes life with a major physical disability ignominious, embarrassing, humiliating, and dehumanizing is not the need for extensive physical assistance, but the dehumanizing social contempt toward those who require such aid.

Russ Fine believes that McAfee's desire to die also resulted from his inadequate care. Public officials control costs by requiring patients to live in the most cost-effective facilities, but McAfee said that if he couldn't live in his own apartment he would rather die. According to Fine, McAfee "was very vocal about inferior nursing care, which was the rule, not the exception, in these marginal health-care facilities that had accepted these contracts."[60]

Once, Fine had brought McAfee a Thanksgiving dinner and the two were watching a televised football game while waiting for McAfee's family to arrive. Fine was drowsing in an armchair when he suddenly realized that McAfee had stopped breathing. Aides soon got Larry breathing and Fine then saw tears streaming out of his eyes. "He didn't really want to die," Fine concluded. "He was just terrified."[61]

It should be noted that McAfee, like Bouvia, wanted to work, but getting paid for working would have made him ineligible for publicly funded assistance in housing or for Medicaid.

Cases such as Bouvia's and McAfee's suggest that we often give severely disabled people three grim choices: to become a burden on their families, to live miserably in a large public institution, or to kill themselves.

Disability Culture

During the last decades, people with disabilities increasingly resisted discrimination, asserting their right to 24-hour-a-day attendants, public transportation, and good housing.[62] They asserted that they had a condition, not an illness. For them, "Disability Culture" is not bad, but a source of identity.

Indeed, the disabled community is the only minority that one may join at any time. James Meredith had to sue in 1962 to become the first black person admitted to the University of Mississippi, and so also quadriplegic Edward V. Roberts had to sue to be admitted to the University of California. But has society more successfully integrated the races than the disabled?

People with disabilities despise Mattel's "Share-a-Smile Becky" in a wheelchair (sold in some hospitals' gift shops) and demonstrate outside of classes of Princeton bioethicist Peter Singer, whose views on quality of life, they fear, will allow society to easily kill the disabled or deny them adequate resources. They hectored the Hemlock Society (now called Compassion and Choices) for being too sympathetic to the assisted death of non-terminal patients. They cite psychologist Faye Girsh, this society's executive director, who testified on behalf of Bouvia, on behalf of Jack Kevorkian, on behalf of George DeLury who in 1996 in Manhattan killed his wife in the late stages of multiple sclerosis, and on behalf of Canadian Robert Latimer, who in 1993 killed his 12-year-old daughter with cerebral palsy. Disability groups accused Girsh of siding with rich, well-insured, autonomous elites, not of securing better conditions for the disabled.

FURTHER READING AND RESOURCES

"A Man of Endurance," *20/20* television show on March 22, 1999, on Donald Cowart's case. Call 1-800-CALL-ABC to order tape.

"Elizabeth Bouvia: 10 Years Later," *60 Minutes* Special, www.cbs.com.

Pat MilmoreMcCarrick, "Active Euthanasia and Assisted Suicide," Scope Note 18, *Kennedy Institute of Ethics Journal* no. 1 (March 1992).

James Rachels, *The End of Life*, Oxford, UK: Oxford University Press, 1986.

Lonnie Kliever, *Dax's Case: Essays in Medical Ethics and Human Meaning*, Dallas, TX: Southern Methodist University Press, 1989.

DISCUSSION QUESTIONS

1. Can decisions be justified by their outcomes? What if, when they had the opportunity, Bouvia or Cowart had killed themselves? Would that mean the physicians who prevented their earlier deaths were wrong?
2. How do you know when you've really properly treated depression and "debilitating symptoms" when a patient has sustained a terrible accident or is dying? Isn't that a Catch-22, where you only know you've successfully treated it when the patient decides to live?
3. Is the right to die glamorized in movies? What if the paralyzed fighter, portrayed by actress Hillary Swank in *Million Dollar Baby*, had to suffocate slowly for 20 minutes in dying? What if her reflexes kicked in and her body resisted? She lost bowel and bladder control? It didn't work and she was left comatose or brain-damaged?
4. Right now, society seems to exalt young bodies, sexiness, athleticism, and wealth. Do these images set young people up for failure? As most people can't have these traits, what message do these images send to people who are the opposite? Is this a good set of values to live by?
5. How do diversity and autonomy go together, or not? Will some ethnic groups be more interested in autonomy in medicine than others? Is autonomy more meaningful to some than others? Should autonomy be defined as a check or balance against the power of the medical establishment over the individual?