

DOCUMENT RESUME

ED 422 531

CG 028 555

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 TITLE At Death's Door: What Are the Choices? An Issue Book for National Issues Forums.
 INSTITUTION Public Agenda Foundation, New York, NY.; National Issues Forums, Dayton, OH.
 SPONS AGENCY Charles F. Kettering Foundation, Dayton, OH.
 ISBN ISBN-0-7872-3915-1
 PUB DATE 1997-00-00
 NOTE 33p.
 AVAILABLE FROM Kendall/Hunt, 4050 Westmark Dr., Dubuque, IA 52002; toll-free phone: 800-228-0810.
 PUB TYPE Opinion Papers (120)
 EDRS PRICE MF01/PC02 Plus Postage.
 DESCRIPTORS *Death; Decision Making; Suicide; *Terminal Illness
 IDENTIFIERS *Assisted Suicide

ABSTRACT

This paper questions how society should care for people who are suffering and near death? Underlying this issue are very difficult questions about the evolving rights of patients, medical standards, and societal norms--questions about the American way of death, which often involves needless pain and unwanted treatment. Three choices are presented in a brief proposal format for use with National Issues Forums. "Choice 1: Let Patients Die with Dignity," holds that physician-assisted suicide is a humane way of death that is widely and secretly practiced today. "Choice 2: Improve Care for the Dying," raises the concern that dying patients often suffer needlessly in our healthcare system, which routinely ignores patient's final wishes concerning treatment. Correcting the existing system is recommended. "Choice 3: Above All, Sustain Life," is based on the premise that life is invaluable and should be inviolable, and society and the medical community must strengthen their commitment to preserving life. References "For Further Reading" and checklists "In Support" and "In Opposition" are presented with each choice. A summary that displays comparable points for each viewpoint is included. National Issues Formats are described, and ballots to be used before and after attending forum meetings are provided. (EMK)

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At Death's Door

What Are the Choices?

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A note to the reader about NIF books

Each book in this series for the National Issues Forums outlines an issue and several approaches, or choices, that address a problem and its solution. Rather than conforming to any single public proposal, each choice reflects widely held, but contrasting, concerns and principles. Panels of experts review manuscripts to make sure the choices are presented accurately and fairly.

Unlike most periodicals, issue books do not identify individuals or organizations with partisan labels such as Democrat, Republican, conservative, or liberal. The goal is to present ideas in a fresh way that encourages readers to judge them on their merit. Issue books include quotations from experts and public officials when their views appear consistent with the principles of a choice. But these quoted individuals might not endorse every aspect of a choice as it is described here.

At Death's Door

What Are the Choices?

By Michael deCourcy Hinds

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<p>How should society care for people who are suffering and near death? That's the issue, and underlying it are very difficult questions about the evolving rights of patients, medical standards, and societal norms – questions about the American way of death, which often involves needless pain and unwanted treatment.</p>		
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At Death's Door

What Are the Choices?



Paul Hoesfer/NT Pictures

Advocates and opponents of physician-assisted suicide demonstrate in front of the U.S. Supreme Court.

Claire S., 68, is a widow. Close friends and family have moved away from the small town where she lives, and terminal illness keeps her housebound. Two years ago, she developed breast cancer. Surgery didn't cure the disease, but continuing chemotherapy slows its pace. Painkillers provide some relief, but often she doesn't have strong enough medicine or high enough doses to make her pain bearable. Claire, a retired accountant, sees no point in continuing a lonely life of pain and suffering. But she is afraid to attempt suicide alone, fearing that she will "botch" it. She wants her physician's help.

How do Americans want Claire's physician to respond? The doctor's options include:

- ☑ Continuing treatment that sustains life and hope.
- ☑ Halting chemotherapy that prolongs her life.
- ☑ Treating her for depression.
- ☐ Relieving her pain with medication, in high doses if necessary, despite the chance that an overdose may unintentionally end her life.
- ☐ Prescribing a lethal drug she can use to take her own life – if the doctor is willing to risk prosecution.

Claire's unsettling plea for help was presented at a symposium on physician-assisted suicide, sponsored by the Ethical Culture Society in New York. Claire isn't a real person, but a composite of dying patients who are crying for help. Symposium participants discussed many ways society could help the Claires of America, but the answers only seemed to spawn new questions.

Physician-assisted suicide, it turns out, is the tip of the iceberg. At first glance, the issue is how society can respond humanely to a relatively small number of dying patients like Claire who clearly would like to shorten their lives. But beneath the surface is a mountain of questions about the evolving rights of patients, medical ethics, societal norms, and the quality of care patients receive when they become very ill.

The American way of death has become a major public issue in recent years for many reasons. Because of advances in medical technology, death is no longer just a natural event but, in many cases, it is a medical procedure that follows a decision to forego or discontinue life-sustaining treatment. Meanwhile, patients are seeking more control over the circumstances of their death – particularly when, for many patients, the dying process is a gauntlet of high-tech care, unwanted treatments, severe pain, and depression. The nation's medical establishment has advocated for more humane care of terminally ill patients, but reforms have so far proven elusive.

To help citizens discuss this emotional, sprawling topic, this guide outlines the issue of physician-assisted suicide and three general approaches the nation might take.

A Century-Old Debate

On June 4, 1990, a woman suffering from Alzheimer's disease used Dr. Jack Kevorkian's suicide machine, sparking a national debate about the American way of death. But this was really just the latest round in a debate that began as early as the 1870s, when physician-assisted suicide was widely discussed in periodicals, books, medical societies, and state legislatures. The Ohio legislature, which took the issue the most seriously, considered and finally rejected a 1906 bill to legalize physician-assisted suicide. Arguments for and against physician-assisted suicide have not changed much in 100 years.

Discussions of physician-assisted suicide ebbed and flowed throughout the twentieth century until Dr. Kevorkian began his crusade to legalize the practice in 1990. Since then, several books on death have become national best-sellers, including Derek Humphry's *Final Exit*, a manual with explicit instructions for committing suicide; it sold 540,000 copies within 18 months of its publication in 1991. Perhaps the best evidence that the physician-assisted suicide debate has entered mainstream America: judges in the 1997 Miss U.S.A. beauty pageant asked a contestant to share her views on the subject.

The issue of physician-assisted suicide has also re-entered the political arena. Impatient with legislative inaction, voters initiated ballot measures in Washington state in 1991 and in California in 1992. Both measures, which failed to pass, would have permitted doctors to prescribe or administer lethal drugs to terminally ill patients. In 1994, Oregon voters legalized physician-assisted suicide and established rules for screening patients, intended to make sure patients seeking physician-assisted suicide are competent, terminally ill, in great pain, and intent on ending their lives. The law has been stayed pending review by courts and reconsideration by voters in November 1997.

In its first ruling on physician-assisted suicide, in June 1997, the U.S. Supreme Court left it up to the states to govern the practice of physician-assisted suicide. The justices

unanimously upheld laws in New York and Washington that make it a crime for a doctor to give lethal drugs to a terminally ill patient who wants to die. However, the court endorsed current medical practice for treating pain aggressively, even if that leads to premature death – as long as the doctor's intention was to improve the care of the dying patient.

The justices said that, while there is no general constitutional right to assisted suicide, they were not “foreclosing” all future claims of such a right for some patients. “Throughout the nation, Americans are engaged in an earnest and profound debate about the morality, legality, and practicality of physician-assisted suicide,” wrote Chief Justice William H. Rehnquist. The court's inconclusive ruling “permits this debate to continue, as it should in a democratic society,” he added.

Evidence that the physician-assisted suicide debate has entered mainstream America: judges in the 1997 Miss U.S.A. beauty pageant asked a contestant to share her views on the subject.

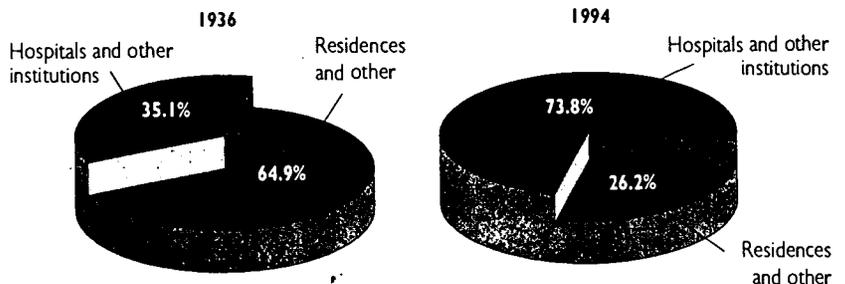
Saving Lives and Ending Them

Spectacular advances in medicine have given the physician-assisted suicide debate a new sense of urgency. Until 1920, pneumonia and influenza were the leading causes of death and nearly all Americans died at home. Today, penicillin and other wonder drugs usually cure illnesses like pneumonia, and none of the top five causes of death are infectious diseases. Instead, degenerative diseases like cancer lead the list of killers, causing an estimated 70 percent of all deaths. Americans struck by these diseases usually reach death's door after a protracted illness.

But instead of going through the door, many patients pause, their lives artificially sustained by ventilators, dialysis machines, feeding tubes, and the rest of the miraculous technology in the

Americans Increasingly Die Away From Home

Place of death, all Americans, 1936 and 1994



Sources: Vital Statistics of the United States, 1937; Centers for Disease Control

intensive care units and hospital wards where most Americans die. In this environment, where biological life can be sustained almost indefinitely, death often follows a decision to end treatment. The scope of medical intervention is suggested by its cost: an estimated 30 percent of the nation's total healthcare budget is spent in the last six months of life, much of it in the last month.

It's a perplexing situation: on the one hand, patients want to benefit from all the scientific advances and optimism that drive medical practice today; on the other hand, modern medicine often makes death resemble a science experiment, denying patients a peaceful and comfortable parting with families in familiar surroundings.

Recognizing Patient Autonomy

Twenty-five years ago, amid a rising public clamor to give patients more control over their bodies and their treatment, the field of biomedical ethics was born, and with it, the phrase "patient autonomy." This was the start of the backlash against the traditional practice of medicine, in which paternalistic physicians dictated treatment in what they thought were the best interests of the patient, but often without informing the patient of the diagnosis or obtaining consent for the treatment. Today, such behavior would be considered grounds for malpractice, except in medical emergencies.

Medical practice and laws governing terminal care are in perpetual flux. Here are some major tension points:

- ▣ Dying patients may state preferences for receiving or refusing aggressive treatments such as resuscitation or emergency surgery; they may also write advance directives, living wills, or give a family member or friend the power of attorney to make healthcare decisions. But studies indicate that most doctors ignore these preferences or overrule them, deeming them medically unsound. By contrast, relatively few healthy people make plans for their end-of-life care, and those who do plan ahead often change their minds when they become very sick.
- ▣ Many dying patients, and most cancer patients, suffer considerable pain. While the prevalence of unrelieved pain has not been extensively studied, pain management specialists say that a great many patients suffer needlessly – often because patients don't know enough to complain and because doctors are fearful of giving a lethal overdose of

As stark evidence of the growing public concern about the way we die, Derek Humphry's book, *Final Exit*, made the bestseller list, and many readers attend his lectures to learn the best way to commit suicide.



Lonny Shavelson/Impact Visuals

Debating the Rights of the Dying

- 1870s First major debate about physician-assisted suicide in the U.S.
- 1906 Ohio legislature rejects bill to legalize assisted suicide.
- 1938 National Society for the Legalization of Euthanasia is formed.
- 1941 New York legislature rejects bill to legalize assisted suicide.
- 1973 American Hospital Association issues a "Patient Bill of Rights," which says patients should have the right to refuse life-sustaining treatment.
- 1976 New Jersey Supreme Court permits the parents of comatose Karen Ann Quinlan to disconnect her respirator.
- 1988 Unitarian-Universalists become the first religious body to approve of assisted suicide for the terminally ill.
- 1990 Dr. Jack Kevorkian, a retired pathologist in Michigan, begins his crusade to legalize physician-assisted suicide by helping a woman with Alzheimer's disease end her life.

In its first right-to-die decision, the Nancy Cruzan case, U.S. Supreme Court rules that competent people have a constitutional right to refuse treatment, and that legal guardians can make that decision for incompetent patients.
- 1991 Voters in Washington narrowly reject a ballot initiative to legalize physician-assisted suicide.
- 1992 California voters reject a similar measure.
- 1994 Voters in Oregon approve a ballot initiative to legalize physician-assisted suicide, but the law is stayed pending judicial review.
- 1996 Two federal appellate courts, in overturning state bans on assisted suicide, rule that terminally ill patients have a constitutional right to physician-assisted suicide.
- 1997 U.S. Supreme Court throws out lower court decisions, ruling that there is no general constitutional right to assisted suicide. But the court leaves open the possibility that some limited right to die could be claimed in the future.

painkillers. Doctors also worry about patients becoming addicted to narcotics. Chronic pain can lead to depression, and sometimes to suicidal thoughts. Studies indicate that most doctors are not trained to diagnose or adequately treat pain or depression.

□ The costs of uninsured hospital care can drain the resources of patients and their families. One major study suggests that nearly one in three families with a terminally ill family member exhausts all or most of their savings paying hospital bills insurance doesn't cover.

□ The physician treating a patient for pain may inadvertently end the patient's life by prescribing or administering an overdose of painkillers. But doctors can also use this legal practice as a cover for *intentionally* – and thus illegally – ending patients' lives.

□ Patient autonomy is a major aspect of the assisted-suicide debate. Some advocates of physician-assisted suicide see it as a natural evolution of patients' rights, as the ultimate right of patients to determine the timing and circumstances of their own deaths. Some opponents see physician-assisted suicide as patient autonomy run amok, where physicians are asked to end lives, in violation of the Hippocratic oath and 2,400 years of professional ethics. Still other opponents say public demands for the right to physician-assisted suicide demonstrate, more than anything else, the high level of frustration with a healthcare system that routinely fails to honor dying patients' preferences for treatment while letting them suffer needless pain and depression.

A Right to Assisted Suicide?

Advocates for physician-assisted suicide assert that Americans have a sovereign right over their own bodies. Further, they say citizens should be as free to obtain assistance in suicide as they are now free to refuse unwanted medical treatment or to make life-and-death decisions about reproduction. Advocates also claim that since some patients already have a legal right to end their lives by asking a physician to disconnect their life-support systems, patients who are not on

life-support systems should have an *equal right* to have a physician help them end their lives.

Opponents see a major difference between the right to refuse a physician's treatment and a right to ask a physician to prescribe lethal drugs. Society has no obligation to end an individual's life; on the contrary, opponents say, society is obligated to protect life and prevent suicide.

A Framework for Discussion

To promote an informed discussion of physician-assisted suicide, this issue book

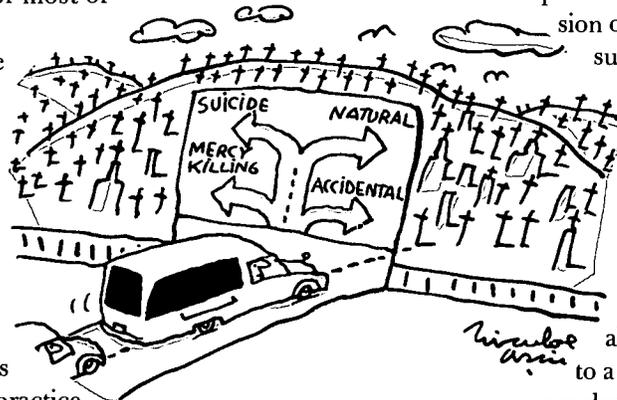
presents three approaches, or choices, that the nation might take:

Choice One says society must protect life, but must also protect the right to a humane death. When

near death and in unbearable pain, patients should be able to receive a physician's assistance in ending their lives. It happens now anyway, but in a secretive way that spawns error and abuse. Let's regulate it.

Choice Two says the debate about physician-assisted suicide has arisen primarily because the healthcare system routinely fails to honor patients' wishes about treatment and fails to relieve their pain and depression. Giving patients more control over their treatment and relieving their symptoms is a far better solution than supervising suicides.

Choice Three says life is invaluable and should be inviolable, and society and the medical community must strengthen their commitment to preserving it. Medical science has extended life, and now some want to abuse that science to shorten life. That would create confusing public policies and weaken public trust in medicine. Assisted suicide is a crime.



For Further Reading/At Death's Door

- Margaret Pabst Battin, *The Death Debate: Ethical Issues in Suicide* (Upper Saddle River, N.J.: Prentice Hall, 1996).
- Jonathan D. Moreno, ed., *Arguing Euthanasia: The Controversy Over Mercy Killing* (New York: Simon and Schuster, 1995).
- Carol Wekesser, ed., *Euthanasia: Opposing Viewpoints* (San Diego: Greenhaven Press, 1995).

Let Patients Die With Dignity



Lonny Shavelson/Impact Visuals

Facing certain death after a long battle with cancer, mystery writer Mary Bowen Hall hugged her son before taking an overdose of sleeping pills to end her suffering.

“I’m not depressed, I’m exhausted,” Louise J., a Seattle woman told *The New York Times*. She was explaining why she was making plans to commit suicide. Her idea was to live as long as possible, and then end her life just before her fatal brain disease corroded her thoughts and feelings in the final weeks of life. “I’m in constant pain,” she said. “I’m getting weaker by the day. I want to do this at home, before my body’s here and my brain isn’t.”

Louise’s doctor was sympathetic, and contacted Compassion in Dying. Co-founded by the Rev. Ralph Mero, a Unitarian-Universalist minister, the nonprofit organization provides medical, spiritual, and emotional support to Washington residents in Louise’s situation. The organization helps only those terminally ill patients who are lucid, repeatedly seek assistance in ending their lives, and are relatively close to death. A panel of volunteer health professionals makes sure patients meet all the criteria, and that every possible effort to relieve their symptoms has been made. The organization does not provide the means to hasten death, but most patients have no trouble obtaining medication from their physicians, usually with an unstated understanding of its intended use. If the patient desires it, volunteers attend the death, because they believe patients should not have to die alone – and some patients keep family members away to shield them from criminal prosecution. The patient’s doctor records the death as due to natural causes.

Louise hung onto life for as long as she could, but her physical health and mental acuity began to deteriorate rapidly in August 1993. With possibly only weeks to live, Louise – with her mother, a friend, and the Rev. Mero gathered in her small Seattle apartment – crushed 40 sleeping pills into a mixture of applesauce and ice cream, and swallowed it. As her mother stroked her hand and the Rev. Mero prayed, Louise fell into a wakeless sleep.

Dying With Dignity

“I do think that all human beings have a moral claim to humane treatment,” the Rev. Mero later told *The Times*. Supporters of Choice One agree. They recognize society’s compelling interest in protecting life, but believe it should be tempered by an individual’s right, under certain limited conditions, to choose the time and circumstances of death. In this view, society has no interest in protecting the lives of a relatively small number of competent patients who are near death, suffering unbearable pain, and repeatedly ask for assistance in suicide. In these situations, society’s primary obligation is to relieve pain and suffering as compassionately as possible.

The best way to accommodate the competing rights and responsibilities of society and patients, in this view, is by legalizing physician-assisted suicide and closely regulating it to prevent errors and abuse.

What Can Be Done

Supporters of Choice One generally favor the following measures:

- Legalize physician-assisted suicide, making it a socially accepted, stigma-free medical procedure for the relatively few patients who qualify.
- Enact strict rules and medical screening procedures for physician-assisted suicide. Among other things, rules would restrict these practices to mentally competent adults who are terminally ill, suffer unbearable pain, and make repeated requests for help ending their lives.
- Permit physicians to practice physician-assisted suicide by administering a lethal medication when a competent adult meets all the other guidelines but is physically unable to commit suicide alone.
- Prosecute physicians who violate any of these laws and rules.
- Require insurers to provide health and life insurance benefits to people who die under a doctor’s care.

Legalizing assisted suicide would also yield other benefits; notably, it would free dying patients and their families from the stigma of suicide, which only adds to their suffering. For although Americans may legally take their own lives, suicide carries very negative connotations in our culture, having long been considered a cowardly act, a sin, or a symptom of mental illness.

It is tragic when people, still full of productive potential, kill themselves in fits of depression or because of substance abuse. But, in this view, suicide can be a rational medical decision for those relatively few, mentally competent, terminally ill patients who experience life as torture. Documented cases of people who wanted a

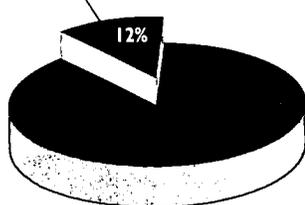
physician’s help in ending their lives include a terminally ill quadriplegic, who daily prayed for death; a physician, who did not want to be kept alive on a ventilator but did not want to die of the

Doctors Already Respond to Many Assisted-Suicide Requests

Many doctors receive requests

Percentage of 828 doctors in Washington state who reported receiving a request from a patient for help in committing suicide

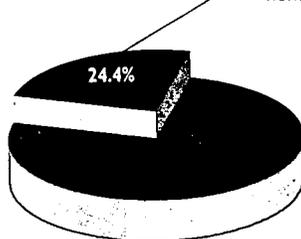
Doctors who reported receiving requests from patients



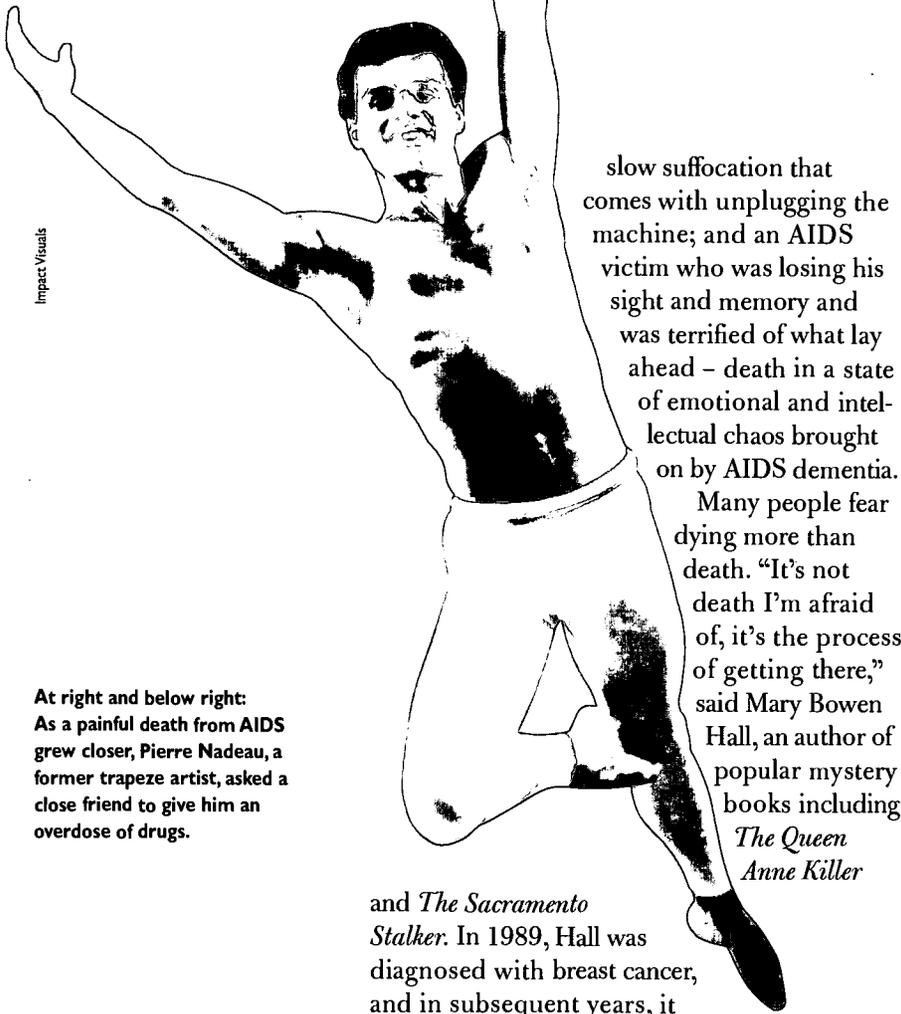
Many requests are honored

Percentage of 156 patient requests that doctors honored by prescribing a lethal dose of drugs

Requests that doctors honored



Source: “Physician-Assisted Suicide and Euthanasia in Washington State: Patient Requests and Physician Responses,” *Journal of the American Medical Association*, March 1996



Impact Visuals

At right and below right: As a painful death from AIDS grew closer, Pierre Nadeau, a former trapeze artist, asked a close friend to give him an overdose of drugs.

slow suffocation that comes with unplugging the machine; and an AIDS victim who was losing his sight and memory and was terrified of what lay ahead – death in a state of emotional and intellectual chaos brought on by AIDS dementia.

Many people fear dying more than death. “It’s not death I’m afraid of, it’s the process of getting there,” said Mary Bowen Hall, an author of popular mystery books including *The Queen* and *Anne Killer*

and *The Sacramento Stalker*. In 1989, Hall was diagnosed with breast cancer, and in subsequent years, it spread to her bones. She tried many treatments, including bone marrow transplants, but she slowly wasted away, suffering bouts of excruciating pain and panic. She lost control of her bodily functions and had to wear diapers. And, most humiliating of all for her, she had to be tied to her bed to prevent a fall. Before taking her life with a medication prescribed by a compassionate doctor in 1994, she said: “There is nothing to be gained by anyone from these next few days of misery. It is ridiculous and humiliating for me to lie here dying for days. There is no quality left to my life and nothing I need to do.”

Compassionate Help in Dying

Despite the risk of being charged with a felony and losing their medical licenses, 4 in 10 doctors repeatedly say in surveys that they are willing to help terminally ill patients commit suicide. Three in 10 doctors say they are willing to inject patients with lethal drugs when the patients can’t commit suicide themselves.

Doctors aren’t just talking. In a landmark 1996 study in Washington state, 12 percent of the doctors surveyed said that in the previous year they had received patient requests to help them die. The doctors acknowledged responding to a quarter of these requests by providing prescriptions for lethal drugs or by injecting lethal drugs, according to the study, done at the U.S. Veterans Affairs Puget Sound Health Care System in Seattle.

What’s Wrong With This Picture?

Compassionate American doctors are being forced to make life-and-death decisions in a hostile legal environment that isolates them and encourages secrecy – and that’s bad medicine, in this view. Consider the impact of secrecy: only 15 percent of the patients seeking death obtained a second opinion; only 24 percent were referred to psychiatrists or psychologists for counseling or medication; and two patients committed physician-assisted suicide after making only one request to die, the Washington study reports.

In normal medical practice, doctors would discuss these difficult cases with their peers and make referrals to specialists, but as the researchers conclude: “Open, real-time discussion of an individual patient request is unlikely to occur while physician-assisted death remains illegal.”

As Choice One supporters see it, Americans should no longer be asking whether physician-assisted suicide should be allowed, but rather, under what conditions.



Lenny Staveland/Impact Visuals

Oregon Sets the First Standard

A major concern about legalizing physician-assisted suicide is that abuses could occur. For instance, society's most vulnerable members might feel pressure to choose death rather than run up medical bills for relatives, insurers, or taxpayers to pay. Choice One shares this concern but says the best way to address it is by legalizing physician-assisted suicide, bringing the now-secretive practice into the open, and strictly regulating it. In this view, government regulation would set up a comprehensive screening process to limit physician-assisted suicide to mentally competent patients who are near death, suffer unbearable pain, and repeatedly request assistance in dying.

As it is now, physician-assisted suicide is widely practiced, but its availability depends more on the physician's values and willingness to take risks than on the patient's values and health. And doctors who take the risks as a matter of conscience know that they have to act alone, violating professional standards that are intended to reduce the chances of making tragic mistakes.

Despite the risk of being charged with a felony, 4 in 10 doctors say they will help terminally ill patients commit suicide.

To remedy this situation, voters in Oregon approved a 1994 ballot measure called the Death With Dignity Act, which legalizes physician-assisted suicide and regulates it. The law, which has been stayed pending court review, sets many rules that Choice One endorses, including the following:

- Patients seeking suicide assistance must be mentally competent adults with less than six months to live. They must request assistance in writing and then orally repeat the request 15 days later.
- Physicians must ensure that patients have complete information about their diagnosis and therapeutic alternatives, including pain-control techniques and hospice care.
- A second physician must examine the patient to confirm that the disease is terminal, and that the patient is acting voluntarily. Physicians must refer the patient for psychological counseling if

they suspect any emotional disorder is clouding the patient's judgment.

- The patient must be asked to inform his family, but is not required to do so.

- Qualified patients who commit suicide under a doctor's care will not lose any life or health insurance coverage.

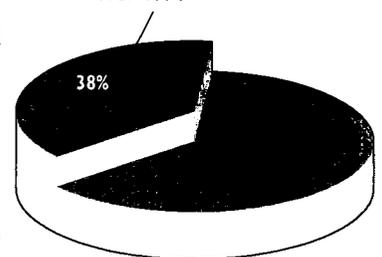
Oregon's regulations are a step in the right direction, but need considerable refinement, say Choice One supporters. One major problem with the law is that it wrongly forbids physicians from helping patients who meet all the requirements but are physically unable to commit suicide themselves.

When terminally ill patients are also physically immobilized, society must give special consideration to their requests for physician-assisted suicide, in this view. These patients want to escape their suffering by committing suicide, but can't do it alone because they cannot move or swallow. In these rare cases, physicians should be permitted to administer a lethal drug or, using new computer technology, make it possible for the patient to initiate the lethal injection by blinking an eye or speaking.

Choice One says this practice, which now occurs in secret, should be available to patients who meet all the other guidelines.

Prolonging Death

Percentage of patients dying in hospitals who spent 10 or more days in an intensive care unit (ICU) in a coma or on a ventilator, 1989-1994



Source: The Study to Understand Prognoses and Patient Preferences for Outcomes and Risk of Treatment (SUPPORT), Robert Wood Johnson Foundation and National Institute of Mental Health, 1995

In Support

✓ Citizens expect society to protect their lives, and that should also mean protecting their right to end their lives in a dignified, humane way. Society must be flexible in responding to the needs and last wishes of the dying.

✓ No interest is served by prolonging the misery of a relatively small number of terminally ill patients who want to die. They deserve compassionate treatment, and should not have to seek it in secret.

✓ This approach respects patients' autonomy and desire for dignity, instead of forcing them to linger on helplessly and hopelessly.

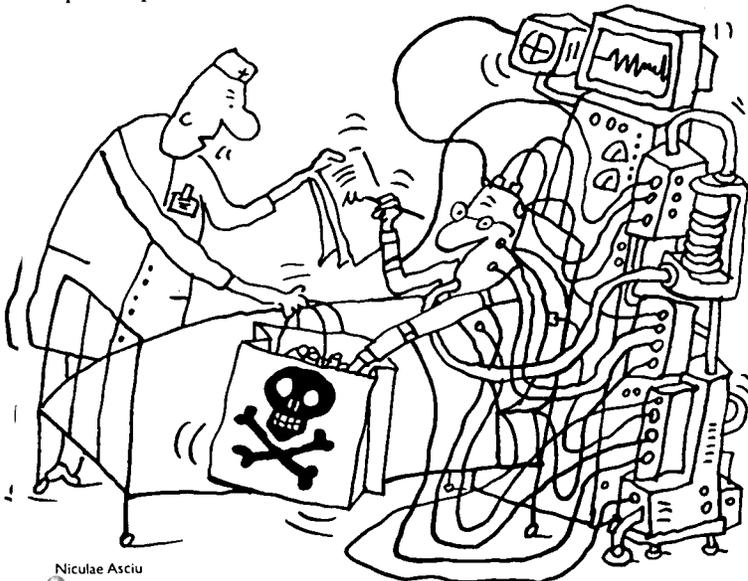
Since doctors already help many patients die, it would be better for everyone if they did it openly, so that it could be regulated and made available to eligible patients.

✓ As long as regulations are strict and rigorously enforced, the danger of abuse will be kept to a minimum.

✓ When a dying patient with intolerable pain wants to commit suicide but isn't able to move or swallow, it's only humane for a doctor to help.

✓ Once a decision has been made to end a life, it is better to do it quickly and painlessly. Physician-assisted suicide would be more humane than withdrawing treatment, nutrition, water, and air, which is currently allowed.

✓ Recognizing the patient's right to choose the timing and circumstances of death eases psychological suffering. A study in Washington state found that many patients who asked for lethal prescriptions never used them.



Niculae Asciu

In Opposition

✗ This is a very dangerous choice that threatens society's ability to protect life.

✗ Abuses would be inevitable. Research indicates that doctors who support physician-assisted suicide admit knowing relatively little about pain management and report relatively high levels of stress and professional burnout.

✗ Nearly all suicidal people are depressed and need treatment, not death. Requests for assisted suicide come mostly from chronically ill, not terminally ill, patients who suffer more from anxiety than pain.

✗ Once legal, a right to die could become a duty to die for patients who feel financial or emotional pressure from relatives, medical professionals, or insurers.

✗ Given current pressures to ration healthcare, legalizing physician-assisted suicide would create impossible conflicts of interest and undermine public trust in medicine.

✗ This choice blurs the critical difference between a physician who legally withdraws medical treatment to let nature take its course and a physician who overrides the course of nature by prescribing lethal drugs.

✗ This choice misses the real problem: our healthcare system fails to provide humane care for the dying or to honor patients' final wishes to avoid aggressive treatment.

✗ Some supporters of assisted suicide don't want it legalized. They say it's better the way it is: widely available, but carefully practiced by physicians under threat of criminal prosecution.

✗ Some say government should not decide who qualifies for assistance in suicide. They say physicians should help anyone in pain.

For Further Reading/Let Patients Die With Dignity

- Lisa Belkin, "There's No Simple Suicide" (*The New York Times Magazine*, November 14, 1993).
- Derek Humphry, *Final Exit: The Practicalities of Self-Deliverance and Assisted Suicide for the Dying* (New York: Dell Publishing, 1991).
- Timothy E. Quill, M.D., *Death and Dignity* (New York: W.W. Norton & Company, 1993).

Improve Care for the Dying



Michelle McDonald

Home hospice care provides comfort for incurable patients who do not want to die in pain or suffer through unwanted treatment.

“I’ve just plain lived too long,” said the retired teacher in Minneapolis.

She told her doctor that she had buried her family and outlived most of her friends as well as her own 83-year-old body. Crippled by arthritis, she lived in pain and isolation. “I wish there was some way you could help me end my life,” she said.

Recalling this conversation in the October 1996 *Minneapolis-St. Paul Magazine*, her physician, Dr. Steven Miles, said he replied: “I personally do not assist patients’ suicides. But let’s keep talking. Let’s see what we can do in the course of three months to bring your quality of life closer to your criteria for living.” Miles, a specialist in geriatrics, put her in touch with a social worker and a visiting nurse. He replaced her over-the-counter arthritis medicine with a narcotic, which relieved her pain and increased her mobility. And he prescribed an antidepressant, which lifted her dark mood within a month.

When she died of a stroke two years later, it turned out that she had expressed her appreciation in a remarkable way: she asked in her will that her ashes be shared equally by her social worker, visiting nurse, and doctor.

Fix the System

Choice Two says the extraordinary public consideration of physician-assisted suicide is the societal equivalent of an individual suicide attempt, which is nearly always a depressed person’s cry for relief of pain and suffering, not death. Society should respond to this public cry for help, in this view, by greatly improving the care of dying patients.

When patients like the retired teacher voice a suicidal wish to escape pain and suffering, they are convinced that death is the only exit. But they are wrong. Doctors like Miles and his team of healthcare professionals can nearly always drive away suicidal impulses with adequate treatment for pain, suffering, and depression. But physicians like Miles are the exceptions to the rule in American healthcare, a system that routinely fails to make patients comfortable, especially dying patients. This is not news to the medical establishment: the major professional organization, the American Medical Association, with 300,000 members, acknowledges in a 1996 report, “Expertise in pain management is often not available to patients,

and comprehensive and enduring care is the exception.” In this view, the system’s failure leads many Americans to dread the dying process and mistakenly demand a right to speed it up with a medically supervised suicide.

According to Choice Two, society and physicians are obliged to ease the pain and suffering of death. This means doing everything possible to make terminally ill patients comfortable, but at the same time doing nothing to hasten or prolong the dying process. The operative principle should be: let nature take its course, with healthcare professionals easing that course as much as possible.

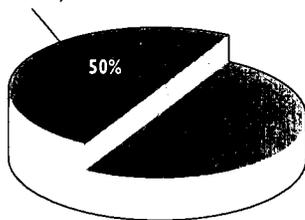
In this view, then, Choice One’s call for legalizing physician-assisted suicide does not address Americans’ underlying concerns about dying – namely, that costly hospital care imposes a huge burden on many families and that hospitals allow many patients to endure severe pain, depression, and unwanted medical procedures. Studies have repeatedly shown that nearly all people who express suicidal thoughts are depressed and respond successfully to treatment for depression – but most doctors admit they are unable to diagnose depression.

“We must focus our efforts and attention on improving the care of the dying,” says Dr. Kathleen M. Foley, sounding the main theme of Choice Two. Foley, co-chief of the Pain and Palliative Care Service at Memorial Sloan-Kettering Cancer Center in New York, continues: “Real autonomy at the end of life can only be realized when a full range of treatment is available and affordable, and patients understand all their options.” Choice Two calls for improving the end of life with improved comfort care, pain management, and mental health treatment. To accomplish this, patients must be given more information and more control over their

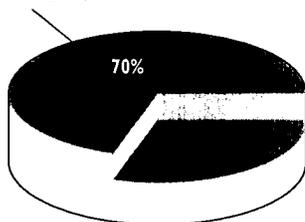
Hospital Deaths: Often painful, costly, and out of patients’ control

Note: Data from study of 10,000 patients dying in hospitals, 1989-1994

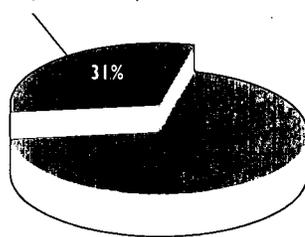
Percentage of patients dying in hospitals who experienced moderate or severe pain at least half the time during their last few days



Percentage of physicians who failed to find out whether patients wanted to be resuscitated in an emergency



Percentage of dying patients’ families that spent all or most of their savings on patients’ hospital care



Source: The Study to Understand Prognoses and Patient Preferences for Outcomes and Risk of Treatment (SUPPORT). Robert Wood Johnson Foundation and National Institute of Mental Health, 1995

What Can Be Done ?

Supporters of Choice Two generally favor the following measures:

- Improve medical training: only 5 of the nation’s 126 medical schools require courses in the care of the dying.
- Expand palliative care, which provides as much comfort as possible to patients at every stage of their illness and treatment.
- Insist that insurers cover palliative and hospice care.
- Remove barriers to effective pain management, including inadequate training of physicians and nurses and overly restrictive regulation of narcotics.
- Provide mental health care for terminally ill patients, who are prone to mental suffering, especially depression.
- Educate patients about end-of-life care. Let patients give legally binding directives, not just preferences, as a way to ensure they don’t suffer through unwanted treatment.
- Make ignoring a dying patient’s directive or allowing a patient to suffer needless pain standard grounds for a finding of malpractice.

treatment, and medical professionals need more training in the care of the dying. Legal and insurance reforms are needed to ensure that patients receive appropriate care. Once the system is fixed, suicide will no longer be an issue.

Treat the Patient, Not Just the Disease

Americans dread the dying process because it’s costly, painful, and filled with unwanted hospital procedures and treatment. “If dying patients want to retain some control over their dying process, they must get out of the hospital,” Dr. George J. Annas flatly states. He is director of the Law, Medicine, and Ethics Program at Boston University.

Take Hazel Welch, a 92-year-old patient with a perforated stomach. She told her doctor that she didn’t want surgery, knowing she would ultimately die without it. But her physician was persuasive and Miss Welch relented. The operation failed, leaving her at death’s door, feeling wretched for two weeks. Before dying, Miss Welch reproached her physician for putting her through this torment. The physician, Sherwin B. Nuland at the Yale-New Haven Hospital in Connecticut, says he regrets only the poor outcome. Not to have tried to save his patient, he writes in his book *How We Die*, would have risked the “scorn of my peers.” As he explains: “The code of the profession of surgery demands

that no patient as salvageable as Miss Welch be allowed to die if a straightforward operation can save her... mine was strictly a clinical decision and ethics should not have been a consideration."

In a nutshell, that professional attitude is what's wrong with American medicine, according to Choice Two. Research confirms that every facet of medical culture - from the training of doctors to insurance reimbursement policies to the over-reliance on high-tech treatment - creates an environment that ruins the chances for most Americans to have gentle, peaceful deaths. Consider some findings of a landmark study, completed in 1995 and sponsored by the Robert Wood Johnson Foundation and the National Institute of Mental Health:

- Patients suffer needless pain. Half of all conscious patients suffered moderate to severe pain at least half of the time during their final days and weeks. Medical authorities say this situation is inexcusable.
- Patients' wishes are routinely ignored. Nearly a third of the 10,000 dying patients surveyed had not wanted to be resuscitated in a medical emergency, but only half of their doctors complied with their request by putting "do not resuscitate" orders on their bedside charts. When doctors did issue these orders, half of the patients who got them had already spent eight or more days in intensive care units, where mechanical ventilation and invasive procedures are commonly used to keep people alive.
- Aggressive treatment drains families' resources. Nearly one-third of the patients' families said they spent all or most of their savings on uninsured hospital services.



Kathleen Foster/Impact Visuals

"If dying patients want to retain some control over their dying process, they must get out of the hospital."

The way we care for dying patients is deplorable, the American Medical Association states in its 1996 report: "We are concerned about providing overly aggressive, unwarranted care while care that is optimally suited to the dying person's needs is often not available in our healthcare system or is not covered by insurance."

Medical schools need to teach doctors how best to care for patients. Only 5 of the nation's 126 medical schools require courses in the care of the dying.

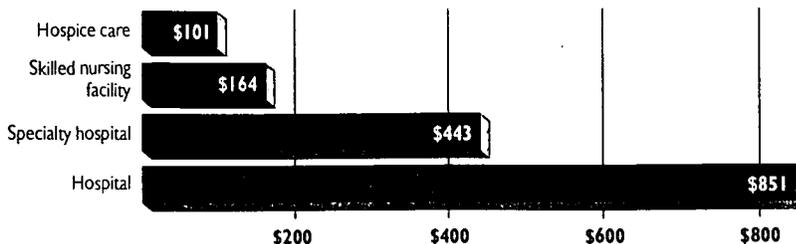
To Comfort Always

Most Americans die in hospitals, where physicians and nurses valiantly fight disease to the death. But in these battles, the pain, suffering, and wishes of patients are often overlooked.

There is an alternative to hospitals: hospice care. Hospice treatment flows from the belief that

Hospice Care Is the Least Costly Option

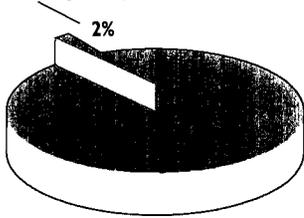
Medicare payments for various kinds of patient care, per covered day, 1994



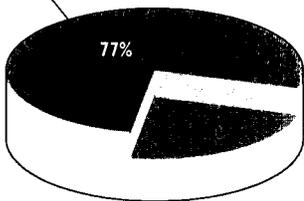
Source: Health Care Financing Administration, Health Care Financing Review, 1996

Comfort Care Can Ease the Dying Process

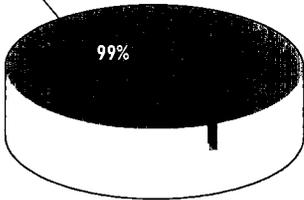
Percentage of cancer patients in hospice care who suffer unmanageable pain



Percentage of hospice patients who die at home



Percentage of hospice patients' families that are satisfied with hospice care



Sources: American Medical Council on Scientific Affairs, 1996; National Hospice Organization, 1996

death should neither be hastened nor postponed; an often-cited credo for hospice care is "to cure sometimes, to relieve often, to comfort always."

There are about 100 hospice care facilities nationwide, serving about 10 percent of the 400,000 patients who get hospice care each year; the rest get hospice care at home. Hospice care emphasizes the relief of pain and other symptoms, and recruits many community volunteers to help improve the patient's quality of life. Consider two major benefits of hospice care:

- **Less financial strain on families.** As an indicator of cost, compare what government insurance programs paid in 1994: \$101 a day for hospice care, and \$851 a day for general inpatient care in a hospital. But, paradoxically, public and private insurers frequently deny coverage for many hospice care services, often limiting reimbursement for such essentials as pain management and home health aides.
- **Greater comfort.** Hospice patients know that they need not suffer pain, and with their

agreement, physicians administer as much medication as necessary to relieve pain. Every medical procedure carries a risk, and the risks of aggressively treating pain include a patient's losing consciousness and even dying. When a physician's intention is clearly to reduce pain, and not to cause death, aggressively treating pain is widely considered morally, medically, and legally sound.

But hospice care isn't the whole answer. For one thing, people who are still receiving extensive treatment usually aren't eligible for hospices. For another, by the time physicians refer patients to hospices, many patients have already endured needless pain and suffering and have, on average, only a month to live. And finally, most home hospice patients do not receive continuing care from physicians trained in comfort care, which is also called palliative care.

What's needed, in addition to expanding and improving hospice care, is a system-wide expansion of palliative care, which seeks to provide as much comfort as possible to patients at every stage of their illness and treatment. And comfort care must include mental health care, because the mental and physical health of the terminally ill often deteriorate together.



Gamma Liaison

Comfort care for terminally ill patients at home is less costly than hospital care, but many insurers do not provide adequate coverage for such essentials as home health aides or treatment to manage pain.

In Support

- ✓ If care for the dying were improved, patients would not want to hasten death.
- ✓ Americans endure needless pain in hospitals. Studies repeatedly indicate that most cancer patients in hospitals suffer severe pain, compared with only 2 percent of cancer patients in hospice care.
- ✓ Nearly all suicidal people suffer from depression; when treated, the desire for death nearly always fades away, studies indicate.
- ✓ If caregivers consistently honored patients' right to refuse treatment, there would be little demand for the right to physician-assisted suicide, the most extreme measure of patient control.
- ✓ Unwanted treatments waste resources that are needed to care for others.
- ✓ Patients have the legal right to refuse treatment, and they should be able to exercise that right.
- ✓ Legal reforms are needed to force improvements in patient care, as voluntary efforts over the years have failed to make enough progress.
- ✓ We know what works: comfort care is extremely effective in addressing the many needs of dying patients and their families.
- ✓ Hospice care is less costly than hospital care, and allows people to die at home. Insurance policies, paradoxically, force many patients into higher-cost hospitals by not providing adequate coverage for hospice costs.
- ✓ Because it is far less costly than hospital care, hospice care relieves some of the financial pressures on families, which are often cited as a reason patients might consider physician-assisted suicide.

In Opposition

- ✗ If terminally ill people want to die, they should have the right to do so.
- ✗ Physicians can relieve severe pain, but some people prefer to end their lives rather than live in a coma-like state induced by heavy sedation and opiates.
- ✗ Short of terminally sedating patients, even the most skillful physicians cannot relieve all the pain suffered by about 2 percent of cancer patients in hospice care, as this choice acknowledges.
- ✗ Choice Two opposes physician-assisted suicide, but supports physicians who treat pain with such large doses of medication that the patient may die. Medicating patients to the point of death is a way some physicians disguise mercy killing.
- ✗ Treatment cannot help patients who are wasting away, losing control of bodily functions, and feeling utterly dependent on others. Shouldn't these patients have a right to end their lives?
- ✗ In calling for more patient control over care, this choice ignores a very important fact: physicians are the medical experts. Allowing patients to issue directives about their treatment would inevitably cause premature deaths.
- ✗ When about 40 million Americans lack basic health insurance, it's highly questionable whether the nation can afford to expand coverage for pain management, home nursing, and psychiatric treatment for terminal patients.
- ✗ Hospice care is not for most people. Studies suggest that most patients are unwilling to give up hope for a cure or a treatment that extends their lives. This means most people will continue to die in hospitals, accepting all the tradeoffs that accompany that decision.

For Further Reading / Improve Care for the Dying

- Daniel Callahan, *The Troubled Dream of Life: Living With Mortality* (New York: Simon and Schuster, 1993).
- Eric J. Cassell, *The Nature of Suffering and the Goals of Medicine* (New York: Oxford University Press, 1991).
- Judy Foreman and Michele McDonald, "Choosing a Good Death" (*The Boston Globe*, June 23, 1996). Also available on the Internet at <http://www.boston.com/globe/hospice/home.htm>



Above All, Sustain Life



Ansell Horn/Impact Visuals

For 2,400 years, the physician's role has involved making medical decisions that extend lives – not subjective decisions that end lives.

Lisa Jarrell was born 32 years ago with cerebral palsy and a life-threatening disability: her esophagus did not reach her stomach. Doctors implanted a feeding tube in her abdomen, but five operations failed to correct the anomaly, and in recent years, she used many medications to treat pain, nausea, and depression. She tried to commit suicide in 1995.

And as her pain and suffering dragged into another year, the multiply handicapped, 72-pound woman was resolved to die, hoping for a physician's assistance. "I am trapped inside this body. I want to be out," she wrote.

When a patient like Jarrell suffers so, physicians work under terrible pressure to find solutions. The easy answer, helping patients commit suicide, isn't a legal option. If it were, its availability could prematurely end the search for solutions, according to Dr. Carlos F. Gomez, Jarrell's physician at the University of Virginia's hospital in Charlottesville.

He persuaded Jarrell to undergo more surgery in 1996. In a 12-hour operation, surgeons used a portion of her stomach to create a new esophagus and – after 11 days of infection, trauma, and other complications – Jarrell was eating her first ice cream. Two weeks later, she was talking about buying clothes and returning to college.

Gomez, who cares for the terminally ill, is a passionate opponent of physician-assisted suicide. "There are always compelling cases, but we can't allow sweeping public policy to be made out of individual, compelling cases," he told *The New York Times*. "Today's compelling case is tomorrow's Lisa Jarrell. That's why I maintain we leave the line where we drew it centuries ago."

Don't Devalue Life

Whether they cite religious belief or secular philosophy, Choice Three supporters agree that life is invaluable and should be inviolable, and that society and physicians must strengthen their commitment to preserving it. Medical science extends life, but now some want to abuse that science to shorten life. That would only create confusing public policies and weaken public trust in medicine. Any retreat from the absolute responsibility to sustain life would lead to a society where the value of life is merely relative to the shifting concerns of the day.

What Can Be Done ?

“Human life, as a gift of God, is sacred and inviolable,” Pope John Paul II writes in his 1995 encyclical, *Evangelium Vitae*. “Not only must human life not be taken, but it must be protected with loving concern.” Suicide, he adds, is “as objectionable as murder” and physician-assisted suicide “can never be excused” and is “gravely immoral.”

Charles Dougherty, director of the Creighton Center for Health Policy and Ethics, makes a secular argument that what’s best for society is ultimately what’s best for the individual. And even if physician-assisted suicide might make sense in isolated cases, he says, legalizing the practice would destroy a common bond that holds society together.

Choice Three calls for recommitting the whole force of society to each patient’s struggle to get well. In this view, Choice One’s call for legalizing physician-assisted suicide is morally and socially intolerable. Choice Two goes out of medical bounds in demanding that patient preferences overrule professional judgment in medical emergencies. And Choice Two goes out of moral bounds by giving a higher priority to patient comfort than to life itself – by promoting the administration of painkillers in high doses that can be life-threatening.

Supporters of Choice Three generally favor the following measures:

- Respond to requests for physician-assisted suicide the way physicians always have: with mental health treatment and counseling.
- Enact a federal law banning all forms of physician-assisted suicide. Oppose state legislation and ballot measures that seek to legalize physician-assisted suicide.
- Require that physicians obtain patients’ or families’ consent before withdrawing or withholding life-preserving treatment.
- Redouble efforts to ensure that physicians do everything possible to sustain life; it’s not their business to decide who should live or die.
- Strengthen criminal laws by imposing mandatory minimum penalties and prison sentences for physicians who assist in suicide.
- To further deter these practices, enact civil laws that make it easier to bring malpractice suits against physicians who assist in a suicide.

Trouble Brewing Already

Unfortunately, in this view, society’s commitment to protecting life is already fraying. For example, physicians are authorized to make medical decisions – often without the consent of patients or their families – to end patients’ lives by withholding or withdrawing life-sustaining treatment, including feeding tubes, that they consider futile.

Choice Three insists that physicians stop making these life-and-death decisions about treatment, especially since physicians acknowledge that they can rarely locate the point when treatment becomes futile. This is no minor concern: one in three doctors say they have withdrawn life-support systems without the knowledge or consent of the patient or a family member; and 3 percent said they had done so over the objections of a patient or family member, according to a 1995 national study published in the *American Journal of Respiratory and Critical Care Medicine*.

Choice Three also warns that if society grants terminally ill patients a fundamental right to be assisted in suicide, courts would inevitably be asked to expand this right to patients who are too immobilized to commit suicide without physical assistance, or who are chronically ill. And since the law already permits legal guardians to refuse treatment on behalf of incompetent

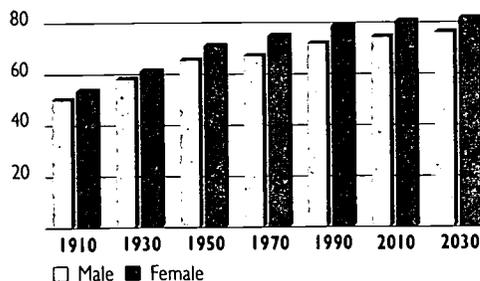
Any retreat from the absolute responsibility to sustain life would lead to a society where the value of life is merely relative to the shifting concerns of the day.

Science’s Gift of Life:

Medical advances help increase longevity

Life expectancy at birth, by gender, 1910-2030

Note: Data for 2010 and 2030 are projections.



Sources: 1996 Greenbook, House Ways and Means Committee, and National Center for Health Statistics

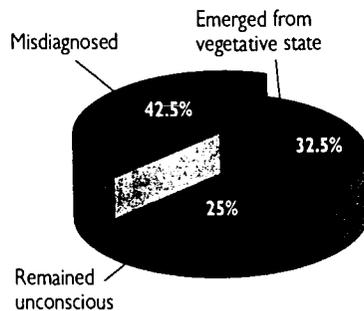
patients, legal guardians might soon find themselves thrust into the role of deciding whether a physician should end the lives of relatives who are demented or in comas, or babies who are born with severe birth defects.

A right to die might also evolve into a duty to die, say those who favor Choice Three, especially for elderly or disabled patients who may feel – or be told – that they are a financial and emotional drain on family and society.

Even 'Hopeless' Patients Recover

Percentage of British patients diagnosed with persistent vegetative state who were misdiagnosed or who emerged from vegetative state, 1992-1995

Note: Persistent vegetative state is diagnosed when a patient is thought to have permanently lost function of the cerebral cortex, and remains permanently unaware.



Source: "Misdiagnosis of the Vegetative State: Retrospective Study in a Rehabilitation Unit," *British Medical Journal*, July 1996

Members of the group Not Dead Yet demonstrate against the legalization of physician-assisted suicide. They fear that legalization would result in pressure on severely disabled or chronically ill people to commit suicide.



And if physician-assisted suicide is redefined as a medical treatment, society might even come to view suicide as a cost-effective way to keep healthcare spending down. Farfetched? In Oregon, where a 1994 law permitting physician-assisted suicide has for now been stayed by court appeals, the legislature has already adopted a rationing plan for the poor: it provides Medicaid funding for physician-assisted suicide but not for treatment, unless it is expected to improve a dying patient's "low quality of life."

Give No Deadly Drug

In the evolution of modern medicine from primitive magic, a historic advance occurred 2,400 years ago when Hippocrates, known as the father of medicine, convinced his colleagues to stop killing incurable patients who wanted to die, according to the anthropologist Margaret Mead. Most medical school graduates still take the Hippocratic oath, in which doctors swear they will "give no deadly drug to any, though it be asked of them, nor suggest any such counsel."

In this view, the physician's only role is to cure illnesses or at least ameliorate their symptoms. Suicide is not a medical procedure or a medical therapy, and physicians cannot assist in suicides without becoming arbiters of life and death and, inevitably, weakening public confidence and trust in medicine. "Permitting assisted suicide would compromise the physician's professional role, because it would involve physicians in making inappropriate value judgments about the quality of life," Dr. John Glasson writes in the 1994 Report of the Council on Ethical and Judicial Affairs of the American Medical Association. By comparison, physicians do not make such judgments when a patient or a patient's legal guardian refuses treatment that artificially sustains life. In this situation, the physician lets the underlying disease end the patient's life.

Given the uncertainty of diagnosis and treatment, the role of physicians must be limited to preserving life, in this view. Two research findings:

- It's hard to estimate how long patients will live. According to a 1995 study at the Oregon Health Sciences University in Portland, one in two Oregon doctors say they can't predict when a patient has less than six months to live, the definition of "terminally ill."
- Diagnoses can be wrong. British and American studies in 1996 found that diagnoses of persistent vegetative states are often made in error.

Consider one near-tragedy: Theresa De Vera, a 21-year-old college student in Los Angeles, had a severe asthma attack in 1996 and slipped into a coma. After three months, physicians diagnosed her condition as a persistent vegetative state. Then one day, within earshot of De Vera, physicians asked family members to be "realistic" about her chances and to consider having her organs "harvested" for transplantation before removing life supports, according to *The Los Angeles Times*. De Vera started to cry. The next month, she pulled out of the coma and started a journey toward complete recovery.

Slipping Down the Slope

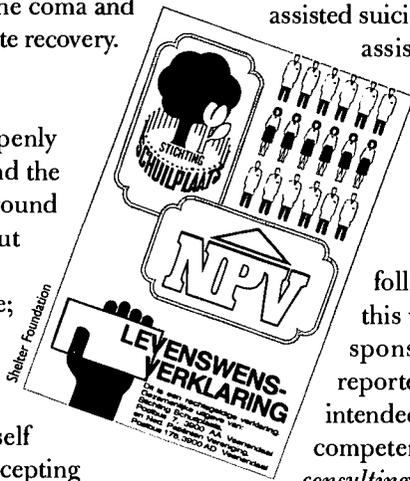
Physician-assisted suicide is openly practiced in the Netherlands and the Dutch experience is debated around the world. Proponents talk about the Netherlands' humane treatment of people who want to die; opponents, including Choice Three supporters, say the Netherlands provides an example of a society putting itself on a slippery moral slope by accepting physician-assisted suicide as a social norm. Consider the path the Netherlands has taken:

- A 1973 court case opens the way for physician-assisted suicide to become an accepted medical practice for ending the lives of terminally ill patients with unrelenting pain.

- Medical guidelines in 1984 go a step further, permitting physicians to administer lethal drugs to incurable adults and children (at the request of a legal guardian).

- A 1985 court decision eliminates the requirement that a patient be terminally ill, and permits physicians to assist in the deaths of chronically ill patients as well as babies born with severe defects such as Down's syndrome and spina bifida.

- A 1993 court decision permits assisted suicide and physician-assisted suicide for people who suffer psychological pain, but no physical pain.



Dr. Fred Rosner, a cancer specialist at Elmhurst Hospital Center in New York, says, "The physician's roles are that of healer and supporter, but not that of killer."

Troubling developments followed these court decisions, in this view. In a 1995 government-sponsored study, Dutch doctors reported making decisions that were intended to end the lives of nearly 1,000 competent patients a year *without ever consulting the patients*; the report's authors justified this apparent lapse as normal medical practice in the care of dying patients.

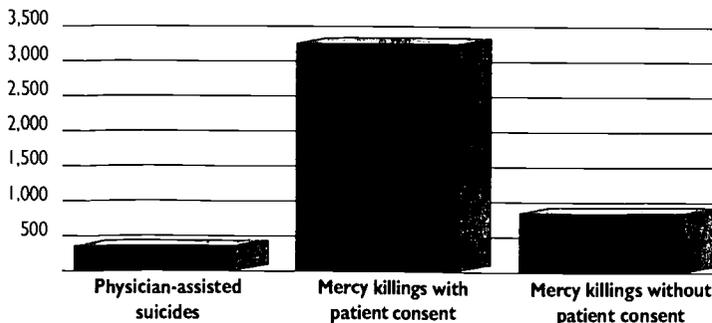
At left: Some Dutch people carry this card to alert physicians that under no circumstances should they end the card carrier's life.

Some Dutch citizens are understandably concerned. The Dutch Patients' Organization, a Protestant group, provides members with a "passport for life," a card conveying the message that the bearer does not want to be killed by a "merciful" doctor under any circumstances.

Dutch Physicians Help Patients Die - With and Without Their Consent

Number of physician-assisted deaths in the Netherlands, 1995

Note: These deaths account for 3.4% of the 135,546 deaths in the Netherlands in 1995.



Source: "Euthanasia, Physician-Assisted Suicide, and Other Medical Practices Involving the End of Life in the Netherlands," *New England Journal of Medicine*, November 1996

In Support

- ✓ Life is invaluable and should be inviolable. The primary responsibility of society is to protect life. Backing away from this principle would devalue life.
- ✓ The physician's only proper role is saving lives and relieving symptoms. Asking doctors to assist in suicide would compromise their role and weaken patient trust.
- ✓ Suicide is a tragic, individual act. Legalizing physician-assisted suicide would make it the social norm.
- ✓ Legalizing physician-assisted suicide would invite the kind of abuses that occur in the Netherlands, where it's widely practiced.
- ✓ Legalizing physician-assisted suicide would also create a dangerous legal precedent, setting the stage for expanding this "right" to legal guardians of children and incompetent patients who are chronically or mentally ill.
- ✓ If assisted suicide is considered an acceptable medical treatment, some patients may feel unduly pressured to end their lives as a way to relieve emotional or financial strains on their families.
- ✓ Asking physicians to help with suicide would force them to make subjective and inappropriate decisions about the quality of a patient's life.
- ✓ Financial pressures to ration healthcare would influence decisions about providing treatment to dying patients. The ink on Oregon's 1994 law was barely dry when regulators wrote rules limiting treatment for dying, low-income patients thought to have a low quality of life.
- ✓ Strengthening our laws against physician-assisted suicide would clarify society's intolerance for this practice.

In Opposition

- ✗ Government should not force people to live when they suffer unbearable pain and are near death.
- ✗ This choice would expand use of aggressive lifesaving treatments in a costly and wasteful manner.
- ✗ The purpose of medicine is to alleviate suffering and sometimes ending a life is the only way to do it.
- ✗ Physician-assisted suicide is now widely practiced in secret, inviting error and abuse. We should legalize it and regulate it.
- ✗ There is no meaningful difference between providing a lethal drug to a dying patient and withdrawing life-sustaining treatment from a dying patient, but only the latter is legal.
- ✗ Any risk from legalizing physician-assisted suicide is outweighed by the right to a humane death.
- ✗ If terminally ill patients obtain a right to physician-assisted suicide, Choice Three worries that courts would extend this right to other patients in circumstances deemed appropriate. Alarming? No, this is the way courts refine all our laws over time.
- ✗ Some people object to Dutch policies on physician-assisted suicide, but there is no scientific basis for claims that they have led to abuses, according to a 1996 editorial in the *New England Journal of Medicine*.
- ✗ When 10 million children have no healthcare coverage, the nation should not expand life-sustaining treatments that are often futile and unwanted by dying patients.

For Further Reading / Above All, Sustain Life

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- Herbert Hendin, M.D., *Seduced by Death: Doctors, Patients, and the Dutch Cure* (New York: W.W. Norton & Company, 1997).
- Rita Marker, *Deadly Compassion: The Death of Ann Humphry and the Truth About Physician-Assisted Suicide* (New York: William Morrow and Company, 1993).



Niculae Asciu

Renovating Public Policy

The introduction of this issue book presented the hypothetical case history of Claire S., the cancer patient who saw no point in continuing her painful downward slide into death. Should society permit her physician to assist in her suicide?

This once unthinkable question is now discussed in legislatures, courts, and even a televised beauty pageant. Americans are not only considering making suicide socially acceptable, they are also reconsidering the job description for physicians, rethinking ethical traditions of medicine that have evolved over 2,400 years. There is something very wrong with the American way of death, and to fix it, citizens are willing to consider radical change. How would the three choices presented in this issue book respond to Claire's plight?

Choice One would say society must preserve life, but should not deny Claire's right to a humane death. Claire is near death, suffers from loneliness and pain, and wants to die. Society serves no interest in prolonging her misery. A compassionate doctor might give Claire enough medication to kill herself but, fearful of legal consequences, the doctor would likely act in secret. But if physician-assisted suicide was legalized and regulated, as this choice proposes, medical professionals could evaluate Claire and help her one way or another – through assisted suicide or a new program of care.

Choice Two would say that if Claire is like most suicidal patients, she suffers from depression. She also suffers from severe pain, clearly indicating that her physician has been inattentive. If comfort care was made widely available, as this choice proposes, Claire could obtain relief from her physical and mental symptoms, and probably a social worker's help to improve her quality of life in other areas. Claire could

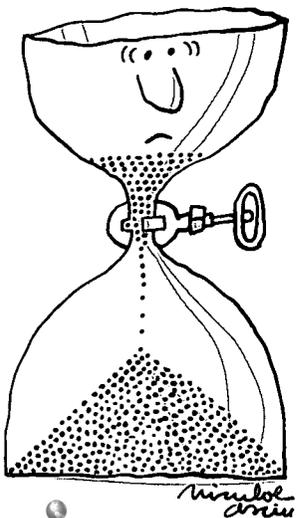
discontinue chemotherapy, which only prolongs her death. With Claire's consent, her physician could take strong measures to ensure that she doesn't suffer unbearable pain, even though an overdose of medication might unintentionally shorten her life.

Choice Three would say society and physicians share a commitment to protecting Claire's life. A physician should never give up hope – even if the patient does, at a low point in treatment. Her physician's responsibility is to continue treating her cancer and symptoms until there is no further hope of preserving her life. If Claire decides to discontinue chemotherapy and let the cancer take its course, her physician must accept that decision. Yet studies suggest that 9 out of 10 dying patients such as Claire, who experience considerable pain and suffering, agree to continue treatment.

In comparing the three approaches, it may help to consider the following discussion points:

■ **Can elements of the three choices be combined?** Supporters of each choice find areas of agreement, but see the issue very differently and promote very different solutions. Choice One fights for a patient's right to physician-assisted suicide and calls for legalizing the practice. Choice Two argues that physician-assisted suicide isn't needed, and is discussed only because the system of care for the dying is broken and needs fixing. Choice Three defends the efforts of society and physicians to preserve all lives and opposes any exceptions as dangerous.

■ **What are some tradeoffs?** Choice One, by having government regulate assisted suicide, would put the state in a new and controversial position as arbiter of life and death. Choice Two, by giving patients much more say in determining their care, could cause many premature deaths when patient directives override sound medical judgment. Choice Three, by calling on physicians to preserve all lives, could cause greater suffering for dying patients who would rather end their lives quickly.



Comparing the Choices

Medical technology has greatly extended American lives, though patients' final days or months are often spent on artificial life-support systems. Death often follows a medical decision to withdraw treatment. Some are demanding a larger role for patients in making decisions about the time and manner of their deaths. Do patients have a right to a physician's assistance in committing suicide? Lawmakers and jurists are wrestling with this question, and they need to know what approach Americans want to take.

Choice I

Let Patients Die With Dignity

- Patients dying in pain have a right to choose the time and circumstances of their death. But society must regulate this humane practice to prevent abuse.

What Can Be Done?

- Legalize physician-assisted suicide to give Americans control over the way they die.
- Enact rules, including one that limits this practice to terminally ill patients with unbearable pain.
- Swiftly prosecute physicians who violate these regulations.

In Support

- Society's interest in preserving life must prevail, but not when death is imminent and pain is intolerable.
- Many physicians secretly help incurable patients end their lives; regulating this practice would reduce error and abuse.
- There is no meaningful difference between unplugging a patient's ventilator and prescribing a lethal drug.

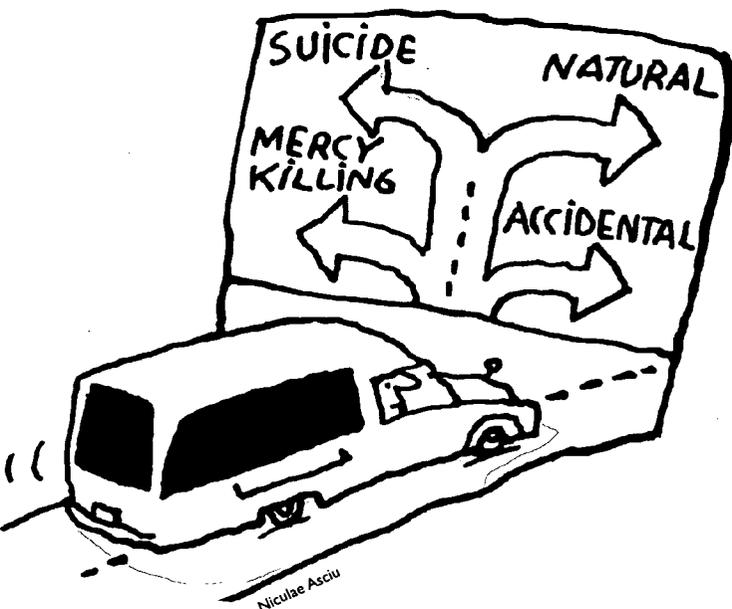


In Opposition

- When patients talk about suicide, they're desperately asking for care, not death.
- A right to die could easily become a duty to die, especially for the elderly.
- Some opponents say this choice doesn't go far enough; physicians should help anyone in serious pain, not just the terminally ill.

A Likely Tradeoff

- By having government set eligibility rules, this choice would put the state in a new and controversial position as arbiter of life and death.



Niculae Asciu

Choice 2

Improve Care for the Dying

- Too many patients suffer from needless pain, depression, and unwanted treatment. Let's fix the system and give patients more control over their care.

What Can Be Done?

- Allow dying patients to issue directives, not just preferences, about care and treatment.
- Expand comfort care as well as insurance coverage for it.
- Relieve pain with high doses of medicine, even though it may unintentionally cause death.

**In Support**

- This choice calls for improving patients' quality of life, not hastening their death.
- Suicidal people usually suffer from depression or pain, or both. These symptoms can be treated effectively.
- Patients need legal authority to control their own care, because caregivers routinely ignore their needs and preferences for end-of-life treatment.

In Opposition

- This choice promotes what is widely viewed as an unregulated form of physician-assisted suicide: treating patients with lethal doses of painkillers.
- Some people prefer death to a life blurred by sedatives and narcotics.
- This choice oversimplifies the complexities of health-care, especially for patients with unpredictable diseases.

A Likely Tradeoff

- By giving patients much more say in their care, this choice would cause premature deaths when patient directives override sound medical judgment.

Choice 3

Above All, Sustain Life

- Life is invaluable and should be inviolable, and society and physicians must strengthen their commitment to preserving life. Any retreat from this devalues life.

What Can Be Done?

- Enact a federal ban on physician-assisted suicide.
- Insist that physicians make every effort to sustain life unless a patient declines treatment.
- Respond to requests for physician-assisted suicide with counseling and mental health treatment.

In Support

- Suicide is a tragic, individual act. Legalizing assisted suicide would make this tragedy the social norm.
- Society cannot legalize assisted suicide without inviting the kind of abuses that occur in the Netherlands, where physician-assisted suicide is widely practiced.
- Involving doctors in assisted suicide would further weaken public confidence in the healthcare system.

In Opposition

- Government should not force people to live when they want to die.
- Any risk involved in legalizing physician-assisted suicide is outweighed by the right of Americans to decide how they want to die.
- Insisting on sustaining life even when patients are in terrible pain would be inhumane.

**A Likely Tradeoff**

- By calling on physicians to preserve all lives, this choice would cause suffering for dying patients who would prefer to end their lives quickly.

What Are the National Issues Forums?

How to start a forum

Forums are initiated at the local level by civic and educational organizations. For information about starting a forum and using our materials, write the NIF Institute, P.O. Box 75306, Washington, D.C. 20013-5306, or phone 800-433-7834.

National Issues Forums bring together citizens around the nation to discuss challenging social and political issues of the day. They have addressed issues such as the economy, education, healthcare, foreign affairs, poverty, and crime.

Thousands of civic, service, and religious organizations, as well as libraries, high schools, and colleges, have sponsored forums. The sponsoring organizations select topics from among each year's most pressing public concerns, then design and coordinate their own forum programs, which are held through the fall, winter, and spring.

A different kind of discussion

No two forums are alike. They range from small study circles to large gatherings modeled after town meetings, but all are different from everyday conversations and adversarial debates.

Since forums seek to increase understanding of complicated issues, participants need not start out with a close knowledge of an issue. Forum organizers distribute issue books such as this one, featuring a nonpartisan overview of an issue and a choice of several public responses. By presenting each issue in a nonpartisan way, forums encourage participants to take a fresh look at the issues and at their own convictions.

In the forums, participants share their opinions, their concerns, and their knowledge. With the help of moderators and the issue books, participants weigh several possible ways for society to address a problem. They analyze each choice, the arguments for and against it, and the tradeoffs and other implications of the choice. Moderators encourage participants, as they gravitate to one option or another, to examine their basic values as individuals and as community members.

The common ground

Forums enrich participants' thinking on public issues. Participants confront each issue head-on, make an informed decision about how to address it, and come to terms with the likely consequences of their choices. In this deliberative process, participants often accept choices that are not entirely consistent with their individual wishes and that impose costs they had not initially

considered. This happens because the forum process helps people see issues from different points of view; participants use discussion to discover, not persuade or advocate. The best deliberative forums can help participants move toward shared, stable, well-informed public judgments about important issues.

Participants may hold sharply different opinions and beliefs, but in the forums they discuss their attitudes, concerns, and convictions about each issue and, as a group, seek to resolve their conflicting priorities and principles. In this way, participants move from making individual choices to making choices as members of a community – the kind of choices from which public action may result.

Building community through public deliberation

In a democracy, citizens must come together to find answers they can all live with – while acknowledging that individuals have differing opinions. Forums help people find the areas where their interests and goals overlap. This allows a public voice to emerge that can give direction to public policy.

The forums are nonpartisan and do not advocate a particular solution to any public issue, nor should they be confused with referenda or public opinion polls. Rather, the forums enable diverse groups of Americans to determine together what direction they want policy to take, what kinds of action and legislation they favor, and what, for their common good, they oppose.

From agreement to action

Forums can lead to several kinds of public action. Generally, a public voice emerges in the results of the forums, and that helps set the government's compass, since forum results are shared with elected officials each year. Also, as a result of attending forums, individuals and groups may decide to take action individually or in association with others to help remedy a public problem, taking actions that citizens can take outside of government.



At Death's Door

What Are the Choices?

One of the reasons people participate in the National Issues Forums is that they want leaders to know how they feel about the issues. So that we can present your thoughts and feelings about the issue, we'd like you to fill out this ballot before you attend forum meetings (or before you read this book, if you buy it elsewhere), and to fill out a second ballot after the forum (or after you've read the material). Before answering any of the questions, make up a three-digit number and write it in the box below.

The moderator of your local forum will ask you to hand in this ballot at the end of the session. If you are not attending a forum, send the completed ballot to the National Issues Forums, 100 Commons Road, Dayton, Ohio 45459-2777.

Fill in your three-digit number here.

1. Here is a list of principles on which policy on dying patients might be based. How important do you think each one should be?
- | | Very important | Somewhat important | Not at all important | Not sure |
|---|--------------------------|--------------------------|--------------------------|--------------------------|
| a. Doctors should be allowed to help dying patients who choose to end their lives with dignity. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Human life is invaluable, and should be preserved for as long as possible. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Doctors and hospitals should honor a dying patient's wish to refuse treatment. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Doctors should do all they can to ease the pain and suffering of dying patients, but nothing more. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e. Doctors should not be prosecuted if they help dying patients end their lives. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f. A doctor should do everything medically possible to save a patient's life, no matter how hopeless the patient seems. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

2. Look at the list in Question #1 again. How strongly is each principle reflected in current policy?
- | | Strongly | Somewhat strongly | Not at all | Not sure |
|---|--------------------------|--------------------------|--------------------------|--------------------------|
| a. Doctors should be allowed to help dying patients who choose to end their lives with dignity. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Human life is invaluable, and should be preserved for as long as possible. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
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| d. Doctors should do all they can to ease the pain and suffering of dying patients, but nothing more. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e. Doctors should not be prosecuted if they help dying patients end their lives. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f. A doctor should do everything medically possible to save a patient's life, no matter how hopeless the patient seems. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

3. Are there other principles that you think should guide policy in this area? Please explain.

4. How concerned are you about the following?
- | | Very concerned | Somewhat concerned | Not at all concerned | Not sure |
|---|--------------------------|--------------------------|--------------------------|--------------------------|
| a. Dying patients who are forced to endure needless pain and suffering. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Patients who say they want to die but really need treatment for pain and depression. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Doctors who violate their oath to preserve life, by helping patients commit suicide. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Patients who choose to end their own lives to reduce medical expenses their families must pay. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e. Doctors and hospitals that disregard patients' wishes to withhold treatment. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f. The huge financial costs to society of keeping dying patients alive. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

5. Do you have any other concerns about public policy in this area? Please explain.

6. How do you feel about these approaches to the problem?
- | | Favor | Oppose | Not sure |
|---|--------------------------|--------------------------|--------------------------|
| a. We should legalize and regulate doctor-assisted suicide, EVEN IF this contradicts the idea of the doctor as healer. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. We should give dying patients more control over their treatment, EVEN IF their wishes might override sound medical judgment and lead to premature death. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. We should maintain the current ban on doctor-assisted suicide, EVEN IF this means some terminally ill patients will endure needless pain and suffering. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

7. Which statement best describes how you feel? (Please choose only one answer.)
- a. I am not at all certain what our public policy should be regarding assisted suicide.
 - b. I have a general sense of what our policy should be.
 - c. I have a clear, definite view of what our policy should be.

8. Are you male or female? Male Female

9. How much schooling have you completed?
 Less than 6th grade 6th-8th grade Some high school High school graduate
 Some college College graduate Graduate school

10. Are you:
 White African-American Hispanic Asian-American Other (specify)

11. How old are you?
 17 or younger 18-29 30-49 50-64 65 or older

12. Have you attended an NIF forum before? Yes No

13. If you answered "yes" to #12, how many forums have you attended? 1-3 4 or more

14. Do you live in the:
 Northeast South Midwest West
 Southwest Other

15. What is your ZIP code? _____

At Death's Door

What Are the Choices?

Now that you've had a chance to read the book or attend a forum discussion, we'd like to know what you think about this issue. Your opinions, along with those of thousands of others who participated in this year's forums, will be reflected in a summary report prepared for participants as well as elected officials and policymakers working on this problem. Since we're interested in whether you have changed your mind about certain aspects of this issue, the questions are the same as those you answered earlier. Before answering the questions, please write in the box below the same three-digit number you used for the Pre-Forum Ballot.

Please hand this ballot to the forum leader at the end of the session, or mail it to: The National Issues Forums, 100 Commons Road, Dayton, Ohio 45459-2777.

Fill in your three-digit number here.

1. Here is a list of principles on which policy on dying patients might be based. How important do you think each one should be?

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- c. Doctors and hospitals should honor a dying patient's wish to refuse treatment.
- d. Doctors should do all they can to ease the pain and suffering of dying patients, but nothing more.
- e. Doctors should not be prosecuted if they help dying patients end their lives.
- f. A doctor should do everything medically possible to save a patient's life, no matter how hopeless the patient seems.

Very important	Somewhat important	Not at all important	Not sure
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. Look at the list in Question #1 again. How strongly is each principle reflected in current policy?

- a. Doctors should be allowed to help dying patients who choose to end their lives with dignity.
- b. Human life is invaluable, and should be preserved for as long as possible.
- c. Doctors and hospitals should honor a dying patient's wish to refuse treatment.
- d. Doctors should do all they can to ease the pain and suffering of dying patients, but nothing more.
- e. Doctors should not be prosecuted if they help dying patients end their lives.
- f. A doctor should do everything medically possible to save a patient's life, no matter how hopeless the patient seems.

Strongly	Somewhat strongly	Not at all	Not sure
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. Are there other principles that you think should guide policy in this area? Please explain.

4. How concerned are you about the following?

- a. Dying patients who are forced to endure needless pain and suffering.
- b. Patients who say they want to die but really need treatment for pain and depression.
- c. Doctors who violate their oath to preserve life, by helping patients commit suicide.
- d. Patients who choose to end their lives to reduce medical expenses their families must pay.
- e. Doctors and hospitals that disregard patients' wishes to withhold treatment.
- f. The huge financial costs to society of keeping dying patients alive.

Very concerned	Somewhat concerned	Not at all concerned	Not sure
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. Do you have any other concerns about public policy in this area? Please explain.

- | | Favor | Oppose | Not sure |
|---|--------------------------|--------------------------|--------------------------|
| 6. How do you feel about these approaches to the problem? | | | |
| a. We should legalize and regulate doctor-assisted suicide, EVEN IF this contradicts the idea of the doctor as healer. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. We should give dying patients more control over their treatment, EVEN IF their wishes might override sound medical judgment and lead to premature death. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. We should maintain the current ban on doctor-assisted suicide, EVEN IF this means some terminally ill patients will endure needless pain and suffering. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

7. Which statement best describes how you feel? (Please choose only one answer.)
- a. I am not at all certain what our public policy should be regarding assisted suicide.
 - b. I have a general sense of what our policy should be.
 - c. I have a clear, definite view of what our policy should be.

8. If you answered "c" to Question #7, please explain below what you think our public policy should be.

9. What is your ZIP code? _____

For the National Issues Forums

Issue books in this series are prepared by Public Agenda in collaboration with the Kettering Foundation.

Public Agenda

Public Agenda was founded in 1975 by public opinion analyst Daniel Yankelovich and former U.S. Secretary of State Cyrus R. Vance. A nonprofit, nonpartisan research and education organization based in New York, Public Agenda has created and produced issue books in this series since 1982. Its research on how citizens approach public issues provides the basis for many innovative educational projects. For more information, contact Public Agenda at 6 East 39th Street, New York, New York 10016. Phone: 212-686-6610.

Kettering Foundation

The Kettering Foundation, a nonprofit, nonpartisan research institute based in Dayton, Ohio (with offices in Washington, D.C., and New York) was founded in 1927. It has provided books, materials, and moderator training for the National Issues Forums since this nationwide network was started in 1982. It is engaged in a wide range of activities to promote civic participation and enrich public life. For information about the Kettering Foundation, contact the foundation at 200 Commons Road, Dayton, Ohio 45459-2799. Phone: 800-221-3657.

Additional Copies

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Acknowledgments

The editors would like to thank their colleagues at Public Agenda and the Kettering Foundation who helped define the choice framework and clarify the presentation: Ed Arnone, Jon Kinghorn, Bob Kingston, and Estus Smith at Kettering; and Jean Johnson, Keith Melville, and Deborah Wadsworth at Public Agenda. We also appreciate the encouragement and support of Dan Yankelovich, president of Public Agenda, and David Mathews, president of the Kettering Foundation.

Reviewers

Special thanks to the consultants who reviewed this manuscript: Jay E. Kantor, ethicist, New York University Medical Center; Dr. Russell K. Portenoy, Co-Chief, Pain and Palliative Care Service, Memorial Sloan-Kettering Cancer Center, New York; Barbara Coombs Lee, Interim Executive Director, Compassion in Dying; Dr. Stephen R. Latham, Deputy Head, Institute for Ethics at the American Medical Association.

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Design and Graphics

Design: Sundberg & Associates Inc
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Cover Illustration: John Lytle
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At the Kettering Foundation

Publisher: Edward J. Arnone
Production Manager: George Cavanaugh
Ballots: John Doble, Ilse Tebbetts
Circulation Coordinator: Victoria Simpson

At Deaths Door:
What Are the Choices?

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ISBN: 0-7872-3915-1



KENDALL/HUNT PUBLISHING COMPANY
Dubuque, Iowa



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