

A Journalist's Resource Guide

***COVERING THE ISSUES
OF DEATH AND DYING***

A primer for journalists covering
stories on the end of life

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INTRODUCTION

Simply put, life is a terminal affair.

But the realities of this affair have become far more complicated in the past generation or two. Death no longer occurs under the sole auspices of nature. Medical technology, social science, economic pressures, and the headline-grabbing activities of those who challenge convention have turned dying into a complex phenomenon that has intensified the terror that most of us feel about death.

This guide is about death and dying. It's designed to help working journalists navigate their way through the mine field of medical, legal, social, and emotional issues that present themselves in the course of reporting stories that deal with the end of life.

Why should journalists care about these issues? Jack Kevorkian, M.D., a.k.a. "Dr. Death," has succeeded in polarizing the moral debate about how we die. While continuing to assist suicides in Michigan and belittle those who oppose him (Kevorkian now admits to attending nearly 100 deaths), he has never been convicted of a crime. Kevorkian has been charged with murder and gone to trial four times. The results: three acquittals and a mistrial. On September 1, 1998 a law banning assisted suicide was scheduled to go into effect in Michigan. Kevorkian has vowed to challenge the law. But it's important that reporters go beyond the sensationalism that surrounds Kevorkian to cover the entire breadth of what is happening in the end-of-life arena, both nationally and internationally.

For example, according to a report issued in August of 1998 by the Oregon Department of Human Resources, at least eight people have legally committed suicide under provisions of that state's Death with Dignity Act, which authorizes physician-assisted suicide. Oregon is currently the only state to have such a law on the books. Voters have approved it twice, but it is still going through intense legal scrutiny. As of this writing, the law is in effect, although some members of Congress are attempting to overturn it via federal statute.

The Lethal Drug Abuse and Prevention Act, aimed at sanctioning physicians for assisting in a suicide, is sponsored by Sen. Don Nickles (R-OK) and Rep. Henry Hyde (R-IL). As of this writing it had passed out of committee in both houses of Congress and was headed to their respective floors for a vote.

The U.S. Supreme Court ruled in 1997 that it was up to each individual state to decide whether or not to legalize physician-assisted suicide. This year, nine states (including Oregon)

have considered legislation banning assisted suicide. Eleven states have introduced bills authorizing the practice. None of them passed, but the debate about assisted suicide rages on everywhere—in courtrooms, at the bedside, and in legislative arenas—providing a controversial vanguard for the larger issues of end-of-life care. However, assisted suicide is only the tip of the iceberg when it comes to important end-of-life issues. Right in your own neighborhood there are stories that deserve your attention.

Death will be a personal reality for all of us, and more of “us” are rushing toward the final chapter of our own lives. The first wave of the Baby Boom generation is now hitting age 50. Many in this “sandwich” generation are stuck between raising their own children while also caring for their aging parents. These members of your prime audience are faced with tough decisions about illness, death and caregiving. They need information.

The year 2011 is not that far away. That’s when the oldest Baby Boomers will reach age 65. The elderly will make up even more of the population than they do today. Every year more people will die than the year before. Society is already being pushed to deal with the medical, economic, and social effects of an aging population. Questions being raised today will play themselves out in the future in ways we cannot now imagine. Your audience needs to understand the ramifications of what is coming.

And then there are the more personal, everyday aspects of death and dying: palliative care, pain management, medical cost issues, and the desire to make life’s final chapter into something that celebrates rather than denigrates the person. These are the issues that have the most meaning for those confronting their own mortality or grief at the loss of a loved one. Those active in the right-to-die movement predict that better palliative care and the aggressive use of pain medication are the issues that will be the primary focus of legislative initiatives in the next few years. All these topics present opportunities to report on issues that are rich in substance and compelling in human drama.

How to Use this Guide

This guide is intended to provide basic background information, story ideas and resources for electronic journalists covering end-of-life issues. Basic definitions and terms associated with death and dying—the first order of business for any journalist—are presented up front in Section I. The remainder of the information is organized into concise sections, designed especially for the working journalist on a tight deadline. Story ideas are included at the end of each section. Here are the topics you will find covered in this guide:

- Section I - Coming to “Terms” with Death

- Section II - Legal and Regulatory Issues (including a comprehensive timeline of milestone events)
- Section III - The Reality of How We Die
- Section IV - Getting Personal - Caring for Terminal Patients
- Section V - The Institutional Response to Death
- Section VI - Professional Caregivers

Additional resource materials at the end of this guide include:

- A comprehensive resource list, including contacts, phone numbers, e-mail addresses, and web sites
- A Glossary of Terms
- References and suggested readings

All of the issues explored in this guide are actively and publicly under debate in our society—and they concern everyone living. Journalists need to make sure they have the latest information before proceeding. This guide is designed to make that preparation quick and easy.

Sensitivity in Reporting

This guide cannot address all the issues surrounding death and dying—especially the emotional and ethical predicaments that may present themselves in the midst of doing the work. Covering stories involving the end of life will likely be among the most challenging assignments in a journalist’s career. How does a reporter reflect the gravity of a life-and-death situation without appearing morbid? How does a reporter adhere to deadlines while respecting the needs of a grieving family? Where’s the line between the “people’s right to know” and the compelling need for personal dignity and privacy at the end of life?

These are questions for your own exploration and discussion with colleagues. In an ideal world, every news organization would have an ongoing dialogue concerning these issues and establish policies to guide staff in these sensitive areas. The very least a reporter can do is

have his or her facts straight going into the story. That's what this guide is all about.

Section I: Coming to “Terms” with Death

When reporting on end-of-life issues, it is important to distinguish the differences among terms. The end of life is a topic ripe for misunderstanding. When a reporter enters the picture, he or she bears a responsibility to ensure that the public’s information is accurate. This responsibility involves not only properly defining terms, but also clarifying—up front to the viewers or readers—which political camp an interviewee is in. Sometimes a subject’s bias is obvious, such as the pro-suicide stance of the Hemlock Society. At other times, the bias is subtle and requires some digging.

The following is an explanation of some of the basic terms reporters will deal with in reporting on end-of-life issues. The Glossary at the end of this guide covers additional terms.

TERMS

A. “Good Death”

What constitutes a *good death*? While definitions are variable and subjective, the Institute of Medicine committee that produced the report *Approaching Death: Improving Care at the End of Life*, says that a good death encompasses:

- freedom from avoidable distress and suffering for patients, families, and caregivers;
- respect for both family members’ and the patient’s wishes;
- consistent clinical, cultural, and ethical standards.

By contrast, the committee defines a *bad death* as one characterized by:

- needless suffering;
- dishonoring the patient’s or family members’ wishes or values, and offending human decency;
- neglect, violence, or unwanted or senseless medical treatments.

B. Physician-assisted Suicide

Assisted suicide is the act of helping another person to commit suicide (for example, by prescribing or procuring a lethal dose of medication with an understanding that the person intends to use it to commit suicide). Most current discussions center around *physician-assisted* suicide—when the person assisting the death is a medical doctor. Although these definitions are somewhat in flux, assisted suicide can be distinguished from euthanasia, in which someone other than the patient actually administers the lethal dose—for example, by injection—with the intent of causing death.

As of this writing, Oregon is the only state that allows physician-assisted suicide, having first passed a ballot initiative to legalize it in 1994. This law limits the practice to adult residents of the state who are certified to be of sound mind and diagnosed with a terminal illness likely to result in death within six months, and who make multiple requests for such assistance.

Public Opinion on Physician-assisted Suicide

Public opinion on this issue is split. According to a 1996 *Washington Post* survey, 50% of the respondents said that physician-assisted suicide should be legal, 40% responded that it should be illegal, and 9% were undecided. Males, the middle-aged, the affluent, and people living on the East or West coast most strongly favored legalization. African Americans were overwhelmingly opposed to it.

In a September 1997 Harris Poll conducted for *USA Today* indicated that a majority (68%) of adults say the law should allow physicians to aid dying patients who want to end their lives. Some 27% were opposed, 4% were unsure and 1% gave no answer. These numbers suggest that how the question is framed has a great deal of influence over the results.

Not Dead Yet is one group that vehemently opposes physician-assisted suicide. This national organization advocates for people with disabilities and their allies. The group believes that legalizing physician-assisted suicide will create a double standard—based on a person's health status—for how society responds to a person's expression of a desire to die. During the 1997 Supreme Court debate on physician-assisted suicide, Not Dead Yet filed an amicus brief arguing that legalizing physician-assisted suicide would violate the Americans with Disabilities Act because assisted suicide would only be legal for persons with disabilities and health impairments.

The Not Dead Yet group argues that often society's and the medical community's definitions of "quality of life" automatically "de-select" those in the disabled community. For example, some definitions of quality of life refer to the person's ability to care for him or herself. Many in the disabled community, even prior to entering a hospital or health facility for a life-threatening illness, already need assistance in activities of daily living such as bathing, dressing, and eating. Defining the quality of life in subjective terms that directly relate a person's worth to his or her ability to care autonomously for him- or herself automatically targets a disabled person and puts that person in a vulnerable position while in a health facility.

Physician Opinion on Physician-assisted Suicide

"If legalized, physician-assisted suicide will be a substitute for rational therapeutic, psychological, and social interventions that might otherwise enhance the quality of life for patients who are dying."

— Kathleen M. Foley, M.D.,
Memorial Sloan-Kettering Cancer Center, New York, NY, and physician-assisted suicide
opponent,
in *The New England Journal of Medicine* (January 1, 1997)

"The notion that all requests to physicians for assisted death stem from undertreated pain, unrecognized depression, or some kind of character flaw is an illusion. The wish to die demands exploration. It may be a clue to a potentially remediable problem, but it may also be rational and consistent with the patient's values and clinical circumstances."

— Timothy E. Quill, M.D.,
physician-assisted suicide proponent,
in *A Midwife Through the Dying Process*

The subject of physician-assisted suicide is a matter of hot debate among physicians around the country. For many doctors the very notion of helping a patient die goes against the prime tenet of the Hippocratic Oath: "First, do no harm." The American Medical Association (AMA) believes the practice is "unethical and fundamentally inconsistent with the pledge doctors make to devote themselves to healing." The AMA goes on to call physician-assisted suicide "a sign of society's failure to address the complex issues raised at the end of life."

In an article in the May, 1998, issue of *Hospital Medicine*, Stephen R. Permut, M.D., J.D., of Temple University School of Medicine in Philadelphia, discusses the legal ramifications of physician-assisted suicide. He summarizes the most compelling arguments against physician-assisted suicide:

- It might compromise the trust fostered in the doctor/patient relationship.
- In the cost-containing environment of managed care, it might be encouraged for vulnerable patients who are “expensive” to care for.
- It may become less than “voluntary” if the decision falls to relatives or agents with questionable motives.
- Once allowed, it may no longer be restricted to terminally ill patients.

Researchers at Mount Sinai School of Medicine find that few physicians around the country are willing to assist in the suicides of their desperately ill patients. In an article in the April 23, 1998, issue of *The New England Journal of Medicine*, researchers report that one out of five doctors with experience in taking care of patients with serious life-threatening illnesses has been asked one or more times by patients for assistance in speeding their deaths, but fewer than 7% of doctors said they had ever complied with such a request.

The 6.4% of physicians who did comply reported a variety of reasons why they believe patients requested help with dying. These reasons, in order of frequency given, were: severe patient discomfort other than pain, loss of dignity, fear of uncontrollable symptoms, actual pain, loss of meaning, being a burden, and dependency.

The study does point out a possible harbinger of the future: A much larger proportion said they would be willing to provide assisted suicide if laws were changed to make the practice legal.

C. The Right to Die

Reporters must be careful when using the term the *right to die*. It has become a catch phrase used differently by those debating end-of-life issues.

The phrase became popular in the 1970s and 1980s when it referred to what was then *the* controversial issue: withholding and withdrawing treatment. (At that time, patients and family members had a difficult time getting physicians to pay attention to these issues.) So the right to die became an umbrella term covering many issues related to end-of-life care, such as withholding and withdrawing treatment, surrogate decision-making, and do-not-resuscitate orders.

Times change. Now there is a large body of case law that deals with patients’ rights regarding withholding and withdrawing treatment, the vast majority of which recognizes the

individual's autonomy right to refuse virtually any medical treatment. And while many end-of-life experts still use the term right to die in referring to withholding and withdrawing treatment, it is now more closely aligned with proponents of physician-assisted suicide and with the "right" to have a physician's assistance in choosing the timing of one's death.

The meaning of the right to die will be debated for a long time. Families, physicians, and patients will continue to face difficult decisions about when and how life should end. Journalists need to be sensitive to the current popular use of the term.

D. Advance Directives

Most Americans plan for emergencies by buying home insurance to ward off financial disaster from fires and floods, and life insurance so that loved ones left behind are cared for. What about planning for a good death? Can an individual actually control the circumstances surrounding his or her death? To a large extent, the answer is "yes." Over the last 30 years, health care decision-making has moved from being entirely physician-directed, to becoming a shared venture between doctor and patient, to being in many cases patient-centered.

An *advance directive* is a document through which patients either provide instructions for the kind of care they do or do not want to receive, or else name another person to make such decisions for them. Advance directives generally take effect when the patient becomes incompetent to make health care decisions during the course of a terminal illness, or else becomes permanently comatose. Each state regulates the use of advance directives differently. There are two types of advance directives: a living will and a durable medical power of attorney.

A *living will* is a type of advance directive that puts a person's wishes about medical treatment in writing so that if the person can't communicate, his or her desires are recorded. State laws may define when a living will goes into effect, and may limit the treatments to which the living will applies. A person's right to accept or refuse treatment is protected by constitutional and common law. Living wills can be very detailed, addressing the patient's wishes regarding procedures such as mechanical ventilation, cardiopulmonary resuscitation, chemotherapy, surgery, artificial hydration, artificial nutrition, blood transfusions, and antibiotics.

A *durable medical power of attorney* is a document that allows patients to appoint someone they trust to make decisions about their medical care when they cannot. This type of advance directive may also be called a *health care proxy* or appointment of a health care agent. The person appointed by such a document may be called a health care agent, surrogate,

attorney-in fact, or proxy. In many states, the person appointed through a medical power of attorney is authorized to speak for the patient any time that patient is unable to make a medical decision—not only for end-of-life decisions.

Advance directives work in tandem with conversations held with health care providers, patients, and their families about what the future holds. Advance care planning may also include a questionnaire that asks the patient to consider provocative questions about his or her values, attitudes toward medical treatments, fear of death, and religious beliefs.

Do People Actually Use Advance Directives?

If both federal and state laws view advance directives as important end-of-life planning tools, why did a recent study find that only 3% of the directives written by patients were specific enough to guide decisions on whether to use a particular life-extending treatment in the patient's actual situation? After reviewing the charts of 4,804 patients, researchers discovered only 688 written advance directives. Among those directives, only 22 were specific enough to guide physicians' decisions about treatment.

That sums up the actual impact of laws on advance directives. Advance directives—living wills, health care proxies, and durable powers of attorney—seldom affect health care decision-making at the end of life, according to the largest study of their impact on seriously ill patients in U.S. hospitals.

In three separate manuscripts in the April 7, 1997, *Journal of American Geriatrics Society*, researchers explain why advance directives usually fail:

- The few patients who write directives seldom tell their physicians about them. Physicians knew that an advance directive existed only in 25% of the cases where patients had completed them.
- Most written directives are too vague to make a difference in the patient's care, and fail to anticipate the actual circumstances that will arise.

Such findings suggest that more patients need to write advance directives and that the processes of writing and implementing directives must be improved to assure the intended impact, according to the study's lead author, Joan Teno, M.D. Teno states that patients must provide both oral and written instructions and discuss them with physicians and family members.

Among the study's other findings:

- Patients who say they want to limit end-of-life care seldom have those wishes documented in the medical record. Patients who told researchers they would not want a resuscitation attempt had an order against it only about half of the time. That was true whether or not the patient had an advance directive.
- Two-thirds of the patients knew about living wills, but less than half knew about durable power of attorney. Only about one-fifth had either one.

E. Do-Not-Resuscitate Orders

Also called a “no code,” DNR (do not resuscitate) is a medical order to withhold cardiopulmonary resuscitation (CPR) if the patient has a cardiac or pulmonary arrest. Prior to writing a DNR order, medical providers must assess with the patient and the patient’s family the patient’s clinical condition and prognosis, describe what CPR involves, and estimate the patient’s survival chance. A DNR order is signed by the physician and put in the patient’s medical record.

Physicians write more DNR orders for people 75 or older than for those younger than 75, regardless of patients’ preferences or prognoses, according to an August 14, 1996, article published in *The Annals of Internal Medicine*. Among the study’s other findings:

- DNR orders were written for only about 31% of the patients in the study and for about 81% of the patients who died.
- DNR orders were most often written within days of death. Only 52% of those patients who stated a preference to forego resuscitation had a DNR order written during their hospitalization, suggesting inadequate communication between doctors and patients around end-of-life decisions.
- Regardless of patients’ preferences or prognoses, the timing of writing DNR orders varied substantially among physician subspecialties, the five institutions, and the age of the patient, even after taking prognosis into account. It took surgeons twice as long to write DNR orders, compared with internal medicine physicians.

STORY IDEAS

1. Contact your state or local Medical Society. Has it taken a formal stand on physician-assisted suicide? Is there a policy for doctors to follow when someone requests help in dying? Is there a committee assigned to deal with the issue?
2. Locate a physician who works with terminally ill patients (perhaps an oncologist). Have patients ever requested physician-assisted suicide? Why did the patient ask? What was the physician's action? How did the patient respond?
3. Is there a disability-rights organization in your locale? Are they active in right-to-die issues? Do they agree with the stand Not Dead Yet has taken against physician-assisted suicide?
4. Check with local hospitals and HMOs—what's their policy on advising patients regarding advance directives and DNRs? Are more people using them? Your first call should probably be to the chair of the organization's ethics committee—this person may be able to provide a wealth of information for story ideas.
5. Talk to the ethics chair of your local public hospital. What do they do when homeless people or local jail inmates are unable to express their end-of-life preferences—especially when these individuals have no “significant others” to consult with regarding right-to-die issues?

Section II: Legal and Regulatory Issues

A. Court Decisions: Federal and State

On June 26, 1997, the United States Supreme Court, by a 9 to 0 vote, ruled that Americans do not have a constitutional right to commit suicide with a physician's help. At the same time, The court also found that the legalization of physician-assisted suicide would not necessarily be unconstitutional, thus leaving the issue of whether to ban or legalize physician-assisted suicide up to the states.

In its ruling, the Supreme Court opened the door for what will be a long-term national debate on physician-assisted suicide—and on what kind of care Americans can expect at the end of their lives. Society will continue to struggle with the question of where to draw the line between an individual's right to self-determination and society's responsibility to protect its citizens.

The legal wrangling over right-to-die issues began over twenty years ago in a New Jersey state court. The debate then dealt with withdrawal of medical treatment. Decisions by state and federal judges over the years led to changes in national and state legislation. Organizations were created to advocate on all sides of the issue. The human drama that has played itself out at the bedside, in the courtroom, and in legislative halls over the past 25 years is worthy of a full-length motion picture. A timeline (see page x) has been provided to put these issues and events into a wider perspective.

Two Landmark Cases: Karen Ann Quinlan and Nancy Cruzan

The 1975 case of Karen Ann Quinlan exemplified the ethical dilemmas brought on by modern medicine's ability to keep patients alive even though they were in a permanent coma. This landmark case was the first of its kind both nationally and internationally to be introduced into a court, according to T. Patrick Hill, a research scholar at the Park Ridge Center in Chicago. The issues presented in court made newspaper headlines and were debated in households around the country.

Karen Ann Quinlan attended a party; friends said she'd been drinking alcohol and possibly taking drugs. Quinlan fell ill, lay down, vomited, and aspirated her own vomit. As a result, she suffered brain damage that put her in a *persistent vegetative state*—she was unable to exist without life-sustaining treatment. Simply put, Quinlan's brain stem was still

functioning, but the upper brain was seriously impaired. “This was not a matter of being brain dead,” says Hill. The fact that Quinlan wasn’t “brain dead” became one of the major concerns when the case went to trial.

Quinlan’s family stated that Karen Ann would not want to be kept alive with no chance for recovery. The Quinlans went to court to receive permission to remove their daughter from a respirator and other machines and to let nature take its course. At the time, the Quinlans thought that Karen Ann would die quickly once the life-sustaining equipment was removed.

A lower New Jersey state court ruled against the Quinlans. Eventually, the case went to the New Jersey Supreme Court on appeal. In 1976, the New Jersey Supreme Court ruled for the Quinlans, saying that the state does not have the right to order the continuation of a respirator. That court used the constitutional principle of privacy, says Hill, in this case meaning that in a situation where the *medical interventions increase while the benefits of that intervention diminish*, there is a point where the rights of the individual take precedence over the rights of the state—specifically the state’s interest in preserving life.

In the Quinlan case, the New Jersey Supreme Court Justices took great pains to emphasize that by *withdrawing life sustaining treatment*, what was being removed was something that was *no longer beneficial to the patient, or that in any way changed the patient’s clinical condition*. So, in effect, the treatment was removed for other considerations and to allow the underlying pathology—in the Quinlan case, a *persistent vegetative state*—to take its course, says Hill. It was a landmark decision that became the formula for many later cases.

Karen Ann Quinlan lived some eleven years after the life-sustaining equipment was removed.

While the Quinlan case established the constitutional principle of privacy as a way of deciding issues of withdrawal of life support or life-sustaining treatments, it also helped to clarify the distinction between the withdrawal of life sustaining treatment and euthanasia or assisted suicide, Hill says. Withdrawing life support allows nature to take its course in a situation where the fundamental clinical condition of the patient is irreparable, in contrast with physician-assisted suicide—which is the act of helping another person to die.

The Nancy Cruzan case further increased public awareness and marked an advance in patients’ rights at the end of life. Cruzan suffered brain damage in a car accident that, as with Quinlan, put her in a *persistent vegetative state*. Cruzan was placed in a rehabilitation center. When her parents saw that there was no sign of improvement, they requested the withdrawal

of Cruzan's feeding tube, so that she could be allowed to die. Although a trial court in Missouri found in favor of the Cruzan family, that decision was appealed by the Attorney General of Missouri.

The family then appealed to the Missouri State Supreme Court, which ultimately overturned the lower state court's decision, on the grounds that there was insufficient evidence to suggest that Nancy Cruzan would have wanted the machinery that kept her alive to be withdrawn. This judgment was reached even though several witnesses testified that Cruzan had made statements prior to her accident that she would not want to live in a vegetative state.

The family appealed to the U.S. Supreme Court, which concurred with the Missouri State Supreme Court and kicked the case back to the state. However, in this case the high court acknowledged that the interest in liberty protected by the Fourteenth Amendment encompassed the right of a terminally ill patient to direct the withdrawal of life-sustaining treatment, including food and fluids, as well as providing a constitutional basis of support for advance directives.

After more legal wrangling with the state of Missouri, which involved providing even more witnesses to attest to the fact that Nancy Cruzan would not want to live in a vegetative state, the Cruzans were allowed to have her taken off the machines. Once the machines were finally removed, she died.

The Other Side of Patients' Rights

Historically, the patients' rights movement has focused on the right of an individual to refuse unwanted medical treatment. Recently, debates about medical futility, treatment rationing, and managed care have caused patients' rights advocates to examine the flip side of patient autonomy—the right to request treatment.

There are some ethicists and health care professionals who believe patient autonomy has gone too far and should be limited. According to these professionals, people should not have the right to request treatment that is inappropriate or futile.

The "Baby K" case exemplifies medical futility. In 1992, an infant was born with anencephaly in a Virginia hospital. Anencephalic babies are born without most of their brain and are generally treated with comfort measures only. However, "Baby K's" mother insisted that her baby receive aggressive treatment. Physicians caring for the baby said it was medically inappropriate and asked a federal court in Virginia to rule on the case. The court ruled that the hospital cannot deny emergency care to any patient, including "Baby K." It is a decision that

divides ethicists. Some argue that such difficult decisions should be left in the hands of those closest to the patient, while others argue that it makes no sense to aggressively treat futile patients.

A similar issue arose in the 1991 case of 87-year-old Helga Wanglie, who was in a vegetative coma in Hennepin County Medical Center in Minneapolis, MN. Her doctors argued that continued treatment would be futile and sought legal permission to turn off life support for Wanglie. Her family argued that her strong religious convictions would have favored continuing life support. The court denied the doctors' request; she died a short time later.

It is important that journalists pay attention to stories involving the “other side” of right-to-die issues. Society will be faced with tough decisions on how far patient autonomy goes as health care costs rise and insurers try to rein in expenditures—especially in a time of growth for managed health care.

Physician-assisted Suicide

1997—The Supreme Court of the United States: Two separate cases involving challenges to state bans on assisted suicide were before the Supreme Court in 1997: *Dennis C. Vacco, Attorney General of New York, et al., Petitioners v. Timothy E. Quill et al.*, and *Washington v. Glucksberg*. The issue reached the high court after Circuit Courts of Appeals in San Francisco and New York found state laws banning physician-assisted suicide to be unconstitutional. In the Washington case, the Ninth Circuit Court of Appeals held that the decision regarding physician-assisted suicide was as personal and intimate as the decision concerning abortion. In New York, the Second Court of Appeals based its ruling on a liberty interest in controlling the time and manner of one's death, in much the same way that the U.S. Supreme Court found that Nancy Cruzan had a right to die by refusing medical care. The two cases were argued before the high court on January 8, 1997.

The Supreme Court ruled unanimously on June 26, 1997, that Americans do not have a constitutional right to commit suicide with a physician's help. This ruling upheld the state laws in Washington and New York criminalizing physician-assisted suicide. But parties on both sides of the issue were able to claim victory after the ruling because the court also found that the legalization of physician-assisted suicide would not *necessarily* be unconstitutional, thus leaving the decision to ban or legalize physician-assisted suicide up to the states.

Rather than settle the issue, the Supreme Court's ruling has opened the door for what will be a long-term national debate. In concurring opinions, several justices emphasized that physicians can take aggressive steps to relieve terminal patients' pain—even if it means

accelerating death. Justice Sandra Day O'Connor wrote that, "There is no dispute that dying patients in Washington and New York can obtain palliative care, even when doing so would hasten their deaths."

However, Justice O'Connor deferred resolving the issue for a future case. "I join the Court's opinions because I agree that there is no generalized right to 'commit suicide.' But respondents urge us to address the narrower question whether a mentally competent person who is experiencing great suffering has a constitutionally cognizable interest in controlling the circumstances of his or her imminent death. I see no need to reach that question in the context of the facial challenges to the New York and Washington laws at issue here."

The non-profit organization Compassion in Dying assumed financial responsibility for legal fees for the physicians and patients involved in the New York and Washington cases. Other organizations filing briefs in support of physician-assisted suicide included the ACLU of Washington, AIDS Action Council, Gray Panthers Project Fund, Hemlock Society, Americans for Death with Dignity, Older Women's League, and the American Humanist Association. Organizations filing opposing briefs included the National Hospice Organization, American Medical Association, American Geriatrics Society, Project on Death in America, American Foundation for Suicide Prevention, and a group of 50 prominent professors of medical ethics.

Action in State Court—Florida: While the U.S. Supreme Court was hearing arguments on physician-assisted suicide, another notable case was making its way through the Florida courts. This case involved AIDS patient Charles Hall, 35, who wished to commit suicide with the help of his physician, Cecil McIver of Palm Beach.

McIver sought to avoid prosecution if he helped Hall commit suicide. The two were responsible for arguing that a ban on assisted suicide violated the state constitution's privacy clause. The Palm Beach Circuit Court initially held that a competent adult who is ill, imminently dying, and acting under no undue influence, has a constitutional right to choose to hasten his own death by seeking and obtaining from his physician a fatal dose of prescription drugs and then subsequently administering such to himself. In its ruling, the court held that a state ban on physician-assisted suicide violated both the Florida Privacy Amendment and the Equal Protection Clause of the Fourteenth Amendment to the U.S. Constitution. The state appealed that decision to the Florida Supreme Court.

In mid-July 1997 Hall lost his battle to have a physician end his life. The Florida Supreme Court ruled that "It is clear that the public policy of this state as expressed by the Legislature is opposed to assisted suicide." Justice Gerald Kogan wrote in his dissent: "When his [Hall's] pain becomes unbearable, which one of us on this Court will be at his bedside

telling him to be brave and bear it?”

B. Federal Legislation

The Patient Self-Determination Act (PSDA)

The Nancy Cruzan case prompted Congress to step in and clarify the governmental role in the complex topic of the right to die. In December 1991, the federal Patient Self-Determination Act (PSDA) went into effect, requiring all health care facilities that receive Medicare or Medicaid funds to inform patients about their rights to refuse medical treatment and to sign advance directives, such as living wills and durable powers of attorney for health care.

According to Choice in Dying, a Washington, DC-based not-for-profit organization, the PSDA requires health care facilities to:

- provide written information to patients about their right to make decisions concerning treatment by completing advance directives;
- ensure compliance with the requirements of state law;
- maintain written policies and procedures with respect to advance directives;
- document in the individual’s medical record whether or not that individual has executed an advance directive;
- educate their staff and the communities they serve about state law governing advance directives; and
- not condition the provision of care or otherwise discriminate against an individual based on whether or not that individual has executed an advance directive.

End-of-life advocates today argue that the PSDA has not achieved the aims of its authors to facilitate the wider and more effective use of advance directives. Legislation to improve some of the shortcomings of the PSDA was introduced in Congress in the fall of 1997 and is making its way through committee. *The Advance Planning and Compassionate Care Act*, if passed, would:

- require advance directives made in one state to be valid in other states;
- encourage Medicare beneficiaries to discuss end-of-life issues with a trained

professional;

- expand Medicare’s drug benefit to include non-intravenous medications for the relief of pain for patients with a life-threatening disease; and
- create a national 24-hour hotline that will give the latest information about where and how to get good end-of-life care.

In addition, the law would require any existing medical directive to be put in a prominent place in the patient’s medical chart so that doctors and nurses can easily see it. The bill also directs the Secretary of Health and Human Services to gather information and data in order to advise Congress on an approach to further improve end-of-life decision making for Medicare beneficiaries.

C. State Legislation

The particulars involving the use of advance directives differ from state to state. The Nancy Cruzan case resulted in a U.S. Supreme Court ruling acknowledging the individual’s right to refuse medical treatment—even if it leads to death. However, the court also held that the state, in its capacity to protect the sanctity of life, can insist upon a *high standard of evidence* of the patient’s wishes. While this is defined state to state, in general it means that there must be evidence that a patient has stated or written that he or she would not want to live in a compromised/vegetative state if that were ever to happen.

November 1997: Oregon’s Measure 16 Approved by Voters for the Second Time

As of this writing, Oregon is the only state that allows physician-assisted suicide. Ballot Measure 16, the Oregon Death with Dignity Act, narrowly passed (with 51% of the vote) in 1994. Legal injunctions kept it from being enforced. (See Timeline on page x.) The 1997 U.S. Supreme Court decision, which kicked the matter of legalizing physician-assisted suicide back to the states, set the stage for another referendum on the issue. In November, 1997, Oregon voters approved the same law again—this time with 61% of the vote. According to reports to the state Department of Human Resources, at least 10 people have requested physician assistance under provisions of the Death with Dignity Act, and eight of them have “officially” died under its auspices. The major provisions of the law are as follows:

- The patient must be an adult (18 years of age or older), certified to be of sound mind and a resident of Oregon.

- The patient must be diagnosed with a terminal illness that is predicted to result in death within 6 months.
- The patient must make two oral requests and one written request for physician-assisted suicide, with a waiting period of at least 15 days after the written request before the prescription is given. The written request must be witnessed by two individuals, with at least one of them not a relative or heir.
- Only oral medication can be used in the act of assisting the suicide.

As of this writing, the Oregon law still stands, even though some members of Congress have sought to overturn it. U.S. Attorney General Janet Reno ruled in 1998 that the Justice Department would not use agents of the Drug Enforcement Administration to go after physicians who prescribe drugs used in assisted suicides.

This year, nine states (including Oregon) considered legislation banning assisted suicide. Eleven states have introduced bills authorizing the practice. None of them passed, but the debate rages on everywhere.

There has been a silver lining in all of the legal wrangling over physician-assisted suicide in Oregon. The organization Compassion in Dying reports that hospice referrals in Oregon have gone up 20 percent since the law's last passage. In addition, they say Oregon now leads the nation in the per-capita prescribing of morphine to control the pain of terminally ill patients.

July 1998—Michigan Legislators Take Action to Stop Kevorkian

On July 2, 1998, the Michigan Legislature passed a bill banning assisted suicide, after four years of watching Dr. Jack Kevorkian assist dozens of people who wished to die. Governor John Engler has vowed to sign the ban, which was to go into effect September 1. The bill would make assisted suicide a crime punishable by up to five years in prison and a \$10,000 fine. The measure "ought to put Jack Kevorkian out of business and end that sorry spectacle that's been playing out these many years," Engler said.

As expected, Kevorkian reacted defiantly to the passage of the bill, accusing lawmakers of legislating morality and vowing to go to trial immediately after the law goes into effect. "The Michigan Legislature is a tool of the Inquisition, said Kevorkian, "It is a lie. They would burn us at the stake if it wasn't for a jury."

STORY IDEAS

1. What is your state's law on physician-assisted suicide? Does your state ban the practice? Have there been challenges to legalize it? Are there any state legislators who are proposing changes in state law?
2. What is your state's law regarding advance directives? Are there any changes in the works? How many people use advance directives? Choice in Dying (202/338-9790) can provide a state-by-state breakdown of laws governing living wills and the appointment of health care agents. Is there anything in your state's law that makes it easy or difficult for people to express their end-of-life preferences?
3. Do a story about ethics committees in your local hospital. How do they handle advising patients about advance directives and DNRs? Are there systems set up that insure they get followed? What do they do when patients request help in dying? Conversely, what happens when a patient or family member requests treatment that is considered "medically futile"?
4. Talk to the head of your local Medical Society. What impact has the passage of Oregon's "Death with Dignity" had on physicians' practice? What do they think of the law? Has the publicity led to more referrals to hospice programs, or greater attention to the care needs of dying patients?

Timeline: Milestone Events in Death and Dying

1974 – The first hospice program in the United States begins serving patients in New Haven, CT.

1975 – The family of Karen Ann Quinlan goes to court in New Jersey to receive permission to remove their brain-damaged daughter from life-support systems. A lower court rules against the Quinlans.

1976 – The New Jersey Supreme Court rules for the Quinlans, saying the state does not have the right to order the continuation of respiratory support for the Quinlans' daughter. Karen Ann lives for 11 years after the life-sustaining equipment is removed.

1980 – The Hemlock Society is founded, supporting the choice of a competent, dying patient for humane, dignified and certain death with the help of a physician.

1988 – The American Academy of Neurology officially supports the right of patients in a persistent vegetative state to forego artificial nutrition and hydration.

1989 – The American Medical Association adopts the position that physicians could withhold or withdraw life-sustaining treatment with informed consent from their patients.

1990 – The U.S. Supreme Court rules against Nancy Cruzan's parents, who wanted to disconnect life-support systems from their daughter, an accident victim living in a persistent vegetative state. The High Court rules there was insufficient evidence that Nancy Cruzan would have wanted life-sustaining equipment removed, and sends the case back to the State of Missouri. Missouri state courts—after hearing more witnesses provided by the Cruzans—allow her to be taken off feeding tubes. After the machines are removed, Cruzan dies.

Spring 1990 – Dr. Jack Kevorkian attempts to place an ad in a Michigan newspaper. “Jack Kevorkian, M.D. Bioethics and Obiatriy. Special Death Counseling. By appointment only.” The ad is refused.

June 4, 1990 – Dr. Jack Kevorkian assists the suicide of Janet Adkins in Michigan. She dies of an injection of potassium chloride in the back of a Volkswagen camper van.

December 1990 – The first murder charge against Dr. Kevorkian is dropped.

July 1991 – Legal request by Hennepin County Medical Center, Minneapolis, MN, to turn off life support for 87-year-old Helga Wanglie, in a vegetative coma, is denied. Wanglie dies a week later.

November 1991 – Voters in Washington State defeat, by 54 to 46%, a ballot initiative seeking to legalize physician-assisted suicide and euthanasia.

December 1991 – The Federal Patient Self-Determination Act (PSDA) becomes effective, requiring all health care facilities that receive Medicare or Medicaid funds to inform patients of their right to refuse medical treatment and to sign advance directives, such as living wills and durable powers of attorney for health care.

1992 – Baby “K” case is argued in a Virginia court, which rules that hospital personnel could not deny emergency treatment to an infant born with a severely damaged brain.

November 1992 – California Death with Dignity Act, Proposition 161, to legalize physician-assisted suicide, is defeated by voters.

January 1993 – Large-scale study published in *American Journal of Public Health* documents the degree to which doctors and nurses fail to honor the treatment wishes of hospitalized, terminally ill patients, despite well-established legal and ethical principles and even the urgings of their own consciences.

November 1993 – *New England Journal of Medicine* article by Drs. Timothy Quill, Christine Cassel, and Diane Meier offers “proposed clinical criteria for physician-assisted suicide.”

January 1994 – *Compassion in Dying et al v. Washington State* is filed in U.S. District Court, challenging the constitutionality of a state law banning physician-assisted suicide.

March 1994 – A federal judge rejects the Washington State law making assisted suicide a crime. The judge holds that competent, terminally ill adults have a constitutional right to physician-assisted suicide.

March 1994 – Federal Agency for Health Care Policy and Research publishes massively researched clinical practice guideline, *Management of Cancer Pain*; California holds statewide Summit on Effective Pain Management, hosted by state Department of Consumer Affairs.

May 1994 – Jacqueline Kennedy Onassis dies in her New York City apartment, focusing

international attention on end-of-life issues such as dying at home.

July 1994 – A case is filed in U.S. District Court in New York, challenging the ban on physician-assisted suicide in that state. The lawsuit, involving 3 physicians, a 76-year old woman with cancer and two people with AIDS, is eventually considered as part of the U.S. Supreme Court’s landmark 1997 decision on physician-assisted suicide, along with similar Washington case filed earlier in the year.

Summer 1994 – Dr. Kevorkian receives the Humanist Hero Award from the American Humanist Society.

October 1994 – Project on Death in America is launched in New York City, funded by billionaire financier George Soros’ Open Society Institute.

November 1994 – Oregon approves Measure 16, the Death with Dignity law, with 51% of the vote.

November 1994 – The *Journal of the American Medical Association* reveals that nearly one-third of families caring for a family member with a life-threatening illness lost most or all of the family savings—even with hospitalization insurance.

December 1994 – A preliminary injunction to block Oregon Measure 16 as unconstitutional goes into effect.

November 1995 – The SUPPORT study is published in the *Journal of the American Medical Association*, the largest study ever conducted in the U.S. on problems in end-of-life decision making.

December 1995 – A permanent injunction blocks implementation of Oregon’s Measure 16.

March 1996 – In a survey of Washington state physicians, 12% respond that they had received one or more requests for physician-assisted suicide; 4% had received one or more requests for euthanasia.

April 1996 – Compassion in Dying wins another case in New York, where the 2nd Court of Appeals strikes down a state law making it a felony to assist in a suicide.

July 1996 – The world’s first right-to-die law goes into effect in Australia. The Northern

Territory's Rights of the Terminally Ill Act is overturned in March 1997. By that time four terminally ill cancer patients will have committed suicide with a doctor's help.

Summer 1996 – Dr. Kevorkian helps 13 people die in a four-month time span.

November 1996 – Cardinal Joseph Louis Bernardin dies of cancer in Chicago, after making a riveting national drama of his courageous and public confrontation with terminal illness.

January 1997 – Two Circuit Court of Appeals cases are argued before the U.S. Supreme Court. The cases stem from earlier rulings that declared laws banning physician-assisted suicide in Washington and New York to be unconstitutional.

January 1997 – A Florida judge rules that a 35-year old man dying of AIDS has a right to commit suicide. This is the first ruling by a state judge in favor of physician-assisted suicide. Florida's Attorney General appeals the decision.

March 1997 – The American Medical Association takes a public stand against physician-assisted suicide, calling it “unethical and fundamentally inconsistent with the pledge physicians take to devote themselves to healing.”

June 1997 – The U.S. Supreme Court, in a 9-0 decision, overrules two Circuit Court of Appeals cases by holding that there is no constitutional right to physician-assisted suicide. However, the court also holds that the legalization of physician-assisted suicide would not necessarily be unconstitutional, leaving the issue up to individual states to decide, and underscores the importance of improving care for dying patients.

June 1997 – The Florida State Supreme Court reverses a lower court ruling in favor of an AIDS patient, to allow his physician to aid him in dying.

June 1997 – The Institute of Medicine releases a study concluding that too many people suffer needlessly at the end of life. The study goes on to say that economic, legal, and organizational obstacles get in the way of offering excellent end-of-life care and that physicians and other providers are not adequately trained to care for dying patients.

September 1997 – A Harris Poll conducted for *USA Today* shows that a majority (68%) of adults favor laws that allow physicians to aid dying patients who want to end their lives. Only 27% are opposed.

October 1997 – the U.S. Supreme Court refuses to hear the first challenges to Oregon's Death

with Dignity Act.

October 1997 – The Advance Planning & Compassionate Care Act is introduced in the U.S. Senate.

November 1997 – Oregon voters approve the Death with Dignity measure for the second time; this time with 60% of the vote.

December 1997 – Americans for Better Care of the Dying, a national advocacy group, is launched in Washington, DC, by SUPPORT co-principal investigator Dr. Joanne Lynn.

May 1998 – American Society of Clinical Oncology releases a position statement, "Cancer Care During the Last Phase of Life," at its annual symposium in Los Angeles.

June 1998 – U.S. Attorney General Janet Reno announces that the Justice Department has ruled out challenging the Oregon assisted suicide law under the Civil Rights Act, and that federal drug agents will not pursue Oregon doctors who comply with the law. In response, Rep. Henry Hyde (R-IL) and Sen. Don Nickles (R-OK) introduce the Lethal Drug Abuse Prevention Act, aimed at overturning Reno's ruling and using DEA authority to investigate and punish physicians accused of assisted suicide.

June 8, 1998 – Dr. Jack Kevorkian says two healthy kidneys removed from his latest patient are available for transplant. No one takes him up on the offer.

July 2, 1998 – The Michigan Legislature passes a bill banning assisted suicide. The law, effective September 1, would make the act punishable by up to five years in prison. Dr. Kevorkian vows to challenge the law in court. Meanwhile, Merian's Friends gathers enough signatures to put on the November 1998 ballot Proposition B an initiative to legalize assisted suicide in the state.

August 1998 – Oregon Department of Human Resources announces that it has received reports of at least 10 patients obtaining lethal medications under the Death with Dignity Act, and that eight of them have used the lethal prescription to end their lives.

Section III: The Reality of How We Die

Americans are afraid of the process of dying—and with good reason. A “good” death that involves excellent comfort care and the involvement of family members and loved ones is still a rarity in this country. The responsibility for guaranteeing a good death falls on the shoulders of individuals, society, and the health care system. There is a price to pay when patients, family members, and physicians ignore or avoid confronting the discomfiting issues involving death and dying. Leaving decisions about the end of life to “chance” can be disastrous for everyone involved.

STUDIES

A. SUPPORT

The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) was a groundbreaking and extremely influential study on end-of-life issues. SUPPORT is the largest study conducted in the U.S. on how to improve end-of-life decision-making and reduce the frequency of a mechanically supported, painful, and prolonged dying process. The study was funded by the Princeton, NJ-based Robert Wood Johnson Foundation; its main findings were published in the November 222/29, 1995, issue of the *Journal of the American Medical Association*. New studies building on the vast SUPPORT data base continue to be published frequently, offering a rich trove of information for journalists about the realities of end-of-life care.

SUPPORT examined the medical records of 9,105 adults hospitalized with one or more of nine life-threatening diagnoses and an overall six-month mortality rate of 47%. Phase I, a two-year descriptive study of 4,301 patients in five teaching hospitals, produced the following findings:

- Physicians didn't know their patients' wishes. If patients didn't want cardiopulmonary resuscitation (CPR), doctors didn't know about it half the time (47%).
- Some 46% of do-not-resuscitate (DNR) orders weren't written until one or two days before death, suggesting little advance planning in terminal illnesses.
- Some 38% of patients spent at least 10 days in intensive care, where aggressive treatment is the norm.

- Pain was common. Half of the patients able to communicate in the last three days of life said that they were in severe pain.

SUPPORT’s Phase II, conducted from January, 1992, to January, 1994, involved 4,804 similarly ill patients and interventions aimed at improving on the findings from Phase I. For years doctors had said there were two main problems in improving end-of-life care. The first was the lack of accurate predictions of survival (prognosis). The second involved problems of communication between doctors on one hand and patients and families on the other. The SUPPORT intervention aggressively addressed both of these issues.

Patients were enrolled either in a “control group” that received customary care or an “experimental group,” in which doctors and families had special help of three kinds:

- a nurse whose job was to talk to patients and families about their concerns, keeping lines of communication open and clear between them and the hospital and physician staff;
- computer-generated reports for physicians that estimated a patient’s probability of surviving six months and predicted how disabled the patient would be in the next two months; and
- detailed written instructions on the patient and family’s wishes regarding treatment—including pain control and “heroic measures” like resuscitation—and whether they wanted to discuss their treatment with their physician.

Researchers involved with the study stated flat-out that Phase II of SUPPORT failed. The three-part intervention didn’t affect the amount of time patients spent in the intensive care unit, in a coma, or on an artificial breathing machine before dying. Reports of pain increased slightly. The costs of care didn’t change. The observation phase revealed persistent shortcomings in communication, frequent aggressive treatment, and the negative characteristics of hospital death—shortcomings that persistently resisted the best remedies that the researchers could devise.

In other words, the Phase II interventions didn’t make any difference in improving the system failings identified in Phase I. Patients targeted by these interventions had no better outcomes than the status quo.

B. Institute of Medicine Study

The Institute of Medicine (IOM)'s Committee on Care at the End of Life released its massive study, *Approaching Death: Improving Care at the End of Life*, in June, 1997. The study identified four broad elements involved in caring for dying patients:

1. understanding the physical, psychological, spiritual, and practical dimensions of care giving;
2. identifying and communicating diagnosis and prognosis;
3. establishing goals and plans; and
4. fitting palliative and other care to these goals.

The IOM study identified four broad deficiencies within the U.S. health care system involving the care of people with life-threatening and incurable illnesses:

1. *Too many people suffer needlessly at the end of life.* Such suffering is derived from two causes. The first is through errors of omission, in which caregivers do not provide palliative and supportive care to patients. The second is through errors of commission, in which caregivers do what is known to be ineffective or even harmful to patients.
2. *Economic, legal, and organizational obstacles get in the way of offering excellent care at the end of life.* For example, physicians are frustrated and intimidated by outdated and scientifically flawed drug-prescribing laws, regulations, and interpretations by state medical boards.
3. *Education and training for physicians and other health care providers fails to provide them with the appropriate attitudes, knowledge, and skills required to care well for dying patients.* Health professionals continue to be under-prepared to recognize the final phases of illnesses, to understand and manage their own emotional reactions to death and dying, and to communicate sensitively with patients and their families.
4. *The current knowledge base is insufficient for consistent, scientifically sound end-of-life care.* Clinical and biomedical research have focused on developing knowledge that adds to the prevention, detection, or cure of disease and to the prolongation of life, neglecting end-of-life care. More information is needed to understand the degree to which dying people suffer symptoms or experience death alone rather than surrounded by those who care about them,

and whether people achieve a dying that is consistent with their community's norms, preferences, and palliative care principles. Methods and tools to measure outcomes of care appropriate to the end of life are needed to monitor and improve the quality of care for dying patients.

C. Seven Deadly Myths

In mid-1997, the Washington, DC-based Alliance for Aging published the report, *Seven Deadly Myths: Uncovering the Facts About the High Cost of the Last Year of Life*, based on a comprehensive review of Medicare data, medical literature and other statistical evidence. The Alliance is a citizen advocacy organization promoting scientific research in human aging and working to ensure healthy longevity for all Americans. Its report examines common assumptions about the high cost of dying in America, and identifies the reality behind these seven common myths. Journalists can use the study to help stop the spread of misinformation.

Myth #1: It is common for older people to receive heroic, high-tech treatments at the end of life.

Fact: Only a fraction of people over age 65 receive aggressive care at the end of life, and the older people are, the less likely that they will receive such care.

Myth #2: The majority of older people die in hospitals.

Fact: The majority of older people do not die in hospitals, and the older people are, the more likely they are to die in nursing homes.

Myth #3: Aggressive hospital care for the elderly is futile; the money is wasted.

Fact: Many older people who receive aggressive care survive and do well for an extended period of time.

Myth #4: If all elderly patients had living wills or other kinds of advance directives, it would resolve dilemmas of how aggressively to provide care.

Fact: Even when patients have advance directives, they often have little impact on or relevance to end-of-life decision-making.

Myth #5: Putting limits on health care for the very old at the end of life would save Medicare significant amounts of money.

Fact: Limiting acute care at the end of life would save only a small fraction of the nation's total health care bill.

Myth #6: The growing number of older people has been the primary factor driving the

rise in America's health care expenditures over the past few decades.

Fact: Population aging does not so far appear to be the principal determinant of rising health care costs.

Myth #7: As the population ages, health care costs for the elderly will necessarily overwhelm and bankrupt the nation.

Fact: Population aging need not impose a crushing economic burden, especially if we start now to conduct the necessary research and develop policies on health care at the end of life.

STORY IDEAS

1. What efforts are being made to “humanize” the process of death within your local health care organizations? Talk to members of ethics committees at your local hospitals and HMOs. Contact local oncologists, talk to a local hospice organization. Are things being done to make a “good death” more accessible to health care consumers?
2. Interview a local physician and find out what actually happens during a patient's last days. At what point does a physician determine that a patient is dying? How does the physician define the *active* phase of dying? What are the misconceptions that people often have about the dying process? What can families and health professionals do to create a supportive environment for this process?
3. How do your local hospitals and HMOs deal with DNRs and advance directives? Are there efforts made to insure that medical personnel are aware of patients' wishes? Are there professionals available to help patients and family members deal with the issues involved?
4. Get in touch with the department in your state capitol that tracks medical care statistics. What percentage of people in your state die in intensive care units? How many people die in their own homes? In nursing homes? Have the figures changed over the years? Are there any trends that would help you describe how death happens in your locale?

Section IV: Getting Personal: Caring for Dying Patients

A. Palliative Care

“We live so long while dying now, and it can be such valuable time. It is clear that we could do much, much better at alleviating pain, reducing isolation, and following patient wishes at the end of life.”

Joanne Lynn, M.D.,
Director of the Center to Improve Care of the Dying, George Washington University Medical Center, Washington, DC.

Palliative care, also called comfort care, involves efforts to relieve a terminally ill person’s pain and other symptoms of illness—i.e., to palliate their suffering. The goal is to provide comfort and maintain a high quality of life, not to cure the patient. Palliative care affirms life and regards dying as a natural process that is a profoundly personal experience for the individual and family. Experts also point out that there is often a need for palliative care even when the person is not dying—although it becomes of paramount importance when the patient is known to be terminally ill.

Comprehensive palliative care programs address mental health and spiritual needs in addition to physical comfort care. This type of care usually requires a team of people, including nurses, physicians, clergy members, social workers, counselors, volunteers, family members, and others who provide support for the sick patient and their loved ones. Hospices (see Section V) are specialized programs known for offering a full range of palliative care to terminally ill patients.

The Palliative Care Task Force of the Robert Wood Johnson Foundation’s Last Acts Campaign has developed the following precepts of palliative care:

- respecting patient goals, preferences, and choices,
- comprehensive caring,
- utilizing the strengths of interdisciplinary resources,
- acknowledging and addressing caregiver concerns, and

- building systems and mechanisms of support

Most physicians are not trained in palliative care, nor are they taught how to communicate effectively with a patient about the fact that he or she is dying. One of the greatest challenges in teaching physicians about caring for dying patients is to convince them that dying and death are not medical failures. Rather, these are part of life and should be treated as such.

It is crucial for physicians to receive solid palliative care training. Dying brings out primal fears of pain and abandonment, as well as concerns that death will be difficult and undignified. These fears are well-founded. A recent study in the January, 1997, issue of *The Annals of Internal Medicine* found that over 50% of the patients who died did so in hospitals, and nearly 50% of all patients were fed by tube, ventilated on a machine, or had a try at resuscitation. The study describes reports by family members about the dying experience of older (over age 80) and seriously ill people at five medical centers between 1989 and 1994. Those reports from family members indicated that 40% of patients had severe pain most or all of the time in the last three days of life. Additional findings include the following:

- Two-thirds of patients found their physical or emotional symptoms were difficult to tolerate. These rates were not restricted to cancer or to intensive care units—serious symptoms and aggressive treatments occurred with every disease studied.
- The proportion of deaths that occurred in hospitals, nursing homes, homes, and hospices varied strikingly by condition. Patients with colon cancer died at home 45% of the time, while only 19% of patients with cirrhosis and 15% of those with advanced age died at home. One-third of the elderly died in nursing homes.
- Resuscitation was attempted on one-tenth of the patients at the end, most commonly for those with end-stage cardiac failure, for whom the rate was 15%.
- Shortness of breath affected most patients, 80% had severe fatigue, and 62% had debilitating emotional symptoms.

It is apparent that palliative care services are lacking in this country. The American Society of Clinical Oncology surveyed 3,200 oncologists in the winter of 1997-98. A full 56% of them reported difficulty in obtaining palliative care consultations for their terminally ill patients, more than 10 times the rate of difficulty reported in Britain or Canada. The same survey reveals that patient depression remains one of the greatest end-of-life treatment challenges. Clinical depression is an issue for 40% of dying patients; half of the oncologists do not feel competent to meet their patients' needs in this area.

B. Pain Management

It's perverse, your classic Catch-22: a dying patient may not be able to receive a consistent, appropriate dose of pain medication because of laws written to save that patient—and any other individual—from becoming hooked on drugs. Unfortunately, drug addiction is not high on a dying patient's worry list, and not terribly relevant, given his or her limited life expectancy. The Institute of Medicine's report on end-of-life care sums up the problem this way: "Addiction to opioids appropriately prescribed to relieve pain and other symptoms is virtually nonexistent, whereas underuse of these medications is a well-documented problem."

Generally speaking, both proponents and opponents of physician-assisted suicide agree on one thing: more needs to be done to ease the physical pain and suffering of the dying patient. This focus on pain management is one of the "silver linings" of the national debate on physician-assisted suicide. Oregon, the only state allowing physician-assisted suicide, now leads the nation in prescribing morphine to control the pain of terminally ill patients. The Advance Planning and Compassionate Care Act, now under consideration in Congress, would expand Medicare's drug benefit to include non-intravenous medications for the relief of chronic pain in patients with a life-threatening disease.

Many physicians appear to be uninformed about how patients can benefit from pain medications. Findings by the American Society of Clinical Oncology pose a challenge for physician education programs around issues of pain management. The study concluded that about 25% of the physicians do not provide optimal pain management, according to responses made to clinical vignettes included in the survey. Ninety five percent of the 3,200 doctors surveyed did say they felt competent to manage pain, yet more than one-half of them reported that more than 20% of their patients die in pain. An earlier study by the University of Wisconsin Pain and Policy Studies Group corroborates the need for physician training. Some 50% of 300 physicians surveyed in 1992 underestimated the relief that cancer patients can receive from pain treatment, such as morphine.

A new five-state study shows that daily pain among elderly nursing home residents with cancer is widespread and often untreated, especially among older and minority patients. The study, appearing in the June, 1998, issue of the *Journal of the American Medical Association*, involved data collected on 13,625 cancer patients aged 65 or older living in 1,492 nursing homes from 1992 to 1995. Some 26% of the 4,003 patients who reported daily pain received no analgesics, not even an aspirin or acetaminophen tablet.

"At some point nursing home staff and in-house doctors may give up on patients who they know are going to die," says study author Giovanni Gambassi, M.D., visiting professor in

the Center for Gerontology and Health Care Research at Brown University. “The results of our study are particularly alarming since there are ways to treat patients to greatly relieve their conditions. There is no acceptable excuse for not treating pain appropriately in terminally ill patients.”

According to the report, patients older than 85 years were about 50% less likely to receive any analgesic than those aged 65 to 74. The study also found that African Americans were 50% less likely than whites to receive any pain medication. Although not statistically significant, similar under-treatment was noted for Hispanics, Asians, and American Indians.

The current legal atmosphere in this country does not always make it easy for those physicians who do understand appropriate pain management to prescribe the drugs their patients need. For example, in some states the laws written to prevent illegal distribution of opioids (the collective term for codeine, morphine, and related analgesics) require doctors to fill out triplicate prescription forms. This triplicate form is available to the state medical board, which, if it chooses, may pursue disciplinary measures against physicians for their prescribing behaviors. Triplicates have been shown to discourage physicians from prescribing opioids.

In addition, some state laws actually limit the dosages a physician may prescribe to one patient at any given time, forcing patients who require larger doses of pain medications to constantly renew prescriptions. The inconvenience to both the patient and the physician may also interrupt the pain management if the prescription can't be filled in a timely manner. This especially concerns patients who are either treated at home or in a facility that does not have an on-site physician.

Addiction and Dependence

Terminally ill patients are unlikely to become drug addicts. Morphine doesn't produce euphoria in pain patients, which means a craving does not develop for anything beyond pain relief, according to Dr. Dwight Moulin of the University of Western Ontario in a 1996 *Lancet* article. Current research in drug addiction is focusing on the interplay of lifelong emotional stress and brain chemistry disorders—not generally an issue for terminally ill patients.

Unfortunately, the issue is surrounded by ignorance, generated by the culture's instinctive fears of drug abuse. In fact, drug experts draw a clear distinction between *tolerance* and *physical dependence* on opioids versus addiction. Tolerance for a drug occurs when a constant dosage produces declining effects, or when a higher dose is needed to maintain an effect. A patient may also experience a physical dependence on opioids, which is characterized by a withdrawal effect following the discontinuation of a drug. This is not limited to opioids

and is quite common in pain management patients.

It's crucial that physical dependence and tolerance are not seen as addiction or substance abuse. An addict, according to the federal Controlled Substances Act, is defined as someone who habitually uses an opioid in ways that endanger public health or safety. Generally, tolerance and physical dependence are clinically acceptable consequences of a consistent use of opioids for pain management. And most terminally ill patients do not have to deal with the drug withdrawal issues associated with physical dependence, because of their limited life expectancy.

C. Socio-Cultural Issues

There is evidence that race and culture affect the quantity and quality of medical care one receives in this country. As mentioned previously, a recent study of pain management among nursing home patients revealed that African Americans were 50% less likely than whites to receive any form of pain medication. A similar trend was noted for Hispanics, Asians, and American Indians. Another study shows that African-Americans hospitalized with a serious illness are less likely to receive any one of five common intensive care procedures. The study, appearing in the July 1996 *Journal of General Internal Medicine*, found that seriously ill white patients were about one and a half times more likely than African-Americans to undergo surgery, dialysis, pulmonary artery catheterization, endoscopy, and bronchoscopy. African Americans also utilized fewer resources, overall, than other patients. Ironically, the report, *Race, Resource Use, and Survival in Seriously Ill Hospitalized Adults*, revealed that the African-American patients ultimately fared better than white patients who received the additional, high-tech care.

The study findings remained the same even after adjusting for severity of illness, the patient's own preferences for care, and several socio-economic factors, such as family income and the presence and type of health insurance the patient had—any of which might have helped to explain the disparity in care and access to resources.

Closer examination of patients with congestive heart failure found that physician specialty is linked to increased resource use and that African-American patients had cardiologists as their attending physicians less often than white patients. However, patients cared for by cardiologists did not have better survival rates.

“While one of the questions raised by this study is the possibility of physician bias, we would have expected the African-American patients to have had worse survival, which is not the case,” observed Russell S. Phillips, M.D., lead author of the study and an internist with the

division of general medicine and primary care at Boston's Beth Israel Hospital. "In fact, they did better than the white patients," Phillips said. "It could be that some of the medical procedures we routinely use are not important to survival and that sometimes these procedures may create additional medical complications, resulting in a poor outcome."

The findings support the need for further research to determine whether decisions about medical care are made differently for African-Americans and for white patients, and if so, why.

Cultural Diversity

Data contained in a May 1997 report, *The Quest to Die with Dignity*, confirms that Americans, regardless of age or ethnic or religious background, consider their own deaths with a mixture of dread and procrastination: they fear dying hooked up to machines, but avoid discussing their fears with others and postpone putting their wishes in writing because the subject is so unpleasant.

The study, issued by American Health Decisions of Appleton, WI, is based on an analysis of 36 intensive focus groups involving 385 people in 32 cities. "These findings challenge the presumption held by many that ethnic and religious differences, as well as age, account for big differences with respect to peoples' attitudes about preferences at the end of life," said Beverly Tyler, lead author of the study and executive director of Georgia Health Decisions. "Certainly there are specific instances where this is the case. But overall, we found enormous and somewhat surprising consensus across the population.

"What's clear from this study is that one of the things that ails this country is the process of death in and of itself," said Tyler. "We need to educate people about their choices and change the way the health care system addresses the dying. That may mean reconsidering some ideas, such as living wills, that just haven't worked very well, and coming up with something that fosters trust and understanding in the doctor-patient relationship."

But the group also said that the health care industry should take note of people's cultural and religious background, which may lead to differences in attitudes about death. The study did reveal these cultural and ethnic tendencies concerning end-of-life issues:

African-American

Responses for this ethnic group showed that they are:

- more likely to trust physicians;
- most uncomfortable with discussions about death;
- more likely to agree that physicians should initiate end-of-life discussions;
- split on the issue of mandating living wills;
- agreed that age should never be a factor in making end-of-life decisions;
- more likely than other ethnic groups to indicate that a lesser quality of life would be acceptable to them if their lives were saved; and
- less likely to support physician-assisted suicide.

White

Responses for this ethnic group show that they are:

- more likely to trust physicians;
- more comfortable with discussions about death;
- more likely to agree that physicians should initiate end-of-life discussions;
- less likely to support mandatory living wills;
- split on whether age should be a factor in making end-of-life decisions;
- more likely to agree that quality of life is important in making end-of-life decisions; and
- somewhat more likely to support physician-assisted suicide.

Native American

Responses for this ethnic group showed they are:

- less likely to trust physicians;
- less comfortable with discussions about death;
- more likely to agree that physicians should initiate end-of-life discussions;
- always agreed that age should never be a factor in making end-of-life decisions;
- always agreed that quality of life is important in making end-of-life decisions; and
- most unlikely to support physician-assisted suicide.

Hispanic

Responses for this ethnic group showed they are:

- split in their trust of physicians;
- more comfortable with discussions about death;
- more likely to agree that physicians should initiate end-of-life discussions;
- most likely to support mandatory living wills;
- always agreed that age should never be a factor in making end-of-life decisions;
- more likely to agree that quality of life is important in making end-of-life decisions; and
- likely to support physician-assisted suicide.

Asian

Responses for this ethnic group showed they are:

- split in their trust of doctors;
- more comfortable with discussions about death;
- less likely to agree that physicians should initiate end-of-life discussions;
- unlikely to support mandatory living wills;

- more likely than other ethnic groups to indicate that age should be a factor in making end-of-life decisions;
- much more likely to agree that quality of life is very important in making end-of-life decisions; and
- more likely to support physician-assisted suicide.

Unfortunately, health care professionals in this country are not generally trained to deal with issues of cultural diversity. Culture affects the way we communicate with others, our core value systems, and our perceptions of time. It is easy for cross-cultural communication to get snarled even under the happiest of circumstances. Factor in the discomfort most of us feel when dealing with end-of-life issues, and it's a wonder we communicate at all.

Spiritual Issues

Issues of religion, spirituality, and the human confrontation with mortality represent another huge, under-explored area that is vitally relevant to the quality of life of dying patients. While religion is a sensitive issue, challenging reporters to show great tact, all dying patients—regardless of their religious beliefs—confront the universal human need to find answers and meaning in their life and their death.

One recent effort to shed light on these profound human questions is a telephone survey of 1,212 adults by the George H. Gallup International Institute, on behalf of the Nathan Cummings Foundation and the Fetzer Institute. The study, released in December of 1997, found that professional clergy and physicians were not seen as the most trusted source for the kind of spiritual support and solace that Americans say they would want to have at the end of life. The majority of those surveyed say it would be important for them to have someone with them as they were dying and to have someone with whom they could share their fears and concerns. Half consider prayer important at the end of life, and 44% would like to reach spiritual peace as they are dying.

The Institute's George H. Gallup, Jr., concludes, "The overarching message that emerges from this study is that the American people want to reclaim and reassert the spiritual dimension in dying."

STORY IDEAS

1. How available is palliative care in your community? Are there enough (if any) hospice

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*A Journalist's Resource Guide, Covering the Issues of Death and Dying. For more information, contact the Radio and Television News Directors Foundation (RTNDF), 1000 Connecticut Avenue, NW, Suite 615, Washington, DC 20036
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programs? Talk to a local oncologist. How does she/he deal with issues of pain management? Are there resources available to physicians? What services are lacking? Is there anything outstanding about services provided in your community?

2. If a hospice program exists in your community, contact a patient and his/her family who are hospice patients. What are some of the finer, personal touches provided by the hospice? How do they define and deliver palliative care? What do “average” citizens need to know about these programs?
3. What is the length of stay in local hospice programs? Are a significant proportion of patients referred in the last few days of life? Is this viewed as a problem by health professionals or family survivors? Do the hospice, physicians, and family survivors have differing views on why this happens?
4. Contact your state’s medical board and find out if it sets guidelines on prescribing pain medications. What disciplinary actions are in place for physicians who violate the policies? How does the board keep track of this information, and what will trigger an investigation of a physician who is viewed as violating the policies? What is the board’s view of prescribing high doses of opioids to treat cancer pain? For other kinds of chronic pain?
5. Contact a local hospice or hospital that treats a high percentage of AIDS patients. How is pain treated for AIDS patients who contracted the HIV virus through drug use? Given the patients’ history of drug abuse, do physicians treat such patients differently when prescribing pain medication?
6. Is there a significant minority culture in your community? If so, contact community leaders for that minority group and find out what cultural beliefs may impact end-of-life decisions. Contact the local hospital that treats different minority groups. What programs does the hospital have in place to address patient differences?
7. Are prominent local clergy active in hospice or palliative care programs? Is there an interfaith clergy group that is active in addressing end-of-life issues?

Section V: The Institutional Response to Death

“Today’s medical practice is so fragmented that often there is no one person in control, and medical technology often over-influences patient care.”

— George W.B. Starkey, M.D.,
Associate Clinical Professor of Surgery, Harvard Medical School

A. Where People Die

Most people like to imagine that they will have a say in where they die. But the truth is, most people won’t. Where people die—whether in hospitals, nursing homes, hospices, alternative care settings or at home—is determined by a combination of factors far more complicated than simple preference. The cold facts show that personal finances, medical mandates, family decisions, and even geography often outweigh a dying person’s wishes about where he or she spends the final days of life.

The 1998 *Dartmouth Atlas of Health Care*, produced by Dartmouth University researchers and published by the American Hospital Association, confirmed the surprising fact that geography can play a large part in determining where patients die. Health care providers across the country do not share a uniform policy on hospitalizing dying patients or utilizing technology at the end of life. The chance of being in a hospital intensive care unit at the time of death varied widely around the country—from 5% to more than 29% in certain regions. For example, in most parts of Louisiana, 50% of Medicare patients who died in 1994-1995 were in the hospital, whereas in Oregon, only 20% were. The study attributed these geographical variations in where people die to regional differences in physician preferences and availability of hospital beds and intensive care units.

Analysis of SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment) data by Dr. Joanne Lynn corroborates this finding. There was a three-fold difference between the five medical centers participating in the SUPPORT study as to whether or not patients died at home, and the single greatest determinant of whether patients died in the hospital was the local per capita licensed hospital bed rate.

Hospitals

Given the choice, few people want to die in a hospital. The reasons for this reluctance are varied—people perceive hospitals as cold and sterile, they fear that the hospital is somehow

the cause of death, and they worry about pain, abandonment, and dehumanization caused by hospital routine. However, the *Dartmouth Atlas* presented the disturbing finding that many end-of-life decisions do not coincide with patients' preferences. For example, while few patients indicated a desire to end their days in a hospital intensive care unit, one-third do.

The American population is getting older—fast. The number of Americans 85 and older is expected to double by the year 2030. To keep pace with the rising numbers of the aged, the American Hospital Association is giving increasing attention to end-of-life programs and services. It is participating in a variety of studies to improve communication and decision-making regarding end-of-life care and is collaborating with institutions around the country dedicated to improving the care of the dying.

Nursing Homes

Nursing homes do even worse than hospitals in the popularity polls about where patients would prefer to die. The largest clinical study ever conducted in the United States on decision-making at the end of life showed that almost a third of the patients *would rather die* than live in a nursing home. This startling fact was presented in 1997 SUPPORT findings, and published in the *Journal of the American Geriatrics Society*. An additional third (37%) would be either “very unwilling” or “somewhat unwilling” to live in a nursing home. Only one-quarter the participants (26%) indicated any willingness at all.

Despite this aversion to nursing homes, the study indicated that 4 in 10 persons who were 65 years old in 1990 *will* enter a nursing home sometime before their death, and more than one-fifth of them will spend five years or more there.

This was the first time a major study has asked seriously ill patients to state a preference between living in a nursing home and dying. The response rocked the medical world, and stirred up a hornet's nest of discussion around the issues of involuntary medical care, assisted suicide, and pressures on unwilling or incapable families to provide unpaid home care for their loved ones.

“Why so many people are unwilling to live permanently in a nursing home needs to be explored,” wrote the study's lead author, Dr. Thomas J. Mattimore of the UCLA School of Medicine in Los Angeles.

The study's researchers were also quick to disavow instant alternatives to nursing home care: “We are not suggesting that patients who state they would prefer to die than live in a nursing home be given carte blanche to home care by an unwilling or incapable family,” the researchers wrote. “Nor are we suggesting that assisted suicide should be considered for such

individuals. Not infrequently patients preferences cannot be followed. However, concerning permanent nursing home placement, these can be elicited to help guide care.” Currently, each year 10% of Americans over age 65 are admitted to a nursing home for some period of time, and 5% of this age group live permanently in nursing homes.

In July, 1998, President Clinton proposed sweeping reform of the nation’s nursing home industry, calling for frequent and random inspections of facilities, with strict penalties for violations. Clinton called for enforcement of regulations in the nation’s 16,800 nursing homes to ensure that neglect and abuse cannot be hidden.

Clinton’s statements came two days before a Congressional hearing in which the General Accounting Office presented findings of poor care in 1,400 nursing homes in the state of California. California’s nursing home industry came under fire in 1997 when a coalition of nursing home activists and relatives of nursing home patients filed a major lawsuit against two nursing home chains—the first whistle-blowing suit of its kind—alleging that the chains provided substandard care in 24 nursing homes while collecting millions of dollars in Medicare and Medicaid payments.

Nursing homes are big business in America—and getting bigger. During fiscal year 1997, the federal government paid \$30 billion to nursing homes to pay for the care of 1.6 million elderly and disabled patients, according to the U.S. Health and Human Services Office of the Inspector General.

B. Hospice

“I think it is realistic to hope for a future in which nobody has to die alone and nobody has to die with their pain untreated.... When people are relatively comfortable and know that they are not going to be abandoned, they frequently find ways to strengthen bonds with people they love and to create moments of profound meaning in their final passage.”

— Ira Byock, M.D.,
hospice physician, in his book, *Dying Well*

The word *hospice* comes from the same root as hospitality. In early Western civilization, it was used to describe a place of shelter and rest for weary or sick travelers on long journeys. Earlier this century, hospices had evolved into religiously inspired centers dedicated to caring for seriously ill and dying patients. This Medieval notion of service to the dying was wedded to the modern science of pain management, symptom control, and grief counseling by Dame Cicely Saunders, founder of the first modern hospice, St. Christopher’s, which opened in a London suburb in 1967.

Hospice today refers to a concept of comprehensive palliative care for terminally ill patients, not necessarily a place. Using a combination of skilled symptom management, aggressive treatment of pain, psycho-social support, and attention to spiritual and emotional concerns, hospice teams and physicians work to offer patients the possibility of a comfortable, peaceful, dignified death. Dying at home is what most patients say they want to do, and hospice care offers that possibility.

However, it is important to distinguish the term hospice care from *home care*—which is a more generic term for the wide variety of health care services that can be provided in the home setting. Hospice care focuses on the comprehensive treatment of dying patients, while home care treats the physical symptoms of sick people, many of whom will survive or even recover from their illness.

People who can't benefit from curative treatments may be offered hospice care when their physician believes they have less than six months to live—usually far less. Referrals can also come from other sources, such as clergy members or other health professionals. Patients are served by a hospice care team, which provides palliative medical care and basic support services to both the patient and family members. The team includes physicians, nurses, counselors, therapists, social workers, aides, and volunteers. Hospice care is available 24 hours a day.

Some 90% of hospice care is provided in patients' homes. However, some dying patients can't use this option, because they live alone or with someone who is not able to care for them or because their care needs become too great to manage at home. In such cases, inpatient hospice care may be offered through a contracting hospital, a skilled nursing facility, or the hospice's own inpatient facility.

The first hospice program in the United States began serving patients in 1974. According to the National Hospice Organization (NHO), there are more than 3,000 hospice programs in all fifty states, the District of Columbia, and Puerto Rico. In the 1990s, the annual growth of new hospices has averaged around 8%. In the year 1996, hospices served 450,000 dying Americans.

C. The Cost of End-of-Life Care

How much does it cost to die? And who pays for it?

Here are some points to consider when analyzing the costs of end-of-life care,

according to the Institute of Medicine's 1997 report, *Approaching Death: Improving Care at the End of Life*:

1. The relatively small percentage of people who die each year account for a large percentage of total health care spending.
2. Predictable variations occur in how much a dying person and a survivor spend respectively in the final year before a person's death.
3. The older a person is when he dies, the *less* Medicare payments he typically receives.
4. The older a survivor is when a family member dies, the *more* his or her expenditures for that dying person typically are.
5. Chronic and terminal illness have serious financial consequences for families.
6. Personal health care spending has greatly increased in recent years over the lifetime of the average American. However, this increase cannot be totally attributed to the growing costs of end-of-life care, as is often assumed. The increase in personal health care spending is also caused by other factors, such as population growth, inflation in the economy, and higher medical costs.

1. Insurance and Care at the End of Life

Very little research has been done on the effects of insurance on end-of-life care, according to the Institute of Medicine report. The study found that health insurance may ease the financial burden of illness and encourage people to get beneficial care that they might otherwise forego. However, insurance may also encourage the use of services that have little value, raising costs without increasing value.

The report also found that health plan restrictions may adversely affect people with advanced illness. Managed care plans typically apply one or more of the final six restrictions from the list below. Managed care restrictions affect people by:

- limiting the scope or level of benefits to encourage economical choices by patients,
- creating financial incentives for practitioners and providers to provide less care,
- requiring that services be authorized in advance,

- creating protocols or other tools to govern care,
- establishing productivity standards or appointment schedules,
- covering services only if provided by designated physicians and other health care providers or applying higher cost sharing requirements if patients use physicians outside the plan network, and
- limiting the number, type, and geographic distribution of designated providers of specialized services.

End-of-life care is often associated with hospice care, according to the report. However, only a minority of Medicare beneficiaries qualify for hospice benefits. Most older individuals still die in institutional settings, especially hospitals, without the benefit of a referral to hospice.

2. Illness Threatens Family Security

One study, published in the December 21, 1994 issue of *The Journal of the American Medical Association*, revealed that even *with* hospitalization insurance, nearly one-third of families caring for a family member with a life-threatening illness lost most or all of the family savings. The multi-site study looked at more than 2,000 hospitalized patients. According to the study, another 29% of families reported losing their family's major source of income.

The Impact of Serious Illness on Patients' Families also found that, due to the cost of illness, many families had to make changes in their lives such as moving to a less expensive home, delaying education, and putting off medical care for other family members. Financial impact was felt most severely by the families of younger, poorer, and more functionally dependent patients. Families of younger patients are just as likely to suffer financially as those of older patients, suggesting that younger adults may need catastrophic coverage just as much as elderly people do. This study utilized data from the massive SUPPORT research project on care for seriously ill, hospitalized patients.

3. Who Pays for Hospital Care?

Medicare is the federal program that provides health insurance coverage for 37 million elderly and disabled Americans. Since the early 1980s, Medicare, administered by the federal Health Care Financing Administration (HCFA), has reimbursed most hospital stays on a

prospectively determined, diagnosis-related basis. For a given diagnosis, the hospital is paid a flat fee for each hospital stay, regardless of its length. Simply put, the plan assumes that hospitals will get a mix of patients in each diagnosis-related group (DRG), with some patients costing it more than the DRG rate and some costing less. It is assumed that the differences will average out over all patients.

Medicare is comprised of two separate programs:

- Part A, also known as Hospital Insurance (HI), helps pay for stays in hospitals and nursing homes, as well as home health care.
- Part B, also known as Supplementary Medical Insurance (SMI), helps pay for physicians, laboratories, and other outpatient health expenses.

Anyone aged 65 or older who is also eligible for Social Security benefits is automatically eligible for Part A coverage. So are disabled individuals under age 65 who are eligible for Social Security Disability benefits (although only after a 24-month waiting period) and those with end-stage renal disease. In 1996, beneficiaries paid \$42.50 per month to enroll on Part B, which is an optional program. All citizens over age 65 are also eligible for Part B coverage, regardless of their Social Security status. Together, Medicare Parts A and B cost the federal government an estimated \$178 billion in 1995, accounting for 11.7% of all federal spending.

According to the Institute of Medicine report, people have major concerns about Medicare's hospital payment policies, in that they may encourage premature patient discharge and discourage appropriate inpatient palliative services. Indeed, early analyses of the DRG payment approach suggested that Medicare beneficiaries were being discharged from hospitals "quicker and sicker." Premature discharge not only threatens the health of the individual, but also places a heavy emotional burden on family members.

4. Who pays for Nursing Home Care?

Approximately 50% of all nursing home funding is provided by Medicaid, a joint federal-state program for which nursing home patients may qualify after spending down their own financial resources. *Spending down* refers to patients having to literally use up most of their own assets, and then when they are poor enough to qualify for public assistance, they can also enroll on Medicaid. Medicaid pays some of the costs for nearly 7 in 10 nursing home residents.

5. Who Pays for Hospice Care?

Currently, nearly 80% of hospices are certified to provide Medicare hospice services and be reimbursed by Medicare. Hospice is also a Medicaid-covered benefit in 41 states plus the District of Columbia. More than 80% of employees in medium and large businesses are offered hospice coverage by their private health plan. And 82% of managed care plans now offer hospice services, along with most traditional health insurance plans.

In 1994 Medicare spent \$1.2 billion of its roughly \$200 billion budget on hospice services, and by 1995 federal Medicare/Medicaid expenditures on hospice had grown to \$1.8 billion, reflecting steady yearly growth from just \$77 million in 1986.

In September, 1997, the Department of Health and Human Services' Office of the Inspector General, as part of its Operation Restore Trust investigations of health care fraud and abuse, recommended that HCFA modify its hospice Medicare and Medicaid payments by lowering the hospice payments for patients who reside in nursing homes, and to revise requirements for hospices services provided to terminally ill nursing home residents.

This recommendation was based on research by the Inspector General revealing that hospice patients residing in nursing homes received fewer nursing visits than recommended by the National Hospice Organization, which recommends that hospice patients receive visits from nurses twice a week, and visits from nursing aides 1.5 times a week.

STORY IDEAS

1. Obtain a copy of the *1998 Dartmouth Atlas of Care*. Where are people dying in your state and community? Is a ready availability of hospital beds and acute treatment options resulting in over-aggressive end-of-life treatment?
2. Contact a local nursing home (especially one that is part of a large chain of nursing homes). Do they have procedures and policies that go into effect as their patients approach death? Are there efforts made to help ensure a "good death"? Is it common to transfer a resident to a hospital when that resident is actively dying?
3. Follow a local hospice physician or nurse as he/she tends to dying patients. What is involved in the work? How much coordination among hospice team members and volunteers is required? How much paperwork is involved? What are the most challenging/rewarding aspects of working with terminally ill patients? How does the hospice try to ensure that its patients experience a "good death"?
4. Check with local insurance companies and HMOs. Do they provide hospice benefits? If

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not, why? If so, how much of the cost of care does the insurer actually cover. Contact a local hospice program. How are their services covered financially? Are difficulties in financing preventing people from receiving the palliative care they need?

5. Talk to a local oncologist. How do family finances figure into the care of their terminally ill patients? What are the difficult issues that have to be met?

Section VI: Professional Caregivers

The underlying motivation of medical care and medical education in this country is to conquer disease. This being the case, it's no wonder that most physicians see death as a sign of their own failure. Add to that the discomfort that most of us feel even broaching the subject of death and the distress that comes from a medical crisis, and it's easy to understand why end-of-life issues seldom get properly addressed—by either patients or physicians.

This situation is slowly changing. The debate about physician-assisted suicide is forcing the medical profession to address the end-of-life needs of their patients. The move to managed care has accelerated the examination of appropriate technology for treating terminally ill patients. Aging Baby Boomers—whose caregiving responsibilities are mounting—are having a harder time keeping issues of mortality at bay. We are being forced to face reality.

A. Ethics in the Medical Profession

Jessica Muller, Ph.D., a professor in the Medical School at the University of California, San Francisco, has outlined the following bioethical end-of-life issues now being addressed by the medical profession.

1. *Financial concerns:* American medical culture historically has been set on preserving life—at any cost. That may be changing as the use of managed care increases, and cost savings are factored into almost every medical decision. While there is ample evidence that money has been wasted on futile treatments for the terminally ill, there is now a concern that this thinking will go too far in the other direction and we won't provide care due to cost constraint issues. How do we determine which treatments are “too expensive”? How do we insure that lack of money is not used as an excuse for not providing care that is needed?
2. *The appropriate use of technology:* This issue is tied into financial concerns and also includes moral issues of who gets treated. Do alcoholics “deserve” a life-saving liver transplant? Does someone suffering from Down's Syndrome get a heart transplant, even if they have a limited life expectancy? What do we do about those who are unable or unwilling to care for themselves after receiving complex medical treatment?
3. *Physician-assisted suicide:* At some point, individual physicians will have to address this issue. “Physicians will have to decide what path to take—whether to openly assist in a suicide, or do it under the table as it has been done in the past,” Muller asserts.

B. Patient-doctor Relationships

The relationship between patients and doctors is going through a painful transformation. The days of physician house calls are long gone, and with them the sense of familiarity between patients and their family doctor. Medical appointments are often rushed. Treatments from a variety of specialists can result in fragmented care. Personal access to a wealth of medical information, especially through the Internet, means doctors are no longer seen as “paragons” of medical wisdom. Physicians are being forced to deal with mounting paperwork and organizational red tape. The fear of malpractice suits is a constant specter in medical practice.

For these and other reasons, it is harder for patients and physicians to develop a trusting relationship. Dealing with end-of-life issues can be made more problematic when there is no long-standing sense of familiarity and mutual respect. For example, what happens when family members disagree about end-of-life treatment options and the physician has little or no sense of what the patient would want? Many doctors fear that over time, laws allowing physician-assisted suicide will further erode their relationship with patients, increasing doubts that physicians are truly looking out for their patients’ best interests.

The deterioration of trust in the patient-doctor relationship was confirmed by data from American Health Decisions in its 1997 report, *The Quest to Die with Dignity*. Focus group participants said they no longer feel close to their doctor, or else see a different doctor for every appointment or every time their employer switches health plans. The lack of trust may explain why many participants initially resist a role for doctors in helping them plan for the end of their lives, or in suggesting that they should complete a living will.

C. Medical Education and Training

“The medical profession needs to take the lead in developing guidelines for good care of dying patients. Identifying the factors related to physicians, patients, and the health care system that pose barriers to appropriate care at the end of life should be the first step in a national dialogue to educate health care professionals and the public on the topic of death and dying.”

— Kathleen M. Foley, M.D.,
Memorial Sloan-Kettering Cancer Center, New York, NY,
in *The New England Journal of Medicine*, January 2, 1997

The Institute of Medicine report *Approaching Death: Improving Care at the End of Life* identifies several elements of professional preparation needed to care for dying patients. These elements include:

- a command of relevant scientific and clinical knowledge;
- mastery of appropriate technical, communication, and interpersonal skills;
- an appreciation of ethical and professional principles of care; and
- the development of organizational skills to help patients and families navigate the health care system.

Health care professionals are troubled by patterns of inadequate care for dying patients and are seeking improvements. An article in the June 17, 1997, issue of *The Journal of the American Medical Association* points out the problems facing patients, their families, and health care professionals who provide care for the dying:

- Many dying patients suffer severe pain.
- Most oncologists report feeling unskilled at pain management.
- Serious chronic illness threatens many patients with financial impoverishment.
- Advance care planning remains the exception rather than the rule.

It's obvious that medical education hasn't yet recognized the value of teaching physicians about death and dying. One study showed that only 5 of 125 medical schools in this country offered a separate, required course on end-of-life care in 1994. Some 117 responded that the topic was covered in a broader course, while 66 schools offered an elective course on death and dying. For 40 of those 66 schools, the elective also covered additional subjects. In 1996, there were only 6 schools with separate required courses, while 120 included the topic in a broader course. In Canada, a 1996 review of medical curricula showed that all 16 schools require time for palliative care education.

Another recent study revealed that physicians are no more accurate than medical interns are when it comes to understanding seriously ill patients' preferences at the end of life. The study, published in the April-June 1997 issue of the journal *Medical Decision Making*, showed that neither interns nor physicians accurately understood whether their patients wanted to undergo cardiopulmonary resuscitation (CPR). In addition, both physicians and interns had little understanding of patients' willingness to live with a series of undesirable outcomes, such as chronic pain and lifelong tube feedings.

The study compared medical interns' and attending physicians' abilities to predict the

choices of their seriously ill adult patients for end-of-life care. The study surveyed 230 seriously ill adult patients (or surrogates designated by the patient) in a private, urban teaching hospital. They were asked about their desire to receive CPR if their hearts were to stop beating, their current quality of life, and their attitudes towards six other common adverse outcomes (chronic pain, life on a permanent ventilator, lifelong tube feedings, permanent coma, chronic forgetfulness, and nursing home residence). The medical intern and attending physician who cared for these patients were asked what the patient would say for each of the items. This study is part of SUPPORT (the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments).

Traditional Physician Education

It may be helpful for reporters to understand how physicians are trained. The first two years of undergraduate medical education are devoted to classroom instruction. In the last two years, prospective physicians are introduced to a series of patient interactions in clinical settings, along with other skill development opportunities. While these undergraduate programs provide a conceptual, scientific, and ethical foundation for students, it is during medical residencies that physicians learn to care for patients. Residencies take place after graduation from medical school, and are usually oriented around a particular specialty. They almost also are conducted in hospitals, an environment that emphasizes high-tech treatment.

Medical students are hard-pressed to meet their already busy clinical course demands without having to include what some perceive as “softer” issues, such as the social sciences. It is often difficult for medical students to justify receiving training in palliative care. Advances in technology increase the pressure on students just to keep up with “what’s new.”

Not only does medical school fail to provide actual instruction in the care of dying patients, it also fails to give students opportunities to examine their own emotional strengths and weaknesses, life experiences, beliefs, and preconceived ideas about death and dying. Another obstacle to changing or adding to the curriculum is the fact that most physicians care for few dying patients. An average internist cares for only 6 to 10 dying patients a year. However, regardless of their specialty, physicians deal with patients who have life-threatening illnesses. The comfort care principles emphasized in palliative care would be of tremendous benefit to such patients, and could also be applied to patients with many other chronic conditions.

Improving Physician Education

Programs to improve physicians' palliative care education are under way at every step of the medical education process. In March, 1997, the American Medical Association (AMA) launched the first phase of a long-term project to educate physicians on improving care for the dying. The program's main goal is to ensure that practicing physicians are equipped with the knowledge and skills to provide the best possible care for dying patients. This first major initiative of the AMA's new Institute of Ethics is anticipated to reach all practicing physicians throughout the country within two years.

The American Board of Internal Medicine (ABIM), which certifies specialists in internal medicine, now requires residency training to incorporate care for the dying. ABIM developed a guide for residency programs that defines physician competence in end-of-life care, including good pain management. ABIM also increased the number and quality of questions linked to end-of-life care in its certifying exam. The upshot is that internal medicine residency programs must now place more emphasis on these issues and provide training opportunities in hospices and home care settings.

There is an overall awareness among medical schools of the need to update their curriculums so physicians become skilled in end-of-life care. The Association of American Medical Colleges (AAMC) is helping schools develop outcomes that measure whether graduates have achieved a set of core skills, values, attitudes, and knowledge needed for their relationships with their patients.

The University of California-San Francisco Medical School has received a grant to review end-of-life content in the fifty most-used medical textbooks in the United States and then work with the publishers, editors, and authors of these texts to improve the quantity and quality of information about dying. Research cited by Stephen McPhee, a physician at the Medical School and director for the medical textbook project, shows that leading medical textbooks are deficient in the coverage of end-of-life issues. "Textbook chapters on fatal disease focus on prognosis," McPhee said, "and are rarely concerned with treating symptoms, mode of death, decision-making about terminal care, and the impact of death on a patient's family and care team."

The National Board of Medical Examiners (NBME) is developing end-of-life questions for the United States Medical Licensing Examination. NBME president Tom Bowles says that strengthening this area of content in the medical licensure examination reflects an appropriate priority in medical studies. The exam influences faculty decisions about what to teach and encourages students in their selection of areas to study.

The Veterans Health Administration has received a grant to establish a faculty

development program that would train residents to provide better care for dying patients. Thirty faculty fellows will be selected from VA-affiliated internal medicine training programs throughout the country over the next two years. These faculty members will develop programs to teach a holistic, interdisciplinary philosophy of care, emphasizing communication skills, empathy for patients, and planning that focuses on patients and their families. These principles will apply to care given in diverse settings, including hospitals, hospices, nursing homes, and patients' own homes.

Other current initiatives in medical education include the following:

- Choice in Dying in Washington, DC, is working with a group of 11 medical schools to develop mentors and standards for teaching death and dying issues.
- The University of Illinois-Chicago College of Medicine is offering a course teaching pediatric residents to communicate with grieving parents.
- Loyola University of Chicago is trying to help students understand how important it is to incorporate a discussion of spirituality as it is related to curing and healing. Students are learning to become comfortable with performing a spiritual inventory on most patients.
- New York Medical College in Valhalla has developed a two-month course in empathy for first-year medical students.
- George Washington University medical school has been teaching students how to deliver bad news to patients and understand the importance of talking to patients about advance directives and other end-of-life concerns.
- The Medical College of Wisconsin, Milwaukee, is developing a pilot project to incorporate end-of-life care into the curricula of 30 internal medicine residency programs in the Midwest.

Nursing Education

“Nurses move in the zone of the sacred. In the practice and tradition of nursing, there’s a sense of creating a space for the end of a patient’s life and viewing it as a human event, not just a biological one. That’s strong in the practice of nursing.”

— Patricia Benner R.N., Ph.D.,
University of California San Francisco, School of Nursing

Nurses are the main providers of care for dying persons and their families. Nurses have daily contact with patients that no other provider does; it is the nurse who follows a physician's orders to keep a patient comfortable. This includes administering the pain medication that a physician orders. It also includes withdrawing therapy if that is what's been ordered.

Training in palliative care and end-of-life issues varies among nursing schools. Colleen Scanlon, R.N., M.S., J.D., former director of the Center for Ethics and Human Rights at the American Nurses Association, says that until the recent focus on palliative care, nursing education reflected the same aggressive, hi-tech interventions that dominated medical practice.

But efforts are under way to ensure that nurses have appropriate training to administer care to the dying. The American Association of Colleges of Nursing is looking at end-of-life issues and the need for curriculum development and implementation.

A national nurse-led project to improve the quality of nursing education in pain management and end-of-life care has been launched at the City of Hope National Medical Center's Department of Nursing Research and Education in Duarte, California. Efforts will focus on increasing the emphasis on pain management and end-of-life care in nursing textbooks, licensing examinations, and educational organizations.

The American Nurses Association has developed position statements on end-of-life issues that deal with assisted suicide, euthanasia, Do Not Resuscitate (DNR) decisions, medically provided nutrition, advance directives, and the Patient Self Determination Act. The papers all focus on providing guidance for nurses as they care for patients and families.

Many specialty nursing organizations—which include those representing hospice and oncology nurses—are committed to addressing any shortcomings nurses may have in dealing with dying patients.

STORY IDEAS

1. If there is a teaching hospital in your area, find out if there are any initiatives in place to

train either new or practicing physicians in how to care for dying patients.

2. Inquire about the curriculum at a nearby medical and/or nursing school. What formal training exists in palliative care? Have course offerings changed in the past few years? How do schools in your area compare in this regard with other institutions in the country?
3. Talk to a physician experienced in caring for terminally ill patients. Was he/she trained properly for this role? What do they think needs to be done to improve physician education in this area? How do they deal with the pressure “to cure instead of care”? Talk to relatively new physicians. Do they feel prepared to deal with end-of-life issues and the emotional aspects of this area of medical practice?
4. Contact the New York-based Project on Death in America (PDIA, 212/887-0150). Find out if there is a PDIA Soros Scholar in your area and, if so, do a story on his or her activities. This Faculty Scholars Program supports outstanding clinicians, educators, and researchers in disseminating existing models of good care and creating new approaches to educating health professionals. Each year the program awards about ten two-year fellowships, of up to \$70,000 per year. Reporters can receive a list of current and past scholars, as well as the topic each one is studying. (Or visit its web site: www.soros.org/death.html)

Section VII: Resource Materials

A. Resource list: Contacts and Web Sites

American Disabled for Attendant Programs Today (ADAPT)
201 South Cherokee
Denver, CO 80223
303/733-9324

ADAPT is an organization that fights for accessibility and community-based attendant services for the disabled community.

Alliance for Aging Research
2021 K St., NW, Suite 305
Washington, DC 20006
Contact: Daniel Perry, Executive Director
202/293-2856
www.agingresearch.org

This group's study, *Seven Deadly Myths: Uncovering the Facts About the High Cost of the Last Year of Life*, explores—and explodes—some common assumptions about the costs of end-of-life care, based on a review of Medicare data and the medical literature.

Beth Israel Medical Center
Department of Pain Medicine and Palliative Care
1st Avenue at 16th St.
New York, NY 10003
Contact: Carol Bohdan
212/523-7741
www.stoppain.org

Ira Byock, M.D.
Palliative Care Service
341 University Av.
Missoula, MT 59801
406/728-8643
E-mail: ibyock@aol.com

Veteran hospice physician, author of *Dying Well*, and past president of the American Academy of Hospice and Palliative Medicine.

Christine K. Cassel, M.D., FACP

Chair of the Department of Geriatrics and Adult Development
Mount Sinai Medical Center
1 Gustave L. Levy Place, Box 1070
New York, NY 10029
212/241-4840

Center to Improve Care of the Dying
George Washington University
2175 K St., NW, Suite 820
Washington, DC 20037
Contact: Joanne Lynn, M.D., Director
202/467-2222
www.gwu.edu/~cicd

This center is involved in research, advocacy, and education to improve the care of dying patients and those suffering with severely disabling diseases. Also supports an advocacy group: Americans for Better Care of the Dying (ABCD), which has its own newsletter and Web site: www.abcd-caring.com.

Choice in Dying
1035 30th St., NW
Washington, DC 20007
Contact: Bettina Wang, Director of Communications
202/338-9790
202/338-0242 [fax]
www.choices.org

Choice in Dying is a national, not-for-profit organization dedicated to fostering communication regarding end of life decisions among individuals, their families, and health care professionals. CID is well known for creating the first living will in 1967, and is the largest provider of information, education, and counseling about advance directives—the general term for living will and medical power of attorney. CID can also provide reporters with a state by state breakdown of laws governing living wills and the appointment of health care agents.

Episcopal Diocese of Washington Committee on Medical Ethics
P.O. Box 569
Garrett Park, MD 20896
Contact: Cynthia B. Cohen, Ph.D., J.D., Chair

301/942-6077

Are Assisted Suicide and Euthanasia Morally Acceptable for Christians? Perspectives to Consider addresses the issue of assisted suicide/euthanasia as part of a larger report being developed entitled *Toward a Good Christian Death*.

Kathleen M. Foley, M.D.
Memorial Sloan-Kettering Cancer Center
also Director of the Open Society Institute's Project on Death in America
400 West 59th Street
New York, NY 10019
Contact: Julie McCrady
212/548-0100
212/247-3890 [fax]
e-mail: foleyk@mskcc.org
www.soros.org/death.html

Dr. Foley has extensive expertise in pain management and care for patients at the end of life, and PDIA runs many interesting programs on end-of-life issues.

The Fred Friendly Seminar
Before I Die: Medical Care and Personal Choices
Contact: Seminars, Inc. - WNET
356 W. 58th St., Room C1035
New York, NY 10019
www.wnet.org

In April 1997, WNET aired a Socratic Dialogue examining end-of-life issues facing many Americans.

Georgetown University St. Francis Center
The School-Based Mourning Group Project: A New Approach to Assisting Bereaved Inner City Youth/The Georgetown University School of Medicine/Department of Psychiatry
3800 Reservoir Road, NW
Washington, DC 20007
Contact: Janice L. Krupnick, Ph.D.
202/687-1496

The program's goal is to further develop, evaluate, and disseminate new service delivery programs for bereaved school-age children in low-income, inner-city public schools who have experienced the death of a parent due to violence, substance abuse, or AIDS.

The Hastings Center
Route 9D
Garrison, NY 10524-5555
914/424-4040
914/424-4545 [fax]

Reporters should request a copy of The *Hastings Report's* Special Supplement, November-December 1995. This issue includes essays based on SUPPORT research. The Hastings Center is a private, nonprofit, nonpartisan research and educational organization founded in 1969 to examine ethical issues in medicine and the life sciences.

Institute of Medicine
Committee on Care at the End of Life
Report: *Approaching Death: Improving Care at the End of Life*
2101 Constitution Av., NW
Washington, DC 20418
Media Contact: Dan Quinn
E-mail: news@nas.edu
202/334-2138

Approaching Death: Improving Care at the End of Life is the result of information gathered between January 1996 and January 1997 by a committee of end-of-life experts including ethicists, physicians, and health policy specialists. The study offers data, analysis, case studies, and extensive reading lists and resources. The Institute of Medicine is a private, non-profit organization that provides health policy advice under a congressional charter granted to the National Academy of Sciences. Non-media members can receive a copy of the report from:

National Academy Press
2101 Constitution Av., N.W., Box 285
Washington, DC 20055
800/624-6242 or 202/334-3313

The Last Acts Campaign
Robert Wood Johnson Foundation
Route 1 and College Road East
P.O. Box 2316

Princeton, NJ 08543-2316
Contact: Mollie Katz, Burness Communications
301/652-1558
www.lastacts.org/

Three communications agencies are also handling information on The Last Acts Campaign:

Barksdale & Co., Vienna, VA
Contact: Shawn Taylor Zellman
703/827-8771

Burness Communications, Bethesda, MD
Contact: Mollie Katz
301/652-1558

Stewart Communications, Chicago, IL
Contact: Karen Long
312/464-4988

In response to distressing findings from the SUPPORT study, the largest clinical study ever conducted with dying patients, a growing coalition of more than 160 organizations has come together to improve the quality of care for dying patients in the U.S. Former First Lady Rosalynn Carter is the Honorary Chair of The Last Acts Campaign, which was initially supported by a \$1.7 million grant from the Robert Wood Johnson Foundation. Last Acts includes virtually every major relevant interest group ranging from the American Medical Association to the American Association of Retired Persons. The coalition will seek specific reforms aimed at altering the behavior of physicians and other health care providers, payers of care, hospitals, nursing homes, and consumers. The Last Acts campaign includes eleven committees and task forces working on various issues in end-of-life care. Reporters will find a wealth of information on RWJF's Last Acts Web site, including press releases from various SUPPORT study reports, a Press Club for the news media, and links to other sites.

Diane E. Meier, M.D.
Palliative Care Initiative
Mount Sinai School of Medicine
Mount Sinai Medical Center

1 Gustave L. Levy Place
New York, NY 10029
212/241-8258

National Conference of Catholic Bishops/United States Catholic Conference
3211 4th St., NE
Washington, DC 20017-1194
Contact: Msgr. Francis Maniscalco, Director of Communications
202/541-3000
www.nccbuscc.org

The National Conference of Catholic Bishops and the United Catholic Conference are the organizations of the American Catholic hierarchy. Through these distinct but closely related organizations—one a canonical entity, the other a civil corporation—the bishops fulfill their responsibilities of leadership and service to Church and nation.

The Park Ridge Center
Retrieving Spiritual Traditions in End-of-Life Care
211 E Ontario St., Suite 800
Chicago, IL 60611-3215
Contact: Lawrence J. O’Connell, Ph.D.
or T. Patrick Hill, Research Scholar
312/266-2222

This education program is being developed to foster the establishment of structured, supportive environments in which individuals and faith-based communities can draw upon, revitalize, and expand spiritual and practical resources.

Dr. Jesus Rodriguez, Board Certified Chaplain
Director of Educational Programs
AIDS Pastoral Care Network
4753 North Broadway, Suite 800
Chicago, IL 60640
312/334-5333
312/334-3293 [fax]

Sacramento Health Care Decisions
ECHO (Extreme Care, Humane Options)
4747 Engle Road
Carmichael, CA 95608

Contact: Marjorie Ginsberg, Project Director
916/484-2485
916/484-2486 [fax]

ECHO offers community recommendations for appropriate, humane medical care for dying or irreversibly ill patients, proposing goals and strategies to be adopted by acute care facilities and providers in northern California's healthcare system.

Katherine E. Slaughter, RN, MSN, CCRN
University Hospitals of Cleveland
Surgical ICU
11100 Euclid
Cleveland, OH 44106
216/844-2120
216/844-2114 [fax]

Karen J. Stanley, RN, MSN, AOCN
Kaiser Permanente
9961 Sierra Av.
Fontana, CA 92335
909/427-5450
909/427-7363 [fax]

Supportive Care of the Dying: A Coalition for Compassionate Care
c/o Providence Health System
4805 NE Glisan St., 2E07
Portland, OR 97213
Contact: Sylvia McSkimming, Executive Director
503/215-5053
503/215-5054 [Fax]
e-mail: Sylvia_McSkimming@phsor.org

An initiative of 11 Catholic health systems and the Catholic Health Association to develop a new model of care for the dying.

Joan Teno, M.D., M.S., Associate Professor of Community Health
Center for Gerontology and Health Care Research
Brown University
Box GB219

Providence, RI 02912
401/863-1606
401/863-3489 [fax]
E-mail: JoanTeno@Brown.edu

United Hospital Fund
Hospital Palliative Care Initiative
350 Fifth Av., 23rd Floor
New York, NY 10118
Contact: Debra Halper
212/494-0729 or 212/492-0737
www.uhfnyc.org/initiat/initiat.htm

This is a multi-year, multi-million dollar, multi-hospital research and demonstration initiative. Its goals are to analyze and improve the quality of hospital care for persons near the end of life and to develop new hospital-based palliative care in New York City hospitals.

University of Ottawa
Institute of Palliative Care
43 Bruyere Street
Ottawa, Ontario
Canada K-1N5C8
Contact: John Seely, M.D.
613/562-6301
613/562-4226 [fax]
www.pallcare.org

Bioethics

For extensive bioethics contacts and resources, reporters should tap into a key Web site: www.library.upenn.edu/resources/healthscience/disciplines/bioethics.html
Scroll to the bottom of the first page of this site for additional links offered by YAHOO.
Beth Israel Medical Center
Ethics and Medicine Program
Contact: Connie Zuckerman, Associate Director
212/420/4132

Nancy N. Dubler
Director, Division of Bioethics
Montefiore Medical Center
111 East 210 St.
Bronx, NY 10467
718/920-6226
718/920-4630 [fax]

Kennedy Institute of Ethics
Georgetown University
Box 571212
Washington, D.C. 20057-1212
202/687-8099
202/687-8089 [fax]
guweb.georgetown.edu/kennedy/

The Joseph and Rose Kennedy Institute of Ethics was established at Georgetown University in 1971 as a teaching and research center to offer moral and ethical perspectives on major policy issues. It is the largest university based group of scholars in the world devoted to research and teaching in biomedical ethics and other fields of applied ethics. Institute faculty members represent a variety of academic disciplines including philosophy, religion, medicine, social science, and law. Bioethical issues such as in vitro fertilization, abortion, health resource allocation, use of life-sustaining technologies, organ transplantation, euthanasia, and gene therapy have always been a particular emphasis of research at the Kennedy Institute of Ethics. The Institute also houses the National Reference Center for Bioethics Literature, the most extensive collection in the world of material relating to ethics; produces BIOETHICSLINE, an online medical ethics database; and conducts regular seminars and courses in bioethics.

Steven Miles, M.D.
Associate Professor
Center for Biomedical Ethics
University of Minnesota
2221 University Av., #110

Minneapolis, MN 55414
612/626-9756
Email: miles001@maroon.tc.umn.edu

National Bioethics Advisory Commission
MSC-7508
6100 Executive Blvd., Suite 5B01
Rockville, MD 20892-7508
Contact: Patricia Norris, Communications Director
301/402-4242

The National Bioethics Advisory Commission (NBAC) provides advice and makes recommendations to the National Science and Technology Council and to other government entities regarding bioethical issues. The NBAC was established in October 1995 by Executive Order. Access the web site www.bioethics.gov/ for information on NBAC members.

M. Colleen Scanlon, RN, MS, JD
(Former Director of Center for Ethics and Human Rights at the American Nurses Association)
Vice President for Advocacy
Catholic Health Initiatives
1999 Broadway, Suite 2605
Denver, CO 80202
303/298-9100

The University of Pennsylvania Center for Bioethics
3401 Market Street #320
Philadelphia, PA 19104-3308
Contact: Arthur Caplan, Ph.D., Center Director
E-mail: Caplan@mail.med.upenn.edu
215/898-7136
215/573-3036 [fax]
www.med.upenn.edu/bioethics

The Center for Bioethics is the largest bioethics center for the study of ethical issues in research, medicine, healthcare, and bioethical issues in genetic engineering, gene therapy, enhancement, managed care, physician-assisted suicide, pharmaceuticals, animal research, DNA banking, and other bioethics questions. The center is actively involved in bioethics public education and outreach, and has extensive clinical ethics

and bioethics training programs.

Cross-Cultural Issues

Barnard College
Cross-Cultural Dimensions of Death and Mourning in Relation to Organ Donation
Barnard College
Columbia University
3009 Broadway
New York, NY 10027-6598
Contact: Lesley A. Sharp, Ph.D.
212/854-5428

This study involves an anthropological investigation into the cross-cultural dimensions of death and mourning, and their relevance to professional versus lay attitudes in the context of organ donation and procurement in urban Manhattan. Preliminary research reveals that the donation process alters grieving and may, in fact, prolong or even intensify the period of grief and mourning. The final objective of the anthropological findings of this project will be to suggest future policies and training guidelines for procurement professionals.

Marjorie Kagawa-Singer
Assistant Professor
UCLA School of Public Health and Asian American Studies Center
Box 951722
Los Angeles, CA 90095-1772

Barbara Koenig
Stanford Center for Biomedical Ethics
701A Welch Rd., #1105
Palo Alto, CA 94304

Federal Government

Congressional Budget Office (CBO)
Ford House Office Building
2nd and D Streets, SW

Washington, DC 20515
Contact: Hank Cox, Press Contact
202/226-2600

CBO is the official “scorekeeper” of federal spending, estimating the costs of changes in existing and proposed laws.

Government Accounting Office (GAO)
441 G St., NW
Room 7149
Washington, DC 20548
Contact: Susan Becker, Public Relations Specialist for Health Care Issues
202/512-3009

The health care branch of the GAO studies health financing and health access with special emphasis on improving Medicare and Medicaid and reducing health care costs.

Health Care Financing Administration (HCFA)
428-H Hubert Humphrey Building
200 Independence Av., SW
Washington, DC 20201
Contact: Christopher Peacock, Director of Press Relations
202/690-6726

HCFA is the agency within the Federal Department of Health and Human Services that oversees Medicare and Medicaid.

U.S. House of Representatives, Commerce Committee
2125 Rayburn House Office Building
Washington, DC 20510
Contact: David Fish, Press Secretary
e-mail: Commerce@hr.house.gov
202/225-5735

The Commerce Committee shares jurisdiction over Part B of Medicare with the Ways and Means Committee.

U.S. House of Representatives, Ways and Means Committee
1102 Longworth House Office Building

Washington, DC 20510

Hospice

The American Academy of Hospice and Palliative Medicine
11250 Roger Bacon Drive, Suite 8
Reston, VA 20190
Walter Forman, M.D., President
703/787-7718
703/435-3390

American Hospice Foundation
1130 Connecticut Av., NW, Suite 700
Washington, DC 20036
Contact: Naomi Naierman
202/223-0204
202/223-0208 [fax]
www.americanhospice.org

Constance Holden, R.N., M.S.N.
Executive Director
Hospice of Boulder County
2825 Marine St.
Boulder, CO 80303
303/415-3402
303/449-6961 [fax]

Hospice Foundation of America
2001 S St., NW, #300
Washington, DC 20009
202/638-5419
202/638-5312 [fax]
www.hospicefoundation.org

Hospice and Palliative Nurses Association
Medical Center East, Suite 375
211 N. Whitfield St.
Pittsburgh, PA 15206-3031

412/361-2470
412/361-2425 [fax]
e-mail: hnafan@pipeline.com
www.hpna.org

Mary Labyak, CEO
Hospice of the Florida Suncoast
300 E. Bay Drive
Largo, FL 33770
813/586-4432
813/581-5846 [fax]

National Association for Home Care/Hospice Association of America
228 Seventh St., SE
Washington, DC 20003
Contact: Karen Woods, HAA Executive Director (202/546-4759)
NAHC main number: 202/547-7424
202/547-3540 [fax]
www.nahc.org/home.html

Since 1982, NAHC has remained committed to serving the home care and hospice industry, which provides services to the sick, the disabled, and the terminally ill in the comfort of their homes. HAA is its affiliated association for hospices.

National Hospice Organization
1901 N. Moore St., Suite 901
Arlington, VA 22209
Karen A. Davie, President
703/243-5900
703/525-5762 [fax]
www.nho.org

NHO's membership includes 2,400 hospice programs, 48 state hospice organizations (plus the District of Columbia), and 5,000 individuals. Reporters can find a local hospice by tapping into NHO's web site, which offers the option to type in a two-letter state abbreviation to find a nearby facility. NHO is loaded with facts and statistics on hospice.

David A. Simpson, Executive Director
Hospice of the Western Reserve
300 E. 185th St.
Cleveland, OH 44119
216/383-2222
216/383-3750 [fax]

Brad Stuart, M.D., Hospice Medical Director
VNA and Hospice of Northern California
1110 N. Dutton Av.
Santa Rosa, CA 95401
800/861-1715

Pain Management

American Academy of Pain Management
13947 Mono Way #A
Sonora, CA 95370
Contact: Richard S. Weiner, Ph.D., Executive Director
209/533-9744
209/545-2920 [fax]

American Academy of Pain Medicine
4700 West Lake Av.
Glenview, IL 60025-1485
Contact: Jeffrey W. Engle, CMP, Account Executive
847/375-4731
847/375-4777 [fax]

American Chronic Pain Association
PO Box 850
Rocklin, CA 95677-0850
Contact: Penny Cowan

916/632-0922
916/632-3208 [fax]

American Pain Society
4700 W. Lake Av.
Glenview, IL 60025
847/375-4715
847/375-4777 [fax]
www.ampainsoc.org

American Society of Pain Management Nurses
1550 South Coast Highway, Suite 201
Laguna Beach, CA 92651
Contact: Kim Herrera, Executive Director
888/342-7755

City of Hope National Medical Center
Mayday Pain Resource Center
1500 E. Duarte Rd.
Duarte, CA 91010
Contact: Betty Ferrell
626/359-8111
www.cityofhope.org/medinfo/mayday.htm

A clearinghouse to disseminate information and resources for improving the quality of pain management.

International Association for the Study of Pain
909 NE 43rd St., Suite 306
Seattle, WA 98105-6020
Contact: Louisa E. Jones, Executive Officer
206/547-6409
206/547-1703 [fax]

David Joranson
Pain and Policy Studies Group of the University of Wisconsin
1900 University Av.
Madison, WI 53705
608/263-7662

608/263-0259 [fax]
e-mail: joranson@facstaff.wisc.edu
www.medsch.wisc.edu/painpolicy

The Pain and Policy Studies Group's Web site contains laws, regulations, and medical board guidelines on the use of controlled substances for pain management, organized by state.

The Mayday Fund
30 Rockefeller Plaza
New York, NY 10112
Contact: Fenella Rouse, Executive Director
212/649-5800

Philanthropy dedicated to the relief of pain.

The Resource Center of the American Alliance of Cancer Pain Initiatives
1300 University Av., Room 4720
Madison, WI 53706
608/265-4013
608/265-4014 [fax]
e-mail: alliance@mail.com
www.wisc.edu/trc

The Resource Center provides an informational link to the community of state cancer pain initiatives—which are grassroots advocacy groups promoting the approach to cancer pain articulated by the World Health Organization and the U.S. Agency for Health Care Policy and Research's Clinical Practice Guideline, *Management of Cancer Pain*.

Society for Pain Practice Management
11111 Nall, # 202
Leawood, KS 66211
Contact: David Waldman, JD, Executive Director
913/491-6451

913/491-6453 [fax]

Physician-assisted Suicide

Carl H. C. Coleman, J.D.
Executive Director
New York State Task Force on Life and the Law
5 Penn Plaza
New York, NY 10001-1803
212/613-4303

The Center for Ethics in Health Care
Oregon Health Sciences University
3181 SW Sam Jackson Park Road, L101
Portland, OR 97201-3098
Contact: Susan W. Tolle, M.D., Director
503/494-4466
e-mail: tolles@ohsu.edu

The center, which takes a neutral stand on physician-assisted suicide, focuses on enhancing compassion in health care delivery. Copies of the Physician Orders for Life-Sustaining Treatment research results, and other materials, are available, including *Oregon Death with Dignity Act: A Guidebook for Healthcare Providers*.

Compassion in Dying
410 E. Denny Way, Suite 111
Seattle, WA 98122
Contact: Barbara Coombs Lee, PA, FNP, JD
Executive Director
206/256-1636
www.compassionindying.org

This advocacy group sponsored the court challenges to New York and Washington state laws banning physician-assisted suicide.

The Hemlock Society
PO Box 101810

Denver, CO 80250-1810
800-247-7421
303/639-1202
303/639-1224 [fax]
www2.privatei.com/hemlock/

The Hemlock Society USA supports the choice of a competent, dying patient for a humane, dignified and certain death with the help of a physician. Founded in 1980 by Derek Humphry, the organization has 25,000 members nationwide, 80 chapters and community groups, and a quarterly publication.

National Right to Life Committee
419 7th St., NW, #500
Washington, DC 20004
202/626-8800
Email: nrlc@nrlc.org

Not Dead Yet
7521 Madison St.
Forest Park, IL 60130
Diane Coleman, Co-Founder and President
708/209-1500

Not Dead Yet is a national organization for people with disabilities and their allies who oppose the legalization of physician assisted suicide. During the 1997 Supreme Court debate on physician assisted suicide, Not Dead Yet filed an amicus brief arguing that legalizing physician assisted suicide would violate the Americans with Disabilities Act because assisted suicide would only be legal for persons with disabilities and health impairments.

Oregon Right To Life
4335 River Road N.
Salem, OR 97303
Contact: Gayle Atteberry, Executive Director
503/463-8563

503/463-8564 [fax]
www.ortl@ortl.org

This group helped the plaintiffs in a lawsuit challenging Oregon's Measure 16 by financing the fight against the measure.

The United States Supreme Court
1 First St., NE
Washington, DC 20543
Public Information Office
Room G-37
202/479-3211

For a copy of the court's June 1997 opinion on physician-assisted suicide, reporters should refer to Case #951858.

Another source of information on this case and the many amicus curie briefs filed on both sides is the Web site of the Center for Bioethics at the University of Pennsylvania: www.med.upenn.edu/~bioethic/PAS.

Timothy E. Quill, M.D.
Department of Medicine
Genessee Hospital
224 Alexander St.
Rochester, NY 14607
716/263-6355

Carol E. Sieger
Staff Attorney
Choice In Dying, Inc.
1035 30th St., NW
Washington, DC 20007
202/338-9790

Professional Education

American Board of Internal Medicine
End-of-Life Patient Care Project
510 Walnut St., Suite 1700

Philadelphia, PA 19106-3699
Contact: Linda Blank
Vice President for Clinical Competence and Communications
215/446-3500
www.abim.org

American Medical Association
Education for Physicians in End-of-life Care (EPEC)
515 North State St.
Chicago, IL 60610
Contact: Linda Emanuel, MD
Vice President for Ethics Standards
312/464-4979
www.ama-assn.org

This is a profession-wide educational program to teach physicians how to provide quality advance care planning and comprehensive palliative care, presenting train-the-trainer educational programs for physician educators and disseminating continuing medical education materials to all practicing physicians in the country.

Association of Academic Medical Centers
Education of Physicians About Dying
Hackensack University Medical Center
30 Prospect
Hackensack, NJ 07601
Contact: R. Knight Steel, M.D.
201/996-2503

This project will review the requirements of the residency review committees of internal medicine and family practice; the examinations of the primary boards of internal medicine and family practice; and the requirements and examinations for the subspecialties of geriatrics, oncology, and cardiology. The review will determine how these training programs involve information regarding care for dying patients, pain management, and advance directives.

Decisions Near the End of Life
c/o Education Development Center
55 Chapel St.
Newton, MA 02158

Contact: Karen Heller
617/969-7100 X2343
e-mail: kheller@edc.org
www.edc.org/CAE

Decisions is an institution-based, multi-disciplinary continuing medical education program jointly sponsored by EDC, the Hastings Center, the American Medical Association and the American Hospital Association, aimed at improving the way ethical decisions are made within participating institutions.

Laurel Herbst, M.D.
Medical Director
San Diego Hospice
4311 3rd Av.
San Diego, CA 92103
619/688-1600
www.sdhospice.com

San Diego Hospice's 24-bed Inpatient Care Center provides a focus for an extensive professional training and research program.

Project on Death in America
Open Society Institute
Soros Faculty Scholars Program
400 West 59th St.
New York, NY 10019
Contact: Julie McCrady
212/548-0100
www.soros.org/death.html

The Faculty Scholars Program of the Project on Death in America supports outstanding clinicians, educators, and researchers in disseminating existing models of good care, developing new models for improving care for the dying, and creating new approaches to the educate of health professionals. One of the goals of the scholars program is to promote the visibility and prestige of clinicians committed to this area of medicine and to enhance their effectiveness as academic leaders, role models, and mentors for future generations of health professionals. The individual work of the fellows and their collaborative efforts will foster new approaches to key problems and help transform the culture and care of the dying. Each year the program awards approximately 10 two-

year fellowships, which are renewable for a third year, of up to \$70,000 per year.

David Weissman, M.D.
Medical College of Wisconsin
9200 W. Wisconsin Av.
Milwaukee, WI 53226-3596
414/257-6117
414/257-6246 [fax]
e-mail: dweissmn@hemonc.mcw.edu

Medical director of a hospital palliative care program, director of a project to incorporate end-of-life care into internal medicine residency programs, and editor of the new *Journal of Palliative Medicine*.

State and Community-wide Initiatives and Resources

National Conference of State Legislatures
1560 Broadway, #700
Denver, CO 80202
303/830-2200
Washington-based Health Policy Tracking Service: 202/737-1069
www.ncsl.org

Community-State Partnerships to Improve End-of-life Care
National Program Office
Midwest Bioethics Center
1021-1025 Jefferson St.
Kansas City, MO 64105
Contact: Myra Christopher, M.S., Director
816/842-7110
816/842-3440 [fax]
e-mail: partners@midbio.org

This \$11.25-million program of the Robert Wood Johnson Foundation aims to promote broad-based changes in public policies and practices to improve care of the dying by funding community and state coalitions working towards developing systems of high-quality, comprehensive end-of-life care.

Colorado Collaboration on End-of-life Care

c/o Program in Health Care Ethics, Humanities and Law
University of Colorado Health Sciences Center
Campus Box B 137
4200 E. 9th Av.
Denver, CO 80262
303/315-5096
303/393-7798 [fax]

Maryland Project on Care at the End of Life
Baltimore, MD
Contact: Jack Schwartz in the state Attorney General's office, 410/576-6344
or Ruth Gaare at John Hopkins Bioethics Institute, 410/614-4188

Coalition for Dialogue on Death and Dying
H.C. 31, Box 520
Bath, ME 04538
Contact: Michael Murphy
c/o Hospice of Midcoast Maine
207/729-3602

Missoula Demonstration Project, Inc.
The Quality of Life's End
320 East Main
Missoula, MT 59802
Contact: Barbara Spring, Ph.D., Executive Director
406/728-1613
406/543-7769 [fax]
e-mail: mdpqol@aol.com

This long-term, 15-year, community-based project will conduct research to define the attitudes, expectations, and experiences related to death and dying in Missoula County, MT. The information will provide the platform for future interventions and research to bring quality to dying patients' final days.

Web Sites

Sources for Seniors

American Association of Retired People

Wealth of information on caregiving, advance directives, and insurance, with listings of national and community-level resources.

www.aarp.org

Seniorcom

Provides useful information including health and wellness news with links to senior resources and services.

www.senior.com

Seniors-Site

Well-organized with much practical information for seniors, their families, and caregivers, categorized on a site map in a user-friendly way.

www.seniors-site.com

Caregiving

ALS Association

www.alsa.org

Alzheimer's Association

National voluntary organization dedicated to research, education, and support services; the site features online caregiver publications, including a brochure on the 10 warning signs of Alzheimer's.

www.alz.org

Alzheimer Web

Provides basic information, research developments, links to international Alzheimer's resources, and a chat forum for caregivers.

www.werple.mira.net.au/~dhs/ad.html

The Alzheimer Page

A place to post and read personal stories about coping with caregiving to Alzheimer's patients.

www.biostat.wustl.edu/hyperlists/alzheimer

American Association of Critical-Care Nurses

The AACN, 76,000 members strong, conducts education programs for critical care nurses; site

includes bookstore and events calendar.

www.aacn.org

American Cancer Society

Overview of the organization, along with information about the disease, and clickable map to locate programs in each state of the union.

www.cancer.org

American Medical Association

Sponsored by the 150-year-old association of physicians. Includes an "On-line Doctor Finder," searchable directory of JAMA articles and links to other medical sites.

www.ama-assn.org

The Body

Provides information from more than thirty HIV/AIDS organizations, with extensive listings of hot lines and other resources, plus a forum for asking questions of the experts in the field.

www.thebody.com

Candlelighters Childhood Cancer Foundation

www.candlelighters.org

Interfaith Volunteer Caregivers

News and information about this national network of caregiving programs, with online forum for sharing personal stories.

www.nfivc.org

National Association for Home Care

Extensive listings of publications and videos for professional and general audiences, plus a directory of over 19,500 home care and hospice agencies.

www.nahc.org

National Family Caregivers Association

A 1994 NFCA survey found that there are approximately 18 million family caregivers in the United States; the organization addresses their needs with outreach programs and a newsletter.

www.nfcacares.org

Hospice

Children's Hospice International

Provides information and support services for children with life-threatening conditions and their families.

www.chionline.org

Hospice Foundation of America

Supports the hospice concept through educational programs and grants; site includes online version of Journeys, a newsletter to help individuals deal with grief and loss.

www.hospicefoundation.org

Hospice Web

Excellent introduction and overview; full of useful information.

www.teleport.com/~hospice

National Hospice Organization

Founded in 1978, NHO is the oldest and largest nonprofit public benefit organization devoted to hospice care. Site features searchable database to locate hospices throughout the United States.

www.nho.org

Planning and Decision Making

Choice in Dying

Explanation of advance directives, with forms for every state available by downloading or mail order.

www.choices.org

Eldercare Web

An array of information with focus on economic impacts, such as feasibility of purchasing long-term care insurance.

www.elderweb.com

Government Agencies

Medicare & Medicaid Agency

Information, fact sheets, statistics and latest regulations, presented by the Health Care Financing Administration, the federal agency that administers the programs.

www.hcfa.gov

National Institute on Aging

Lists and describes educational publications on medical and scientific aspects of aging, with ordering instructions.

www.nih.gov/nia

Social Security Online

The official Web site of the Social Security Administration; provides information, forms, and resources.

www.ssa.gov

Medical Ethics and Patients' Rights

The Center for Bioethics at the University of Pennsylvania

Discussion of medical ethical issues for professionals and non-professionals, with special Bioethics for Beginners sections.

www.med.upenn.edu/~bioethic

Death and Dying

Growth House

The extensive links provided on this web site are especially helpful to reporters. The site includes extensive information regarding key concerns about death and dying.

www.growthhouse.org

Innovations in End-of-life Care: An International Online Journal

A new end-of-life information clearinghouse now under development by Education Development Center of Newton, MA.

www.edc.org/lastacts/jrnl.hm.html

International Network for the Definition of Death

www.changesurfer.com/BD/Network

Last Acts

Information about Last Acts, a campaign to improve care and caring at the end of life, is

available on the Robert Wood Johnson Foundation's Web site. On the site, you'll find a directory of resources, press releases, a calendar of conferences and other events, and recent reports.

www.lastacts.org

The End of Life: Exploring Death in America

Based on National Public Radio's ongoing series on end-of-life issues, with transcripts, resources, bibliography and readings on death and dying.

www.npr.org/programs/death

Project on Death in America

Far-ranging investigation of coming to terms with death and dying in contemporary America.

www.soros.org/death

Webster Death, Dying and Grief Resources

Includes information and links related to general grief and healing, aging, hospice and home care, depression and suicide.

www.katsden.com

Bereavement

Bereavement and Hospice Support Netline

A comprehensive directory of bereavement programs and support groups across the United States.

www.ubalt.edu/www/bereavement

The Compassionate Friends

Self-help organization for families that have lost a child.

http://longhorn.jjt.com/~tcf_national/

GriefNet

<http://griefnet.org>

Sudden Infant Death Syndrome Network

Support resources for families and others touched by tragedy of SIDS.

www.sids-network.org

The Grieving Well Center

Support services and information on grieving for organizations, adults, children and families.
www.ncbcenter.org

End-of-life Issues

Compassion in Dying

Provides counseling, emotional support and information for terminally ill patients and intensive pain management, comfort or hospice care, and rational suicide.

www.compassionindying.org

DeathNet

Rich archive of "right-to-die" materials, services, and resources. Includes extensive information on living wills and an online bookstore with over 3,000 titles on end-of-life issues.

www.islandnet.com/deathnet

Euthanasia.com

Tremendous resource for research on euthanasia, mercy killing, assisted suicide, and living wills, organized to be user-friendly. Includes international contacts and links.

www.euthanasia.com

Euthanasia Research and Guidance Organization (ERGO)

Compendium of information and latest news on "right-to-die" issues, plus glossary of terms.

www.rights.org/deathnet/open

Euthanasia World Directory

Comprehensive site including newsletters, essays, books and laws with links to various right to die societies and Ergo! and Dr. Jack Kevorkian.

www.FinalExit.org

International Anti-Euthanasia Task Force

Extensive information and background materials on euthanasia, assisted suicide, advance directives, disability rights, and pain control.

www.iaetf.org

Not Dead Yet

Disability rights organization that strongly opposes the legalization of assisted suicide. Site contains articles, legal briefs, links, and more.

www.acils.com/NotDeadYet

Spiritual and Religious Issues

National Catholic Bioethics Center

Adheres to the teachings of the Catholic Church; provides information on ethics in health care.

www.ncbcenter.org

B. Glossary of Terms

Passive euthanasia: The deliberate disconnection of life support equipment, or cessation of any life-sustaining medical procedure, permitting the natural death of the patient.

Active euthanasia: Deliberate action to end the life of a dying patient.

Active voluntary euthanasia: A lethal injection by a doctor into a dying patient to end life by request of the sufferer.

Active involuntary euthanasia: Lethal injection by a doctor into a dying patient without that person's express request.

Advance Directive: A legal document to help guide patients' decisions about care at the end of life in the event they are unable to make decisions on their own. The Patient Self Determination Act of 1990 mandated that health care institutions inquire about and document existing advance directives whenever a patient is admitted to the hospital.

Agent: Also called *proxy*. A sick person appoints an agent or proxy to make medical decisions in case the patient becomes unable to make them him or herself. An agent can be a family member or a close trusted friend. Patients can appoint a second person as an alternate proxy, in case the first person is unavailable to act for the patient.

Artificial nutrition and/or hydration, medically administered: Providing nourishment or fluids mechanically, or other than by mouth, such as by nasal-gastric tube, gastrostomy tube, or intravenously. All such methods are viewed as medical treatments that may be withheld or withdrawn at the request of a patient or the patient's legal representative.

Assisted suicide: Helping another person to commit suicide (for example, by prescribing or procuring a lethal dose of medication with an understanding that the person intends to use it to commit suicide). Assisted suicide becomes euthanasia when someone other than the patient actually administers the lethal dose, i.e., by injection, with the intent of causing death.

Autonomy: The ability to determine a course of action for oneself, without constraints imposed either by others or by personal psychological or physical limitations. Autonomy requires both capacity to make decisions and the ability to act, or to direct others to act, on the choices made. In the context of medical care, respecting individual autonomy means permitting a patient to choose whether to accept or refuse specific or all medical treatments.

Beneficence: Preventing harm and promoting the patient's welfare or best interests.

Bioethics: Study of the moral problems which face modern medicine.

Brain damage: This refers to a brain injury which causes some type of functional impairment. Life support systems are optional.

Brain death: When a patient has lost all brain functions and there is no blood flow to the brain. Patients that are brain dead can't move and don't respond to loud noise, painful touch, or temperature. The body can't breathe without a ventilator.

Coma: Prolonged unconsciousness from which a patient may recover.

Capacity or capability (to make health care decisions): The ability to understand the treatment choices being presented, to appreciate the implications of the various alternatives, and to make and communicate a choice. Lack of capacity is not a legal judgment; rather, it is a medical opinion that is typically required by state law to be certified in writing by one or two physicians.

Competency: An individual's ability to perform certain functions, such as conducting business affairs, executing a will or contract, or taking care of one's personal needs. An individual is presumed to be competent unless a court has determined otherwise. Under many state laws, a person who has been declared incompetent by a court may still have the capacity to make health care decisions.

Confidentiality: Protecting medical and personal information on patients and their families from disclosure to third parties, except with the written permission of the patient or as necessary to provide medical care.

Conscientious objection: The right of health care providers (institutions as well as individual practitioners) to decline to act in violation of their ethical principles, whether based upon moral values or professional standards.

C P R (Cardiopulmonary resuscitation): Non-surgical massage of a heart which has stopped to try to get the organ working again. Procedure will almost always be started unless there is a DNR order.

Do Not Resuscitate (DNR) orders: Also called a "no code." DNR orders refer to withholding CPR if there is a cardiac or pulmonary arrest. Prior to writing a DNR order, providers must assess with the patient and the patient's family the patient's clinical condition and prognosis, a description of what CPR involves, and an estimate of the patient's survival chance. This information is put into the patient's medical record. A DNR is a medical order, signed by a physician.

Double effect (principle of): A principle which recognizes that one's actions may have multiple effects, and that the primary purpose of an act is determinative. For example, it is considered appropriate to administer morphine to the terminally ill to relieve pain or respiratory distress, even if the accompanying secondary effect may be depressed respiration or a slight hastening of death, as long as the primary intent is symptom control (to maintain patient comfort). It is not considered acceptable to administer morphine with the primary intent of causing death.

Durable power of attorney: (see health care proxy)

Ethics: A system of moral standards or values.

Euthanasia: Literally translated, it means a "good death." Used in medical care, the term means a death caused by the deliberate actions of someone other than the patient, with the intention of ending a patient's life. It does not include the withholding or withdrawal of life-maintaining treatment, such as mechanical ventilation or a feeding tube, to permit the natural process of dying to occur. Euthanasia, even at the request of a patient, constitutes homicide under the laws of every jurisdiction within the United States.

Futile treatment: A medical intervention that will not provide any real improvement in the patient's overall condition, prognosis, or comfort level. Physicians may refuse to order procedures that are deemed to be medically futile, even though the patient or family may request the procedures.

Health care proxy: A proxy or health care agent is the person you appoint to make medical care decisions if you should become unable to make those decisions for yourself. This proxy should understand your wishes and be willing to accept the responsibility to make medical decisions for you.

Heroic measures: A term used by patients and providers to characterize a spate of high-technology medical interventions that may be applied, usually regardless of a patient's condition.

Hospice: A non-institutional health care alternative, with an emphasis on palliation of all symptoms for terminally ill persons. Most hospice care is delivered to patients in their homes. Persons enrolled in hospice programs are determined to have a prognosis of six months or less to live and have given up on cures. Rather, they are looking for comfort care and support for themselves and their family from a team of nurses, social workers, home health aides, volunteers, and clergy, in consultation with their attending physician.

Informed consent: A patient giving permission to a physician to carry out a medical procedure after she/he is made fully aware of the benefits, risks, and any alternatives.

Nonmaleficence: Avoiding the infliction suffering on the patient; the term is associated with the maxim *primum non nocere* (first, do no harm).

Pain: Physical pain is defined as an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage, or both, according to the International Association for the Study of Pain.

Pain Control: A state in which physical pain is alleviated and the patient is comfortable. Appropriate intervention for comprehensive management of physical pain include: opioids, nerve blocks, psychological intervention, guided imagery, implantable devices, palliative radiation, and chemotherapy.

Palliative care: Palliative care is the total care of patients whose disease is not responsive to curative treatments. Palliative treatment involves a team of providers who tend to control the patient's pain, other symptoms, and the psychological, social, and spiritual problems related to death and dying. Palliative care's goal is to achieve the best possible quality of life for patients and their families.

Persistent Vegetative State: Severely brain-damaged person in a permanent coma from which they will not recover. Almost always on life-support systems.

Physician-assisted suicide: When a physician medically hastens death in consultation with a terminally ill patient. Several states have attempted to legalize physician-assisted suicide; only one, Oregon, has done so.

Right to die: Popular general term reflecting a basic belief that end-of-life decisions should be an individual choice.

Slow code (or Blue Code): The deliberate slow response to a medical alert of heart or breathing stoppage which is designed to make resuscitation impossible.

Slippery slope: Theory that the sanctioning of an act which, in itself, may not be morally repugnant or illegal on a small scale, could lead to other similar and wider actions which are.

Suicide: The intentional taking of one's own life.

Suffering: Suffering goes beyond the unpleasant sensations or distressing symptoms of pain and includes the terror, anguish, and hopelessness that dying patients may experience.

Thanatology: The description or study of the phenomena of death and of psychological mechanisms for coping with them.

Terminal illness: Refers to an illness or condition that is incurable and irreversible. When a person is diagnosed as terminally ill, death is expected in a relatively short period of time.

Terminal sedation: The process of sedating someone to unconsciousness to relieve his or her symptoms. Symptoms may become so severe with dying patients—nausea, constant retching, seizures—that the only way to control the symptoms is to sedate the patient until he or she is unconscious. While in this state, patients are not given fluids, so death comes from dehydration.

Ventilator: A machine that helps a patient breathe. Sometimes it is used temporarily until a person can breathe on his or her own; other times it is a permanent breathing aid. In the latter case, a tube is often placed directly into a patient's windpipe via a procedure called a tracheotomy.

Veracity: The duty to tell the truth and not deceive others, intentionally or unintentionally.

Withdrawal of treatment: To discontinue a medical intervention.

Withholding of treatment: To decide not to initiate a medical intervention.

credit: PBS Online, WNET Station, www.wnet.org; National Hospice Organization; *LAWFUL EXIT: The Limits of Freedom for Helping in Dying*, by Derek Humphry, Norris Lane Press, 199_.

C. References and Suggested Reading

Bernstein, Judith R. WHEN THE BOUGH BREAKS: FOREVER AFTER THE DEATH OF A SON OR DAUGHTER. Kansas City, Mo.: Andrews & McMeel, 1997.

Smith, Douglas C. LAST RIGHTS: A PRACTICAL GUIDE TO RESPECTING THE RIGHTS AND DIGNITY OF THE SICK AND DYING. Indianapolis, Ind.: Macmillan USA, 1997.

Woodman, Sue. LAST RIGHTS: THE RIGHT TO DIE IN AMERICA. Beverly Hills, Calif: Dove, 1997.

Furman, Joan, and David McNabb. THE DYING TIME: PRACTICAL WISDOM FOR THE DYING AND THEIR CAREGIVERS. New York: Bell Tower, 1997.

Byock, Ira, M.D. DYING WELL: THE PROSPECT FOR GROWTH AT THE END OF LIFE. New York: Riverhead, 1997.

Callanan, Maggie, and Patricia Kelley. FINAL GIFTS: UNDERSTANDING THE SPECIAL AWARENESS, NEEDS, AND COMMUNICATIONS OF THE DYING. New York: Bantam, 1997.

Caplan, Arthur. MORAL MATTERS: ETHICAL ISSUES IN MEDICINE AND THE LIFE SCIENCES. New York: Wiley, 1995.

Dubler, Nancy Neveloff, and David Nimmons. ETHICS ON CALL: TAKING CHARGE OF LIFE-AND-DEATH CHOICES IN TODAY'S HEALTH CARE SYSTEM. New York: Vintage, 1993.

Edison, Ted (Editor). THE AIDS CAREGIVER'S HANDBOOK. New York: St. Martin's 1993. (orig. pub. 1988)

Grollman, Earl A. (Editor). BEREAVED CHILDREN AND TEENS: A SUPPORT GUIDE FOR PARENTS AND PROFESSIONALS. Boston: Beacon Press, 1995.

-----CONCERNING DEATH: A PRACTICAL GUIDE FOR THE LIVING. Boston: Beacon Press, 1974.

-----TALKING ABOUT DEATH: A DIALOGUE BETWEEN PARENT AND CHILD.
Boston: Beacon Press, 1991.

Grollman, Earl A., and Kenneth S. Kosik. WHEN SOMEONE YOU LOVE HAS ALZHEIMER'S: THE CAREGIVER'S JOURNEY. Boston: Beacon Press, 1996. Thorndike, Me.: G.K. Hall, 1997.

Hendin, Herbert. SEDUCED BY DEATH: DOCTORS, PATIENTS, AND THE DUTCH CURE. New York: Norton, 1996.

Humphry, Derek. FINAL EXIT: THE PRACTICALITIES OF SELF-DELIVERANCE AND ASSISTED SUICIDE FOR THE DYING. Eugene, Ore.: Hemlock Society, 1991.

Keiser, Bert. DANCING WITH MISTER D: NOTES ON LIFE AND DEATH. New York: Doubleday, 1997.

Kubler-Ross, Elisabeth. ON DEATH AND DYING. New York: Collier, 1993. (orig. pub. 1969)

Lamm, Maurice. JEWISH WAY IN DEATH AND MOURNING. Flushing, N.Y.: Jonathan David Publications, 1972.

Larue, Gerald A. PLAYING GOD: DECIDING YOUR LIFE AND DEATH. Wakefield, R.I.: Moyer Bell, 1996.

Leary, Timothy, with David Prince. DESIGN FOR DYING. San Francisco: Harper, 1997.

Levine, Stephen. A YEAR TO LIVE: HOW TO LIVE THIS YEAR AS IF IT WERE YOUR LAST. New York: Bell Tower, 1997.

Lynn, Joanne, M.D. (Editor). BY NO EXTRAORDINARY MEANS: THE CHOICE TO FOREGO LIFE-SUSTAINING FOOD AND WATER. Volume 517 (Medical Ethics Series). Bloomington, Ind.: Indiana University Press, 1989.

Marker, Rita. DEADLY COMPASSION. New York: William Morrow, 1993.

Nuland, Sherwin B. HOW WE DIE: REFLECTIONS ON LIFE'S FINAL CHAPTER. New York: Vintage, 1995.

Quill, Timothy E., M.D. DEATH AND DIGNITY: MAKING CHOICES AND TAKING CHARGE. New York: Norton, 1994.

-----A MIDWIFE THROUGH THE PROCESS: STORIES OF HEALING AND HARD CHOICES AT THE END OF LIFE. Baltimore, Md.: Johns Hopkins University Press, 1996.

Quindlen, Anna. ONE TRUE THING. New York: Dell, 1995.

Ray, M. Catherine. I'M HERE TO HELP: A GUIDE FOR CAREGIVERS, HOSPICE WORKERS, AND VOLUNTEERS. New York: Bantam, 1997.

Rinpoche, Sogyal. THE TIBETAN BOOK OF LIVING AND DYING. San Francisco: Harper, 1993.

Rollin, Betty. LAST WISH. New York: Random House, 1996.

Rosenblum, Daniel. A TIME TO HEAR, A TIME TO HELP: LISTENING TO PEOPLE WITH CANCER. New York: Free Press, 1993.

Spiro, Howard M., Mary G. McCrea Curnen, and Lee Palmer Wandel (Editors). FACING DEATH: WHERE CULTURE, RELIGION, AND MEDICINE MEET. New Haven, Conn.: Yale University Press, 1996.

Wilcock, Penelope. SPIRITUAL CARE OF THE DYING AND BEREAVED. Ridgefield, Conn.: Morehouse, 1997.

Suggested Articles

Angell, Marcia, M.D. "The Supreme Court and Physician-Assisted Suicide: The Ultimate Right." THE NEW ENGLAND JOURNAL OF MEDICINE. January 2, 1997.

Belkin, Lisa. "The Relief Team." MIRABELLA. July/August 1996.

Berman, Laura. "Six Months to Live." REDBOOK. April, 1996.

Carter, Stephen L. "Why the Courts are Dead Wrong." THE NEW YORK TIMES MAGAZINE. July 21, 1996.

Fein, Esther B. "Failing to Discuss Dying Adds to Pain of Patient and Family." THE NEW YORK TIMES. March 5, 1997.

-----"Gift for a Dying Daughter: Orders to Spare Her Pain." THE NEW YORK TIMES. March 6, 1997.

Foley, Kathleen, M.D. "Competent Care for the Dying Instead of Physician-Assisted Suicide." THE NEW ENGLAND JOURNAL OF MEDICINE. January 2, 1997.

France, David. "This Doctor Wants to Help You Die." NEW YORK MAGAZINE. January 13, 1997.

Gordon, Suzanne. "Doctors Are Remiss at the Deathbed." THE LOS ANGELES TIMES. October 10, 1996.

Kolata, Gina. "Living Wills Aside, Dying Cling to Hope." THE NEW YORK TIMES. January 15, 1997.

Lynn, Joanne, M.D. "Caring at the End of Our Lives." THE NEW ENGLAND JOURNAL OF MEDICINE. July 18, 1996.

Nuland, Sherwin B. "How We Die is Our Business." THE NEW YORK TIMES. January 13, 1997.

O'Malley, William J. "Making Sense of Suffering and Death." AMERICA. April 13, 1996.

Rosenthal, Elisabeth. "When a Healer is Asked, 'Help Me Die.'" THE NEW YORK TIMES. March 13, 1997.

Various Contributors. "The Age Boom: A Special Issue." THE NEW YORK TIMES MAGAZINE. March 9, 1996.

Various Contributors. "A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)." JAMA: THE JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION. November 22/29, 1995.

Various Contributors. "Dying Well in the Hospital: The Lessons of SUPPORT." THE HASTINGS CENTER REPORT: SPECIAL SUPPLEMENT. November/December 1995.

Wilkes, Paul. "A New Pro-Life Movement in the Making." THE NEW YORK TIMES MAGAZINE. July 21, 1996.

Woodward, Kenneth L., and John McCormick. "For the Journey Everyone Must Face, Cardinal Joseph Bernardin Illuminated the Trail." NEWSWEEK. November 25, 1996.