THE DEVELOPMENT, STATUS, AND FUTURE OF PALLIATIVE CARE

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The constants of the human condition are birth and death. No research, no new technology, no prayer, and no divine intervention has ever changed these defining characteristics of our species, and nothing we can foresee is likely to change them. But the nature of the experience—how we are born, how we die—has changed profoundly in the last several hundred years. For most of human history, death was a near random event, due to injury, infection, starvation, or childbirth. Humans were at least as likely to die during birth, infancy, childhood, or young adulthood as they were during middle age or old age. The meaning and the ritual attached to illness and death were predicated on this fact—death was common and unpredictable; it afflicted old and young and rich and poor alike; and it played a central role in the life of the community and the family.

Between 1900 and 2000, life expectancy in the United States rose from forty-seven to seventy-seven years—equivalent to the gain in longevity between the Stone Age, more than ten thousand years ago, and 1900. A gain of this magnitude in the relatively short evolutionary time frame of a century has had dramatic effects on the human experience of illness and dying and death. Where illness and death were once central and routine community experiences, with rituals designed to heal and to reintegrate the bereaved into new roles and new relationships, modern medicine and technological innovations have removed them from their place of gravity at the close of each life and have made them seem to be accidental and almost unseemly failures, associated with the belief that they could and should have been prevented.

Yet in the last two decades Americans have begun to recognize the limitations of technology and modern medicine in meeting the needs of the chronically and seriously ill, and also to fundamentally restructure the care that people require during the last years of their lives. These developments have spawned a new field of medicine called palliative care—from the Latin *palliare*, to clothe. Palliative care focuses on the relief of suffering for patients with serious and complex illness and tries to ensure the best possible quality of life for them and their family members. It is delivered at the same time as other appropriate curative and life-prolonging treatments and is not limited to the terminally ill. In this respect, it is not limited to hospice care, a component of palliative care focused on the care of the terminally ill who have opted to stop life-prolonging treatments.

Palliative care has grown rapidly in the United States in recent years and is now poised to become a universally available approach to meeting the needs of the country’s sickest and most vulnerable patients. It is a central part of the solution to America’s health care crisis, since it improves the quality of care and reduces costs for a key population—those with serious, complex illnesses who, while they number less than 10 percent of patients, account for more than two-thirds of health care spending.

This chapter examines the field of palliative care. It begins by exploring why the care of seriously ill patients has become such an important issue in the United States, and why the current health care system (or lack of a system) is unable to cope with it. It then looks at past efforts to provide care for dying people, the way that treatment of pain has evolved, and the growth of hospice care. This is followed by an analysis of legal,
social, and political concerns and of the research that has highlighted the problems and offered potential solutions, many of which have been tested and launched by private philanthropy. Finally, it reports on the state of palliative care in America and offers some thoughts on its future.

**CARE OF THE SERIOUSLY ILL: WHY IS IT AN IMPORTANT ISSUE?**

The unprecedented growth in the numbers and the needs of the chronically ill, especially the elderly; the availability and widespread use of costly medical technologies that may prolong life without restoring health or functional independence; exponential cost increases due both to larger numbers of persons turning to the health care system for help and to per-capita increases in health care spending attributable to technological advances and overuse; the crippling impact of employer-based health insurance on the American economy and the lack of government control over rising drug and device pricing; the failure to recognize and treat the pain and other distressing symptoms experienced by seriously ill people; and the consequent widespread dissatisfaction with and confusion about the medical care system—all form the context and justification for attention to medical care of the seriously ill and those approaching the end of life and the rapid recent growth of the field of palliative care.

**America Is Aging, and More People Are Living with and Suffering from Years of Chronic Illness**

From the standpoint of sheer numbers, the population of the United States is aging, and the odds of living a long life and dying during old age are far better than they were a hundred years ago. The average baby born in the United States today can expect to live to age seventy-eight, despite the fact that the United States is ranked forty-second in the world in life expectancy at birth, behind Jordan, Guam, and the Cayman islands. If a man survives to age seventy-five, he can expect to live ten years longer, on average; a woman living to age seventy-five can expect to live twelve years longer. As a result of this dramatic increase in longevity, about 20 percent of the American population will be over age sixty-five by 2030, as compared to less than 5 percent in 1900—a demographic shift unprecedented in human history, and one for which our society is unprepared. While many people died of acute infectious illness a century ago and for millennia before then, today the leading causes of death are chronic degenerative diseases such as heart failure, emphysema, stroke, dementia, and cancer—diseases with which people may live for years, and sometimes for decades, before they die.

During the twentieth century, the location of care for the dying shifted away from the home and into hospitals and nursing homes—institutional settings where more than 70 percent of American citizens now die. The reasons for this shift are complex and include financial incentives built into the health care system that favor institutional death as well as the burden that long-term chronic care of functionally dependent loved ones places on families.
In addition, the successes of modern public health and medical care have created an expectation that all illness can be treated, if not cured, and that *ipso facto*, with enough research, death itself is preventable. Hence family members’ worry that if they had just gotten another opinion, searched a little harder on the Internet, or pushed for an experimental treatment, they could have forestalled decline and death. This anxiety is part of the reason for overuse of health care services, and for costly and burdensome medical care near life’s end.

**The Impact of Public Health Measures and Modern Medicine on Longevity**

In the mid-nineteenth century, scientists began to develop the germ theory of disease based on observations of epidemic infections from unclean drinking water. The subsequent separation of drinking water from sewage led to dramatically reduced infant, child, and maternal mortality and a gain in life expectancy at birth from under fifty years at the start of the twentieth century to nearly eighty years at present. A smaller portion of the last century’s dramatic thirty-year gain in life span can be attributed to the discovery of antibiotics and the widespread use of vaccination during World War II. Most of the century’s gain in life expectancy predates the recent rise in preventive and high-technology medicine, such as the control of blood pressure and smoking and the effective treatment of heart disease, stroke, and cancer (see Figure 1).

Fully 75 percent of the gain in life expectancy occurring during the twentieth century is due to decreased mortality for persons under the age of forty, resulting in a much higher likelihood of living to old age. This large gain is both the context for and a contributor to our present challenge—how to understand the meaning of serious
illness and death when it comes, and what our society owes us when we reach this stage in our lives.

Modern medical care and technology have also contributed to longevity in the United States. A recent study attributed roughly half of the 50 percent reduction in death from coronary heart disease during the last two decades in the United States to medical therapies and half to reductions in risk factors such as control of lipids, hypertension, and smoking.²

Consequences of an Aging Society The successes of public health and modern medical care have led to unprecedented growth in the number of older adults. The current generation of older people is healthier and less disabled than its predecessors, with additional gains in active life expectancy due to public health and biomedical research leading to new treatments for, and later onset of, chronic diseases.

But although the proportion of people with chronic disability is declining and more people are living longer and better, the sheer number of the elderly with chronic disability (seventy-seven million people will be over age sixty-five by 2040) means that an unprecedented number will experience prolonged functional dependency and frailty before they die. Some 57 percent of Americans age eighty and older report a severe disability.³ The probability of needing help from another person to get through the day because of functional dependency increases with age; more than 40 percent of persons over sixty-five report at least one functional limitation, and more than 70 percent of those over age eighty require personal assistance with one or more of their everyday activities.⁴ This functional impairment is due in great part to the rising prevalence of cognitive impairment after age sixty-five: more than 13 percent of the over-sixty-five population and 42 percent of those eighty-five or above have Alzheimer’s disease, the most common cause of dementia (prevalence is even higher if vascular dementia is included), a number projected to rise by more than 50 percent by 2030 with the aging of the baby boom generation. Not surprisingly, and as an unintended consequence of modern medical successes, as death rates from heart disease, cancer, and stroke have declined in the last few years, Alzheimer’s as a cause of death has skyrocketed, increasing by 33 percent between 2000 and 2004.

Caring for Seriously Ill People Is Very Costly

In 2007, health care spending in the United States reached $2.3 trillion (16.9 percent of the nation’s gross domestic production, or GDP), and it is expected to reach $4.2 trillion by 2016 (20 percent of GDP).⁵ Medicare spending (government health insurance for those over sixty-five and the disabled) is growing exponentially in tandem with the numbers, needs, and cost of care of its beneficiaries (see Figure 2).

Although nearly forty-six million Americans are uninsured, the United States spends roughly twice as much per person as other industrialized nations (more than $7,500 for every American, man, woman, and child), and those countries provide health insurance to all their citizens, and do so at under 11 percent of GDP (see Figure 3).
Despite our high expenditures, a 2008 Commonwealth Fund survey of chronically ill adults in Australia, Canada, France, the Netherlands, New Zealand, the United Kingdom, and the United States found that U.S. patients are more likely to forgo needed care because of costs (54 percent), run into problems with care coordination (34 percent), and experience a significant medical error (34 percent).

The primary factors driving these high costs are both intensity and pricing of service delivery—the United States uses more of the newest (and costliest) technologies and delivers various invasive procedures (such as magnetic resonance imaging and coronary bypass procedures) at a rate several times higher than other developed nations.

In addition, prices for medical care services in the United States are significantly higher than those in other countries (see Figure 4), and Americans spend five times as much per person ($486) as the OECD (Organization for Economic Cooperation and Development) median ($74) on health insurance and administrative costs.

Individuals with five or more chronic illnesses are the largest consumers of health care and account for two-thirds of all Medicare spending. This patient population represents about 20 percent of all Medicare beneficiaries and is the group most likely to benefit from palliative care services (see Figure 5).

The costs associated with the number and expense of new life-prolonging technologies (such as kidney, heart, lung, and liver transplantation, implantable cardiac defibrillators, drug-eluting stents for coronary artery disease, ventricular assist devices, and new drugs to battle cancer) have risen dramatically. Medical ethicist Daniel Callahan...

![Graph showing total expenditures on health as percent of GDP and average spending on health per capita (US PPP).](image)

Source: The Commonwealth Fund; Data from OECD Health Data 2008 (June 2008). Reprinted with permission.


![Bar chart showing MRI units per million population.](image)

Source: The Commonwealth Fund; Data from OECD Health Data 2008 (June 2008). Reprinted with permission.
argues that the unquestioning commitment to medical progress, regardless of cost and
no matter how marginal the benefit, threatens to swamp other social priorities, such
as education, safe roads, clean air, and universal access to health care. Despite the
acknowledged critical nature of the problem, little or no social consensus exists on the
distribution of our finite resources among social goods, or on the place of death as a
necessary and appropriate part of a healthy life in a healthy society.

The fact is that these numbers pose a threat to American economic competitiveness
in the world market, and the current world financial crisis may help create the social
consensus necessary for a reexamination of the current model of health insurance in
the United States and also of the built-in financial incentives favoring hospitalization,
procedural care, and more specialist intervention in the system.

Dissatisfaction with Care of the Seriously Ill

Despite uniquely high per-capita expenditures, Americans with serious illness, their
families, and their doctors and nurses are not satisfied with the care system. Accord-
ing to the 2006 Health Confidence Survey, dissatisfaction with the health care system,
specifically how much it costs, has doubled since 1998, with 28 percent of respondents
rating it fair and 31 percent rating it poor because of rapid growth in out-of-pocket
expenses. Of Americans responding to a national representative survey conducted by

FIGURE 5. Two-Thirds of Medicare Spending Is for People with Five or More
Chronic Conditions.

Source: The Commonwealth Fund; from G. Anderson and J. Horvath, Chronic Conditions: Making the
Case for Ongoing Care (Baltimore, MD: Partnership for Solutions, December 2002). Reprinted with
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the Commonwealth Fund, 46 percent called for fundamental change and 30 percent for a complete rebuilding of the health care system; 42 percent reported experiencing inefficient, poorly coordinated, or unsafe care. Among family members of Medicare decedents, substantial percentages reported inadequately treated pain (24 percent), inadequate emotional support (50 percent), and poor communication from physicians (30 percent); interestingly, the hospice care given at home was ranked excellent by more than 70 percent, compared with fewer than 50 percent of those whose family members had died in a hospital or a nursing home.

EFFORTS TO COPE WITH DEATH AND PROVIDE CARE FOR THE DYING

I don’t want to achieve immortality through my work. I want to achieve it by not dying.

Woody Allen

A Brief History

In The Hour of Our Death, published in 1981, author Philippe Ariès described death and the history of Western attitudes toward it as both a communal and an individual act, associated with the ritual and ceremony of any major life milestone. These rituals have been transformed in the last hundred years by the simultaneous decline of religious faith in many Western nations and the advent of the scientific revolution. The key components of this rite of passage are the individual’s role in the acceptance of his coming death; the opportunity to say goodbye; and the period of mourning and bereavement. Ariès divides his study into four overlapping historical periods: “The Tame Death,” “The Death of the Self,” “The Death of the Other,” and “The Invisible Death.”

The Tame Death roughly corresponds with pre-Christian through the early Middle Ages. Death was central, routine, and unpredictable and was tamed through social rituals and codes of behavior. From earliest recorded history, death was a central and common part of the life and rites of the community—“rites in the bedroom or those of the oldest liturgy express the conviction that the life of a man is not an individual destiny but a link in an unbroken chain, the biological continuation of a family or a line that begins with Adam and includes the whole human race. The community was weakened by the loss of one of its members . . . it had to recover its strength and unity by means of ceremonies . . . death was not a personal drama but an ordeal for the community, which was responsible for maintaining the continuity of the race.”

The Death of the Self begins in the Middle Ages, when mendicant Christian orders worked to convert a quasi-pagan population, with a corresponding rise in individuals’ fears about their own death and an afterlife of punishment for sin. A change in attitude developed with the rise in the sense of individual fate as opposed to collective
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destiny—an individual destiny in an afterlife that could be secured by good behavior, prayer, simony (purchase of divine favor), and control of what happens after death through the use of wills and testaments.

The Death of the Other corresponds to the subsequent (post-Middle Ages) rise in the centrality of the family and a few intimate relationships, and the associated Romantic Movement (the deathbed scene, *ars moriendi* [the art of dying], weeping, drama). After the Middle Ages, the rise of intimate family relationships replaced the community as the primary seat of loyalty and personal survival. The rise of the family, with the associated realization that there is good and bad in each person, reduced both the conceivability and the acceptability of punishment for sin through hell and eternal damnation and encouraged a vision of permanent reunion with loved ones after death.

Arguing that death has been banished as an unacceptable and unendurable truth in our own century, Ariès describes the Invisible Death, our current phase, as a period where death is unconsciously or theoretically believed to be avoidable with enough investment in research—an expectation strengthened by the successes of public health and modern medicine in allowing, for the first time in human history, most people in Western societies to live to old age. If the presumption is that science can defeat death, each death that does occur requires explanation, is something that could theoretically have been prevented, and hence must reflect a failure—a failure of the family to find the right doctor; of the patient to take proper care of himself or herself; of the doctors to know the latest protocols; of the hospital to prevent the unpreventable; of society to invest adequately in research. Despite the fact that over 80 percent of Americans report a religious affiliation, someone or something under human control must be to blame if death is preventable.

If death is avoidable and therefore a failure, it is unsuitable for everyday life—stigmatized, hidden, and avoided in polite conversation. Since each of us still dies, each person (and the family) may come to experience his or her own dying and death as a mistake, something that could have been prevented, a personal failing, or someone else’s fault—in a word, wrong.

Combining the stigma of death with the widely held belief that modern medicine and hospitals can perform miracles in the battle against death, the hospital and the nursing home have become the dominant sites for gravely ill, dying people (more than 70 percent of deaths in the United States occur in an institution). The health care institution offers families a break from the work of caring for a seriously ill person, a place to hide from prying eyes, and a respite from the shame and failure implicit in the dying process. The hospital is believed to have the professionals and the technology necessary to defeat disease and keep death at bay. The modern ritual of death involves several prolonged stays in a hospital—often in an intensive-care unit. This ritual allows the family to say to their friends and neighbors, “We did everything possible, we got the best care possible;” to keep the concrete and physically distressing aspects of the illness at a controlled and safe distance; and to avoid
being labeled as a friend of death because of the acceptance of death. The physician becomes the agent of his society—battling death is the *raison d’être* of modern medicine.

Tolstoy was among the first to write about the stigma of death in his great novella *The Death of Ivan Ilych*. Ilych, a middle-class government functionary, is dying of cancer, but no one tells him the truth. His doctors and family all talk around the illness with euphemism, and the patient, desperate for genuine human relationship, experienced even greater suffering due to their denial of death’s reality.

*What tormented Ivan Ilych was the lie, this lie that for some reason they all accepted, that he was only sick and not dying, and that if he would only remain calm and take care of himself, everything would be fine; whereas he knew very well that no matter what was done the result would be only worse suffering and death. He suffered because no one was willing to admit what everyone, including himself, could see clearly. He suffered because they lied and forced him to take part in this deception. This lie that was being told on the eve of his death, that degraded the formidable and solemn act of his death . . . had become horribly painful to Ivan Ilych.*

Leo Tolstoy, “The Death of Ivan Ilych”

Hiding from the indecency of death extends to the mourning process. By the mid-twentieth century, the traditional community mourning rituals and codes of behavior that not only reintegrated the bereaved back into the world of the living but that also helped the group recover from the threat of death and loss in their midst—wearing black, avoiding social events—had all but disappeared in the United States and other developed nations. The loss of these codes and rituals of bereavement in the last two centuries has left us with little protection from the terror of nature and death. Hence the modern tendency to repress references to death and to suppress evidence of mourning. As Geoffrey Gorer wrote in *Death, Grief, and Mourning in Contemporary Britain*:

*At present death and mourning are treated with much the same prudery as the sexual impulses were a century ago . . . Today it would seem to be believed, quite sincerely, that sensible rational men and women can keep their mourning under complete control by strength of will and character, so that it need be given no public expression, and, if indulged at all, in private, as furtively as if it were an analogue of masturbation.*

Not only have the dying person and the grieving survivor been effectively banished from mainstream society but the reality of death itself has become taboo. It is treated as a contagious disease, something to avoid and to protect one’s children from. Reaction against the stigma and the isolation of the dying that accompanied the view of death as somehow optional or preventable is the foundation of the hospice and, subsequently, palliative care movements in the United States.
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Growth in the Use of Opioids for Treatment of Pain

"Pain is a more terrible lord of mankind than even death himself."  
Albert Schweitzer, 1922

"It has no future but itself."  
Emily Dickinson, 1896

"Pope John Paul II has issued an apostolic letter on suffering in which he says physical, mental and moral pain pose a mystery that can lead to spiritual growth and salvation."  

Through much of the nineteenth century, pain was viewed as God’s punishment for sin and a means of spiritual purification through suffering; it was felt to have healing power in and of itself. Invoking the biblical injunction “In sorrow, thou shalt bring forth children” (Genesis 3:16) as justification, some believed that the pain of childbirth was necessary to transform women into appropriately self-sacrificing mothers. Morphine was first isolated from crude opium in 1803, though opium and its derivatives had been used for millennia. Queen Victoria began using general anesthesia during childbirth in 1853. By the late 1880s, surgical anesthesia was widespread, and an increased demand for surgery transformed hospitals from charitable asylums for the poor and the dying into purveyors of cures and the relief of suffering from disease.

The neurological underpinnings of pain were first studied in the late 1800s, and by the mid-twentieth century pain was understood as the body’s warning to avoid injury. “The evolutionary purpose of pain was no longer to heal, to punish, or to ennoble, but to provide a mechanical warning of actual or potential damage to cells and tissues in a specific body area,” according to the noted pain researcher Raymond Houde. The twentieth century also saw the earliest efforts to measure and assess pain in humans, and to attempt quantitative study of the effectiveness of analgesics. Henry Knowles Beecher, at Harvard, wrote about the inextricable role of emotion in the experience of pain in 1959, and he, Raymond Houde, at Memorial Sloan-Kettering Cancer Center, and Cicely Saunders, at St. Christopher’s Hospice in London, conducted the fundamental studies of opioid analgesia that led to modern opioid pharmacotherapy. Modern opioid pharmacology includes listening to the patient as the best source of information about pain intensity and impact. “I found that I got the same answer from just asking the patient as I did by going through a long series of testing,” Houde said. It also includes keeping pain under steady control with scheduled dosing (rather than waiting for a pain crisis before offering analgesia) and having “rescue doses” available to relieve unpredictable or breakthrough pain.
Perhaps few persons who are not physicians can realize the influence which long-continued and unendurable pain may have on both body and mind... Under such torments the temper changes, the most amiable grow irritable, the bravest soldier becomes a coward.

S. Weir Mitchell, M.D., 1872

Understanding that chronic pain is actually harmful to the organism, as opposed to merely an unpleasant side effect of disease, was recognized as early as the 1870s and was well established by the middle of the twentieth century. John C. Liebeskind, a noted pain researcher at UCLA, provided evidence that pain actually leads to measurable immunosuppression and associated increased risk of death from cancer and other diseases. In 1943, W. K. Livingston wrote in *Pain Mechanisms*, “Pain is a sensory experience that is subjective and individual; it frequently exceeds its protective function and becomes destructive... If such disturbances are permitted to continue, profound and perhaps unalterable organic changes may result in the affected part... A vicious circle is thus created.”

Chronic pain is a symptom of many conditions and affects 76.2 million Americans, more than diabetes, heart disease, and cancer combined. Pain is a significant national health problem and is the leading cause of disability, suffering, and impaired quality of life. It is the most common reason individuals seek medical care, accounting for up to 80 percent of doctor visits. More than 25 percent of people in the United States report having had a chronic pain condition at some point in their life, and the associated disability is a major liability for workers, employers, and society. More than 70 percent of cancer survivors have significant pain, and fewer than 50 percent of these report receiving adequate treatment.

In hospitalized and seriously ill patients, pain has been associated with increased length of stay, longer recovery time, and poorer patient outcomes, all of which have implications for health care quality and cost. A study of the experience of 9,105 seriously ill patients at five major American teaching hospitals reported moderate to severe pain in half of conscious patients during the last three days of life.

Both patients and physicians agree about the extent of the problem of untreated pain. In a 1993 survey, 88 percent of physicians treating cancer patients reported that their own training in pain management was fair to poor; and 86 percent admitted that their patients were undermedicated for pain. Racial minorities, the poor, patients with HIV-AIDS, women, and the elderly are all less likely than white males to receive appropriate pain treatment.

Translation of the growing body of evidence that pain is bad for your health, and that relief of pain improves clinical outcomes, into routine clinical practice falls short. The multidisciplinary pain clinic has emerged as the standard of practice, utilizing a range of approaches including pharmacology, physical therapy, behavioral therapies, acupuncture, hypnosis, and family education. Many Americans cannot, however, get insurance coverage for modern comprehensive multidisciplinary pain programs, and this has reduced access to and availability of these services in many communities.
DEBORAH’S STORY

Deborah, as I’ll call her, is a thirty-seven-year-old mother of three young children, a practicing psychotherapist, and a breast cancer survivor. Despite state-of-the-art treatment from the best oncologists in New York City, her cancer spread to her bones, causing progressive and severe pain. Her oncologists focused on administration of chemotherapy and suggested ibuprofen and Tylenol, neither of which helped. Her pain got so bad that she was unable to take care of her kids and had to stop going to work. She spent most of her time curled on her side in bed, since the pain was much worse if she moved. She has been to the emergency room twice for the pain, but the doctors there were willing to give her only six tablets of Tylenol with codeine. When these were gone, she left messages for her oncologist, but three days later she had not received a call back. In desperation, she called her obstetrician, who referred her to a palliative care doctor. Her sister and her husband got her to the appointment and she was begun on oral morphine liquid in the office, with dose adjustments until the pain was reduced from 10 out of a possible 10 to 5 out of a possible 10 (with 0 being no pain and 10 being the worst imaginable pain). She went home with instructions for around-the-clock and rescue doses of the analgesic. Within three days, her pain was down to 2 out of a possible 10, and she was able to return to her family and work responsibilities and continue her pursuit of effective treatments for her breast cancer. Deborah wonders how she got through her illness without this kind of help, and she thinks that every patient with cancer should have not only an oncologist but also a palliative care doctor to manage all aspects of their illness.

The Hospice Movement

Origins and Growth The term “hospice”—from the Latin hospitium, the same linguistic root as “hospitality”—denotes a place to host, receive, and entertain guests or strangers. The term can be traced to medieval times, when it referred to a place of shelter and rest for weary or ill travelers. The original hospices, from the fourth to eleventh centuries, were houses of rest and shelter for pilgrims and crusaders traveling to and from the Holy Land; these hospices were usually kept by religious orders.

The earliest hospitals and hospices were one entity, again based in the church. St. Bartholomew’s Hospital, in London, was founded in 1123 and became a secular hospital in 1546 “for the ayde and comforte of the poore, sykke, blynde, aged, and impotent persones beying not hable to helpe themselffs nor havyinh any place certeyn whereyn they may be lodged, cherysshed, or refreshed, tyll they be cured and holpen of theyre diseases and syknesse,” wrote a surgeon, in a letter to Henry the Eighth. During the eighteenth and nineteenth centuries, religious orders established hospices to care for the dying in France, Ireland, and London. One of these—St. Joseph’s Hospice
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for the Dying Poor, established by the Irish Sisters of Charity—was Cicely Saunders’s first exposure to hospice care.

The modern hospice movement began with a few middle-aged women determined to bring attention to the medical and emotional abandonment of the dying: Cicely Saunders in London, Florence Wald in New Haven, and Elisabeth Kübler-Ross in Chicago. Building on the grassroots work of volunteers and religious orders who stepped up to care for dying people, these three women together were able to bring professional and public attention to the societal abandonment of the dying and their families: Saunders through the establishment of St. Christopher’s Hospice in London and the conduct of research and education in the clinical setting; Wald, under Saunders’s tutelage, established the first American hospice, in Branford, Connecticut; and Kübler-Ross by writing the revolutionary *On Death and Dying*. 

Saunders, who died in 2005, was a nurse, a social worker, and a physician. She is the acknowledged founder of the modern hospice and palliative care movements. In 1967, she launched the modern hospice movement by founding St. Christopher’s Hospice. She mandated the inclusion of education and research as a core component of the mission of St. Christopher’s and was one of a few pioneering researchers in the effective management of pain with opioid analgesics. “It appears that many patients feel deserted by their doctors at the end. Ideally, the doctor should remain the centre of a team who work together to relieve where they cannot heal, to keep the patient’s own struggle within his compass, and to bring hope and consolation to the end,” she wrote.

Saunders visited Yale University in 1963 and gave a lecture to medical students, nurses, social workers, and chaplains on the concept of specialized care for the dying. Her lecture included before-and-after photos of cancer patients and their families, showing dramatic differences after good symptom control. Upon the invitation of Florence Wald, then dean of Yale’s School of Nursing, Saunders returned to Yale as a visiting professor in 1965. In 1968 Wald took a sabbatical at St. Christopher’s, returning to America to initiate the modern American hospice movement.

The greatest fear of the dying and their families is the fear of pain. Sadly, this fear has often been justified. Terminal pain is frequently treated ineptly and the public myth that death from cancer involves unremitting distress is perpetuated. There are many reasons why terminal pain has been so poorly controlled. Until recently, the care of the dying has rarely been included in the training of doctors and nurses. With a few notable exceptions, medical and surgical textbooks have ignored the problems of pain control.

Cicely Saunders, 1995

After studying the work of both Cicely Saunders and Elisabeth Kübler-Ross, Florence Schorske Wald established the Connecticut Hospice in 1974. This entity provided both home and inpatient care and served as a stimulus to the development of hospices across the United States. In an interview she said, “Hospice care for
the terminally ill is the end piece of how to care for patients from birth on. It is a patient-family–based approach to health care that belongs in the community with natural childbirth, school-based health care, mental health care, and adult care. . . . As more and more people—families of hospice patients and hospice volunteers—are exposed to this new model of how to approach end-of-life care, we are taking what was essentially a hidden scene, death, an unknown, and making it a reality. We are showing people that there are meaningful ways to cope with this very difficult situation.”

An international best-seller, Elisabeth Kübler-Ross’s On Death and Dying brought attention to the Western “death-denying” culture and her theory about the five stages of grief (denial, anger, bargaining, depression, and acceptance) that a dying person typically goes through. Articulating an early version of what today would be called “patient-centered care,” she said in a 1975 radio interview, “The question is really, ‘What does it mean to die with dignity?’ To die with dignity to me means to die within your character. That means there are people who have used denial all their life long; they will most likely die in a stage of denial. There are people who have been fighters and rebels all their life long, and, by golly, they want to die that way. And to those patients, we have to help them, to say it’s O.K.”

**Financing Hospice Care** A Department of Health, Education, and Welfare (HEW) task force reported in 1978 that “the hospice movement as a concept for the care of the terminally ill and their families is a viable concept and one which holds out a means of providing more humane care for Americans dying of terminal illness while possibly reducing costs. As such, it is the proper subject of federal support.” This was followed by funding of a demonstration program in 1979, the creation of a Medicare hospice benefit in 1982, and the establishment of eligibility criteria in 1986 meant to control costs by trying to restrict access. Specifically, eligibility for federal reimbursement of hospice care requires that two physicians certify that the patient will die within six months “if the disease runs its normal course” and that the patient agrees to give up regular insurance coverage for life-prolonging treatments related to the terminal illness. In part as a consequence of these criteria, hospice became associated with “giving up” the fight for life in the minds of both the public and health professionals.

**The Current Status of Hospice Care** As the number and the needs of the chronically ill elderly have grown in the United States, the number of hospice providers grew by more than 30 percent between 1997 and 2007 (see Figure 6). In 2007, an estimated 1.4 million patients were cared for in a hospice, accounting for approximately 39 percent of all deaths in the United States, a number that has steadily increased in the last decade. Overall family satisfaction with hospice care is high, with 75 percent rating care received as excellent. Reasons for growth in hospice utilization are many and include a rise in hospice services in nursing homes, growth in the population living with advanced and end-stage chronic diseases, and greater recognition of and familiarity with the benefits of hospice care. Growth of this magnitude is accompanied by quality
challenges. Much of the recent increase in hospice providers involved small for-profit hospice organizations. Delivering high-quality care to seriously ill patients with complex conditions requires some financial economies of scale that are impossible to achieve by small hospices serving few patients. Only 16.2 percent of American hospices serve more than a hundred patients per day. Despite regulatory concerns about the rise in the numbers of patients turning to hospice and the increasing length of stay for some hospice patients, recent data demonstrate substantial cost savings to Medicare (averaging $2,309 per patient) among hospice patients served for several months, depending upon the diagnosis.37

Referral to hospice tends to occur late in the dying process, when prognostication becomes more reliable. Length of stay in the hospice program has held steady at a median of 20.6 days, and approximately one-third of patients live for less than a week after their admission to hospice. More than half of hospice patients have terminal illnesses other than cancer and over two-thirds were over age seventy-five in 2006. About three-quarters of hospice patients die in their homes, whether they are residing in a nursing home (23 percent) or a private residence (47 percent).38
The Medicare Hospice Benefit and the “Failure to Die” Syndrome

The link between prognosis and eligibility for hospice care has its roots in the care of patients with advanced malignancies. The typical course for such cancer patients involves an acceptable quality of life and functional status until several months before death, whereupon fatigue, weakness, and other symptoms predominate. Once a patient with metastatic solid tumor malignancy loses functional independence and becomes debilitated, a prognosis can reliably be estimated at three to four months. Although modern anticancer and supportive therapies have lengthened survival during advanced stages of illness, this link between declining function and short prognosis led to designation of the six-month criterion for eligibility for Medicare funding of hospice care.

For many cancer patients, this point of transition from functional independence to dependence remains a reasonably reliable marker of prognosis. But only 23 percent of Americans die of cancer, and for the remaining 77 percent of people who die from other diseases, functional status and debility are not good predictors of prognosis. In fact, patients in these disease categories can live for years with serious functional impairment and painful symptoms. The personal care and assistance they require can result in a substantial burden on their families and society at large. Not surprisingly, patients most likely to be referred for hospice are those placing the highest burden on family caregivers.

The referral of chronically ill noncancer patients to hospice for their palliative care needs has led to what has been named the “failure to die on time” phenomenon. Because of the difficulty of predicting how long patients, especially those with noncancer diseases such as dementia and end-stage heart disease (the leading cause of death in the United States), will live, and the fact that many of these patients live longer than the six months that Medicare expects to cover, the use of the hospice benefit for patients who “fail to die on time” has received federal government scrutiny for possible fraud and misuse. Since the Medicare criteria were designed to limit access to the hospice benefit to patients who were clearly dying and to prohibit double dipping—getting high-tech expensive modern life-prolonging care while simultaneously receiving sophisticated and coordinated hospice care at home—the argument is that reimbursing hospice care for patients who live on despite their significant impairments is a misapplication of a benefit intended to care for the dying.

According to the New York Times, “Over the last eight years, the refusal of patients to die according to actuarial schedules has led the federal government to demand that hospices exceeding reimbursement limits repay hundreds of millions of dollars to Medicare. . .[As a result,] hundreds of hospice providers across the country are facing the catastrophic financial consequence of what would otherwise seem a positive development: their patients are living longer than expected.” The risk of fraud and abuse allegations and the possibility of receiving a large fine have led many hospices to reduce access for seriously ill patients with unclear prognoses. The majority of these patients are hospitalized repeatedly during the months before their death.
The Development, Status, and Future of Palliative Care

TIMELINE

1963: Cicely Saunders lectures at Yale University.

1965: At the invitation of Florence Wald, then dean of the Yale School of Nursing, Saunders becomes a visiting faculty member of the school.

1968: Wald takes a sabbatical from Yale to work at St. Christopher’s and learn about hospice.

1969: On Death and Dying, based on more than five hundred interviews with dying patients, is published. Written by Dr. Elisabeth Kübler-Ross, a faculty member of the University of Chicago’s School of Medicine, the book identifies five stages through which many terminally ill patients progress. The book becomes an internationally known best-seller. Kübler-Ross makes a plea for home care as opposed to treatment in an institutional setting and argues that patients should have a choice and the ability to participate in the decisions that affect their destiny.

1972: Kübler-Ross testifies at the first national hearings on the subject of death with dignity, which are conducted by the Senate Special Committee on Aging. In her testimony, Kübler-Ross states, “We live in a very particular death-denying society. We isolate both the dying and the old, and it serves a purpose. They are reminders of our own mortality. We should not institutionalize people. We can give families more help with home care and visiting nurses, giving the families and the patients the spiritual, emotional, and financial help in order to facilitate the final care at home.”

1974: The first American hospice, the Connecticut Hospice Institute, is established in Branford, Connecticut, by Wald and colleagues.

1975: The first comprehensive palliative medicine program is established at the Royal Victoria Hospital in Montreal by Balfour Mount. Mount coined the term “palliative care.”

1976: The New Jersey Supreme Court rules, in the case of Karen Ann Quinlan, that ventilator therapy may be withdrawn from a young woman in a persistent vegetative state. The court rules that decisions to continue or withdraw life support should be guided by evidence of the patient’s preferences or wishes. The Quinlan decision leads to the widespread use of hospital ethics committees and advance care planning.

1976: The International Congress on Palliative Care holds its first meeting, in Montreal.

1978: A Department of Health, Education, and Welfare task force reports that “the hospice movement as a concept for the care of the terminally ill and their families is a viable concept and one which holds out a means of providing more humane care for Americans dying of terminal illness while possibly reducing costs. As such, it is the proper subject of federal support.”

Continued
Continued

1979: The federal Health Care Financing Administration initiates demonstration programs at twenty-six hospices across the country to assess the cost-effectiveness of hospice care and to help determine what a hospice is and what it should provide.

1980: The W. K. Kellogg Foundation awards a grant to the Joint Commission on Accreditation of Healthcare Organizations (JCAHO, now the Joint Commission) to investigate the status of hospice and to develop standards for hospice accreditation.


1983: JCAHO initiates hospice accreditation.

1986: The Medicare hospice benefit is made permanent by Congress and hospices are given a 10 percent increase in reimbursement rates. In an effort to control costs by reducing access, criteria for eligibility for hospice care include (1) physician certification of a prognosis of under six months and (2) patient agreement to give up insurance coverage for medical care focused on cure or life-prolonging treatments.

1987: The first American academic hospital palliative care program is established by Declan Walsh at the Cleveland Clinic, designated a World Health Organization Demonstration Project in 1991 in recognition of “its unique model of a much needed service.”

1990: The U. S. Supreme Court recognizes in the case of Nancy Cruzan—a young woman in a persistent vegetative state receiving artificial nutrition and hydration by feeding tube—a patient’s rights to refuse unwanted treatment if his or her wishes have been expressed in a “clear and convincing” way. The decision leads to a federal law, the Patient Self-Determination Act, requiring hospitals and other health care settings to counsel patients about their right to complete an advance directive stating their wishes for future care under circumstances of cognitive impairment.

1994: Oregon’s Death with Dignity Act passes on a ballot measure, legalizing access to physician-assisted suicide for patients meeting eligibility criteria.

1996: The Ninth Circuit Court of Appeals in San Francisco overrules a Washington state law against physician-assisted suicide. The Second Circuit Court of Appeals strikes down New York State’s law against physician-assisted suicide. Both rulings are appealed to the Supreme Court.

1997: Congress passes legislation banning taxpayer dollars from financing physician-assisted suicide. The Supreme Court rules that mentally competent terminally ill people do not have a constitutional right to physician-assisted suicide, leaving the issue up to the states. Oregon voters reaffirm the right to physician-assisted suicide by passing for the second time the Death with Dignity Act.

1997: The Institute of Medicine issues an influential report, Approaching Death: Improving Care at the End of Life.
2001: The National Consensus Project for Quality Palliative Care, a foundation-funded initiative to develop guidelines and standards for palliative care clinical programs, is established. Its members consist of the five major national palliative care organizations in the United States: the American Academy of Hospice and Palliative Medicine, the Center to Advance Palliative Care, the Hospice and Palliative Nurses Association, the Last Acts Partnership, and the National Hospice and Palliative Care Organization.

2004: The National Consensus Project for Quality Palliative Care issues consensus guidelines.

2005: Terri Schiavo was a young Florida woman in a persistent vegetative state from 1990. Her husband and guardian petitioned the court to remove her feeding tube based on prior evidence of her wishes. Her parents contested this, triggering a widely publicized eight-year legal and political battle. The tube is removed in 2005, and Terri dies thirteen days later amid intense protest from right-to-life activists.

2006: In October, the American Board of Medical Specialties (ABMS) announces approval of the creation of hospice and palliative medicine as a subspecialty of ten participating member boards. The co-sponsoring boards include the American Boards of Internal Medicine, Anesthesiology, Family Medicine, Physical Medicine and Rehabilitation, Psychiatry and Neurology, Surgery, Pediatrics, Emergency Medicine, Radiology, and Obstetrics and Gynecology.

2007: Building on the National Consensus Project guidelines, the National Quality Forum establishes its National Framework and Preferred Practices for Palliative and Hospice Care.

2008: The first ABMS-recognized hospice and palliative medicine board-certifying examination is offered. The Accreditation Council for Graduate Medical Education approves program requirements for fellowship training in hospice and palliative medicine.

2008: The state of Washington becomes the second state to pass a ballot measure legalizing physician-assisted suicide, a measure modeled closely on Oregon’s Death with Dignity Act.

In part as a consequence of this cure-versus-care mentality codified in the Medicare hospice benefit, medical care is falsely but widely understood to have two mutually exclusive goals: either to cure disease and prolong life or to provide comfort care. Consequently, the decision to focus on reducing suffering is typically made only after life-prolonging treatment has been ineffectual or disproportionately burdensome and death is imminent. The either/or nature of this choice is driven largely by the reimbursement system; that is, regular Medicare and other insurers cover curative therapies and the Medicare hospice benefit covers comfort care. The false dichotomy built into U.S. health care financing of hospice—cure versus care, not both—led to the phenomenon of hospice referral too late to secure its benefits and has been a spur to the growth of nonhospice palliative care in the United States in the last ten years.
SOCIAL, LEGAL, AND ETHICAL CONCERNS LEADING TO CHANGE IN THE CARE OF PERSONS WITH SERIOUS ILLNESS

The decades of the 1980s and 1990s followed the introduction of new medical technologies, the shift away from home and into hospitals for the care of serious illness, and the medicalization of serious illness and the dying process. The excesses of the “technology imperative”—if the technology exists, we must use it—led to public and legal reaction manifested by a rise in the field of medical ethics and the “right to die” movement. A number of legal cases focused debate on a series of ethical principles in conflict: the sanctity of life versus the right to control what is done to one’s own body; medical paternalism versus self-determination; and distributive justice versus self-determination.

The fundamental principles that had guided the practice of medicine—relieve suffering, do no harm—were upended by the seemingly limitless ability of modern medical technology to prolong life. Almost without discussion, the primary moral principle underlying medical practice became the obligation to prolong life regardless of the toll in suffering, poor quality of life, or cost. Hence the unforgettable first day of my internship in 1977, spent subjecting an eighty-nine-year-old man with end-stage heart failure to repeated resuscitation attempts in the coronary care unit. The message was clear—my job as a physician was to prolong life for as long as possible regardless of the cost in suffering and resources, and regardless of the likelihood of benefit. Other messages, equally powerful and similarly unstated, were conveyed when no one on the team stopped to speak with the patient’s eighty-seven-year-old wife after he died; no one asked me how I was handling this violent death of one of my patients on my first day as a real doctor; and there was no pause to talk about why we had done this and what the pros and cons of this kind of medical care might be. The gravity and profundity of the ending of his life were neither acknowledged nor honored.

Because of Nancy [Cruzan], I suspect hundreds of thousands of people can rest free, knowing that when death beckons, they can meet it face-to-face with dignity, free from the fear of unwanted and useless medical treatment. I think this is quite an accomplishment for a twenty-five-year-old kid.

Lester “Joe” Cruzan, Nancy Cruzan’s father, 1990

Informed Consent and Medical Decision Making: The Right to Refuse Unwanted Medical Treatment

The indiscriminate application of life-prolonging technologies and a series of dramatic legal cases challenging this practice led to a new organizing principle—respect for patients’ wishes—as a counterbalance to the medical paternalism driving efforts to prolong life, regardless of its quality or the suffering imposed by the process. The earliest attempts to put the brakes on the reflexive use of medical technology involved the affirmation of the right of people to refuse unwanted medical treatments, based on
the fundamental right of persons to control what is done to their own bodies. In 1960, the Kansas Supreme Court in _Natanson v. Kline_ wrote, “Anglo-American law starts with the premise of thoroughgoing self-determination.” The legal principle of informed consent by which patients accept or reject an offered therapy (based on communication about and understanding of its risks, benefits, and alternatives, and on deliberation and decision in the context of personal values and preferences) grew out of this principle of patient self-determination. In essence, patients have the right to refuse unwanted medical treatment. The application of the principle of informed consent in medical decision making was articulated in a series of influential court decisions.

Case law, reinforced by state legislation, set out the current legal requirements for providing, withholding, or withdrawing life-sustaining treatments. The principles, in general, require evidence of the patient’s wishes. These can be expressed directly by the patient, or, if he or she has lost the capacity to express a decision (for example, if the patient is in a coma), through the “substituted judgment” of a surrogate decision maker. Surrogates can be designated by the patient when well through a health care proxy or a durable power of attorney. Alternatively, surrogates may invoke their knowledge of the patient’s wishes based on past conversations, written documents such as living wills, or, in lieu of such information, on the surrogate’s assessment of what is in the best interests of the patient.

**Advance Directives**

Advocate directives are a means for a person who can make rational decisions to anticipate and control future medical decisions under circumstances of diminished capacity. Advocate directives are formal and legally recognized mechanisms to express one’s wishes for future care, and include:

- Do-not-resuscitate (DNR) orders, which specify the circumstances under which a patient does not wish attempted resuscitation.
- Living wills, which contain an expression of the person’s values—values that should guide decisions to provide or withhold treatment under circumstances of life-threatening illness and loss of decisional capacity.
- Health care proxies and durable powers of attorney, which designate a trusted person to make decisions about medical treatment if a patient is not able to do so. The appointed proxy or agent is supposed to represent the patient’s (and not his or her own) wishes and values.

The Patient Self-Determination Act, enacted by Congress in 1990, mandates federally funded institutions (which include almost all hospitals and nursing homes) to provide state-specific written information about advocate directives and to record the presence of such directives. There is no requirement for doctors or nurses to conduct these conversations, and the result in many places has been the delivery of a piece of paper (with no counseling) to the patient by an admitting clerk. Because of this, the act has had little effect on advance care planning.
**SEMINAL CASE LAW ON THE RIGHT TO DIE**

*Karen Ann Quinlan:* In 1975, this twenty-one-year-old was in a persistent vegetative state after loss of consciousness. Her parents requested the discontinuation of her ventilator after several months without improvement. The hospital refused, and legal battles ensued. The Quinlans invoked the Catholic moral theology teaching that “extraordinary means” are not required to preserve a patient’s life, defined as placing an undue burden that is beyond basics needed for “ordinary” sustenance of life (air, food, water, hygiene, dignity). The New Jersey Supreme Court, quoting extensively from a 1957 address by Pope Pius XII, ruled in favor of the parents, and the ventilator was withdrawn. Quinlan lived nine more years, until 1985, with artificial nutrition and hydration via a feeding tube. This case and its aftermath led directly to the establishment of formal ethics committees in hospitals, nursing homes, and hospices, and to the development of the legal underpinnings of advance health directives.

*Nancy Cruzan:* In 1983, this twenty-five-year-old was thrown from her car and survived in a persistent vegetative state after resuscitation. After four years with no improvement, her parents requested removal of the feeding tube, but the hospital demanded a court order. Since food and water did not meet the extraordinary measures standard established in *Quinlan,* the Missouri courts refused to provide such an order. Their decision was upheld by the United States Supreme Court, which recognized the right of a person to refuse unwanted medical treatment and articulated a standard that “clear and convincing” evidence of the person’s previously stated wishes was needed for a court to authorize withholding of medical treatment. After three friends of Cruzan’s came forward with “clear and convincing” evidence of her wishes, a Missouri court gave permission to remove the tube, and it was removed in 1990. Cruzan died twelve days later, amid protests from the pro-life activist group Operation Rescue. The Cruzan case led to the development of federal law requiring that all hospitals and nursing homes inform their patients about advance directives and give them the opportunity to complete one. Almost all states have laws governing decisions to withhold or withdraw life-sustaining treatments, living wills, health care proxies, and durable powers of attorney. Nancy Cruzan’s grave marker reads “Born July 20, 1957 / Departed January 11, 1983 / At Peace December 26, 1990.”

*Terri Schiavo:* In 1990 this twenty-six-year-old suffered a cardiac arrest at home. She was resuscitated to a persistent vegetative state. Eight years later, her husband and guardian requested withdrawal of the feeding tube. Terri had no living will, and evidence of her wishes presented by her husband and others was challenged by her parents and right-to-life and disability advocacy groups. The legal and media battles lasted eight years and included fourteen appeals in Florida, five federal district court suits, Florida legislation (“Terri’s Law”) struck down by the Florida Supreme Court, congressional subpoenas, federal legislation, and four denials of certiorari by the United States Supreme Court. Senators Bill Frist and Rick Santorum and House Majority Leader Tom DeLay threatened contempt of Congress sanctions. Congress passed the “Palm Sunday Compromise,” giving jurisdiction to the federal courts. President Bush flew to Washington from his vacation in Texas to sign the bill into law. The Supreme Court again declined to hear the case, and the tube was removed. Terri Schiavo died thirteen days later, in 2005, amid intense protest and threats from right-to-life activists.42
Virtually every state has passed legislation authorizing advance directives, and the prevalence of such directives among patients with serious and chronic illness has grown in recent decades, ranging from 15 to 20 percent of the general public to more than 80 percent of seriously ill adults. While the prevalence of do-not-resuscitate orders has risen dramatically in recent years, it varies by disease type, ethnicity, age of patients, and care setting, suggesting a rise in acceptance of advance planning decisions prior to death in some patient populations.

Unfortunately, aside from decisions not to attempt cardiopulmonary resuscitation when a patient dies, other forms of advance care planning (such as living wills) do not appear to significantly influence decisions actually made at the bedside for seriously ill patients. The reasons advanced to account for this include the impossibility of anticipating the contingencies of future health status and the types of decisions that might be necessary; the common occurrence of people changing their minds in favor of continuing aggressive life-prolonging therapies as the reality of death approaches; denial and aversion of healthy people to thinking about future illness and disability; the emotional difficulty faced by duly appointed proxies when asked to make decisions (such as withdrawing a ventilator or a feeding tube) that will be perceived as the proximate cause of a loved one’s death; and the failure of medical professionals to seek out or honor these directives under circumstances of life-and-death decision making. To date, the use of advance directives has been ineffective in improving quality and controlling costs.

A promising new form of advance directive called the MOLST or POLST (medical or physician orders for life-sustaining treatment) was developed in Oregon and has been adapted by other states. This directive is designed for patients in their last year or two of life and allows patients and physicians to make advance decisions, reflected in physician orders, about hospitalization, DNR orders, artificial nutrition and hydration, and other treatments. It is designed to accompany the patient from setting to setting, and, at least in Oregon, has resulted in a dramatic decrease in hospitalization of terminally ill nursing home patients.

**The Right to Die, Assisted Suicide, and Euthanasia**

Public anxieties about end-of-life care, fear of loss of control once one is in the medical care system, and rising demands for patient self-determination have led to a resurgence of millennia-old debates about the morality of suicide during terminal illness, and physician-assisted suicide in particular. Debates about euthanasia date back to at least 400 B.C., with the Hippocratic Oath, which states, “I will give no deadly medicine to anyone if asked, nor suggest any such counsel.” English common law has prohibited it since the Middle Ages. Growing support for the legalization of euthanasia during the twentieth century was partially reversed with the horror caused by the Nazis’ involuntary euthanasia of individuals with mental or physical disabilities. In the United States, euthanasia and the right to refuse or stop life-sustaining treatments based on common law rights to self-determination have been debated for at least the last hundred years.

A heated legal and ethical debate has centered on euthanasia, a Greek word meaning “good death” and referring, generally, to a death caused by another person, sometimes described as a mercy killing. The substance of the debate on euthanasia and assisted
suicide has centered on whether it was ever rational for a person to seek a hastened death, no matter how great the burden imposed by an illness; whether, by definition, a desire to die was a manifestation of treatable despair and depression; and whether it was ever ethical for a physician to, in effect, validate a patient’s assessment that he or she would be better off dead.

Opponents were concerned that legalization, with its implications of societal approval of the act and concurrence that a diminished life is a societal burden and not worth living, would have a subtle coercive effect on the treatment of seriously ill patients. Opponents also noted that the requirement for a physician’s agreement and active participation further stigmatized the sick person, again through the subtle message that the doctor, too, agrees that the patient would be better off dead. Organized religious groups have mounted highly effective media campaigns opposing physician-assisted suicide.

Proponents have argued that the right to self-determination extends to the right to determine the timing and circumstances of one’s own death, and that such a process could be safely regulated through the establishment of strict eligibility criteria and reporting transparency. Public opinion polls have consistently indicated strong support for it. Gallup has been surveying the American public about euthanasia since 1936 (see Figure 7). The polls have shown that over the last sixty years, between 37 and 72 percent were in favor of mercy deaths under governmental supervision.

**FIGURE 7.** When a person has a disease that cannot be cured, do you think doctors should be allowed by law to end the patient’s life by some painless means if the patient and his family request it?

<table>
<thead>
<tr>
<th>Year</th>
<th>% Yes</th>
<th>% No</th>
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<tbody>
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<td>37</td>
<td>63</td>
</tr>
<tr>
<td>1950 Jan 8-13</td>
<td>36</td>
<td>64</td>
</tr>
<tr>
<td>1973 Jul 6-9</td>
<td>40</td>
<td>60</td>
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<tr>
<td>1990 Apr-9-18</td>
<td>54</td>
<td>46</td>
</tr>
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<td>1990 Jul 26-28</td>
<td>53</td>
<td>47</td>
</tr>
<tr>
<td>1996 May 10-14</td>
<td>58</td>
<td>42</td>
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<td>2006 May 8-11</td>
<td>72</td>
<td>28</td>
</tr>
<tr>
<td>2007 May 8-13</td>
<td>71</td>
<td>29</td>
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Note: The figure is not to scale.
The issue of physician-assisted suicide generated considerable heat in the 1980s and 1990s, after Dr. Jack Kevorkian, a Michigan pathologist, began publicly offering to help patients end their lives, using intravenous sedatives. The first person he assisted, Janet Adkins, traveled to Michigan in 1990 from the state of Washington because of an early dementia and unwillingness to live out the predictable course of a dementing illness. “I’m for absolute autonomy of the individual, and an adult, competent woman has absolute autonomy. It’s her choice,” Kevorkian said. He claims to have helped a total of 130 people end their lives.

After repeated efforts by the legal system, Kevorkian was imprisoned in 1999 for second-degree murder after the taped and televised voluntary euthanasia death of Thomas Youk, a fifty-two-year-old man with end-stage ventilator-dependent ALS. The public uproar and debate surrounding Kevorkian’s activities led to, on the one hand, a ten-to-twenty-five-year jail term for him (he was paroled in 2007 after eight years in jail, after promising not to return to his previous activities), and, on the other, approval of a state ballot measure legalizing physician-assisted suicide, the 1994 Oregon Death with Dignity Act. 51

Legalizing Physician-Assisted Suicide and the Oregon Death with Dignity Act

In the United States, the debate and legislative efforts have focused on physician-assisted dying (or physician-assisted suicide), where a physician provides a lethal-dose prescription to a patient with the knowledge that the patient intends to use the medicine to hasten death. Physician-assisted suicide is illegal in all states but Oregon and, after passage of a November 2008 ballot measure, Washington. 52

Oregon’s Death with Dignity Act, which passed by a 2.6 percent (31,962-vote) margin in 1994, requires a two-physician certification of a prognosis of under six months; mental competence and no evidence of impaired judgment from depression or other psychiatric illness; two requests separated by at least fifteen days, followed by a written request witnessed by two people; and counseling regarding alternatives including hospice and pain management. Eligible patients receive a prescription, but the doctor may not administer the drugs. The most common reasons for wanting the option of a physician-assisted suicide cited by the patients requesting a prescription were loss of autonomy (100 percent), decreasing ability to participate in activities that make life enjoyable (86 percent), and loss of dignity (86 percent).

Three years after the passage of the measure, a state legislative effort to strike it down was rejected by 60 percent of the voters, reaffirming the legal status of the measure. Also in 1997, Congress passed legislation barring taxpayer dollars from financing physician-assisted suicide, and the Supreme Court ruled that mentally competent terminally ill people do not have a constitutional right to physician-assisted suicide, leaving the issue up to the states. A subsequent attempt in 2001 by Attorney General John Ashcroft to suspend the medical licenses of physicians prescribing life-ending medications under Oregon law was blocked in 2002 by a federal judge, a decision affirmed
by the Ninth Circuit Court of Appeals in 2004. In 2006, in *Gonzalez v. Oregon*, the Supreme Court ruled 6–3 in favor of Oregon, upholding the law.53

Between 1997 and 2007, 341 people ended their lives through the process set forth in the law. In 2007, 49 Death with Dignity Act patients accounted for 0.156 percent of all deaths, or 15.6 people per 10,000 deaths in Oregon. An additional 85 people received a prescription, presumably to have the reassurance that they could take control over the dying process when and if they needed to, but did not use it and died of natural causes.54 Analyses of data from both Oregon and the Netherlands (where for over twenty years physicians who provide voluntary euthanasia by lethal injection to seriously ill patients following strict guidelines have not been prosecuted) suggest that fears about the disproportionate impact of legalization on vulnerable groups who might feel coerced by the absence of good care alternatives (the elderly, the uninsured, minorities, the disabled, women, the poor) are not justified.55 A Washington state ballot measure virtually identical to Oregon’s Death with Dignity Act passed on November 4, 2008, by a margin of 59 percent to 41 percent. Efforts to pass similar ballot measures in Maine, Michigan, and California have failed by narrow margins in recent years.56
Although the debate on the ethics and the legality of euthanasia and assisted suicide invokes strongly held beliefs on both sides, in many respects the issue has more salience for the so-called worried well than it does for persons actually living with serious and life-threatening illness. The literature suggests that a desire for aggressive life-prolonging interventions actually increases as death draws near, and the number of persons invoking their legal right to a physician-assisted death in Oregon is small. These observations suggest that fears of loss of control and unrelieved suffering associated with hypothetical future serious illness are the primary motivators for the endorsement of legalization among healthy voters. The rational policy response to such widespread fear is to improve the quality of care for the seriously ill to the point where such concerns are no longer based in reality. This can be accomplished by investing in policies ensuring reliable access to quality palliative care for all Americans rather than by giving a very small number of sick patients access to their doctors’ assistance with suicide.

RESEARCH ON CARE OF THE SERIOUSLY ILL

SUPPORT, the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment

In the late 1980s, the Robert Wood Johnson Foundation decided to focus on how to improve the care of patients dying in hospitals. Working with a number of prominent academic researchers, the foundation invested more than $29 million in SUPPORT, a randomized multihospital trial of information-sharing for seriously ill patients and their physicians. Research nurses determined patient prognoses and asked patients about their preferences for care. This information was communicated to the treating physicians; the assumption was that information on prognosis and preferences would have an effect on care decisions near the end of life. Surprisingly, however, the intervention had no impact on care processes, patient outcomes, or costs.

Although SUPPORT was a dramatic failure, it did yield important data on the experiences of patients and their families with the medical care system (Table 1). The SUPPORT investigators were among the first to examine the impact of a serious illness on family members, identifying adverse financial, medical, and social consequences that affected the majority. The study demonstrated that high levels of pain were common across all diagnostic categories, even among people who were actively dying and those who had been hospitalized for more than a week. It found that the odds of dying in a hospital had little to do with patient preferences or with physician recognition of prognosis but rather were largely determined by the availability of hospital beds in the community. The publication of the major paper from SUPPORT was covered by all the major media and was a key factor in creation of the “burning platform”—public and professional recognition of a serious quality problem in the care of Americans with advanced illness.
TABLE 1. **Key Findings from SUPPORT**

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<tr>
<td><strong>Pain</strong></td>
<td>Families of 50% of conscious patients reported moderate to severe pain at least half the time during the last three days of life.57 40 to 60% of patients reported moderate to severe pain after 8 to 12 days in the hospital.58</td>
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<td><strong>Families</strong></td>
<td>Serious illness in a family member required high levels of caregiving from family members in 34%; led to job loss or other major life change in 20%; resulted in loss of all or most of family savings in 31%; and resulted in loss of major source of income in 29%.59</td>
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<td><strong>Prognosis</strong></td>
<td>Prognosis is variable and uncertain even close to the time of death.60</td>
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<td><strong>Preferences</strong></td>
<td>Doctor, nurse, and surrogate knowledge of patient wishes is only slightly better than chance. Patients and doctors rarely discuss patient preferences.61</td>
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<td><strong>Advance directives</strong></td>
<td>Advance directives had no measurable impact on care actually received.62</td>
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<tr>
<td><strong>Communication</strong></td>
<td>53% of doctors did not know their patients’ preferences about CPR.63</td>
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<tr>
<td><strong>Intensity of hospital care</strong></td>
<td>38% of those who died spent at least ten days in an ICU.64</td>
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<tr>
<td><strong>Location of death</strong></td>
<td>Location of death is primarily determined by hospital bed availability, not by patient, family, or doctor preferences.65</td>
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<tr>
<td><strong>Age and health care spending</strong></td>
<td>Compared with that of similar, younger patients, the care of seriously ill older adults involves fewer procedures and lower costs.66</td>
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Summarizing the findings from SUPPORT, Joanne Lynn, one of the principal investigators, wrote:

The problem was not just that physicians were not asking patients their views. In addition, patients were not seeking to talk with physicians. . . . No one involved talks much—not physicians, families, or patients. Decisions are made very late in the course of the illness—a practice that risks some harm and precludes planning but protects most patients from having to consider the issues at all and spares families from confronting mortality until doing so is unavoidable. Surely we can do better. . . . It may well be that change requires a much more fundamental restructuring of service supply, incentives, and rewards.67

**The Institute of Medicine Reports**

In 1997, two years after the release of the SUPPORT findings, the Institute of Medicine (IOM) published *Approaching Death: Improving Care at the End of Life*, the culmination of a yearlong study.68 Preparation for the report included public meetings, forty-seven
testimonials from stakeholder groups, review of the literature, and consultation with a broad range of experts. The report called for radical restructuring of the health care system to include fundamental changes in care delivery, policy, financing, education, research priorities, and public and community engagement. In particular, the report recommended:

- A new subspecialty of palliative medicine
- Reform of burdensome constraints on the prescription of opioid analgesics
- Substantial investment in palliative care research by the National Institutes of Health (NIH) and other research establishments
- Revision of textbooks and other curricular materials to include core content on palliative care
- Mandatory health professional education in palliative care across disciplines and levels of training

With support from private sector philanthropy, many of these recommendations were implemented in whole or in part in subsequent years. The IOM subsequently released two additional reports—Improving Palliative Care for Cancer and When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families.

**Variation and Its Implications: The Dartmouth Atlas**

Using Medicare claims data and small-area analyses, researchers at the Dartmouth Medical School have identified wide variation in the provision of effective care (for example, underuse of beta blockers after heart attacks) and utilization of health care resources during chronic illness, due primarily to the number of physicians and hospital beds in different regions. More specialists and more hospital beds in a given community encourage more specialist visits and more and longer hospital admissions for patients living in that community. The extra spending on doctors’ visits, specialist consultations, procedures, tests, and hospital stays in the high-utilization regions do not appear to buy either a longer or a better life. If anything, the data suggest that the higher the utilization of health care, the higher the mortality rate—due, perhaps, to the greater risk of medical errors, poor coordination and poor communication, and other potential harms. Additionally, family members of seriously ill patients living in high-intensity hospital service areas report lower satisfaction with the health care system and lower quality of emotional support, shared decision making, information about what to expect, and respectful treatment. Similarly, physicians practicing in high-intensity service regions report more difficulty arranging elective admissions, obtaining specialty referrals, maintaining good doctor-patient relations, and delivering high-quality care.

If more high-technology medicine applied to care of the seriously ill neither improves care, prolongs lives, nor increases satisfaction of patients, families and their physicians, why are we spending so much money on it, and how do we reorganize the system to facilitate access to truly effective medical care? This question underscores the need to develop different approaches to the care of the seriously
and chronically ill, approaches that can lead to changes in deeply entrenched and highly patterned physician practice styles, starting with the place where this care variation leads to the highest costs and the greatest potential harms—the hospital. As demonstrated by SUPPORT, successful interventions to change physician behavior are notoriously elusive; hence the need for system- and bedside-level interventions to try to change the physician’s usual path of decision making for seriously ill hospitalized patients.

PRIVATE SECTOR PHILANTHROPY AS CATALYST OF SOCIAL CHANGE

Despite the widespread belief that government is the main driver of innovation and quality assurance in health care, the American health care system has little to no centralized organizing authority and is instead influenced by multiple stakeholders, including industry manufacturers of devices and pharmaceuticals, payers, and providers. Unlike other developed nations with centralized national health care plans, the United States has a health care marketplace that comprises an amalgam of for-profit industries and special interest groups (such as commercial insurers, pharmaceutical and device manufacturers, and for-profit hospitals, nursing homes, and hospices), not-for-profit care settings, public payers (Medicare, Medicaid), employer-based insurance (of diminishing affordability and availability) for those under sixty-five, and a rising crisis in access to quality health care for insured and uninsured alike. Although major public policy advances during the last century led to Medicare coverage for all older adults and disabled persons, as well as the Medicare hospice benefit and the Medicare Part D prescription drug coverage plan, to date government has been unable to impose incentives and constraints on overuse and lack of primary care coordination, leading to fragmented, poor-quality care for the seriously ill. Private sector philanthropy, specifically major foundations committed to improving health and health care, stepped into the breach with the substantial and sustained investments necessary to build and integrate a new field of medicine into the mainstream of health care in the United States.

These philanthropic initiatives evolved in a context of the growing interest in patients’ rights, advance care planning, the hospice movement, the “right to die” movement, and Jack Kevorkian’s challenge to mainstream medicine. In the early 1980s, the W. K. Kellogg Foundation, along with the Arthur Vining Davis Foundation, funded the creation of protocols for end-of-life care, pain management, and nursing services. The standards they set regarding care for the dying were recognized by the U.S. government through the creation of the Medicare hospice benefit. As a result of these early foundation-funded efforts, millions of dollars in federal support now flow to the care of over one-third of dying Americans who are served by the more than four thousand hospice programs nationwide.

The other major early investor in this effort was the Robert Wood Johnson Foundation; its commitment was precipitated in part by the difficult personal experiences of several board members. Since the late 1980s, the Robert Wood Johnson Foundation has invested more than $180 million in end-of-life and palliative care—an
investment that helped to create a new and now thriving academic and clinical field in health care.75

In 1994, George Soros, the Open Society Institute founder and chairman, in response to his personal experiences with the deaths of his parents, convened a national group of experts and launched the Project on Death in America. This nine-year, $45 million investment in “understanding and transforming the culture and experience of dying and bereavement” in the United States supported career development for academic leaders, professional and public education, the arts, research, clinical care, and public policy in end-of-life and palliative care.76

In combination, the Open Society Institute and the Robert Wood Johnson Foundation programs led to:

■ Career development support for leaders in medicine, nursing, and social work
■ Development and dissemination of medical and nursing curricula in palliative care
■ Technical assistance for palliative care capacity building in American hospitals
■ Development of new models and settings to enhance access to palliative care
■ Regulatory and policy changes supportive of access to quality palliative care through The Joint Commission
■ Investment in consensus efforts to define quality palliative care through the National Consensus Project for Quality Palliative Care and the National Quality Forum
■ Grassroots coalition building in communities across the United States
■ Public outreach through media, including the Bill Moyers four-part PBS series On Our Own Terms: Moyers on Dying

These initiatives collectively marshaled the resources and built the momentum necessary to launch and begin to sustain a new field. Both entities ceased or greatly reduced their funding in the field (the Open Society Institute in 2003 and the Robert Wood Johnson Foundation in 2006). The work of these and other philanthropic foundations is summarized in the table that forms the appendix to this chapter (“Major Foundation Investments in Building Palliative Care”).

THE GROWTH OF PALLIATIVE CARE

The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care is both a philosophy of care and an organized, highly structured system for delivering care. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with decision making, and providing opportunities for personal growth. As such, it can be delivered concurrently with life-prolonging care or as the main focus of care.

National Consensus Project for Quality Palliative Care and National Quality Forum.77
Many social forces are shaping the emergence of the palliative care movement in the United States. These forces, combined with a strategic infusion of hundreds of millions of private sector philanthropic dollars over the last twenty years, have crystallized palliative care as a solution to many problems facing people with chronic conditions and serious illnesses—a solution that did not require a revolution in health care financing. The major factors contributing to the recent rapid growth in the field include:

- The unprecedented increase in numbers and needs of the elderly
- Recognition of the growing numbers of family caregivers and their unmet needs
- The transformation of demands on the health care system from acute care of infections and heart attacks to long-term management of chronic diseases
- Large numbers of baby boomers in leadership roles learning about the failures of the health care system during care for their parents
- The unsustainable rise in per capita and total health care spending due to expensive new technologies and drugs and more people receiving them
- The influence of the right-to-die movement and the attention of the public to high-profile cases such as Karen Ann Quinlan and Terri Schiavo.
- The recurring debate on the pros and cons of legalized physician-assisted dying, precipitated in part by Jack Kevorkian and his activities.
- Broad media coverage (for example, the film Sicko, the Bill Moyers PBS series On Our Own Terms) of bad experiences with the health care system
- The ascendancy of subspecialty medicine and the associated fragmentation in care, coupled with the collapse of primary care in the United States.

The health care sector has seen fifty years of stunning growth through rapid development of and profit from life-prolonging technologies. As these technologies (drugs, procedures, devices, imaging) are routinely applied to chronically ill people with advanced disease—mostly elderly populations, for whom these treatments have increasingly marginal benefit—the nation’s ability to provide access to them will be challenged.

The relief of suffering and the cure of disease must be seen as twin obligations of a medical profession that is truly dedicated to the care of the sick. Physicians’ failure to understand the nature of suffering can result in medical intervention that (though technically adequate) not only fails to relieve suffering but becomes a source of suffering itself.

Eric J. Cassell, M.D., 1982

Palliative Care: A Key Part of the Solution

Palliative care has emerged as both a response and a possible solution. The predominant delivery model of palliative care in the United States is the hospital consultation service involving a team of professionals (typically physicians, nurses, and social workers, with additional contributions from massage therapists, chaplains, psychologists, psychiatrists,
rehabilitation experts, and others as needed) who provide recommendations and support to primary and specialist physicians caring for seriously ill patients in the hospital. Palliative care teams, which vary in composition based on the stage of the program and the size and needs of the institution, focus on assessing and treating symptoms such as pain, fatigue, and depression; communicating with patient, family, and colleagues inside and out of the hospital in order to gain a full understanding of the medical situation and ascertain the patient’s and family’s preferences and needs; developing and communicating a plan of care consistent with the patient’s and family’s needs and preferences; and assuring the necessary coordination, communication, and follow-up to optimize continuity and quality of care throughout the course of the illness.

In the last ten years, much progress has been made:

- Through the National Consensus Project for Quality Palliative Care, leaders in the field established a consensus process and defined guidelines for quality palliative care in 2004. Building on these guidelines, the National Quality Forum (the nation’s public-private entity for determining the quality of health care) has developed a preferred practice framework for the field. Quality guidelines call for extending palliative care upstream from the dying phase, requiring hospice and palliative care programs to form seamless continuums of care between hospital and community (home and nursing home) settings.

- The Joint Commission, the country’s major accrediting body for health care organizations, now requires assessment and treatment of pain as a condition of accreditation, and the Joint Commission is considering release of a new voluntary certificate program for hospital palliative care programs in 2009–2010.

- Palliative care is increasingly understood as appropriate, independent of prognosis, to be offered to patients with complex or advanced illness in light of patient (and family) needs, whether they will live for years or days.

- As of 2006, the American Board of Medical Specialties has recognized palliative medicine as a subspecialty of medicine, with an unprecedented ten primary parent boards.

- More than sixteen thousand nurses have received nursing certification in palliative care.

- Physician, nursing, and social work education, from undergraduate to midcareer professional levels, has been strengthened in the last ten years, primarily through private sector initiatives supported by both national and regional foundations.

- More than 30 percent of American hospitals report having a palliative care program; and of the larger hospitals that serve the majority of patients (those with more than 250 beds), three-quarters reported an active program in 2006.

- The number of patients served by hospice has increased by 162 percent since 1996—to 1.4 million in 2007—and more than 38 percent of all patients in the United States are served by a hospice program before their death.
The topic of serious illness and even death and dying is more commonplace in the media and popular entertainment (for example, *Away from Her*; HBO’s *Six Feet Under*; *My Life Without Me*; *Big Fish*; *The Savages*; *Wit*; *The Year of Magical Thinking*; *The Diving Bell and the Butterfly*).

Medical schools and residency training programs now require some training in aspects of palliative care as a condition of accreditation.

**Medical, Nursing, and Social Work Education**

The remarkable growth in the number of palliative care programs over the last five to ten years has not been matched by growth in the number of trained clinicians to lead and staff these programs. The mismatch between the nature of the patients served by medical professionals (chronically and in hospitals, seriously ill), their needs (expert symptom management, available and responsive communication about goals of care and how to achieve them, practical and psychosocial support for family caregivers, well-coordinated and communicated care across settings), and the inadequacy of training in the content areas necessary to meet their needs is striking.

**PALLIATIVE CARE: 2008**

- Board-certified physicians: 2,883
- Board-certified nurses:
  - RN: 11,268
  - Nurse practitioners: 394
- Postgraduate palliative medicine fellowship programs: 65
- Postgraduate advanced practice nursing programs in palliative care: 10
- Peer-reviewed journals: *Journal of Palliative Medicine*; *Journal of Pain and Symptom Management*; *American Journal of Hospice & Palliative Medicine*; *Journal of Psychosocial Oncology*; *Death Studies*
- Textbooks (English language): More than 20
- Hospital palliative care programs: 1,299 (2006 data)
- Hospices: More than 4,700
- Patients served by hospice: 1.4 million, 38 percent of all deaths (2007 data)

Survey research and reports from patients and their families indicate that physicians, nurses, and social workers—who deliver the vast majority of direct care to chronically and seriously ill patients—are poorly trained to provide effective and timely palliative
care to patients with serious and complex illness. The poor quality of pain and symptom management, doctor-patient communication, and coordination and continuity of care can be traced at least in part to the inadequacy of curricular content in these areas in both undergraduate and graduate medical, nursing, and social work education. It is not reasonable to expect physicians, nurses, or social workers to be expert in knowledge, attitudes, and skills that they were not taught during many years of undergraduate and postgraduate education. Despite little exposure during training, physicians recognize the importance of palliative care to quality health care. In an international poll conducted by the British Medical Journal in 2008, when physicians were asked which of five public health priorities would make the “greatest difference” to health care, palliative care came in a strong first with 38 percent of the vote, ahead of combating drug-resistant infections in poor nations (22 percent), improving care (17 percent) and pain management (12 percent) in the elderly, reducing excess drinking in young women (8 percent), and reducing adverse drug reactions in the elderly (3 percent).

A number of strategies have been employed to improve medical and nursing education in palliative care, including the pursuit of subspecialty status for palliative medicine and nursing; advocacy for changes in undergraduate and graduate medical, nursing, and social work education accreditation standards; and numerous philanthropically funded efforts to train midcareer physicians and nurses.

**Palliative Medicine Specialty Status** In an effort to gain the credibility afforded to other specialties in medicine—status that is necessary to have influence on training curricula, allocation of research dollars, and improved access to quality care for patients and families—palliative care advocates have pursued formal specialty status as a key strategy. Britain was the first country to make palliative medicine a subspecialty, in 1987, followed by Australia, Hong Kong, New Zealand, Poland, Romania, Singapore, and Taiwan. In 2006, the American Board of Medical Specialties, which confers specialty and subspecialty status, approved subspecialty status for palliative medicine in the United States. The first official ABMS-certified board examination for physicians was given in 2008. It remains to be seen how physicians practicing in ten different medical fields will be served by a single examination.

**Nursing Subspecialty Certification** In an effort to standardize and assure the quality of palliative care delivery by nursing professionals, nurses have also developed formal accreditation requirements and certification examinations for nurse practitioners, registered nurses, certified nursing assistants, and licensed practical nurses. In 2007, the American Board of Nursing Specialties approved accreditation for a master’s-level hospice and palliative care certification program that allows certified nurses to bill insurers for their services. Similarly, the National Board for Certification of Hospice and Palliative Nurses successfully fulfilled National Commission for Certifying Agencies’ accreditation requirements for licensed practical nurses and nursing assistants in hospice and palliative care.
Medical School Education  Surveys of medical school deans by the Liaison Committee on Medical Education (the undergraduate medical education accrediting body) and of graduating medical students by the Association of American Medical Colleges in the 1990s showed that palliative and end-of-life care was covered only minimally in the coursework and the clinical clerkships of medical schools, and almost none of it was required.86

Infusing new content areas into an overcrowded and ever-expanding medical and nursing school curriculum has required strategy and persistence, and it remains a work in progress. In 2000, influenced by the 1997 Institute of Medicine report Approaching Death, the Liaison Committee on Medical Education added a requirement for training in end-of-life care and doctor-patient communication. Subsequent surveys suggest that 87 percent of medical schools are providing some curriculum on these topics, but the range of hours required is broad, and the content and impact of the teaching are unknown.87 A 2006 survey conducted by the Association of American Medical Colleges comparing changes in American medical students’ perceptions of their training in palliative care between 1998 and 2006 demonstrated a significant improvement in the proportion reporting that their exposure was at least adequate for care at the end of life (from 71 percent to 80 percent), pain management (from 34 percent to 55 percent), and palliative care (from 60 percent to 75 percent).88 Although it is not possible to know the extent to which medical students’ opinions translate into improved practice, this change in their perceptions is a positive sign.

A recent systematic review of palliative care training in medical schools found that clinical exposure to palliative care and hospice patients, as opposed to lecture-based classroom teaching, was particularly effective in improving student knowledge and attitudes.89 No data are available to assess the number of American medical schools providing mandatory clinical rotations in palliative medicine. Barriers to requiring palliative care clinical rotations in the medical school curriculum include entrenched local politics and habits influencing medical school course content and priorities; lack of palliative care content in medical school certifying examinations and competency evaluations in clinical training rotations; inadequate numbers of palliative medicine faculty to teach quality care for this patient population; and lack of palliative care program staff capacity to provide bedside teaching. Experts in medical education have called for mandatory required coursework in palliative care, increasing the number of palliative care faculty as role models and teachers, and the establishment of academic medical school departments to lead and strengthen these advances.90

Paying for the faculty necessary to provide palliative care teaching for physicians in training has been a challenge. With few exceptions, philanthropy has been the sole investor in developing academic faculty leaders at medical schools and teaching hospitals, and most of this foundation support has concluded. New funding focused on financial incentives (such as loan forgiveness for physicians and nurses who pursue graduate training in palliative care) to build the palliative care workforce is needed. A report of the Center to Advance Palliative Care and the International Longevity Center called for the federal government to provide funding for core palliative medicine faculty at each of the 129 medical schools in the country—an investment of approximately $10.5 million a year over twenty years.91 These faculty members, in turn, will
be charged with educating and training the next generation of physicians, expanding the workforce pipeline, and conducting the research necessary to create a more robust evidence base to guide palliative care clinicians. To date, the necessary legislation has not been passed.

BASIC PRINCIPLES FOR ENHANCING UNDERGRADUATE MEDICAL EDUCATION IN PALLIATIVE CARE

1. The care of dying persons and their families is a core professional task of physicians. Medical schools have a responsibility to prepare students to provide skilled, compassionate end-of-life care. Additional resources will be required to implement these changes.

2. The following key content areas related to end-of-life care must be appropriately addressed in undergraduate medical education. Note: This list will differ according to the setting and, to some extent, the patient population (for example, children versus adults):

   a. Medical education should encourage students to develop positive feelings about dying patients and their families and about the role of the physician in terminal care.

   b. Enhanced teaching about death, dying, and bereavement should occur throughout the span of medical education.

   c. Educational content and process should be tailored to students' developmental stage.

   d. The best learning grows out of direct experiences with patients and families, particularly when students have an opportunity to follow patients longitudinally and develop a sense of intimacy and manageable personal responsibility for suffering persons.

   e. Teaching and learning about death, dying, and bereavement should emphasize humanistic attitudes.

   f. Teaching should address communication skills.

   g. Students need to see physicians offering excellent medical care to dying people and their families, and finding meaning in their work.

   h. Medical education should foster respect for patients' personal values and an appreciation of cultural and spiritual diversity in approaching death and dying.

   i. The teaching process itself should mirror the values to which physicians aspire in working with patients.

Continued
Continued

j. A comprehensive, integrated understanding of and approach to death, dying, and bereavement is enhanced when students are exposed to the perspectives of multiple disciplines working together.

k. Faculty should be taught how to teach about end-of-life care, including how to be mentors and to model ideal behaviors and skills.

l. Student competence in managing prototypical clinical settings related to death, dying, and bereavement should be evaluated.

m. Educational programs should be evaluated using state-of-the-art methods.

Source: Billings and Block, 1997

Graduate Medical Education Postgraduate medical education—internship, residency, and subspecialty fellowship training—is widely acknowledged to have the greatest impact on the development of medical professionals. These are the years when new physicians are charged with direct (albeit supervised) responsibility for the care of patients in teaching hospitals and associated community settings. The hours are typically arduous, and exposure to chronically and very seriously ill and dying patients in acute care hospital settings constitutes a major part of the training experience. These are patient populations with extreme burdens of disease with multiple coexisting illnesses, a high prevalence of symptom distress, and overburdened and exhausted family caregivers. Developing skill in symptom assessment and management, doctor-patient-family communication, and transitions of care for patients and families are obvious priorities for residency training.

Little research has been conducted on the adequacy and impact of graduate medical education in palliative care. Annual surveys of residency training program directors conducted by the American Medical Association indicate that 60 percent of training programs report a “structured curriculum in end-of-life care.” However, no information was sought on the content, the time committed, or the effectiveness of these curricula. A survey of residency programs in family medicine, internal medicine, pediatrics, and geriatrics published in 1995 found that 26 percent of all residency programs in the United States offered a standard course in end-of-life care, almost 15 percent of programs offered no formal training in care of terminally ill patients, only 8 percent required a hospice rotation, and 9 percent offered an elective.

More recent surveys of medical residents found that they perceived their training as adequate to manage pain and symptoms in 72 percent, telling patients they are dying in 62 percent, describing what to expect with the dying process in 38 percent, and responding to a patient’s request for aid in dying in 32 percent. No direct observational data are available to validate whether residents’ perceptions of the “adequacy” of exposure to these topic areas correlates with the knowledge, skills, and attitudes they will need once in practice. In a 2005 survey of residents reporting how they were
In 1997, the Institute of Medicine called for fundamental changes in the content and quality of health professional education through the development of "a cadre of palliative care experts whose numbers and talents are sufficient to: a) provide expert consultation and role models for colleagues, students, and other members of the health professions; b) supply leadership for scientifically based and practically useful undergraduate, graduate, and continuing medical education; and c) organize and conduct biomedical, clinical, behavioral, and health services research." To achieve the IOM’s goals, a policy report from the Center to Advance Palliative Care and the International Longevity Center–USA recommends five years of academic career development support for at least three faculty members at each medical and osteopathic school in the United States. These Palliative Care Academic Career Awards would be modeled after the successful Geriatric Academic Career Awards currently administered by the Health Resources and Services Administration (HRSA), which have funded several hundred new geriatric faculty members since their inception in 1999. No action has been taken on the IOM’s recommendation.93

Exposure to palliative medicine teaching at both undergraduate and graduate levels has improved in the last ten years, presumably as a consequence of increased programmatic support from private sector philanthropy, academic leadership by palliative medicine physician faculty, growing integration of community hospice programs with medical education and the gradual adoption of curricular standards and competencies for medical trainees. As of 2006, more than 80 percent of the member hospitals of the Council of Teaching Hospitals and Health Systems reported a clinical palliative care program.97 The future challenge is to assure that these programs have the capacity and the opportunity to incorporate mandatory clinical rotations for both medical students and residents into their existing clinical responsibilities.

*FACULTY URGENTLY NEEDED*

Nursing Education Other than family members, nurses provide the great majority of care to patients living with chronic and advanced illness. Nurses witness and remain present for patients when physicians and other professionals have left the bedside. Through their presence and their ability to be with patients who are suffering, nurses are in a unique position to reduce the isolation and loneliness that accompany serious illness.
Expertise in symptom assessment and treatment, communication about the primary concerns of patients and families, and assuring well-coordinated and well-communicated care are core competencies for nursing professionals. Unfortunately, an extensive literature on nursing education documents that, as is true of physicians, nurses receive inadequate education in palliative care, at both undergraduate and postgraduate levels. In an effort to improve nursing education, private sector philanthropy has supported work to assess and strengthen textbook and certifying examination content as well as curricular resources and faculty preparation. The End-of-Life Nursing Education Consortium (ELNEC), administered by the American Association of Colleges of Nursing, has developed and widely disseminated palliative care curricular resources for undergraduate, graduate, faculty, and various specialty audiences, including geriatrics, pediatrics, critical care, and oncology. Nursing certification examinations for advance practice nurses, registered nurses, licensed practical nurses, and certified nursing assistants are offered by the National Board for Certification of Hospice and Palliative Care Nurses and more than ten postgraduate master’s-level palliative nurse practitioner programs are now available in the United States.

Social Work Education  Social workers are central to counseling, case management, and advocacy services for persons with serious illness and their family caregivers. With their focus on the psychosocial aspects of illness, they work not only with patients but also with families and others in making decisions about treatment options, marshaling resources, and helping families cope with the serious illness and death of a relative. The demands on social workers have changed over time. A major reason is the rising pressure to shift seriously ill and dying patients out of hospitals “quicker and sicker” and into less resource-intensive settings such as nursing homes and hospices. This pressure to discharge requires social workers to coordinate a broadening array of services and providers and to navigate an ever more complex and changing set of insurance eligibility and payment rules and regulations.

As is true of physicians and nurses, social work students receive little training in palliative care. Several post–master’s degree programs on palliative care for social workers have been developed, a critical resource for training the faculty members needed to teach this content in social work training programs. Competencies to guide the development of curricular content, credentialing criteria, and new initiatives promoting palliative care curricular content requirements are under way through the Social Work in Hospice and Palliative Care Network. In 2008, the National Association of Social Workers and the National Hospice and Palliative Care
Organization partnered to develop the first palliative care credentialing process for social workers.

**Palliative Care Content in Textbooks** One reason that practicing physicians, nurses, and social workers completed their training with so little expertise in core palliative care skills had been the nearly complete absence of these topics from their major textbooks. Several studies analyzed palliative care content in general medical, subspecialty, and nursing textbooks and found little to no content on how to care for patients in the late stages of the major chronic and serious illnesses, other than vague recommendations to provide “supportive care.” A physician or a nurse consulting these texts could be forgiven for assuming that the management of symptoms, planning for a peaceful death, and supporting families and seriously ill patients in the community is somebody else’s job. Many textbook publishers, to their credit, responded quickly and have added to existing chapters or added new chapters in forthcoming editions of their books.

**Activities of Professional Organizations** Standard-setting and accrediting organizations such as the Joint Commission have made major contributions to focusing the attention of institutions on assessment and relief of pain, communication and coordination of care, and support for families. In an important step, the Joint Commission is considering the launch in 2009–2010 of a voluntary certificate program in palliative care, built on the National Consensus Project for Quality Palliative Care’s and the National Quality Forum’s *National Framework and Preferred Practices for Palliative and Hospice Care*. A certification process signals legitimacy and critical mass for hospital palliative care services and is both evidence of and stimulus for the increased importance of palliative care programs in American hospitals.

**Palliative Care in Hospitals** Based on data from the 2008 American Hospital Association annual survey of hospitals, some 31 percent, or 1,299 of 4,136 responding hospitals, answered “yes” to a question asking whether their institution had “an organized program providing specialized medical care, drugs, or therapies for the management of acute or chronic pain and/or the control of symptoms administered by specially trained physicians and other clinicians; and supportive care services, such as counseling on advanced directives, spiritual care, and social services, to patients with advanced disease and their families.” Such programs have increased in number by 106 percent since 2000. The percentage of hospitals reporting a palliative care program varies dramatically by hospital type and geographic region—the larger the hospital, the more likely it is to provide palliative care. Similarly, faith-based hospitals, teaching hospitals, and nonprofit hospitals are significantly more likely to report the presence of a palliative care program, while smaller hospitals, safety net and sole community provider hospitals, for-profit hospitals, and hospitals located in the South of the United States are significantly less likely to report a program. The Veterans Health Administration has made a strong commitment to assuring access to quality palliative care for veterans.
Palliative Care: Transforming the Care of Serious Illness

across the nation, including hospital palliative care services, home-based hospice care, and development of coordinated delivery systems across care settings.

Regions with greater access to hospital palliative care services are associated with lower rates of in-hospital death and intensive care unit use. A 2008 state-by-state report card comparing access to palliative care across the United States is available at www.capc.org/reportcard.

The statistics point to the rising availability of palliative care services at larger hospitals, where the majority of seriously ill Americans receive their care, and the strong presence of programs in teaching hospitals, where medical students, residents, and fellows receive their training (Table 2). The survey does not tell us anything about the quality of these services or about the likelihood that a patient in need actually accesses palliative care. Similarly, the presence of a palliative care program in a teaching hospital represents an opportunity for training but is no guarantee that students and residents are actually exposed to the program. Finally, the striking absence

<table>
<thead>
<tr>
<th>TABLE 2. 2006 American Hospital Association Annual Hospital Survey: Hospitals Reporting a Palliative Care Program</th>
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<tbody>
<tr>
<td><strong>Palliative Care Programs</strong></td>
</tr>
<tr>
<td>1–74 adult beds</td>
</tr>
<tr>
<td>75–149 adult beds</td>
</tr>
<tr>
<td>150–249 adult beds</td>
</tr>
<tr>
<td>250+ adult beds</td>
</tr>
</tbody>
</table>

Hospital size

Joint Commission–accredited | 1118 | 2938 | 38 |
Residency training, ACGME-approved | 503 | 832 | 60 |
Council of Teaching Hospital member | 226 | 288 | 78 |
Catholic Church–operated | 310 | 537 | 58 |
American Cancer Society–approved cancer program | 698 | 1203 | 58 |
For-profit, investor-owned | 57 | 610 | 9 |
Nonprofit, nongovernment | 1015 | 2460 | 41 |
Federal government, including VA | 60 | 94 | 64 |

of palliative care programs in the for-profit and public hospital sector represents a major opportunity for improvement in both quality and efficiency of services in those settings.

**Palliative Care in Nursing Homes**

The demographics of nursing homes are changing with the aging of our country. Residents are staying longer—often for several years—and the number of people dying in nursing homes is also increasing dramatically (currently 22 percent of all deaths in the United States occur in nursing homes, projected to rise to 50 percent by 2020). These trends point to the importance of well-integrated and culturally sensitive palliative care services in nursing homes. Nursing home leaders have called for improvements in advance care planning and pain and symptom management, and better coordination of transitions between hospitals and nursing homes. There are no national survey data on the presence of skilled and trained palliative care professionals or programs in nursing homes, and little on the satisfaction of patients and families with such care. Teno and colleagues reported low satisfaction with pain management, emotional support, and doctor-patient-family communication among families of Medicare patients who died in four settings (hospital, home care, hospice, nursing home), with nursing homes ranking at or near the bottom. Similarily, Bernabei and colleagues reported high levels of untreated pain among nursing home residents with cancer. The financial stress, perceived and real regulatory barriers, staff turnover, and predominance of for-profits in the nursing home industry all pose significant barriers to wider application of palliative care principles and practices. Recent trends in the growth of assisted-living facilities and other less regulated alternatives to nursing home care point to the need for more research on access to quality palliative care across the long-term-care industry. Neither the public nor the private sector has invested adequately in research to identify and test new models to assure access to quality palliative care for this highly vulnerable population.

A report on palliative care practices in a selected group of progressive American nursing homes revealed the emergence of four dominant models:

- Outside palliative care consultants (physicians or advance practice nurses) called in on an as-needed basis
- Hospice staff providing nonhospice palliative care services
- “Training up” of nursing home staff on core palliative care competencies, including symptom assessment and management
- Improved access to the Medicare hospice benefit for residents meeting the six-month prognosis criterion

These models enable development of tools to help other nursing homes develop similar services. Technical assistance and quality guidelines for these models, as well as health professional training to help frontline nursing home providers meet the palliative care needs of their patients, are required. The opportunity and the obligation to ensure
that quality of life and quality of dying are reliable components of nursing home and other long-term care settings in the future remain unmet. Palliative care training and programmatic supports are among the key solutions to this challenge.

**Palliative Care Research**

Despite its remarkable growth, the field of palliative care rests on an evidence base wholly inadequate to guide quality of care. Three Institute of Medicine reports, two National Institutes of Health state-of-the-science conferences, and the report of the research committee of the American Academy of Hospice and Palliative Medicine have all called for major investments in palliative care research, specifically in the areas of pain and symptom management, communication skills, care coordination, and models of care delivery.\textsuperscript{111}

A recent analysis of sources of funding for palliative care found that fewer than 5 percent of palliative care investigators (identified from PubMed keyword searches between 2003 and 2005) received any NIH funding. More than half of published palliative care research reported only private sector philanthropic support, while less than a third reported NIH support; the remaining palliative care research was conducted with no reported extramural funding of any kind.\textsuperscript{112} Compounding this concern, and despite the fact that the leading causes of death and advanced chronic illness in the United States are cancer, dementia, and diseases of heart, brain, lung, and kidney, less than 1 percent of all grants funded by the major NIH institutes were for research on palliative care aspects of these common disease states.\textsuperscript{113}

Reasons advanced to account for the inadequacy of federal funding for palliative care research include the disease-specific focus of most NIH institutes and the associated lack of an NIH institute focused on palliative medicine; the fact that those NIH study sections composed of scientists charged with peer review and scoring of grant proposals include at most one to two palliative medicine researchers; and the associated fact that, unlike our neighbors in Canada, no NIH study section focuses specifically on the science of palliative medicine and no dollars are dedicated to palliative medicine research. Recommendations aimed at redressing this situation include federal funding for palliative care research; the designation of one or more palliative medicine study review sections; and the development of mechanisms similar to those already well established at the NIH such as investigator-initiated research, center grants, and career development awards in palliative medicine.\textsuperscript{114}

Continued support from the private sector is also crucial for pilot studies and career development support necessary to prepare young and established investigators alike to compete for federal funding. In an effort to catalyze these goals, the Kornfeld Foundation in New York City established the National Palliative Care Research Center (NPCRC) in 2005, with additional support from the Brookdale, Ho-Chiang, and Olive Branch Foundations, and the American Cancer Society, the American Academy of
Hospice and Palliative Medicine, and the National Institute on Aging. In the first year, the request for proposals yielded 101 applications for career development awards and pilot and exploratory projects.

THE NATIONAL PALLIATIVE CARE RESEARCH CENTER

The mission of the National Palliative Care Research Center is to improve care for patients with serious illness and to help with the needs of their families by promoting palliative care research. In partnership with the Center to Advance Palliative Care, the center will rapidly translate research findings into clinical practice.

Specifically, the NPCRC provides a mechanism to

- Establish priorities for palliative care research.
- Develop a new generation of researchers in palliative care.
- Coordinate and support studies focused on improving care for patients and families living with serious illness.

In a parallel effort to catalyze palliative care research for cancer patients, the American Cancer Society has recently invested over $1.5 million in palliative care research, established an expert group of palliative care grant reviewers, and received more than 136 applications in response to its first call for proposals. Although a substantial proportion of these proposals scored in the fundable range, because of a lack of funds only 5 percent were awarded. This experience demonstrates a widespread demand for funding for palliative care research, the availability of qualified investigators to conduct it, and the need for a major federal funding commitment.

THE FAMILY CAREGIVER

In American society, family caregiving has become the linchpin of the long-term-care system. The reasons include the growth in numbers of persons surviving into old age with serious chronic conditions and the trend toward deinstitutionalization—maintaining dependent persons as much as possible in their communities rather than nursing homes, and discharging them from hospitals as quickly as possible, preferably to their homes. Complicating matters, families are no longer clustered in the same community; women often work full time, and the current payment system does not cover long-term care unless one is poor enough to qualify for Medicaid or is terminally ill and eligible for hospice.
It is no exaggeration to say that patients living with chronic and complex illness are abandoned by the health care system unless they require hospital care for an acute illness, a brief period of skilled nursing care after a hospital stay, or are terminally ill and eligible for hospice, all of which are covered by Medicare and most commercial insurers. All other patients—that is, the vast majority with multiple chronic conditions or a serious illness—are left to coordinate and oversee their own care, find their own transportation to their doctor’s office, locate a doctor from the shrinking pool of primary care providers, assure communication between all their specialists, check to be sure there are no risks from taking drugs prescribed by multiple providers, find a doctor who accepts Medicare or Medicaid, and, when these responsibilities become overwhelming, call 911 for a trip to the emergency room.

The interim report of the Citizens’ Health Care Working Group (an entity mandated by Congress, with members appointed by the Comptroller General of the United States) reported, after six hearings, thirty-one community meetings in thirty states and the District of Columbia, review of all major public opinion polls focused on health that were conducted between 2002 and 2006, some ten thousand responses to Web polls, and review of five thousand individual commentaries:

A picture has been sketched for us of a health care system that is unintelligible to most people. They see a rigid system with a set of ingrained operating procedures that long ago became disconnected from the mission of providing people with humane, respectful, and technically excellent health care.¹¹⁵

In the absence of an effective health care delivery system, the responsibility for nearly all aspects of a loved one’s care needs falls to families.

Who Are the Caregivers?¹¹⁶

More than forty-four million adults (21 percent of the adult population) provide unpaid care to other adults who are sick or disabled. Spending an average of twenty-one hours a week providing the care, they are by far the largest source of long-term-care services in the country. About a third of these caregivers are elderly themselves.¹¹⁷ The estimated cost equivalent of this uncompensated care (at an estimated hourly rate of $8 an hour) is $257 billion a year—more than three-quarters of the total dollars ($336 billion) spent in 2005 on Medicare.¹¹⁸ Perhaps not surprisingly, nearly nine out of ten seriously ill patients say they need help with the sorts of things not covered by health insurance, such as transportation to the doctor’s office and help with homemaking (buying groceries, cooking, cleaning) (see Figure 8).¹¹⁹

The typical caregiver is a woman in her midforties who works full time and spends at least twenty hours a week providing care to her mother. Roughly 60 percent of caregivers are women, and women are more likely to provide the most demanding kinds of care, such as helping with bathing, dressing, and toileting for the most physically dependent patients. About a third of caregivers (40 percent of women and 26 percent of men) report emotional strain, a major predictor of morbidity and mortality among caregivers.
FIGURE 8. Family Concerns About Quality of Care at the End of Life for Adult Relatives Who Died of a Chronic Illness in 2000 (Percentage of Family Respondents Expressing Concerns).


The Loneliness of the Long-Term Caregiver

In addition to holding a full-time job, I manage all my husband’s care and daily activities. Being a caregiver requires grit and persistence. It took me 10 days of increasingly insistent phone calls to get my managed-care company to replace my husband’s dangerously unstable hospital bed. When the new bed finally arrived—without notice, in the evening, when there was no aide available to move him—it turned out to be the cheapest model, unsuitable for my husband’s condition. In these all-too-frequent situations, I feel that I am challenging Goliath with a tiny pebble. More often than not, Goliath just puts me on hold.

Carol Levine, 1999

Impact of Caregiving on Caregivers

Although the majority of family caregivers report low emotional stress, physical strain, and financial hardship, those taking on high burdens of physical care, who report poor health themselves, and who feel they had no choice in taking on the caregiver role are more likely to report significant emotional strain. Emotional strain in caregivers is
FIGURE 9. Family Caregivers and the SUPPORT Study.

| Patient needed large amount of family caregiving: | 34% |
| Lost most family savings: | 31% |
| Lost major source of income: | 29% |
| Major life change in family: | 20% |
| Other family illness from stress: | 12% |
| At least one of the above: | 55% |


associated with a 63 percent increase in risk of death (see Figure 9), and the Nurses Health Study (a large longitudinal study of more than fifty thousand nurses) found an 80 percent increase in risk of heart attack or cardiac death among nurses caring nine or more hours a week for a disabled or seriously ill spouse.

What Do Caregivers Need?

Caregiver advocacy organizations call for fundamental changes in federal policies addressing family caregiver concerns, including:

- Protection of caregivers from the health and financial consequences of their role
- Building infrastructure for accessible and safe respite care
- Development of family-friendly workplace policies such as flextime, working at home, and job sharing
- Education and training to prepare caregivers for their role
- Access to a reliable and coordinated “medical home” or primary care provider
- Reliable availability of a trained and supervised direct-care workforce
- Coverage for regular professional assessment and reassessment of the long-term care situation at home.

The capacity to give one’s attention to a sufferer is a very rare and difficult thing; it is almost a miracle; it is a miracle.

Simone Weil, Waiting for God, 2000

PAYING FOR PALLIATIVE CARE

The United States spends more than $2 trillion a year on health care, at a per capita spending rate far higher than that of any other developed nation. Despite continued growth in spending, the United States ranks low on a number of quality benchmarks,
including access, quality, equity, and efficiency. At least in part, this paradox can be traced to a fee-for-service payment system that rewards unnecessary subspecialty care as well as excessive and inefficient medical service. Despite the evidence that primary care leads both to better quality and lower costs, the perverse payment incentives and very high levels of medical student indebtedness upon graduation have led to growth in the number of well-reimbursed “proceduralists” (subspecialist physicians who focus on specific procedures) and a shrinking number of poorly reimbursed primary care and generalist physicians.

Palliative care specialists are not proceduralists. Their expertise involves:

- Comprehensive patient and family assessment (for example, levels of pain and other symptoms, and equipment and care needs in the home)
- Provision of treatment designed to meet those needs (for example, pain medications or ordering a hospital bed and visiting nurse services)
- Discussion with colleagues, family members, and the patient about the patient’s condition, the treatment options, and their concordance with the patient’s goals
- Establishment of a feasible care plan
- Assurance that the plan is coordinated and carried out in the setting that best meets the needs of the patient and family

The current fee-for-service payment system does not compensate physicians and other health care professionals adequately for these kinds of cognitive services, even
though they are of higher quality and lower cost than fragmented subspecialty care. In many ways, it fails to pay for cognitive services at all. For example, the current Medicare payment system will not compensate physicians for the conduct of goals-of-care meetings with family members of seriously ill patients, whether in the hospital, in the office, or at home. Nor will Medicare reimburse the necessary collaborative process of decision making or the services of the interdisciplinary team required to deliver quality palliative care. If a clinician (a physician or a nurse practitioner) is not appropriately recognized and compensated for the intensive and repeated coordination and communication required, it should come as no surprise that the necessary communication and coordination seldom occurs.

The average Medicare beneficiary sees an average of six unique physicians, and those with five or more chronic conditions see fourteen different physicians.
Gallup Serious Chronic Illness Survey, 2002

Emotionally demanding and skilled discussions about prognosis, treatment alternatives and their pros and cons, and gaining an in-depth understanding of the patient’s wishes and values are time-consuming but crucial to the development of a rational and patient-centered plan of care. Failure to conduct such meetings results in a default to multiple fee-for-service specialists, each focused on a specific organ system or disease state, with no single professional synthesizing the inputs and taking responsibility for care of the whole patient. Not only is such care expensive, it is all too often of either marginal or no benefit to the patient.

Although palliative care providers do bill Medicare and other payers for the care they provide, the reimbursement for time-intensive but nonprocedural services fails to cover the salaries of these professionals. As a result, the recent growth in hospital palliative care services has been financed not by fee-for-service reimbursement to hospitals and providers but rather by hospital operating budgets. Hospitals have chosen to absorb the costs of palliative care services because they are persuaded by the business case for palliative care—namely, that hospitals will save money by delivering high-quality palliative care to their sickest and most vulnerable patients, helping them to avoid long hospital and ICU stays and costly interventions of marginal or no benefit. In other words, hospitals have underwritten the costs of palliative care programs for cost-avoidance reasons. This is a frail reed on which to base support for a field so critical to quality care of the growing population of chronically and seriously ill patients.

EXPLAINING THE RAPID GROWTH OF PALLIATIVE CARE: QUALITY AND COST

In the chaotic context that is today’s health care system, the growth of and demand for palliative care is nothing short of stunning. Many factors—including substantial private sector philanthropic investment, the perception of the public and health professionals that modern medicine is failing to meet the most fundamental needs of the most seriously
ill, and the persistent search among idealistic professionals for ways of putting the needs of patients and their families first—have contributed to this phenomenon. First among these factors, however, is the positive impact of palliative care services on both the quality and the costs of care provided to seriously ill individuals and their families.

**Palliative Care Is Quality Care**

> The secret of the care of the patient is in caring for the patient.
> Francis Peabody, 1925

The National Quality Forum, a national not-for-profit membership organization created to develop and implement a national strategy for health care quality measurement and improvement, defines quality as health care that meets six goals:

- Patient-centered (based on the patient’s wishes and goals)
- Beneficial (likely to help the patient)
- Safe (not likely to harm the patient)
- Timely (delivered when it is appropriate, not too early and not too late)
- Equitable (available and applied to all who could benefit)
- Efficient (not wasteful of health resources and patient’s time and effort)

The health care quality movement recognizes that high-quality care depends a great deal more on effective systems than on individual behavior. It seeks to develop standards, best practices, and guidelines and to strengthen public reporting so that high-quality care will be routinely available to patients and their families. The evidence makes clear that palliative care delivers high-quality care in terms of benefit to patients, patient-centered focus, safety, and efficiency—but it is not yet timely or equitable.

- It is patient-centered because the palliative care plan is based on the goals and wishes of patients and families.
- It is beneficial; multiple studies have demonstrated reduced symptoms and improved satisfaction among patients (and their families) receiving palliative care as compared with similar patients who are not.
- It is safe; that is, it is not associated with earlier death.
- It is efficient, as demonstrated by reductions in health care utilization and resulting cost savings.

**Palliative Care Is Patient-Centered and Beneficial**

Recent studies confirm that survivors of patients who died in American hospitals, nursing homes, or at home without hospice have significant concerns about quality of care, with hospitals, nursing homes, and home health agencies all ranking substantially worse than hospice (see Figure 10).
Multiple studies have demonstrated the benefits of palliative care in reducing pain and symptom burden and improving patient and family satisfaction with care. For example, a recent study conducted among more than five hundred family survivors of seriously ill veterans demonstrated a marked superiority of palliative care over usual care in terms of emotional and spiritual support, adequacy of information and communication, care at time of death, access to services in the community, support for well-being and sense of dignity, receipt of care in a setting concordant with patient preferences, and relief of pain and symptoms of post-traumatic stress disorder. Another randomized controlled trial of a brochure plus communications and listening intervention for families of dying ICU patients demonstrated significantly less anxiety, depression, and post-traumatic stress symptoms, for the intervention families as assessed ninety days after the death of their loved one.

**Palliative Care Is Efficient**

In addition to the evidence of its positive impact on quality, palliative care has been shown to reduce hospital costs. Most hospitals in the United States are reimbursed by Medicare through diagnosis-related groups (DRGs), by which they receive a single lump-sum payment per hospital stay, regardless of what the stay actually costs the hospital. For example, the DRG payment for pneumonia with complications is the...
same whether the patient is discharged after five days or twenty-five days, and whether the actual total costs of the stay were $3,500 or $35,000. This payment method gives hospitals a clear financial incentive to invest in programs that can safely reduce both length of hospital stay as well as the costs of each day spent in the hospital.

Palliative care lowers costs for hospitals by reducing both the number of days spent in the hospital and the intensive care unit and the use of costly diagnostic and therapeutic interventions of marginal or no benefit to patients, such as imaging studies, pharmaceuticals, and subspecialty consultations. Studies have shown no difference in mortality or other adverse events associated with hospital palliative care, and, at least in the hospice setting, palliative care appears to be associated with both better survival and lower costs.

Palliative care professionals are able to reduce hospitalizations and costly interventions primarily through enhanced communication with patients and their families. They are able to have open discussions about the realities of the illness and its likely course, and the treatment alternatives and their benefits and risks. Palliative care professionals are skilled at eliciting the primary concerns and goals of patients and their families, an understanding that leads to the development of care plans that will optimize the chances of patients’ achieving their goals. This process often results in a different set of decisions by patients and families—decisions that help them use their time optimally and that typically (but not always) involve lower-intensity and lower-cost settings (such as going home with hospice or moving out of an intensive care unit that is no longer benefiting the patient). Recognition of the so-called cost-avoidance impact of palliative care programs in hospitals has been a major influence on their rapid spread. Palliative care is an exemplar of the growing recognition that lower cost and higher quality actually go hand in hand. There remain, however, some concerns about the way palliative care is currently delivered in the United States.

**Palliative Care Is Not Timely**

Though data are lacking, palliative care does not appear to be timely. The data that do exist suggest that about 30 percent of hospice patients are not referred until their last week of life, and 10 percent in their last twenty-four hours of life—too late to have much impact on the experience of their illness. Similarly, though most data are from single-institution studies, a large proportion of palliative care referrals in acute care hospitals occur late in the hospital stay, well after opportunities to assess goals and make care plans accordingly have been missed.

**Palliative Care Is Not Equitable**

As in virtually all other aspects of America’s health care system, palliative care is not equitably accessible, both in terms of geographic location and patient race and ethnicity. Hospice statistics suggest that African American, Hispanic, and Asian minorities are less likely to receive hospice care than whites. Furthermore, there is considerable geographic variation in access to both hospice and palliative care in the United States (see Figure 11).

Note: Rates were adjusted for differences in age, sex, race, and prevalence of twelve chronic illnesses. Excludes Medicare beneficiaries enrolled in managed care plans. Source: Data: Dartmouth Atlas Project 2006. Adapted and reprinted with permission.

THE WAY FORWARD

Building a Continuum of Palliative Care

One could be forgiven for thinking that seriously ill people spend most of their illness in hospitals, since that is the setting where nonhospice palliative care is most frequently provided. Although about 75 percent of Americans actually die in either a hospital or a nursing home, the vast majority of all serious illnesses are lived through at home, and the burden of care is assumed primarily by family members, with minimal support from the insurance system (unless the patient is eligible and ready for hospice care). If a patient is eligible and ready for hospice (that is, willing to give up insurance payment for life-prolonging or curative therapies and certified by two doctors as likely to be dead within six months), comprehensive interdisciplinary palliative care paid for through the Medicare hospice benefit is largely delivered at home. However, for the patient who is ineligible or unwilling to enter a hospice program, in most communities it is all but impossible to obtain palliative care services at home, in a doctor’s office, or in a nursing home.

Although patients and families trying to manage complex and chronic illness clearly need and benefit from care that is carefully transitioned and well coordinated, the current fee-for-service payment system rewards procedures, hospitalization, and multiple
specialist visits. Further, these perverse payment incentives, while rewarding fragmented care in the most expensive settings, simultaneously deny adequate payment for so-called cognitive (non-procedure-based) services involving coordination, communication, and oversight of the patient as a whole person. Because of this lack of appropriate payment incentives, no clear business case for supporting a continuum of palliative care has emerged outside of hospital settings.

Despite the current fragmented and counterproductive reimbursement system, models to provide palliative care across settings have been successfully developed in some communities, primarily through the efforts of strong community hospice program leaders. These hospice leaders have expanded their services to deliver both hospice and nonhospice palliative care across a range of care settings within their communities.

The efforts are exemplified by the work of two well-established and large community hospice programs: the Hospice and Palliative Care Center of the Bluegrass,143 in Lexington, Kentucky, and the Midwest Hospice and Palliative Care Center,144 in Evanston, Illinois. Leaders of these community hospice programs recognized that substantial numbers of patients in hospitals and nursing homes and at home were in need of palliative care but were not receiving it because they were ineligible for, or unwilling to access, hospice care. Over time, both programs developed nonhospice hospital palliative care consultation services, hospital inpatient palliative care units, office- and home-based palliative care practices, and palliative care consultation teams for nursing homes. Thus, no matter what the stage of illness, the diagnosis, the prognosis, or the insurance coverage, patients served by these programs can obtain palliative care where they are and when they need it. This diversification of service lines builds continuity into the system; eventually, the illnesses of most patients progress to a point where they are both eligible for and willing to receive hospice care. The transition from usual care to hospice care is less abrupt and easier for patients and their families when they have gained familiarity with the benefits of nonhospice palliative care.

The leaders of these two programs were able to develop these innovations by focusing on the needs of patients first, working out the payment mechanisms later, and relying on economies of scale and enhanced income (for example, from more and longer hospice stays) in some areas to compensate for losses in others.145 Their programs are a model for what can be accomplished with appropriate leadership and strong community and philanthropic support. However, palliative care will be not be reliably available across the country in all care settings until the financial incentives rewarding hospitalization, specialty care, and high-technology drugs and devices are shifted to a system rewarding coordination, communication, and patient-centered services at home and in the community (see Figure 12).

Policies to Improve Access to Palliative Care within the Current Payment System

In the absence of fundamental change in the way that health care is organized and compensated, incremental efforts to improve quality are necessary. Achieving the goal of assuring access to high-quality palliative care for all Americans who need it—regardless of geography, diagnosis, prognosis, care setting, stage of illness, family situation, or social class—will require more than the innovative programs described above.
It will require:

- A public knowledgeable about what palliative care is and when they should demand it
- Health care professionals with the knowledge, skill, and attitudes necessary to provide palliative care
- Hospitals, nursing homes, office practices, home care agencies, and others equipped with the resources necessary to deliver palliative care services

These requirements have policy implications, as illustrated in Table 3.

**TABLE 3. Policy Recommendations to Improve Access to Quality Palliative Care**

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<tr>
<th>Goals</th>
<th>Policy Recommendations</th>
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<tr>
<td>Patients and families will know what palliative care is and when to demand it.</td>
<td>Federal and private sector investment in a major social marketing campaign</td>
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<tr>
<td>Medical professionals have the knowledge and skills to provide quality palliative care.</td>
<td>Legislation will assure that NIH funding for palliative care will at least quadruple from its current level to approximately 2 percent of the total NIH grants budget. All major NIH Institutes will fund palliative care research. To assure peer review, study sections of grant reviewers responsible for evaluating palliative care research will include at least three palliative care scientists, and one or more palliative care specific study sections will be formed.</td>
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In summary, government and regulatory policy is required to bring the palliative care innovation to scale. Success will be achieved when all patients with advanced illness and their families can reliably access high-quality palliative care no matter where they live, what illness(es) they have, what their stage of disease, and where they need care. Policy solutions range from the quick and easy (career development awards for palliative medicine and nursing faculty; lifting the cap on GME dollars for palliative

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<tr>
<td>Regulatory and accrediting bodies responsible for undergraduate and</td>
<td>Regulatory and accrediting bodies responsible for undergraduate and postgraduate medical, nursing, and other health professional education will mandate adequate and required curricular content and time commitment to palliative care skills and knowledge.</td>
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<td>postgraduate medical, nursing, and other health professional</td>
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<td>education will mandate adequate and required curricular content and</td>
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<td>time commitment to palliative care skills and knowledge.</td>
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<td>Both the federal and private sector will support junior faculty</td>
<td>Both the federal and private sector will support junior faculty palliative care career development awards similar to the Geriatric Academic Career Award.</td>
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<td>palliative care career development awards similar to the Geriatric</td>
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<td>Academic Career Award.</td>
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<td>Reimbursement will be commensurate with complexity for cognitive</td>
<td>Reimbursement will be commensurate with complexity for cognitive and prolonged professional services through establishment of palliative care professional current procedural terminology (CPT) billing codes.</td>
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<td>and prolonged professional services through establishment of</td>
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<tr>
<td>palliative care professional current procedural terminology (CPT)</td>
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<td>billing codes.</td>
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<td>Lift the government cap on hospital graduate medical education (GME)</td>
<td>Lift the government cap on hospital graduate medical education (GME) training slots to assure salary support for ACGME-accredited palliative medicine fellowship training programs. Develop additional private sector support for palliative medicine fellowship training.</td>
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<td>training slots to assure salary support for ACGME-accredited</td>
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<td>palliative medicine fellowship training programs. Develop additional</td>
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<td>private sector support for palliative medicine fellowship training.</td>
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<td>Hospitals and other care settings are equipped to deliver and support</td>
<td>Hospitals and other care settings are equipped to deliver and support palliative care services.</td>
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<td>palliative care services.</td>
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<tr>
<td>Change regulatory and accreditation requirements so that health care</td>
<td>Change regulatory and accreditation requirements so that health care institutions must deliver quality palliative care as a condition of accreditation.</td>
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<td>institutions must deliver quality palliative care as a condition of</td>
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<td>accreditation.</td>
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<tr>
<td>Medicare and other payers create payment incentives for hospital</td>
<td>Medicare and other payers create payment incentives for hospital and provider delivery of palliative care to appropriate patient populations.</td>
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<td>and provider delivery of palliative care to appropriate patient</td>
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<td>populations.</td>
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<td>Public and private investment in development and testing of clinical</td>
<td>Public and private investment in development and testing of clinical models for effective efficient delivery of palliative care in nursing home, office practice, home care, and long term-acute care settings.</td>
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<tr>
<td>models for effective efficient delivery of palliative care in</td>
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<tr>
<td>nursing home, office practice, home care, and long term-acute care</td>
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<td>settings.</td>
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medicine fellowships accredited by the Accreditation Council for Graduate Medical Education; increasing NIH allocations for palliative care research) to more complex long-term efforts (such as payment reform, accreditation requirements, and curricular change).

BACK TO BASICS: WHAT ARE THE ENDS OF MEDICINE? WHAT ARE THE ENDS OF A SOCIETY?

We are all in this together. Consider the kind of health care system we would design for our future selves if we had the choice and could not know what family we’d be born into. It would include health care available to everyone regardless of social class or income, with priority for surviving childbirth and childhood, treatment of curable and remediable illness, assurance of relief for those who suffer, and practical support for family caregivers and community resources. Even if our societal resources are infinite, all of us will still die. All of us are profoundly interdependent and interrelated. All of us need our families to help care for us when our turn comes, and all of us rely on societal infrastructure and resources to help us when we are in need, protect our families from financial ruin imposed by illness, and assure us an equal shot at a long and healthy life.

Palliative care has emerged in American health care on the platform of these truths. It cuts through our cherished myths of personal immortality and the false god of the technology imperative. It recognizes that serious illness and the suffering that accompanies it is a universal human condition, affecting every one of us. It is designed to address the fact that serious illnesses in modern America are almost always chronic—we live for a very long time with what will eventually kill us. It recognizes that families are the mainstay of the ill and that families need information, guidance, and support to help them fulfill their responsibilities. It strives to redress the fragmentation and discontinuities of the health care system, recognizing that the patient and the family still need care when they leave the hospital or the doctor’s office. Palliative care wins trust because it begins and ends with what patients and families say they want and need: relief from pain and other symptom distress; kind and respectful treatment; information necessary to retain control over decisions; help for families; and an opportunity to strengthen relationships with others, seeking meaning through human connection “as deep calls to deep in the roar of waters” (Psalms 42:7).
# APPENDIX

## Major Foundation Investments in Building Palliative Care

<table>
<thead>
<tr>
<th>Research</th>
<th>Description</th>
<th>Funding Sources</th>
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</thead>
<tbody>
<tr>
<td>SUPPORT, which clearly demonstrated poor quality care in terms of pain, communication, family burden, health care utilization</td>
<td>Robert Wood Johnson Foundation</td>
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<tr>
<td>Research on spirituality during serious illness and near the end of life</td>
<td>Fetzer Institute; Nathan Cummings Foundation</td>
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<tr>
<td>Grief Research: Report on Gaps, Needs, and Actions</td>
<td>Open Society Institute</td>
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<tr>
<td>Improving pain management through research, training, technical assistance</td>
<td>Mayday Fund</td>
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<tr>
<td>Establishment of the National Palliative Care Research Center</td>
<td>Initial funding by Emily Davie and Joseph F. Kornfeld Foundation; subsequent funding by Olive Branch Fund, Brookdale and Ho Chiang Foundations, American Cancer Society, American Academy of Hospice and Palliative Medicine, and National Institute on Aging</td>
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<thead>
<tr>
<th>Leadership Development</th>
<th>Description</th>
<th>Funding Source</th>
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<tbody>
<tr>
<td>Faculty Scholars Program of the Project on Death in America: 87 grantees at more than 60 medical and nursing schools, building the academic and clinical field</td>
<td>Open Society Institute</td>
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<tr>
<td>Social Work Leadership Development Awards</td>
<td>Open Society Institute</td>
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<tr>
<td>Palliative Medicine Leadership Forum: Annual retreat to strengthen and build academic physician leaders</td>
<td>Robert Wood Johnson Foundation</td>
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<td>Faculty Development in the Veterans Health Administration</td>
<td>Robert Wood Johnson Foundation</td>
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<tr>
<td>Physician Education</td>
<td>2,000 EPEC (Education in Palliative and End-of-Life Care) graduates, and millions trained by these graduates</td>
<td>Robert Wood Johnson Foundation</td>
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<td>Improving Residency Training in End-of-Life, Medical College of Wisconsin</td>
<td>Robert Wood Johnson Foundation</td>
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<td>Promoting “caring attitudes” among health professionals; improving communication and self-care skills in physicians in training</td>
<td>Arthur Vining Davis Foundation</td>
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<td></td>
<td>Harvard Medical School's Program in Palliative Care Education and Practice: Intensive two-week midcareer training; more than 400 graduates as of December 2008</td>
<td>Robert Wood Johnson, Good Samaritan, Jane and the late Charles Weingarten, and Green Family Foundations; Open Society Institute</td>
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<td>The Initiative for Pediatric Palliative Care</td>
<td>Open Society Institute; Aetna, Schwartz, Nathan Cummings, and Argosy Foundations</td>
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<td></td>
<td>End of Life/Palliative Education Resource Center (EPERC): Provides curricular materials on the Web</td>
<td>Robert Wood Johnson Foundation</td>
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<td></td>
<td>Stanford University Medical School Faculty Development Program, 10/1/98–9/30/02</td>
<td>Department of Health and Human Services; Department of Veterans Affairs; John A. Hartford, Robert Wood Johnson, and Josiah Macy Foundations</td>
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<td></td>
<td>Palliative medicine fellowship training</td>
<td>Emily Davie and Joseph S. Kornfeld Foundation; Open Society Institute</td>
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<tr>
<td>Nursing Education</td>
<td>As of December 2007, 4,200 graduates who have educated more than 125,000 nurses using train-the-trainer model via End of Life Nursing Education Consortium (ELNEC)</td>
<td>Robert Wood Johnson Foundation, Aetna Archstone, Oncology Nursing and California HealthCare Foundations, Open Society Institute, and the National Cancer Institute.</td>
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<td></td>
<td>Nursing Leadership Consortium on End of Life Care</td>
<td>Open Society Institute</td>
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<tr>
<td><strong>The Development, Status, and Future of Palliative Care</strong></td>
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</table>

<p>| End-of-life educational materials for nursing school faculty and practicing nurses, University of Washington School of Nursing | Robert Wood Johnson Foundation |
| Strengthening Nursing Education in Pain Management and End-of-Life Care, City of Hope National Medical Center | Robert Wood Johnson Foundation |
| <strong>Exploring New Care Models</strong> | <strong>Promoting Excellence in End-of-Life Care: 22 demonstration projects delivering palliative care to special populations (e.g., children, mentally ill, the poor, Native Americans), medical conditions (Alzheimer’s, HIV/AIDS), and challenging settings (prisons, rural areas, nursing homes, cancer centers)</strong> | Robert Wood Johnson Foundation |
| <strong>Capacity Building</strong> | Center to Advance Palliative Care: Disseminates technical assistance and tools in support of hospital palliative care programs, 1999–present | Robert Wood Johnson, John A. Hartford, Aetna, JEHT, Milbank Rehabilitation, Brookdale, Donaghue, Fan Fox and Leslie R. Samuels, Ho Chiang, and Archstone Foundations; Department of Veterans Affairs, 1999–present |
| Investment in palliative care program capacity building in New York City hospitals | Open Society Institute; United Hospital Fund; Greenwall, Fan Fox and Leslie R. Samuels and JM Foundations |
| Investment in palliative care program capacity building in California | Archstone and California HealthCare Foundations |
| United Hospital Fund of New York City: Hospital Palliative Care Initiative and Community-Oriented Palliative Care Initiative in New York City | Open Society Institute; United Hospital Fund; United Way of New York City |</p>
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<tr>
<th>Initiative</th>
<th>Description</th>
<th>Institutions</th>
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<tr>
<td>Initiative to Improve Palliative Care for African-Americans</td>
<td>Developed research education policy agenda and built coalitions to improve access</td>
<td>U.S. Cancer Pain Relief Committee; Open Society Institute; Dade Community Foundation; Foundation for End-of-Life Care</td>
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<tr>
<td>Duke Institute on Care at the End of Life</td>
<td>Develops professional and public educational materials, coalitions, and outreach through faith and cultural communities</td>
<td>Open Society Institute; Robert Wood Johnson Foundation</td>
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<tr>
<td>Palliative Care in Prisons and Jails</td>
<td>Development of National Guidelines (Guiding Responsive Action in Corrections at End-of-Life)</td>
<td>Robert Wood Johnson Foundation</td>
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<tr>
<td>National Consensus Project Guidelines for Quality Palliative Care</td>
<td>Robert Wood Johnson, Arthur Vining Davis, California HealthCare, Charitable Leadership, and Milbank Rehabilitation Foundations; Mayday Fund</td>
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<tr>
<td>Development of the National Quality Forum’s national framework for palliative and hospice care quality measurement and reporting</td>
<td>Robert Wood Johnson Foundation</td>
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<tr>
<td>Textbook Project</td>
<td>Reviews of palliative care content in major medical, nursing, and social work textbooks, demonstrating near complete absence of palliative care content, resulted in addition of content to many major texts</td>
<td>Robert Wood Johnson Foundation; Open Society Institute</td>
</tr>
</tbody>
</table>
### Public Outreach

Public education and community organizing about end of life care (the Last Acts campaign), including a four-part PBS program, *On Our Own Terms: Moyers on Dying*, seen by more than 20 million people; the Writers Project, which developed scripts and story lines on care of the dying for popular television; technical support from the Media Resource Center for the film *Wit*; and American RadioWorks’ *The Hospice Experiment*

| | Robert Wood Johnson, Nathan Cummings, Kohlberg, John D. and Catherine T. MacArthur, and JL Foundations; Open Society Institute; Laurance S. Rockefeller Fund; Mutual of America Life Insurance Company |

| | Community grief and bereavement initiative: Model interfaith, schools, prison, and community programs in support of bereavement |
| | Open Society Institute |

| | American Pain Foundation: To improve consumer access to information about pain and its management |
| | Open Society Institute; Anderson Family Living Trust; Disabled American Veterans Charitable Service Trust; Gess Donor Fund; Kamish Living Trust; Nathan Bruckenthal Memorial Trust; Reflex Sympathetic Dystrophy Hope Group; California Community; Emmert Hobbs, Herb Block, Mary R. and Joseph R. Payden, Medtronic, Milbank Rehabilitation, and William and Joanne Moeller Foundations |

| | Grief at School Program: Trained school-based professionals to identify and help grieving children. |
| | Open Society Institute |

<p>| Professional Journals | Supported a series of articles on palliative care topics in major medical and nursing journals |
| | Robert Wood Johnson Foundation |
| Accreditation and Regulation | Supported addition of pain as a fifth vital sign as Joint Commission accreditation requirement for hospitals and nursing homes | Robert Wood Johnson Foundation |
| Medical Licensure Examinations | Supported the National Board of Medical Examiners to assess and add palliative care questions to the U.S. Medical Licensing Examination | Robert Wood Johnson Foundation |
| Health Policy | Community-State Partnerships to Improve End-of-Life Care: Developed community coalitions in 21 states | Robert Wood Johnson Foundation |
| | Systematic analysis of drug regulations and their impact on pain management via the Pain &amp; Policy Studies Group | Open Society Institute |
| Pioneer Programs in Palliative Care | 9 case studies | Milbank Memorial Fund; Robert Wood Johnson Foundation |
| | Palliative Academic Career Awards: Policy report calls for federal funding of career development awards for junior faculty in palliative medicine | Open Society Institute; Greenwall Foundation |
| Protecting Americans from religious restrictions at end of life; promoting policy to strengthen advance care planning | Nathan Cummings Foundation |
| Americans for Better Care of the Dying: Social, policy, and professional reform | Open Society Institute |</p>
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<tr>
<th>Support for palliative care professional membership organizations (American Academy of Hospice and Palliative Medicine, Hospice and Palliative Nursing Association) and for Social Work Summit on Palliative and End-of-Life Care</th>
<th>Open Society Institute</th>
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<tr>
<td>Support for National Hospice and Palliative Care Organization</td>
<td>Open Society Institute; Robert Wood Johnson Foundation</td>
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<tr>
<td>Support for standards for training, practice, and certification by the American Board of Hospice and Palliative Medicine; led to establishment of American Board of Medical Specialties–approved subspecialty for palliative medicine</td>
<td>Open Society Institute; Robert Wood Johnson Foundation</td>
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<tr>
<td><strong>Spirituality and Palliative Care</strong></td>
<td><strong>Templeton Foundation</strong></td>
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<tr>
<td>George Washington Institute for Spirituality and Health</td>
<td><strong>Building Private Sector Investment</strong></td>
</tr>
<tr>
<td><strong>Collaborative to Advance Funding in Palliative Care</strong></td>
<td>Open Society Institute; Robert Wood Johnson, Emily Davie and Joseph S. Kornfeld, Fan Fox and Leslie R. Samuels, and Altman Foundations along with 15 other participant foundations</td>
</tr>
<tr>
<td><strong>Arts and Humanities</strong></td>
<td>Engaged artists in diverse media on topics of serious illness and death</td>
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</tbody>
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Palliative Care: Transforming the Care of Serious Illness

NOTES


17. Oral History Project of the John C. Liebeskind History of Pain Collection of the UCLA Louise M. Darling Biomedical Library, manuscript collection no. 127.16.


32. Saunders, C. 1958 Available at: http://www.bmj.com/cgi/content/full/331/7509/DC1


Palliative Care: Transforming the Care of Serious Illness

52. Whatever its legality or illegality, the practice is not unknown. A national representative survey of American physicians conducted in 1996 found that since entering practice, 18.3 percent of the physicians reported having received a request from a patient for assistance with suicide and 11.1 percent had received a request for a lethal injection (a practice that is illegal in all states.). Sixteen percent of the physicians receiving such requests reported that they had written at least one prescription to be used to hasten death, and 4.7 percent said that they had administered at least one lethal injection.


63. SUPPORT, 1995.

64. SUPPORT, 1995.


The Development, Status, and Future of Palliative Care


77. National Consensus Project for Quality Palliative Care; National Quality Forum.


74 Palliative Care: Transforming the Care of Serious Illness

93. Institute of Medicine, 1997.
108. Teno JM, Claridge BR, Casey V, et al. 2004
The Development, Status, and Future of Palliative Care


Palliative Care: Transforming the Care of Serious Illness


146. The number and diversity of foundation and philanthropic investments in the field of palliative care is remarkable. This list was culled from websites, publications, and personal communications with program leaders and funders and is not intended to be a complete chronicle. Apologies to funders who should have been but are not included in this list.