

Transforming Death in America

A State of the Nation Report



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*With thanks to Victoria Weisfeld, whose leadership and wisdom
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ACKNOWLEDGMENTS

Funded by The Robert Wood Johnson Foundation, *Last Acts* is a national coalition dedicated to improving care and caring near the end of life. In the five years of the program's existence, it has grown to include more than 700 organizations. In early 2000, *Last Acts* commissioned this report detailing the current status of death and dying in America—the state of the nation—and offering some suggestions about further changes that can be anticipated.

This report was developed in response to the well-informed and provocative publication, *Health and Health Care 2010: The Forecast, The Challenge*, prepared by the Institute for the Future (IFTF) and published in San Francisco in 2000. Describing alternative scenarios, *Health and Health Care 2010* offered a glimpse into the future of health care in the United States. We are indebted to the IFTF for providing the framework we used to consider how end-of-life care will evolve.

The future of end-of-life care portrayed in this document is based on information from a variety of sources, including data provided by the IFTF report, published and unpublished literature from the end-of-life field, and from interviews with nationally-known experts in the end-of-life and related fields. We appreciate the time, expertise, and wisdom our many key informants¹ were willing to share with us.

¹A list of key informants is included as Appendix 1.

FOREWORD

How will our society wend its way to a time and place when our lives may end with dignity? What will propel us—who will help us? How long is the path our society must follow toward improved caring for people who are at life's end? Can we speed our course?

We face few questions so poignant as those posed about how, as a society, we meet the end of life. *Last Acts* has not only set about to address these questions but also to take on the daunting task of making better answers possible.

In 2000, the Institute for the Future (ITF) published *Health & Health Care 2010, the Forecast, the Challenge*, funded by The Robert Wood Johnson Foundation. In it, the ITF forecast the future of many aspects of health and health care—from medical technology to the health care workforce, from demographics to public health. From that work has come reports on the futures of mental health, the chronically ill, children's health, and the elderly. The ITF is indebted to *Last Acts* for applying the work of *Health & Health Care 2010* to end-of-life care and for the honor of working with a group of purposeful and powerful advocates.

Significant demographic and social changes identified in the 2010 forecast are at hand that may speed improvements in end-of-life care if we, as a society, can capitalize on these changes:

- Americans are becoming more ethnically diverse;
- the population of those over the age of 65 is growing;
- empowered new consumers are aging; and
- traditional family caregivers are working.

Americans Are Becoming More Ethnically Diverse

By 2010, over 30 percent of the U.S. population will be people of color. Diversity varies by region. In the West, nearly 45 percent of the population will be African-, Hispanic-, Asian-, or Native-American, and the South and Northeastern United States are changing similarly. This diversity of cultures suggests that work on end-of-life issues really does have to be local and responsive to culture in order to garner the grass roots support necessary to bring about change.

Key to all work in health and social welfare is determining what it is about a person's culture that is germane to the issue at hand. What cultural aspects must we integrate to build strong momentum to support dying well?

The Population of those over 65 Is Growing

Nearly 40 million Americans will be 65 or older by 2010. The baby boomers—those born between 1946 and 1964—will begin to turn 65 in 2011. Their numbers will drive an elder boom by 2020 when more than 16 percent of the resident population—roughly 53 million people—will be 65 years old or older (U.S. Census Bureau). These boomers can become a critical force in improving

end-of-life care because, as they seek care for their parents and later for themselves, they will impose their own values on their search for end-of-life care.

Empowered New Consumers Are Aging and Will Seek End-of-Life Care

In 1998, the IFTF published a report on what it called the *new consumer*—those with at least one year of college, an annual household income of at least \$53,000 in 1998 dollars, and a computer. *New consumers* want choices, control, information, and service. *New consumers* will be the majority of health care consumers by 2005, and patients who don't take an active role in their own care will be a thing of the past. Aging baby boomers are over-represented among *new consumers*. As the baby boomers face end-of-life issues for themselves and their parents, they will expect providers to supply information and to work in collaboration with them to make decisions about care. Active, empowered consumers can be a true force for change if their energy can be harnessed.

Traditional Family Caregivers Are Busy

Historically, adult daughters and elderly wives have typically cared for the ill and dying. That profile has changed in recent times. Although women are not the only family caregivers, society has relied heavily upon them. Today, the majority of women work. By 2015, more than 80 percent of women between the ages of 25 and 54, 60 percent of women ages 55 to 64, and 10 percent of those over 65 will be working outside the home. Almost everyone shouldering the burden of caregiving will be working. Thus, caregivers will need a different support system than what was available for their mothers and grandmothers.

Driving toward Evolution in End-of-Life Care

Together, increasing ethnic diversity, aging, the empowered *new consumer*, and women's changing lives may create a greater demand for better end-of-life care and services. At the very least, there is a group that will soon be ripe to receive the information necessary to create a national dialogue on end-of-life care—a group for whom such issues are becoming increasingly important.

The Barriers Ahead

To meet the needs of people within our increasingly diverse society can seem daunting. The challenge is to learn what it means to be a patient and a patient's family member in different cultures. By 2010, when the first baby boomers reach 65, they will have grown accustomed to living healthy active lives, in which costly medical interventions have brought spectacular results. They may demand heroic intervention at the end of life that may or may not mean better care or better outcomes. The needs of working family caregivers, female or male, are likely to mount, and the fragmented services available today will need to coalesce to support them.

THE WORK AHEAD

Honoring the Individual

This will increasingly require us to understand the influences of ethnicity and culture on how people view end-of-life issues and how well they do or do not advocate for death on their own terms.

Engaging the New Consumer

The *new consumer* can be a mighty force for change in end-of-life care. How their desire for self-determination and self-care plays out will depend upon reaching them and ensuring that the choices surrounding these issues are made salient to them.

Supporting Caregivers

Family caregivers will need support in juggling work, family, and potentially their own illnesses and deaths, as they face the duties necessary to provide skilled care to dying loved ones. The demographics and psychographics are in favor of driving change in the end-of-life arena. The question—the challenge—is whether society can use these forces to move toward cultural change, new policy initiatives, social support, and health care financing that advance quality end-of-life care for all.

The Institute for the Future is honored to have contributed in a small way to the work of *Last Acts* and stands poised to write about the future of end-of-life care as it evolves.

Katherine Haynes Sanstad
Director
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San Francisco, CA

EXECUTIVE SUMMARY

Since publication of the landmark SUPPORT study¹ documenting serious deficiencies in care for dying patients and their families and the subsequent publication (1997) of *Approaching Death: Improving Care at the End of Life*,² the Institute of Medicine's comprehensive report on end-of-life care, there have been notable improvements in the quality of care for dying individuals and their families as well as in access to such care. *Transforming Death in America* describes changes that have taken place in recent years and the current status of end-of-life care in the United States. The description was developed after an extensive review of the end-of-life literature and Web sites as well as numerous interviews with experts. Based on an analysis of the current environment and the Institute for the Future's detailed prognostication for health and health care during the next ten years, the authors of *Transforming Death in America* discuss further changes that are likely in end-of-life care as well as recommendations for expediting these changes.

Considering the deep-seated antipathy of Americans to facing death and dying, change is occurring relatively quickly in end-of-life care. Public discussion of the issues is increasing and is now focused on how best to care for dying individuals and their families. End-of-life care is "on the radar screen." Consensus is growing among experts about the definition of good end-of-life care, referred to as the gold standard. Most agree that quality treatment for pain and other physical symptoms; a supportive, comfortable physical and emotional environment; care that respects the individual's dignity and need for self-determination; and attention to spiritual issues—all within the context of the individual's and his or her family's experiences, values, and preferences—are central to good end-of-life care. This paradigm for quality care near the end of life corresponds to a more general shift in the nation's orientation from health care that is disease-centered to health care that is more patient-centered.

Transforming Death in America details three areas of particularly significant change in end-of-life care during the past few years. These areas—professional readiness, system readiness, and cultural readiness—constitute the infrastructure for the provision of quality care. Specifically, the gaps in professional education are being addressed by significant increases in material about end-of-life care in both general and specialized medical, nursing, and social work journals. Medical and nursing textbooks are beginning to include more content about end-of-life care. Several noteworthy

¹Support Principal Investigators. "A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)." *Journal of the American Medical Association* 274:1591–1598, 1995.

²Field, M.J., Cassel, C.K., eds. Committee on Care at the End of Life, Division of Health Care Services, Institute of Medicine. *Approaching Death: Improving Care at the End of Life*. Washington, D.C.: National Academy Press, 1997. Noting that too many people experience significant and needless pain and suffering at the end of life, *Approaching Death* highlights a number of deficiencies, including that:

- Legal, organizational, and economic obstacles impede reliably excellent care at the end of life;
- The education and training of physicians and other health care professionals do not provide them the attitudes, knowledge and skills required to care well for dying patients;
- Current knowledge and understanding are insufficient to guide and support the consistent practice of evidence-based medicine at the end of life; and
- People are not comfortable talking realistically about the end of life and have not learned to value the period of dying.

projects have focused successfully on integrating teaching about the care of dying patients, particularly pain management, into existing medical school curricula.

New opportunities for postgraduate medical training now exist, and there is a certification exam in palliative medicine. Foundation-funded programs have produced several cohorts of physician exemplars who provide role models for medical students, postgraduate trainees, and practicing physicians. A major continuing education program, *Education for Physicians on End-of-Life Care (EPEC)*, will ultimately reach every practicing physician in America. A similar program, *End-of-Life Nursing Education Consortium (ELNEC)*, has just begun for nurses. New initiatives are emerging to address education about care and caring near the end of life for social workers, clergy, and pharmacists. Dedicated educators and practitioners have planted the seeds for improvements in education about the care of dying people in nearly every important domain.

In terms of system readiness, hospitals around the country are developing inpatient and outpatient palliative care programs. The hospice community is addressing barriers to utilization of hospice care and working with nursing homes to address barriers to integrating hospice care in long-term care facilities. National programs such as the *Last Acts* campaign have crafted principles for the delivery of palliative care, and numerous groups have either created or adopted voluntary guidelines, policies, and standards for quality end-of-life care.

Laws in virtually every state support the use of advance care planning, as does the federal government. Initiatives in many states seek to improve pain management and enhance consumer education about end-of-life issues. These efforts support important community-based activities. Finally, Congress and the state legislatures are beginning to acknowledge the serious funding gaps for end-of-life care; experts now are searching for solutions to close these gaps. All of these initiatives take the country many steps closer to more coherent and compassionate care for patients and families.

Death is often referred to as the last societal “taboo.” Because it is such a difficult subject for Americans, the least progress among the three domains has been made in creating cultural readiness. However, even in this arena, observable change is occurring. For example, journalists have been reporting about end-of-life issues beyond Jack Kevorkian for a number of years. The popular media, particularly television, is increasingly focusing on end-of-life care, and several best-selling books have been published that draw public attention to death and the dying process. Still, there is little evidence of consumer activism on this issue.

In addition to the professional, systemic, and cultural changes that are improving end-of-life care, there are at least eight external factors that create a context in which additional change will happen. Chief among them are America’s changing demographics, increasing ethnic diversity, and turmoil in the U.S. medical delivery system.

Transforming Death in America documents progress in recent years in the quality and availability of end-of-life care for patients and their families. It also examines the distance the nation must cross before the gold standard for end-of-life care is universally available. Focusing on the future, *Transforming Death in America* notes that the seeds for crucial changes in professional and system

readiness have been planted and are beginning to grow. Cultural readiness, particularly consumer engagement, now should be a focus for attention and resources. The authors offer nine high-priority recommendations for community- and individual-level efforts to assure that the changes that have begun will continue and flourish:

1. Strengthen community-specific efforts and focus resources on these efforts. The communities can be geographic, religious, or other communities of interest, but they must be located, at least in part, at a grass-roots level and involve people committed to each other for some clear reason.
2. Respond to the challenge of the lengthening post-retirement phase of life, or the “third age.” Take specific steps to embrace the “dignity and creativity, the social importance and public significance, the self-respect and civic virtue of older people,”³ and promote ways for older people to achieve meaning during this time.
3. Recognize ethnicity. Ensure access for ethnic populations and assure sensitivity to the cultures and values of these diverse populations.
4. Respond to vulnerable populations. Ensure that the needs of vulnerable populations, particularly the frail elderly, the very poor, and those with little education, are addressed.
5. Proactively address the growing crisis in paid and family caregiving. Families pay a significant toll when there are insufficient health system and community-based supports.
6. Attend to language. Develop end-of-life initiatives that are responsive to issues of language, both to assure that translations from English are accurate and attuned to nuance and to assure that messages are meaningful in light of the culture and values of the people for whom the translation is made.
7. Promote incentives. Since facing one’s mortality appears to have a heavy price, the value and benefits that are also inherent must be made clearer. Address the age-old question: What’s in it for me? People who face the end of their lives and create good last chapters find it rewarding. Those rewards need to be better understood and promoted.
8. Create and implement an appropriate research agenda. Change is generally expedited by data supporting its necessity and direction. The goal of the research agenda would be to identify gaps in current knowledge and address them as rapidly as possible.
9. Support durability. Efforts must be sustained at a local level by involving community leaders and by creating measurable outcomes. Success must be recognized and celebrated, but put in context, as the task will be ongoing and unlikely to be completed in our lifetime.

³Laslett, P. “The Third Age and the Disappearance of Old Age,” p. 10 of *Preparation for Aging*, Heikkinen, E., et al. (eds.) New York: Plenum Press, 1995.

INTRODUCTION AND OVERVIEW

The ground-breaking 1995 SUPPORT study¹ was the first rigorous, widely publicized study to document serious deficiencies in the way America cares for dying people and their families. It was followed in June 1997 by the Institute of Medicine (IOM) report, *Approaching Death: Improving Care at the End of Life*,² a comprehensive analysis of the myriad deficiencies in end-of-life care. *Approaching Death* highlighted the following as fundamental deficiencies:

- legal, organizational, and economic obstacles that impede reliably excellent care at the end of life;
- education and training for physicians and other health care professionals that do not teach them the attitudes, knowledge, or skills required to care for dying patients;
- knowledge and understanding that are insufficient to guide and support the consistent practice of evidence-based medicine at the end of life; and
- public discomfort with discussions about death or the potential for positive experiences near the end of life.

The documentation was incontestable, and the conclusions were clear: far too many people needlessly suffered physically, psychologically, spiritually, and socially at the end of life. Their preferences regarding care were too frequently ignored and their families often left in emotional despair and financial ruin.

However, change had begun during the period of time covered by these studies and has continued since their completion. The right to refuse medical treatment and public awareness of physician-assisted suicide gained increased attention during the 1990s.

In 1990, in the case of *Cruzan v. Director, Missouri Department of Health*,³ the United States Supreme Court recognized that a competent individual has a constitutional right to refuse unwanted medical treatment regardless of whether the person is terminally ill, including the right to withdraw life-sustaining treatments or to refuse to begin them. The *Cruzan* case received considerable attention, as did Supreme Court decisions in two 1997 cases (*Washington v. Glucksberg* and *Vacco v. Quill*)⁴ that addressed constitutional challenges to state laws making it a crime to assist in a suicide. In these cases, the Supreme Court upheld the right of states to legislate whether to ban or to permit assisted suicide. The Supreme Court concluded that the distinctions between assisted-suicide and either withholding or withdrawing life-sustaining treatment were “important,” “logical,” and “rational.” As a result, it is constitutionally permitted for states to allow com-

¹Support Principal Investigators. “A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT),” *Journal of the American Medical Association* 274: 1591-1598, 1995.

²Field, M.J., Cassel, C.K., eds. Committee on Care at the End of Life, Division of Health Care Services, Institute of Medicine, *Approaching Death: Improving Care at the End of Life*. Washington, D.C.: National Academy Press, 1997.

³*Cruzan v. Director, Missouri Department of Health*, 497 U.S. 261 (1990).

⁴*Washington et al. v. Glucksberg et al.*, 117 U.S. 2258 (1977). *Vacco, Attorney General of New York et al. v. Quill et al.*, 117 U.S. 2293 (1977).

petent persons to refuse life-sustaining treatments while banning physician-assisted suicide. Amidst all of the publicity about the activities of Dr. Jack Kevorkian, Oregon became the only state to legally permit, in limited circumstances, physician-assisted suicide.

The SUPPORT study results and *Approaching Death* received well-deserved attention from health care professionals and federal and state policy makers. Many people concluded that the interest in physician-assisted suicide was directly related to the serious problems associated with obtaining good end-of-life care in the United States. Thus, the increased focus on physician-assisted suicide and the Supreme Court cases created a strong impetus for improving the way America cares for dying individuals and their loved ones.

Similarly, demographic trends are contributing to this impetus and making improved end-of-life care an imperative. The most rapidly growing elderly group in the United States consists of people age 85 and older. The end-of-life trajectory has changed, and while lives are longer, in their later years people frequently confront chronic, progressive diseases that impose functional limitations and require substantial care. Good end-of-life care is among the many needs of the nation's older citizens.

The changing demographics also highlight the looming shortage of caregivers. At a time when the need for caregiving is increasing dramatically, the shortfall includes licensed professionals such as nurses, other paid assistants and aides, and unpaid family members. As the need for caregiving grows, the percentage of the population that is in the labor force is shrinking. The fact that caregiving is poorly paid and hazardous makes it particularly unattractive to workers who have other options. The shortage of paid caregivers is compounded by the fact that family support may also not be available because families are having fewer children and have become increasingly fragmented and dispersed.

In the face of the increasing momentum for improvement in end-of-life care, change now is occurring relatively rapidly. Describing the state of the nation, experts speak of a time of fertile chaos. There is considerable activity, and it is a struggle to keep abreast of new developments. The results of a 1999–2000 environmental scan⁵ show considerable consensus on two points. First, the landscape has changed dramatically since the SUPPORT study findings and *Approaching Death* were issued. Second, there is far more to do to assure that good end-of-life care is reliably available in the United States.

In terms of progress, the level and quality of public discussion in the United States have changed dramatically, and end-of-life issues are now “on the radar screen.” The discussion has shifted from Jack Kevorkian and physician-assisted suicide, to serious efforts to figure out how best to care for dying people and their loved ones. Professional education has been an area of particular activity and progress. Pain management and medication issues are becoming better understood.

Nonetheless, greater strides are needed in research, finance, and health-system reform, as well as in public-awareness and engagement. No one suggests that good end-of-life care has become the

⁵Initial presentation by Margaret Ann Metzger to *Last Acts* Strategic Planning Committee on April 5, 2000, at Lansdowne Resort, Leesburg, Virginia.

norm. In fact, experts' views diverge widely on the significance, to say nothing of the sustainability, of the changes already made. Views differ substantially about whether the barriers to good end-of-life care are fully understood; whether the American taboo against contemplation or discussion of death has been successfully breached; and the extent to which *sustainable* progress has occurred.

To some extent, these divergent opinions are caused by differences in expectations. How goals are defined and how the change process is understood influence expectations. It is easier to appreciate the extent of the progress to date—the infrastructure that is being built to support and sustain further change—if the broad scope and difficulty of achieving the desired goal is understood. Significant improvement in end-of-life care is a large and ambitious goal that requires a shift in social and cultural orientation toward illness, caregiving, dying, death, and grief. The process of sustainable cultural change takes a generation or more.

Although experts differ on the significance and sustainability of the changes we see, most experts agree that we are striving toward the goal of creating routine availability and ease of access to what is now considered the gold standard for care near the end of life. Much thought has been devoted to what this gold standard includes. As expressed in *A Vision for Better Care at the End of Life: Five Principles of Palliative Care*,⁶ the growing consensus suggests that good end-of-life care means early access to excellent care and caring that addresses physical, psychological, spiritual, and social needs. It permits each person to experience a dying process—long or short—that comports with his or her own values, needs, and preferences. Good end-of-life care acknowledges the uniqueness of each person and of each person's death, and includes the following elements:

1. Pain and other physical and psychological symptoms should be alleviated and comfort maximized by medical care that conforms to best-practice standards and is consistent with the person's values and preferences.
2. The physical and emotional environment should be as pleasant and supportive as possible and include time spent with loved ones and other people of choice.
3. Dying persons and their families should be cared for in a manner that respects inherent dignity.
4. Dying persons should be able to exercise personal autonomy (control) to the extent desired and feasible.
5. Dying persons should be able to explore issues of meaning and spirituality, with support from others, as desired.

This gold standard is quite consistent with a fundamental shift in our overall understanding of health and health care.⁷ The shift involves expanding the biomedical model that seeks primarily to defeat disease and find cures for acute episodic illnesses to a model that places heavy emphasis on patient-centered care, that recognizes death as a life-cycle event, and that gives attention to chronic and terminal diseases that have no cure. Figure 1 compares the salient features of these models.

⁶*A Vision for Better Care at the End of Life: Five Principles of Palliative Care* is a shorter, consumer version of *The Precepts of Palliative Care* developed by the Last Acts Task Force on Palliative Care, December 1997, copies of which are available at www.lastacts.org.

⁷*Health and Health Care 2010: The Forecast, The Challenge, Institute for the Future*, Jossey-Bass Publishers, San Francisco, 2000. See Chapter 12.

Figure 1
Characteristics of a Shift in the Conception of Health and Health Care

OLD MODEL

Definition: Health as physical health and the absence of disease

Goal: To find a cure for disease

Context: Acute episodic illness and treatment of disease

Value: Defeat death

EXPANDED MODEL

Definition: Health as wellness, including mental, social, spiritual, and physical health

Goal: To promote functional capacity and well-being

Context: Includes chronic illness and treatment of the whole person as well as acute illness and treatment of disease

Value: Prevent illness, injury and untimely death, relieve suffering, and care for those who cannot be cured

The gold standard for end-of-life care builds on this expanding understanding of health and health care by emphasizing more than the physical and by treating the dying person in the context of his or her family and the family's needs.

The technology needed to attain this gold standard for care near the end of life is currently available. We can achieve the care we seek. However, such care cannot yet be presumed or assured. At least two major cultural shifts must occur in order to make this standard the norm. We must change the American culture, which is so death-denying that progress is difficult, and we must change the culture of the health care system so that the needs of dying patients and their families become a higher priority.⁸

In summary, there have been notable improvements in the way America cares for dying individuals during the past decades. The dedicated organizations and individuals creating these changes can look with pride on their work. As this report will describe, professional education, public awareness, and health care services related to end-of-life care are beginning to flower. There are good reasons to hope and expect that dying in the United States will become a substantially better experience than it has been.

Still, there is a long way to go before people in this country can count on high-quality care and caring near the end of life. This report presents the authors' picture of the future of end-of-life care and the impact of current trends. The authors conclude by highlighting nine high-priority recommendations for community- and individual-level efforts to ensure that the changes that have begun will continue and flourish.

⁸Based on a discussion of the "Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)," by the prominent bioethicist, Daniel Callahan, at the first *Last Acts* National Leadership Conference in March 1996.

STATE OF THE NATION— DEATH AND DYING IN AMERICA

This section of the report focuses on developments in each of the following three domains:

1. **Professional Readiness:** Training the interdisciplinary team.
2. **System Readiness:** Developing supportive environments within medical institutions, guidelines and accreditation standards, and supportive public policy, legislation, and regulation, including the areas of payment and financing.
3. **Cultural Readiness and Public Engagement:** Making people aware of the components of good end-of-life care and empowering them to expect and demand such care.

Progress in each of these domains will create the infrastructure essential for improving end-of-life care, so that it more closely approaches the gold standard. But the process of change is analogous to a three-legged stool: progress will be expedited if development across the three domains can be achieved and synchronized. To the extent that development lags in one or more domains or is absent entirely, progress is substantially slowed, if not toppled.

OVERALL CHANGE

Current efforts to improve end-of-life care are happening amidst heightened interest in end-of-life issues and a sense that improvements are both possible and urgent. This climate results largely from the notable achievements of recent decades. The infrastructure for change at the clinical level is falling into place. Medical- and nursing-school curricula, as well as continuing education programs, are being developed and have become increasingly available, along with opportunities for at-the-bedside experiences with end-of-life care and caring. The legal environment has changed significantly, and laws in virtually every state support the use of advance directives and advance care planning.⁹

Joanne Lynn, M.D., reminds us of the depth of change that has taken place:

When I first started working in hospice in 1978, most cancer patients came to hospice with terrible pain and had never been given any opioid medication (narcotics). Today that would be scandalous. Some cancer patients still don't get adequate pain treatment, but virtually all have elementary use of opioids. In 1976, our society framed the request of Karen Quinlan's parents to stop her ventilator as a question of whether she might be said to have the "right to refuse treatment." Now, no one doubts that every patient has that right.¹⁰

However, as Linda Emanuel, M.D., told the Senate Special Committee on Aging:

We have made some progress in the last decade, but we are working on the effects of an entire era that denied death and found suffering invisible, or at best annoying, and we have a long way to go.¹¹

Drs. Lynn and Emanuel speak to basic changes over recent decades, and data from earlier baseline studies are available. While the experts agree that some change has happened, measuring change over time has been problematic. The general parameters are fairly obvious, but trend data

⁹Weisfeld, V. and Kaplan, K. *Last Acts Strategic Plan: 2000–2003*.

¹⁰Testimony of Dr. Joanne Lynn to the Senate Special Committee on Aging on July 17, 2000, during hearings on *The End of Life: Improving Care, Easing Pain & Helping Families*.

¹¹Testimony of Dr. Linda Emanuel to the Senate Special Committee on Aging on July 17, 2000, during hearings on *The End of Life: Improving Care, Easing Pain & Helping Families*.

are not readily available. Baseline studies generally have not been repeated, and although some repeat measurements may be made, current work tends to focus on measuring new parameters to establish “benchmarks” for further evaluation.

Many key informants also are concerned that the changes that have occurred will not be sustained unless they become the established norm before media and professional and public attention turn to other issues. The more desirable situation is described by Jack Schwartz, J.D., director of health policy development for the Maryland State Attorney General’s Office. “Good palliative care needs to be considered as fundamental as basic cleanliness and sanitation. Once it is that established, there may still be a lapse or failure from time to time, but you can be sure the problems will get the attention and priority required to assure that they are fixed immediately.”

PROFESSIONAL READINESS: TRAINING AND CREDENTIALS

Education of health care professionals about care for dying patients and their families has been profoundly lacking. There is inadequate training in pain and symptom control; psychological, social, and spiritual support for patients and families; and communicating with patients about palliative care options. These shortcomings present major barriers to good end-of-life care. However, efforts to improve this situation, particularly within medicine, are gaining increased professional legitimacy. Numerous completed and ongoing efforts are instilling physicians and nurses with the knowledge, skills, and attitudes needed to bring about clinical improvement in end-of-life care.

One example is the Faculty Scholars Program developed by The Open Society Institute’s Project on Death in America (PDIA). This program supports outstanding clinicians, educators, and researchers in developing new models for improving the care of the dying and in creating new approaches to palliative care education. Since its inception in July 1994, the Faculty Scholars Program has supported 78 faculty scholars, representing 46 medical schools in the United States, 4 medical schools in Canada and 3 nursing schools. The Faculty Scholars Program has enhanced the visibility of its scholars, who receive the recognition and support that are so critical to becoming more effective leaders and mentors within their respective fields.

The faculty scholars, through academic and clinical excellence, are institutionalizing change in their own hospitals, medical schools, hospices, nursing homes, and professional organizations.

The Professional Literature

The professional literature now strongly reflects increased attention to the care of dying individuals. Interest in the *Journal of Palliative Medicine*, first published in 1998, is high, and its subscriber base has increased rapidly. Effective in 2001, the *Journal of Palliative Medicine* is affiliating with the American Association of Hospice and Palliative Care Medicine, thus increasing circulation by as many as 1,400. Mary Ann Liebert, Inc., the *Journal of Palliative Medicine*’s publisher, notes that its reader list has at least doubled every year and reports it to be one of the publishing house’s fastest-growing publications. Other journals, such as the Web-based *Innovations in End-of-Life Care*, *The Journal of Palliative Care*, *The American Journal of Hospice and Palliative Care*, and *The Hospice Journal*, also are gaining attention.

The general-interest medical literature also reflects increased attention. *The New England Journal of Medicine* has been publishing articles concerning end-of-life issues for a number of years. The November 15, 2000 issue of *The Journal of the American Medical Association (JAMA)* was entirely devoted to end-of-life issues. *JAMA*, which is widely read by medical professionals, has committed to publishing a case-based series of articles on end-of-life topics. *The Western Journal of Medicine* is planning a series of related articles as part of its evidence-based medicine review to start during the summer of 2001. The series will be available in full at www.ewjm.com.

Physician Education

Improvements have been made in all levels of physician education. Medical students, interns, residents, and fellows now are more likely to receive training in end-of-life care. Opportunities are increasing for already-practicing physicians to improve their end-of-life knowledge and skills.

An outstanding example of new educational opportunities for already practicing physicians is Education for Physicians in End-of-Life Care (EPEC), a program initiated by the American Medical Association under the leadership of Dr. Emanuel and now based at the Northwestern University School of Medicine under Dr. Emanuel's leadership. The EPEC project defined core competencies and designed a modular series of curricular material based on them. This material and the training model are grounded on the following premises:

- end-of-life care involves core skills and attitudes needed by physicians across the country;
- it takes too long to wait to educate and send enough medical students into the field;
- physicians learn best in a collegial forum (with their peers); and
- educating practicing physicians requires the use of high-quality and substantive, clinical material that is readily applicable to patient care.

As of the end of January 2001, the EPEC team had trained approximately 850 physician leaders, selected from all 50 states and having institutional backing, to implement further EPEC training. Drawn from data collected through March 2000, 600 of these newly trained teachers have, by conservative estimate, reached approximately 60,000 (10 percent of the total number of physicians in the United States).

In addition, through mailings and publications, EPEC has touched approximately half of the country's practicing physicians and has communicated with all of the medical schools. The ultimate goal of EPEC is to reach every practicing physician in the United States.

Medical Textbooks

Training shortcomings have been compounded by the lack of helpful information on caring for patients at the end of life in top-selling medical textbooks. Textbooks are crucial in training medical students and are authoritative references for clinicians. A 1998 review of the 50 top-selling textbooks in multiple medical specialties found that most disease-oriented chapters contained little or no end-of-life content.¹² This study confirmed earlier reviews of small numbers of medical

¹²Rabow, M.W., Hardie, G.E., Fair, J.M., McPhee, S.J. "End-of-Life Care Content in 50 Textbooks from Multiple Specialties," *JAMA*, February 9, 2000, Vol. 283 (6): 771-78.

textbooks indicating that end-of-life care was not being covered adequately.¹³ The study's investigators contacted editors and publishers to determine whether any of the following changes have been made or are currently planned:

- added end-of-life focused chapter(s) to existing textbooks;
- expanded or added end-of-life content within existing chapters;
- revised indexes to include end-of-life key words; and
- added cross-references to make existing end-of-life content more accessible.

Stephen McPhee, M.D., indicates that, based on current information from the textbooks' publishers and editors, improvements have been or will be made in 36 percent of the textbooks that were reviewed. At a 1999 *Last Acts* national meeting, awards were made for the textbooks judged to have the best end-of-life content. Additional awards were presented at the *Last Acts* national leadership conference in February 2001 to recognize nursing textbooks, medical textbooks, a pharmacy textbook, and one publisher for the most substantial improvement in end-of-life content.¹⁴ The *Last Acts* Provider Education Committee, which oversees this ongoing awards program, expects the program to spur more improvements.

Faculty Development

According to Susan Block, M.D., the results of curriculum research concerning the availability and prevalence of end-of-life training for medical students, interns, and residents suggest "many opportunities for improvement at all levels of training." However, the shortage of faculty trained and comfortable to teach the subject impedes rapid improvement. A week-long faculty development program designed to educate faculty about end-of-life issues is now offered by Harvard Medical School, and a month-long program is offered at Stanford Medical School.

In addition, the Medical College of Wisconsin has launched the End-of-Life Physician Education Resource Center (EPEC), an online community of educational experts and a central repository for educational materials and information about end-of-life issues. Located on the Web at www.eperc.mcw.edu, EPEC helps physician educators locate high-quality, peer-reviewed training materials relevant to undergraduate, graduate, and/or continuing physician education.

Curriculum Content in Medical Education

Several surveys of U.S. medical schools conducted between 1975 and 1993 revealed the schools' uneven provision of education about care of the dying. For example, according to the American Medical Association's Liaison Committee on Medical Education (LCME), during academic year 1993–1994, only 5 of the 126 U.S. medical schools offered a separate required course in the care of the dying. Most schools used part of a larger required course to prepare medical students to treat dying patients (although such preparation was generally minimal), 26 schools provided this preparation as a separate elective course and 40 schools offered it as part of an elective course. The remaining 17 schools covered end-of-life care through an alternative educational experience, such as a hospice clerkship.¹⁵ More recently, the LCME provided (see Figure 2) survey data about

¹³For example, see Carron, A.T., Lynn, J., Keaney, P. "End-of-Life Care in Medical Textbooks," *Ann Intern Med*, January 5, 1999, Vol. 130 (1): 82–6.

¹⁴Lists of the 2001 and the 1999 award winners are included as Appendix 2.

¹⁵"Treating the Dying Patient," *Arch Intern Med*, June 26, 1995, Vol. 155: 1265–1269, citing Liaison Committee on Medical Education, *Annual Medical School Questionnaire, Part 2*, Chicago, Ill.: American Medical Association; 1993–1994.

Figure 2
Medical School Courses

(More than one response could be chosen)

SUBJECT	SEPARATE COURSE	PART OF A REQUIRED COURSE	ELECTIVE COURSE
Death and Dying			
1997–1998	4	121	35
1999–2000	5	118	44
Pain Management			
1997–1998	1	105	34
1999–2000	1	113	44
Palliative Care			
1997–1998	0	97	24
1999–2000	3	109	33

whether the 125 LCME-accredited medical schools teach the subjects of death and dying, pain management and palliative care as separate, required courses, as part of any required courses, or as separate, elective courses.¹⁶

In 1999–2000, the LCME also inquired about whether certain topics related to care of the terminally ill were covered during required lectures and conferences for all students. The following reflects the number of schools sending an affirmative response for each of the listed topics:¹⁷

Symptom Control:	97 schools
Advance Directives:	12 schools
Ethical Issues:	123 schools
Communications with Patients and Families:	120 schools

These data strongly suggest that adequacy in end-of-life care education for medical students remains quite variable and is improving only slowly. “Small numbers of students can, if they choose, get excellent, intensive exposure to state of the art palliative medicine. The vast majority, however, still have inadequate exposure and training,” says Dr. Block.

As medical schools begin to strengthen their end-of-life and palliative care curriculum content, there also have been creative efforts to convey important messages about care and caring near the end of life to medical school communities. For example, the *W;t* Educational Initiative, funded by The Fan Fox and Leslie R. Samuels Foundation and directed by Kenneth Rosenfeld, M.D., and Karl Lorenz, M.D., has brought professional theater companies to medical schools around the country. These theater companies do readings of Margaret Edson’s Pulitzer Prize-winning play *W;t* for large groups of students, house staff, and faculty. Each reading is preceded by a special lecture on end-of-life care and followed by facilitated, small-group discussions in which the actors participate.

¹⁶E-mail dated February 1, 2001, to Margaret Metzger.

¹⁷E-mail dated February 1, 2001, to Margaret Metzger.

Surveys also show that students get little exposure to end-of-life care in their medical school clinical experiences. In a 1997 *JAMA* article, Drs. J. Andrew Billings and Susan Block presented data suggesting that:

While nearly all medical schools offer some formal training about end-of-life care, there is considerable evidence that current training is inadequate, most strikingly in the clinical years. Teaching about palliative care is received favorably by students, positively influences student attitudes, and enhances communications skills. However, curricular offerings are not well integrated; the major teaching format is the lecture; formal teaching is predominantly pre-clinical; clinical experiences are mostly elective; there is little attention to home care, hospice and nursing home care; role models are few; and students are not encouraged to examine their personal reactions to these clinical experiences.¹⁸

Based on a 1997–1998 survey of two Harvard Medical School graduating classes, Dr. Block indicates that third- and fourth-year students, on average, had limited experiences in providing ongoing care to patients who were dying. The experiences they did have—often involving participation in CPR efforts—were frequently brief and traumatizing. Sixty-three percent of the students reported some symptoms of post-traumatic stress disorder, which they related to these deaths. Dr. Block is conducting additional survey work and anticipates having more up-to-date data by early 2002.

One of the earliest initiatives focused on improving medical education about end-of-life care was a project funded by The Greenwall Foundation and implemented by Partnership for Caring. The project, Integrating Teaching about End-of-Life Care into Existing Medical School Programs, provided a laboratory for 12 medical schools in which they could experiment with various approaches to improving existing curricula about end-of-life care. The experiences of this project were instrumental in guiding development of further work in this area.

In addition, issues of spirituality are receiving increased attention in U.S. medical schools. In 1992, only three courses on spirituality and medicine were offered. Today, nearly 80 medical schools teach courses on spirituality and health. A major focus of these courses is the spiritual aspects of care in chronic and terminal illness. Christina Puchalski, M.D., director of an award program that has influenced the development of these courses, notes, “These courses help teach our students to be compassionate caregivers and to continue to care even when disease-specific therapy is no longer available or desired.”

LCME’s medical school accreditation standards published in 2000 state that, “Clinical instruction should cover all organ systems, and must include the important aspects of preventive, acute, chronic, continuing, rehabilitative, and end-of-life care.” Inclusion of this statement in the standards is a milestone indicating the increased recognition of end-of-life care as an important element of medical education. However, the requirement itself is very broad and contains no clear standards. “Medical schools are interpreting the requirement in different ways,” says Dr. Block.

Dr. Block’s research indicates that the lack of systematic training in end-of-life care continues during internship and residency. Residents have limited opportunities to learn from role models, and see few examples of what excellent end-of-life care can offer to patients and their families. Improvements in residency training programs are under way through an initiative called Improving

¹⁸Billings, J.A., Block, S. “Palliative Care in Undergraduate Medical Education,” *JAMA*, Sept. 3, 1997, Vol. 278(9): 733–738.

Residency Training in End-of-Life Care, running from 1998–2002 at the Medical College of Wisconsin. Directed by David Weissman, M.D., this initiative is designed to integrate end-of-life content in more than 200 residency programs. It begins with the development of teams of change agents in each of the participating institutions. Improvements have included the addition of clinical hospice and palliative care rotations, training in end-of-life communication skills, new lecture series discussing pain and symptom control, and faculty development programs.

One noteworthy residency program is the Program on Resident Education to Promote Awareness and Respect at the End-of-Life, a palliative care education program that has been conducted at the Durham Veterans Administration hospital and the Duke University Medical Centers for several years. Among other experiences, medical residents attend an intensive retreat on palliative care designed to teach pain and symptom control and communication with patients at the end of life.¹⁹

Credentials

Currently, there are a small number of opportunities to study palliative medicine as a specialty and a limited number of palliative care fellowships, although the Accreditation Council for Graduate Medical Education does not yet accredit them. As a result, Medicare will not pay for the training, which impedes further development of such programs.

The American Board of Hospice and Palliative Medicine (ABHPM) began offering a certification examination in 1996. As of January 2001, 779 physicians had passed the examination. Over the next several years, the ABHPM will be working with the American Board of Medical Specialties to make palliative medicine a recognized specialty. There remains a division of opinion among physicians as to whether palliative medicine should become a separate specialty or sub-specialty, or should be promoted as a competency required for many types of physicians.

The Accreditation Council for Graduate Medical Education requires that internal medicine residents have patient care experiences in geriatric medicine. It also requires pain management, end-of-life care and advance care planning. In addition, geriatrics, neurology, and internal medicine are the recognized specialty training programs having the most end-of-life care requirements. Family medicine programs also include end-of-life content. Oncology includes some end-of-life care requirements, primarily focused on ethics and pain. In contrast, a review of specialty requirements conducted by Drs. Weissman and Block indicates that, at present, critical care, cardiology, pulmonary, radiation oncology, general surgery, and neurosurgery training include little, if any, end-of-life content.

Linda Blank, vice president of the American Board of Internal Medicine, indicates that about 10 palliative and end-of-life care questions were incorporated in the blueprint for the 2000 American Board of Internal Medicine Certification Examination in Internal Medicine.

Nursing Textbooks

Nurses often have the most contact with dying patients, and the need to educate nurses about end-of-life care is well-recognized. From 1997–2000, the City of Hope Medical Center in Duarte, Cal-

¹⁹Testimony of Dr. James Tulsky on July 17, 2000, on *The End of Life: Improving Care, Easing Pain & Helping Families*, before the Senate Special Committee on Aging.

ifornia, sponsored a program called Strengthening Nursing Education in End of Life Care with three main goals:

- to improve end-of-life content in textbooks;
- to ensure the adequacy of pain management and end-of-life content in the National Nursing Licensing Examination; and
- to support nursing organizations' efforts to promote nursing education and practice in the areas of pain management and end-of-life care.

This project resulted in a number of publications documenting the shortcomings in nursing textbooks with respect to palliative care, end-of-life, and pain management content.²⁰ Project director Betty Ferrell, Ph.D., F.A.A.N., says that substantial changes have already been made to approximately 30 percent of the textbooks reviewed and that changes are being considered for future editions of most of the others.

Nursing Education

An outgrowth of the project is the End-of-Life Nursing Education Consortium (ELNEC) project, which is preparing a core of expert nurse-educators and coordinating national nursing efforts in end-of-life care. The ELNEC project is a partnership between the American Association of Colleges of Nursing and the Los Angeles-based City of Hope. ELNEC began in February 2000 and will continue for three-and-a-half years. The initial call for applicants led to an overwhelming response from more than 400 undergraduate nursing faculty members. Eight, three-day courses are currently scheduled for 550 baccalaureate and associate degree faculty, who can facilitate integration of end-of-life nursing care in basic nursing curricula. These courses have the potential to reach 115,500 nursing students throughout the United States in the first year following faculty training. Two of the eight courses are designed for 225 continuing education providers. These courses have the potential to reach 135,000 practicing nurses through continuing education and staff development programs. The eighth course is scheduled for January 2003 for state board of nursing representatives and is designed to strengthen their commitment to encourage end-of-life care education and practice initiatives. In addition, five ELNEC courses will be offered in conjunction with *Last Acts* regional meetings in 2001 and 2002, adding 500 clinicians trained in the ELNEC curriculum.

In 1999, the Nursing Leadership Consortium on End-of-Life Care (the "Consortium") brought together key national nursing organizations to develop a coordinated and collaborative nursing agenda within the areas of practice, policy, research, and education to improve end-of-life care. Funded by PDIA, the Consortium identified the need to train and increase leadership among nurses as a strategic priority. Building on the priorities set by the Consortium and the commitment and strength of nursing specialty organizations representing over 600,000 nurses, a project known as the Nursing Leadership Academy for End-of-Life Care also is being funded by PDIA. Based in the Institute for Johns Hopkins Nursing, the Nursing Leadership Academy for End-of-Life Care is designed to develop a cadre of expert nursing educators, coordinate national nursing

²⁰Ferrell, B., Virani, R., Grant, M., Juarez, G. "Analysis of Palliative Care Content in Nursing Textbooks," *Journal of Palliative Care*. 16:1/2000, 39–47. Ferrell, B., Grant, M., McCaffery, M. "Analysis of Pain Content in Nursing Textbooks," *Journal of Pain and Symptom Management*. 19:3/March 2000, 216–228. Ferrell, B., Virani, R., Grant, M. "Analysis of End-of-Life Content in Nursing Textbooks," *Oncology Nursing Forum*. 26:5/June 1999, 869–876.

efforts in end-of-life care, and facilitate the dissemination of a core curriculum that provides practicing nurses with the basic knowledge and skills needed to care appropriately for dying patients.

Social Worker Education

Social workers often have the opportunity to work with dying patients and their families but, historically, have not received professional education and training about end-of-life issues. A recent survey of faculty from 30 schools of social work found that few students have access to electives on care of the dying and the bereaved and that faculty have trouble attaining support for research in this area. At the same time, social work students are urgently seeking to learn more of this content because their work so often involves interaction with those who have life-threatening illnesses or are coping with other losses in their lives.²¹

While doctors and nurses have been working for five years or more to survey and update their approaches to education, curriculum development, and research about end-of-life, social work is only now beginning to move along a similar learning curve. PDIA's Social Work Leadership Development Awards have provided project grants to 23 social workers involved in a wide range of training and research and will provide up to seven more awards in 2001. The grantees collaborate with 18 of the 163 masters-degree programs in the United States. These awards focus on strengthening the interdisciplinary work of social workers, physicians, and nurses. Awardees from all three disciplines will participate in annual conferences as well as other efforts to promote dialogue and collaboration.

Another new national social work initiative that is under way combines the efforts of The John A. Hartford Foundation Social Work Geriatric Initiative, the Counsel on Social Work Education, the Society for Social Work and Research, the Association of Oncology Social Workers, and other national social work organizations to participate with PDIA's Social Work Leadership program. The initiative will develop a coordinated approach to promoting end-of-life care in social work practice, education, research, and policy.

Clergy and Spirituality

The importance of the clergy and issues of faith and spirituality to people with terminal illnesses and their families has been receiving increasing recognition. Dr. Puchalski explains that "Spiritual issues are often the most important issues people face at the end of life. People seek to find meaning and purpose in the midst of suffering. It is important that our society and systems of care provide for the expression of people's spirituality."

In 1998, Dr. Puchalski designed and sent a survey to 270 schools that are members of the Association of Theological Schools. The results, based on a 70 percent response rate, indicate that while most of the programs have some topics or lectures on death and dying the curricula needs to include more on the subject.

²¹Christ, G., Sormanti, M. "Advancing Social Work Practice in End-of-Life Care: A Survey of Practitioners and Academicians" *Social Work in Health Care*, 30:2/1999, 81-99. Kramer, B., "Preparing Social Workers for the Inevitable: A Preliminary Investigation of a Course on Grief, Death and Loss" *Journal of Social Work Education*, 34:2/1998, 1-17.

In the summer of 1998, Dr. Puchalski convened a consensus conference of religious leaders and chaplains of many different faiths. The results of this consensus conference included:

- learning objectives and methods of teaching courses on end-of-life care to clergy in training;
- policies to empower clergy in the health care setting; and
- a call for a national conference of religious leaders to develop support and leadership in all religious denominations.

Dr. Puchalski, Dr. Reverend Larry Burton, and a group of leading clergy and chaplains are now planning that conference for the fall/winter of 2001.

In the spring of 2000, the Duke Institute on Care at the End of Life was established in the Duke University Divinity School and is closely affiliated with the Duke University Medical Center. The Institute's national survey of 1,000 seriously ill patients and recently bereaved family members revealed that finding spiritual peace was more important to those facing death than having treatment choices followed, having one's finances in order, or dying at home. Finding spiritual peace ranked second in importance only to pain control and, even then, it was rated with nearly equal importance.²²

Efforts to train clergy and allow them to share their experiences and practical advice with one another have been well-received and appreciated. Many clergy who counsel and support dying people and their families feel inadequately prepared for the task because they have had little formal training. Most programs to train clergy about dealing with dying people and their families are occurring at the local level and there has yet to be a national focus along the lines of EPEC or ELNEC.

For example, Dr. Weissman directed a program designed to educate clergy to be effective end-of-life advocates. The Program to Improve Clergy Understanding of End-of-Life reached 150 Wisconsin clergy, chaplains and parish nurses with a two-step training program designed to help participants work with patients and families as well as medical professionals on behalf of the people the clergy counsel. Another example was the one-day program offered by Partnership for Caring in New York City in May 2000 that was attended by approximately 100 clergy.

Compassion Sabbath is a community-based, interfaith initiative to help clergy and religious leaders address the spiritual needs of dying people and their families. It is led by the Midwest Bioethics Center and was developed by a task force of Kansas City-area clergy and other professionals representing more than 30 faith communities. Compassion Sabbath provided training for more than 900 people, including 400 local clergy of various denominations and faiths who dedicated a Sabbath service to issues surrounding death and dying. The weekend reached thousands, received considerable press coverage and was considered a major success by all participants. Efforts are underway to replicate this program in other cities and to continue the tradition in Kansas City.

Each one of these efforts to educate clergy has been substantially oversubscribed, indicating the recognition among clergy of all faiths that more attention should be devoted to this important area of their congregants' lives.

²²Testimony of Dr. James Tulsky on July 17, 2000, on *The End of Life: Improving Care, Easing Pain & Helping Families* before the Special Senate Committee on Aging.

As part of its efforts to contribute to the knowledge base for clergy and the public, the *Last Acts* Spirituality Committee is holding three meetings to brainstorm with experts and develop projects to promote spiritual care and to help direct attention to end-of-life spiritual issues. The first, in August 2000, was called “Honor the Mystery” and focused on the rituals, culture, language, and myths of the dying experience. The outcome was a decision to create a brochure of themes, suggestions, and resources for distribution in doctors’ offices, hospitals, and other medical settings as well as a Web site catalogue of the way different cultures observe death and dying through various rituals, traditions, and events. The goal is to encourage people to consider the unknown or mysterious quality of life and death.

A second meeting, called “Spiritual Companions,” was held in February 2001 to conceptualize a program to train lay volunteers as spiritual companions for seriously ill and dying people. A third, to be held later in 2001, will address research issues related to spirituality.

Pharmacy

Pain management has been among the most serious of the educational deficits. Despite the need for improved pain management in the United States and the importance of effective pain management to good end-of-life care, there is not yet any program similar to EPEC or ELNEC designed to educate pharmacists and pharmacy students about end-of-life issues. However, efforts are beginning to enhance pharmacy textbooks and to include pharmacy leaders in significant end-of-life discussions.

Summary

Efforts to create end-of-life curricula are most advanced for practicing physicians and medical students, and a comprehensive end-of-life nursing curriculum has been developed and is now in the field. Ironically, this fact heightens concerns that death may be taught and experienced primarily as a medical event rather than a human experience and creates some urgency to speed the development of parallel programs for social workers, clergy, pharmacists, health care administrators, and others.

SYSTEM READINESS

Key leaders working to improve end-of-life care are candid about what they perceive is a critical need for greater system readiness and support. Without such support, they know that making positive change is more challenging and sustaining positive change will be impossible. The development of system support requires both eliminating barriers impeding delivery of good end-of-life care and creating new system supports. While efforts to accomplish both goals are under way and gaining ground, this is an area requiring increased, focused attention in order to match the progress being made with respect to professional training and education.

For purposes of this report, system readiness is being defined broadly to include the following:

- support from the individual health care institutions with missions to deliver care;
- guidelines and accreditation standards that are endorsed by private organizations representing health care practitioners and related professionals; and
- public policy, legislation, and regulation, including payment and financing for both care and research.

The System Readiness section includes a subsection addressing pain management. Pain management has been an area of particular focus and activity across health care and professional education systems and serves, in this report, to illustrate the various ways specific end-of-life issues can be addressed.

Institutions Providing Health Care

One example of interinstitutional support for increased focus and attention to model programs is the Circle of Life Award, which recognizes and honors innovative programs developed to improve end-of-life care and change the culture of death and dying in the nation's health care institutions. Initiated and administered by the American Hospital Association, the Circle of Life Award program is cosponsored by the National Hospice and Palliative Care Organization, the American Medical Association, and the American Association of Homes and Services for the Aging. Three awards were presented in May 2000 to, respectively, Franciscan Health Systems West, Hospice of Florida Suncoast, and Louisiana State Penitentiary. Six other programs received honorable mention. A second cycle of awards will be presented in July 2001. By identifying exemplary models and assuring extensive publicity about the program and the award-winning models, the Circle of Life Award raises the standard for end-of-life care and builds awareness of the importance of serving patients well as they die and supporting those close to them.

Hospitals

The American Hospital Association (AHA) added two questions relating to end-of-life care and pain management services to their 1998 annual survey, which was sent to 6,021 registered hospitals around the United States. The AHA got 4,797 replies, an 80 percent response rate.

Fifteen percent of the responding hospitals (719) indicated that they have an end-of-life care service (defined as an organized service providing care and/or consultative services to dying patients and their families based on formalized protocols and guidelines).

Thirty-six and one-half percent of the responding hospitals (1,751) indicated that they have a pain service (defined as a hospitalwide, formalized program that includes staff education for the management of chronic and acute pain based on guidelines and protocols).

The number of hospitals counted as having the services described above includes only those situations in which the hospital owns and directly provides the service. The numbers do not include hospitals providing the services through their system or network providers or through formal contracts or joint ventures.

Research staff at the Lilian and Benjamin Hertzberg Palliative Care Institute at the Mount Sinai School of Medicine followed up by seeking more detailed information from the 2,015 hospitals that reported having pain management or end-of-life services or both on the 1998 AHA survey. This study was conducted in collaboration with the AHA and the results will be available through the Center to Advance Palliative Care (CAPC) and on the CAPC Web site.

The 2,015 hospitals were asked whether they have a palliative care program. Palliative care was defined as "The active total care of patients whose disease is chronic and progressive, or is not responsive to curative treatment. Emphasis is placed on control of pain, on other symptoms, and psy-

chological, social, and spiritual support.” Hertzberg Institute researchers stated that such programs could include an inpatient palliative care unit, hospital-based palliative care consultation services, outpatient palliative care services, or a hospital-based hospice unit. Fifty-six percent (1,120) of the hospitals responded. Three hundred and thirty-seven (30 percent) of the responding hospitals reported they have a palliative care program. Another 228 (20 percent) of the responding hospitals reported plans to establish a palliative care program. Five hundred and twenty-nine (47 percent) reported they have no palliative care program and no plans to create one. Complete results of this project will be published in the *Journal of Palliative Medicine*, Volume 4, Issue 3, September 2001.

The 1998–1999 data from this first national survey of palliative care programs constitute a baseline against which change can be measured. Before 1998, similar data were not available, so trends are difficult to verify. However, Cynthia Pan, M.D., the principal investigator for the survey, speculates that if such a baseline survey had been done even as recently as 1995, “there probably would have been very little to report.” She also indicates “the 1998–1999 survey data are probably already outdated, given what we know about recent growth trends and the fact that even as we survey, new programs are being developed.”

A recent survey of palliative care programs in U.S. teaching hospitals conducted by J. Andrew Billings, M.D., and Steve Pantilat, M.D., for the *Last Acts* Provider Education Committee, provides another snapshot of the development of palliative care programs. This telephone survey of a random sample of 100 hospitals affiliated with the Council of Teaching Hospitals and Health Systems was conducted in 2000. It had a 60 percent response rate, but percentage results are calculated based on the total sample surveyed rather than on the number of hospitals that responded.

Almost half of the total number of hospitals in the sample report having established pain services. Twenty-six percent reported having either a palliative care consultation service or inpatient unit, and seven percent reported that they have both a palliative care consultation service and an inpatient unit. Twenty percent of hospitals indicated they were planning a palliative care program. Most of the programs are new, averaging four years of existence, and few had the sort of interdisciplinary collaboration that is common in hospice programs. Drs. Billings and Pantilat conclude that palliative care programs, “although found in a minority of surveyed hospitals, are becoming an established feature of academic medical centers in the United States” and anticipate that this will have a “significant impact on the clinical practices of young physicians, and thus on many patients and their families facing terminal illness.”²³

Hospice Programs

The modern day hospice movement in America began in 1971—just four years after the model on which it was based was founded in England by Dame Cecily Saunders, M.D. Hospice was authorized as a benefit under Part A of the Medicare program in 1982 to cover medical and palliative care services for terminally ill beneficiaries.

The U.S. General Accounting Office published a *Medicare Report to Congressional Requesters* in September, 2000,²⁴ documenting that “more beneficiaries use hospice but for fewer days of care.” Ac-

²³Billings, J., Pantilat, S., “Survey of Palliative Care Programs in US Teaching Hospitals,” *Journal of Palliative Medicine* in submission.

²⁴United States General Accounting Office. *More beneficiaries use hospice but for fewer days of care.* (GAO/HEHS-00-182.) Washington, D.C., September 2000.

According to the report, the number of beneficiaries electing hospice care more than doubled between 1992 and 1998, from just over 143,000 to almost 359,000 people annually. The majority of hospice beneficiaries have cancer diagnoses but the enrollment of patients with other diagnoses is rising rapidly. In 1992 only about 24 percent of the Medicare beneficiaries electing hospice had non-cancer diagnoses while in 1998 the percentage was approximately 43. At the same time there has been a dramatic decrease in the number of days of hospice care that each beneficiary receives. From 1992 to 1998 the average length of stay fell from 74 to 59 days, and the median length of stay fell from 26 to 19 days. National Hospice and Palliative Care Organization data, which include utilization by non-Medicare beneficiaries, reveal different figures but confirm that the number of patients is increasing and that the average length of stay is decreasing.

Many describe this increasingly short-term hospice usage as brink-of-death care rather than end-of-life care. Experts express concern that current lengths of stay make it difficult for hospice patients and their families to receive the full benefit of hospice care. A number of factors have undoubtedly contributed to the decreasing length of stay. However, the factors cited most frequently are Operation Restore Trust, an anti-fraud initiative begun by the Office of Inspector General in 1995, and the issuance in 1997 of medical review policies for use by the Medicare fiscal intermediaries in determining hospice eligibility. The Office of the Inspector General conducted investigations and audits of hospice providers to determine whether:

- incorrect determinations of a person's life expectancy were being made in order to meet hospice eligibility criteria;
- incomplete information about restrictions under the hospice benefit program was being given to prospective beneficiaries in order to induce them to elect the hospice benefit; or
- any hospices were avoiding their obligation to pay for costly services by encouraging beneficiaries to revoke their hospice election when they needed costly services that should have been covered under the hospice plan of care.

Experts believe that the difficulty of predicting the trajectory of decline, particularly for non-cancer diagnoses; the investigations; and the fact that criminal penalties can be imposed for submission of false claims, have created a "chilling effect," making physicians reluctant to certify that patients are within six months of death unless death is imminent.

Medicare reimbursement for hospice care in nursing homes has been available since passage of the *Consolidated Omnibus Budget Reconciliation Act of 1985*, and the benefit has been more widely available since the passage of the *Omnibus Budget Reconciliation Act of 1989*. Susan Miller, Ph.D., and Vincent Mor, Ph.D., report, "Provision of the Medicare hospice benefit in nursing homes appears to have extended the benefit to a higher percentage of previously underserved populations. However, access to the benefit in nursing homes does not appear to be equitable across geographic settings, nursing homes, and perhaps across nursing home residents with diverse terminal illness."²⁵

According to Drs. Miller and Mor, there is consensus that more information is needed about the provision of Medicare hospice care in nursing homes. While terminal care in many nursing homes leaves much to be desired, until recently little or no population-based research documented the

²⁵Miller, S.C., Mor, V., Coppola, K., Teno, J., Lalibert, L., Petrisek, A.C. "The Medicare Hospice Benefit's Influence on Dying in Nursing Homes," *Journal of Palliative Medicine*, 1:4/1998, 367-376.

experience of either hospice or non-hospice nursing home residents. Recent research is beginning to answer questions about the appropriateness and effectiveness of hospice in nursing homes and the nature of the value added by hospice services. Evidence suggests that nursing home patients enrolled in hospice have lower rates of in-hospital deaths, lower rates of hospitalization in the month prior to death, and a greater likelihood of attempts at pain management.²⁶ Thus, the value added may be increased quality of life at the end of life. The nature of successful hospice/nursing home partnerships and allocation of responsibility and liability between these two types of organizations need closer research scrutiny.

Department of Veterans Affairs

In the mid-1990s, the leadership at the headquarters of the Department of Veterans Affairs (VA) focused on the need to improve care at the end of life. This issue is of particular importance to the VA because three out of five American men age 65 or older are veterans. In May 1998, a VA National Strategy Summit addressed issues related to end-of-life care in the VA health system. Two key initiatives, Evaluation of Pain as a 5th Vital Sign and Pain Management Education for Clinicians and those in Training Programs, are resulting in improved pain care for veterans around the country. Another, the End of Life Planning Initiative is assuring that veterans have opportunities to address advance care planning issues. Now, VA clinicians document in the medical record of inpatients having a broad range of serious and progressive diseases, the full gamut of advance planning preferences, including symptom control, advance directives, limitations of care, social support, spiritual matters, and financial concerns. Nationwide, nearly two-thirds of those inpatient veterans deemed appropriate for advanced disease planning have discussed their preferences with a clinician and had those preferences documented in their medical records. Some VA hospitals have achieved 100 percent participation.

A forthcoming report being developed by the *Last Acts* Institutional Innovations Committee will improve understanding of the similarities and differences among various types of institutions in the provision of end-of-life care. It will highlight institutional barriers as well as best practices and recommendations.

Voluntary Guidelines, Policies, and Accreditation Standards

Many of the organizations and associations with an interest in end-of-life care have created or endorsed position papers and policy statements articulating their views on end-of-life issues and outlining voluntary guidelines on end-of-life care.

The *Last Acts* Palliative Care Task Force developed five precepts of palliative care²⁷ and publicized them in December 1997, with the formal endorsement of approximately a dozen national organizations and a dozen local organizations. Three years later, over 50 national organizations and almost 100 local organizations have formally endorsed these precepts. Thousands of copies of a shorter, consumer version of the precepts, known as *A Vision for Better Care at the End of Life: Five Principles of Palliative Care*, have been distributed around the country.

²⁶Miller, S.C., Gozalo, P., Mor, V. "Outcomes and Utilization for Hospice and Non-Hospice Nursing Facility Decedents" under contract for U.S. Dept. of Health and Human Services Office of Disability, Aging, and Long-Term Care, www.aspe.hhs.gov/daltcp/reports/oututil.htm.

²⁷The Precepts of Palliative Care developed by the *Last Acts* Task Force on Palliative Care, December 1997, are available at www.lastacts.org.

In 1999, Christine Cassel, M.D. and Kathleen Foley, M.D. published, with support from The Milbank Memorial Fund, *Principles for Care of Patients at the End of Life: An Emerging Consensus Among the Specialties of Medicine*. This document lists core principles for clinical policy and professional practice related to end-of-life care and lists the professional societies that have adopted the principles, either as proposed or with certain modifications.

In addition, as a product of the *Last Acts* Standards and Guidelines Committee, Donald F. Phillips is compiling the *Compendium of Healthcare Organization Guidelines and Position Statements on Issues Related to the Care of the Dying*. This compendium currently includes statements and/or guidelines from 37 organizations and cross-references them by topic.

Voluntary standards and guidelines developed through a consensus process have considerable merit but no legal standing. They are both an indication of a changing environment and an impetus for further change in the environment. Although they cannot be enforced, they may serve as evidence of a standard of care in civil malpractice or disciplinary action cases.

In contrast to voluntary standards and policies, government regulation and private standard setting (on which the government relies for accreditation and reimbursement purposes) create leverage and tend to garner more attention and adherence. Standards that are assessed as part of an accreditation or licensure exam receive particular attention. They are studied, and they become priorities. For that reason, there was considerable excitement when pain standards were endorsed by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), effective for surveys conducted after January 1, 2001.

There is no mandatory national accreditation for hospice care, although the National Hospice and Palliative Care Organization has promulgated voluntary Hospice Standards of Practice. However, as of 1999, there were hospice licensure laws in 44 states that included requirements for operating a hospice program.

Public Policy, Legislation, and Regulation

Five years ago physician-assisted suicide and right-to-die issues galvanized public attention and public-policy debate. Although the U.S. Supreme Court refused to establish a right to physician-assisted suicide, it is now well-accepted under common law and constitutional law that competent individuals have a right to consent to or refuse suggested medical treatment.

Currently, cutting-edge legal questions “tend to push the envelope on the extent of patient control versus doctor control over health-care decisions,” says assistant director of the American Bar Association Commission on Legal Problems of the Elderly, Charles Sabatino, J.D. Such legal questions include determining “whether a treatment is ‘futile’; testing the enforceability of advance directives; questioning the scope of authority of surrogates; debating the merits and dangers of physician-assisted suicide proposals; and more recently, identifying the legal barriers to good palliative care.”²⁸

²⁸See End-of-Life Legal Trends, April 2000, www.abanet.org/elderly/update.html.

A great deal of public policy development is taking place at the state level. In June 1998, the National Conference of State Legislatures (NCSL) and the Center to Improve Care of the Dying published *State Initiatives in End-of-Life Care: A Policy Guide for State Legislators*. Responding to the fact that, in 1997, the Supreme Court affirmed that state legislatures might decide whether or not to legalize physician-assisted suicide, the guide is intended to assure that legislators do not consider physician-assisted suicide without understanding the other options for end-of-life care. The guide informs state legislators about the status of end-of-life care and the various legislative options for improving care for Americans who are at the final stage of life—such as state laws affecting pain management, advance directives, the regulation of those who provide care to dying patients, and the financing of that care. Eleven thousand print copies of the guide were distributed and it is currently available on the NCSL Web site, at the libraries of each state legislature, and from NCSL in hard copy. Supplemental audiotapes also are available.

Activity within the states is increasing and varied. A number of states have established advisory committees, task forces, or commissions to evaluate access barriers to good end-of-life care and make recommendations for improving such care. The earliest, created in 1985 by then-governor, Mario Cuomo, was the New York State Task Force on Life and the Law. More recently, governors in Alabama, Arizona, Colorado, Hawaii, and Michigan have created task forces. Legislatures have created task forces in Florida, Kentucky, Louisiana, and Oregon. In Maryland, Nevada, and New York, the State Attorneys General have taken the initiative. The governors in Utah and Oklahoma each declared specific weeks for devotion to highlighting the importance of quality end-of-life care.

The National Association of Attorneys General created a Working Group on End-of-Life Issues in 1999. Attorneys General from the following states joined the working group: California, Connecticut, Delaware, Iowa, Maryland, Massachusetts, Michigan, Nevada, New York, Oklahoma, Oregon, Rhode Island, South Carolina, Texas, and Washington. While the group has not taken any formal collective action, it is an expression of interest in and receptivity to change on the part of state regulators. State Attorneys General are law enforcement agencies, and their ability to promulgate interpretations of law is a significant resource for advancing improvement in end-of-life care.

The Maryland Attorney General, J. Joseph Curran, Jr., recently issued an opinion about tube feedings under the Maryland Health Care Decisions Act that elaborated on the legal standards to begin, withhold, or withdraw tube feeding. In addition, the Maryland Attorney General has written a letter of advice about pain management for terminally ill nursing home residents and a number of letters answering questions about do-not-resuscitate (DNR) orders, advance care planning and the difference between assisted suicide and symptom management.²⁹ Attorney General Curran's leadership is highlighted along with the work of other state policy leaders in a January 2001 policy brief called "How End-of-Life Care Can be a Positive Issue for Policy Leaders," published as one of the *State Initiatives in End-of-Life Care* series by the Community-State Partnerships in End-of-Life Care program directed by the Midwest Bioethics Center.

²⁹Copies are available at www.oag.state.md.us/Healthpol/index.htm.

Many of the organizations receiving grants from Community-State Partnerships to Improve End-of-Life Care are working with their state executive and legislative branches. The Nevada Community-State Partnership to Improve End-of-Life Care established the Nevada Center for Ethics and Health Policy to carry out activities initiated by the Nevada Attorney General, Frankie Sue Del Papa, under a statewide plan. The Rhode Island Community-State Partnership is working with the Rhode Island Attorney General's Health Advocate on several initiatives. The Minnesota Partnership to Improve End-of-Life Care is a public/private collaboration with the Minnesota Department of Health. The Florida Partnership for End-of-Life Care includes state agencies, the state university system, and private organizations. The Maine Consortium for Palliative Care and Hospice reports twice a year to the Maine legislature about developments and trends regarding dying and end-of-life care in Maine.

At the federal level, members of the 106th Congress introduced numerous bills addressing end-of-life issues. Three major Senate committees and one House committee held relevant hearings. Much of the activity was focused in the Senate Special Committee on Aging whose hearings covered: *The End of Life: Improving Care, Easing Pain & Helping Families* (July 2000) and *Barriers to Hospice Care: Are We Shortchanging Dying Patients?* (September 2000). In other action, Congress approved a five percent increase in the base Medicare daily payment rates for hospice care for fiscal 2001 and loosened the standard for certification of terminal illness. Congress also recognized the needs of family caregivers with passage of the *National Family Caregiver Support Act* in November 2000. In addition, the *Healthcare Research and Quality Act*, sponsored by Senator Bill Frist (R-TN), includes end-of-life populations among those for which the Agency for Healthcare Research and Quality is to "undertake and support research, demonstration projects, and evaluations."

A number of bills affecting end-of-life care were not enacted during the 106th Congress, but may be reintroduced in the 107th. These include the *Pain Relief Promotion Act*, the *Hospice Improvement Program Act*, the *Advance Planning and Compassionate Care Act*, the *Medicare for Individuals with Terminal Illness Act*, and the *Terminal Disability Fairness and Equity Act*.

Pain Management

Inadequate assessment and too little treatment of pain have been documented as serious and widespread problems for patients in the United States. The problem is particularly acute for the elderly in nursing homes and for people with cancer, but it affects a much larger group of patients as well.³⁰ Efforts to improve pain management through research, legal, and legislative advocacy and the development of voluntary standards and guidelines are under way.

As noted earlier, a major advance with respect to private standard setting was the JCAHO's pain standards endorsement, effective for surveys conducted after January 1, 2001. JCAHO accreditation is essential to health care institutions, and the JCAHO standards are studied and become institutional priorities.

³⁰AHCPR, *Acute Pain Management: Operative or Medical Procedures and Trauma. Clinical Practice Guidelines*. www.ahrq.gov/clinic. American Pain Society, *New Survey of People with Chronic Pain Reveals Out-of-Control Symptoms Impaired Daily Lives*. www.ampainsoc.org/whatsnew/release030499.htm. *The Prevalence and Treatment of Pain in US Nursing Homes* conducted by Joan Teno, Chloe Bird, and Vincent Mor of the Center for Gerontology and Health Care Research at Brown University. www.chcr.brown.edu/dying/factsondying.htm.

David Joranson, director of the University of Wisconsin's Pain & Policy Studies Group (PPSG), says, "Recent years have seen an unprecedented increase in the number of states adopting laws, regulations, or guidelines to encourage pain management and lessen physicians' fears of regulatory scrutiny. Ironically, new policies such as some of the intractable pain treatment acts actually regulate pain management with more rather than fewer requirements; other new policies perpetuate the myth that death is hastened when opioids are used to treat pain."

Research published by the PPSG in the *JAMA* on April 5, 2000, showed that between 1990 and 1996, the medical use of opioid pain medications was increasing significantly in the United States, but that the health consequences of opioid abuse, as measured by emergency department admissions involving use of opioids, stayed relatively low and stable. The authors emphasize that if abuse does increase, it should be addressed without interfering in providing pain relief for legitimate purposes.³¹

When asked about recent advances and new resources to improve policy governing pain medications and medical practice, Joranson cited the following:

- publication of a systematic evaluation of federal and state pain-related policies, *Achieving Balance in Federal and State Pain Policy: A Guide to Evaluation*;³²
- creation of Federation of State Medical Boards model state guidelines to encourage pain management and address physicians' concerns about regulatory scrutiny and endorsement of those guidelines by the DEA, the National Association of State Controlled Substances Authorities (NASCSA), and pain organizations;³³ and
- Internet access to the full text of federal and state policies governing pain management and controlled substances.³⁴

However, Mr. Joranson expressed concern that the rate of adoption of positive pain policies at the state level is declining and stated: "It is important that there be efforts to promote good policy at state boards and agencies. I think we have the models; now we need to be sure that the policies are implemented."

The American Bar Association's House of Delegates has recognized the numerous legal barriers to good pain management and, on July 11, 2000, adopted a policy resolution urging state, federal, and territorial governments to:

- remove legal impediments to quality pain and symptom management; and
- support a right to effective pain and symptom evaluation, management, and ongoing monitoring, as part of basic medical care.

The resolution does not take a position on any particular legislation. Instead, it is intended to expedite the correction of imbalances in the perceptions and actions of legislatures, regulatory boards, and enforcement agencies. These bodies have tended to pursue goals relating to drug abuse and avoiding drug diversion at the expense of the pain and symptom management needs of suffering in-

³¹Joranson, D.E., Ryan, K.M., Gilson, A.M., Dahl, J.L. *JAMA*, April 5, 2000, Vol. 283(13).

³²www.medsch.wisc.edu/painpolicy/eguide2000index.htm.

³³www.medsch.wisc.edu/painpolicy/domestic/model.htm.

³⁴www.medsch.wisc.edu/painpolicy/matrix.htm.

dividuals, including those near the end of life. The resolution creates an opportunity for community groups to approach local bar associations about working on pain management issues.

The legal advocacy to improve pain care done by Compassion in Dying's Office of Legal Affairs since 1998 is based on the premise that a major system change is required in order to overcome professional reluctance to prescribe controlled substances. This reluctance has numerous causes, including physicians' fear of prosecution by state medical and nursing boards for perceived excessive prescribing of controlled substances. Because, historically, failure to adequately treat pain has not been prosecuted by state medical and nursing boards, providers see the risk as flowing only from perceived excessive prescribing and not from under-prescribing. Efforts have included:

- letters to the state medical boards, urging them to investigate complaints of inadequate pain care;
- undertreatment cases presented—complete with specific allegations—to state medical and/or nursing boards, sometimes in collaboration with other organizations such as the American Academy of Pain Management and Americans for Better Care of the Dying;
- a lawsuit filed in state court seeking damages from the provider and the institution (based on the theories of medical malpractice and elder abuse) when a state medical board decided not to take corrective action after finding that the complaint of inadequate pain care was valid;
- model legislation drafted and sponsored to require state medical boards to investigate and require corrective action in the form of mandatory continuing medical education in pain management in cases of inadequate pain care;
- a petition seeking that HCFA recognize that Medicare and Medicaid providers have a duty to inform patients about pain management options and provide pain care as a matter of federal and state law; and
- legal defense made available to physicians whose attentive and aggressive pain treatments, pursuant to accepted standards, has nevertheless resulted in state medical board charges.

A further indication that pain management, palliative care, and end-of-life issues are gaining increased federal recognition and legitimacy was the appointment of Ann Berger, M.D., as Chief, Pain and Palliative Care Service, at the National Institutes of Health Clinical Center. Dr. Berger was selected after a lengthy search and considerable debate about the focus and function of the position. She began her job in August 2000. Dr. Berger indicates that her work has been well-received and that she received 275 new patient referrals in less than six months. She is participating in an End-of-Life Interest Group formed at the National Institutes of Health during 2000 with participation from all of the different institutes.

Summary

Despite all of the activity, no overall, coherent national policy on end-of-life care in America currently exists. End-of-life care was not discussed as an issue during the presidential elections and does not seem to be a public health priority. When end-of-life care has been addressed, the focus of policy makers has largely shifted from issues of rights and self-determination to the task of ensuring access to good care and caring at the end of life. Many policy issues remain, among them standards for quality end-of-life care, reimbursement for such care, and issues of legal recourse.

For example, what are the legal options for someone who does not receive good end-of-life care? At what point will failure to treat pain become malpractice? Will there be a time when anything

less than the gold standard in end-of-life care constitutes malpractice? How should responsibility be allocated among patients, professionals, and policy makers?

Finally, we cannot overestimate the importance of continued research. Research creates the underpinning for evidence-based change and the importance of public funding for research is of critical importance.

Financing and Reimbursement

Financing and reimbursement are areas in which responsibility can most easily be defined as belonging to the policy makers. In a recent paper written for the American College of Physicians-American Society of Internal Medicine Committee on End-of-Life Care, Dr. Joanne Lynn and her co-authors examine how Medicare financing shapes the care given dying people and present possibilities for reform. They conclude that current reimbursement policies constitute one of the most significant barriers to improving care and caring near the end of life.³⁵ The paper concludes that, “Medicare’s current financing and regulatory structures do not support sustainable arrangements for reliably excellent care at the end of life,” and elaborates on the ways that Medicare payment arrangements “create serious financial disincentives and disadvantages for providers who wish to deliver good care.”

Yet, Medicare insures approximately three-quarters of Americans as they die. While acknowledging that the current shortcomings in care did not necessarily originate because of Medicare, the paper elaborates on the ways in which Health Care Financing Administration policies deter reform and reinforce current practices. The article lists seven characteristics that Medicare financing should encourage as “Program Elements Essential to Quality Care”:

- continuity of care across care settings and over time;
- use of evidence-based standards and guidelines;
- interdisciplinary teams, often relying principally upon experienced nurses;
- mobilization of services to the patient’s residence, whether at home, in a congregate-living facility, or nursing facility;
- education of patient and family in self-management;
- advance plans for response to expectable urgent situations; and
- quality improvement activities.

Lynn and her coauthors emphasize the need for Medicare reform that will encourage providers to care for people with serious and eventually fatal illnesses. Experts agree that Medicare reforms of this type and others are essential. Many suggest that private sector reforms also are critical. Specifically, managed care and other health care delivery systems need to consider better ways of delivering and reimbursing for care; and our social systems need to assure that support is available to enable families to better care for a member dying at home. In terms of local efforts, more than half of the organizations receiving grants from Community-State Partnerships in End-of-Life Care are in the early stages of exploring financing issues, including possible model-benefit packages for end-of-life care, “pre-hospice” benefits, the need for a Medicaid hospice benefit, the impact of

³⁵*Financing Care for Those Coming to the End of Life: Current Barriers and Opportunities for Improvement*; November 15, 2000; reprints available from the American College of Physicians-American Society of Internal Medicine’s Center for Ethics and Professionalism, 190 N. Independence Mall West, Philadelphia, PA 19106.

Medicaid regulations on pain management, financial incentives for long-term care, continuity of care, and the use of case managers.

CULTURAL READINESS AND CONSUMER ENGAGEMENT

Death is a difficult subject for Americans. Not only are they reluctant to discuss it, they are loath even to consider it. In fact, according to a public opinion survey of people age 45 and older conducted for the National Hospice Foundation in April 1999, Americans are more willing to talk to their children about safe sex and drugs than to discuss end-of-life care with their terminally ill parents. Less than 25 percent of Americans have taken the time to create a written document expressing their thoughts about how they wish to be cared for at the end of life.³⁶

Nonetheless, the public taboo against talking about death has begun to crumble. Karen Orloff Kaplan, Sc.D., President of Partnership for Caring, notes, “We’ve seen important changes during the past ten years. There is increased interest in end-of-life care and the process of death and dying as the baby boomers face the deaths of their parents and grandparents. And when they begin to face their own mortality, their interest in this subject is reinforced.”

Kaplan notes that ten years ago very few people involved in this field were quoted in newspapers, interviewed for TV or radio, got appointments at corporate headquarters, or were welcome at many foundations. No one wanted to fund projects related to death and dying. That situation is slowly changing, as the societal stigma attached to death is breaking down and the potential for better physical, social, and emotional experiences as part of the dying process become known to more people. She also stresses that the taboo hasn’t disappeared and suggests that, therefore, it is sometimes most effective to talk about these issues in the context of caregiving or grief and bereavement.

One of the most significant indicators that the taboo against discussing death is at least fading is the fact that when Bill and Judith Moyers produced “On Our Own Terms: Moyers on Dying,” PBS aired it over four nights in September 2000 and the public watched it in unprecedented numbers. Over 20 million viewers watched “On Our Own Terms,” and the enormous outreach efforts developed in connection with it further increased the level of public awareness, if not public engagement, with this issue. Efforts are now under way to sustain the momentum of the Moyers project and keep the more than 300 outreach communities that formed around the broadcast involved and active in educating their communities and bringing about change.

Other relatively recent arts and media events signal an increasing wave of public interest in care and caring near the end of life. Interest and activity in mainstream publications, media outlets, and other forums is illustrated by the 1997 publication of *Tuesdays with Morrie*, a young man’s story of his former professor’s death from amyotrophic lateral sclerosis (Lou Gehrig’s disease). As of February 2001, this book had been on the *New York Times*’ nonfiction best-seller list for 172 weeks.

W;t, a powerful drama about a professor’s inner life as she struggles with aggressive treatment for ovarian cancer, became a Pulitzer Prize-winning sensation. The play also has been produced and aired as an HBO special for television.

³⁶Fact sheet available at www.nhpco.org.

TIME Magazine ran a cover story called “Dying on Our Own Terms” on September 18, 2000. The September–October 2000 issue of AARP’s *Modern Maturity*, which has a circulation of over 20,000,000 Americans ages 50 and over, featured a story called “The Last Taboo” and included an extensive insert addressing end-of-life issues. *Business Week* published an article called “Giving More Patients a ‘Good Death’” on November 20, 2000. *O, The Oprah Magazine* subsequently featured an article about hospice. Popular TV shows such as *Ally McBeal*, *City of Angels*, *ER*, and *Gideon’s Crossing* have recently included end-of-life story lines and themes in their productions.

Later in 2001, the Knight-Ridder Tribune newspaper service is scheduled to offer a 15-part series, *Finding Our Way*, on end-of-life issues to newspapers nationwide. The series will be accompanied in many local newspapers by local-interest stories and resource lists in many local communities.

Still, we live in an environment and a culture in which there is little or no incentive to face death before it is at one’s doorstep. In reality, the typical American’s idealized scenario—“suddenly dropping dead at a ripe old age without being sick or burdening family”—is increasingly uncommon. Fewer than 10 percent of Americans experience death that way. Unfortunately, the public resists recognizing this reality and thus is generally unable to prepare for and experience what the experts call a “good death.”

Consumer engagement is potentially a powerful mechanism to overcome this disconnect with reality. Consumer engagement involves offering people something they need or want in exchange for some action on their part. Different than consumer education, which, for the most part, is passively received by the public, consumer engagement focuses on changing attitudes and behavior as well as increasing knowledge. The primary challenge in engaging consumers to think and plan about end-of-life issues is to find incentives powerful enough to move people to face the frightening prospect of death.

We know that Americans are becoming less passive and more assertive about their health care needs generally. Some of this increased assertiveness is expressed through Americans’ use of the Internet. According to a survey by The Pew Internet & American Life Project, 55 percent of all Internet users report having used the Internet to locate health information—outranking all other Internet uses, including checking sports scores, stock quotes, or online shopping. An estimated 52 million Americans search the Internet for medical information. Although there are questions about the accuracy and reliability of the information they are finding, it also reflects the curiosity and self-reliance of today’s health care consumer.³⁷

Thus the Internet provides a window for introducing the concept of “dying well” through a medium upon which Americans are becoming increasingly reliant. Many sites provide information related to aging and the end-of-life. A selected list is included (see Appendix 3 of this report). Sites appear and disappear fairly frequently, so any list has a short shelf life, but can be helpful because many of the sites are difficult to locate through popular search engines. It may be that, in addition to its educational value, the Internet will assist users to focus some of their developing assertiveness on improving end-of-life care for themselves and their loved ones.

³⁷*Wall Street Journal*, November 27, 2000, p. B14.

Ideally, consumer engagement incorporates two types of activity. Ira Byock, M.D., director of Promoting Excellence in End of Life Care, the chief medical consultant for Partnership for Caring and the author of *Dying Well*, explains that improving end-of-life care will require both advocacy and activism. He defines advocacy as “the things we do to improve current access to services and quality of care for ourselves or a loved one.” Advocacy is important and requires a level of public awareness about what good end-of-life care can be. Dr. Byock defines activism as “our collective efforts to improve access and quality of care for others and our families in the future.” The evidence suggests, however, that the level of both consumer advocacy and activism regarding end-of-life matters is still insignificant.

In summary, cultural change and public engagement, along with professional readiness and system readiness, form the infrastructure necessary for sustainable improvement to occur in care and caring for dying individuals and their families. The evidence collected and presented in this report suggests that, at least in terms of professional and system readiness, the nation has begun to develop the needed infrastructure. Thus, the stage is set for the gold standard for end-of-life care to become the prevailing model. How we address the next steps will determine the extent to which the gold standard actually becomes the prevailing model and the speed with which universal access to the gold standard becomes available.

CONTEXT FOR CHANGE

No consideration of the future of death and dying in America is complete without highlighting key factors that form the contextual fabric against which the future will develop. These factors include demographics, cultural influences, education and household income, the shifting burden of disease, turmoil in the medical delivery system, medical and information technologies, and costs of care. This section will draw on the work of the Institute for the Future and the Federal Interagency Forum on Aging-Related Statistics, a consortium of U.S. government agencies working to improve the quality and usefulness of data on older Americans. Their reports, *Health and Health Care 2010: The Forecast*, *The Challenge* and *Older Americans 2000: Key Indicators of Well-Being*, respectively, contain thorough considerations of a wealth of information about the health of Americans and the health care available to them.

Demographics: Americans are living longer, and the American population is aging. In fact, Americans born today have a projected life span almost 30 years longer than Americans born a hundred years ago, and the number of older Americans has increased tenfold since 1900. There were 34 million people in the United States age 65 and older in 1995 and 35 million in 2000 (13 percent of the population). By 2010 there will be perhaps 39 million age 65 and older and, by 2030, when the youngest baby boomer will have reached age 65, approximately 70 million (roughly 20 percent of the population). That the population age 85 and over is growing most rapidly is particularly important for anticipating health care and assistance needs, because people in this age group typically require significantly more services than younger people.

The nature of assistance that the elderly living at home receive seems to be changing. Most home care has, and continues to be, provided by family, friends, and members of the community. However, the percentage of people receiving only informal care from family and friends dropped from

74 percent in 1982 to 64 percent in 1994. The percentage using a combination of informal and paid assistance increased from 21 to 28 during the same period. While the need for both medical and personal assistance multiplies as the population ages, the supply of workers to take care of this aging population is shrinking, families are geographically dispersed, and more of the traditional caregivers—women—are working outside the home.

The changing demographics have several significant implications for improving end-of-life care. The growing elderly population in this country suggests that more attention will be focused on issues that concern them. We are already witnessing the proliferation of products, housing, and opportunities for pursuit of leisure time and other activities geared specifically to seniors. Through a variety of publications and other vehicles now available, we can transmit information and tools to seniors that will enable them to engage more readily in planning for and living the last chapter of their lives regardless of its length.

In addition, as noted earlier, sudden catastrophic death is less and less the usual end-of-life experience for the elderly. Increasingly, chronic, progressive debilitating disease is likely. This prospect provides both an opportunity and an urgency for elderly people to consider, discuss, and plan for their last months or years.

Multiple Cultural Influences: The aging population reflects the dramatically increased racial and ethnic diversity in America. In 2000, the non-Hispanic white population age 65 and older was approximately 84 percent of the total. This percentage is dropping and by 2050, that figure is projected to be closer to 64 percent. (By 2010, 32 percent of all Americans will be part of ethnic and racial minority groups.) The trend toward greater diversity is even more pronounced when analyzed regionally, with the greatest concentration of ethnic and racial minorities in the south and the west. Diversity creates challenges when it comes to delivering health care that is culturally sensitive and that reflects different cultural norms about end-of-life care and decision-making. For example, individual autonomy—the primary value and cornerstone of U.S. laws and ethical principles of informed consent and advance directives—is not necessarily a value shared by people with different cultural backgrounds. End-of-life care programs that are culturally appropriate must be developed; delivery systems must be adapted for these programs; and public policies, laws, and regulations must be adjusted to reflect these new realities.

Education and Household Income: The education level of Americans has been steadily increasing since 1950. However, minority populations have not fared as well, and there is a considerable gap in education level for some non-white and Hispanic Americans. The same discrepancies apply to household income, though overall, the number of households having high incomes is increasing.

Income is highly correlated with both health status and access to health care. The worrisome gap between the richest and poorest quartiles is widening. According to *Health and Health Care 2010*, research published in the *British Medical Journal* documents that, “when income disparity among the population widens, the overall health status of the population worsens.”³⁸

³⁸*Health and Health Care 2010: The Forecast, The Challenge*, Institute for the Future, Jossey-Bass Publishers, San Francisco, 2000, page 20, citing Wilkinson, R.G. “Income Distribution and Life Expectancy,” *British Medical Journal* 304:165–68/1992.

Both education and income are relevant to improving end-of-life care. Many low-income people struggle to get adequate acute care and have not focused on whether quality care will be available when they are dying. Individuals with limited health care access will be more difficult to engage in advocacy on their own behalf related to end-of-life care than will those who have always had access to a full range of health care services. Lack of education makes it more difficult for individuals to understand the way health care practitioners currently communicate the complex tradeoffs in decisions about end-of-life care. Future activity should focus on making such information more available to people with varying levels of education.

The Shifting Burden of Disease: The past century has seen a dramatic decrease in the number of deaths from infectious diseases and a simultaneous increase in the incidence of chronic diseases. According to *Health and Health Care 2010*, “The biomedical model of health care, which focuses on a single causative agent for an illness and is concerned primarily with curing, is necessary but not sufficient. Much more needs to be done to create and implement effective health management and disease prevention programs.”³⁹ In terms of end-of-life care, much more needs to be done to entrench concepts related to dying well into health management programs, so that planning around end-of-life issues becomes a routine part of overall health care—particularly for middle-aged and older adults.

Turmoil in the Medical Delivery System: America is experiencing a profound change in the way health care providers are organized and paid, with most of the change generated by employers, governments, and insurers.⁴⁰ Many of the changes are directly related to financial incentives and to the locus of control of medical management. These changes have created enormous dissatisfaction among clinicians and distrust among consumers. The Institute for the Future reports that:

As a new, more educated and informed generation of baby boomer consumers moves through the system and reaches the age where they use more health care services, a new culture of assertive skepticism is replacing the culture of passivity and respect. A rapidly growing group of consumers is trusting plans and providers less, demanding more information and choice from providers and plans, engaging in more self-care and self-management of disease, and showing more interest in sharing their health care decisions with providers. Choice, self-care, and shared decision making are the key elements of consumer empowerment.⁴¹

Medical Technology: Technological advances are likely to increase both longevity and the costs of care. Although such advances can improve the effectiveness of medical care, they can also increase patient and family demands for their use, even in inappropriate situations, and deflect attention from the important psychological and spiritual issues involved in the dying process.

Information Technology: Experts predict that information technology will be used by the health care industry in four areas: process-management systems; clinical information interfaces; data analysis and telehealth; and remote monitoring of health conditions.⁴² As noted earlier in this re-

³⁹*Health and Health Care 2010: The Forecast, The Challenge*, Institute for the Future, Jossey-Bass Publishers, San Francisco, 2000, page 23.

⁴⁰*Health and Health Care 2010: The Forecast, The Challenge*, Institute for the Future, Jossey-Bass Publishers, San Francisco, 2000, page 47.

⁴¹*Health and Health Care 2010: The Forecast, The Challenge*, Institute for the Future, Jossey-Bass Publishers, San Francisco, 2000, page 124.

⁴²*Health and Health Care 2010: The Forecast, The Challenge*, Institute for the Future, Jossey-Bass Publishers, San Francisco, 2000, page 113.

port, Americans' increased use of and reliance on the Internet for health-related information makes the Internet a good vehicle to reach people to educate them about end-of-life issues and about advocating for good end-of-life services for family members. The Internet also provides opportunities to monitor and provide better care for people who are dying at home as well as support services for family caregivers. Caregivers increasingly use the Internet to create online communities to share advice and to express and share their grief.

Costs: After a period of stabilization, health care costs are again rising dramatically—fueled, at least in part, by rapidly escalating drug costs and an aging population. The subject of costs raises access issues as the number of uninsured increases. The subject of costs also raises rationing issues, as the Health Care Financing Administration, employers, and health plans try to stem the increases. Although coverage for many medical treatments is available to Medicare beneficiaries, there is much less satisfactory coverage for long-term care and very little reimbursement for palliative services outside of the hospice benefit.

People pay privately for much of long-term and chronic care costs. These private costs are significant and tend to increase as people age. Research by Donald Hoover, Joel Cantor, and others, presented at the Annual Meeting of the American Public Health Association in November 2000⁴³ indicates that Medicare beneficiaries age 85 and older, on average, have lower Medicare-reimbursed costs during their last year of life than do beneficiaries who die when between ages 65–74. At the same time, non-Medicare costs (paid primarily by Medicaid and families with some paid by private insurance) are, on average, significantly higher during the last year of life for beneficiaries age 85 or older, compared to beneficiaries dying between ages 65–74. This information suggests that, as the population ages, a greater share of the financial costs of care for aged family members will not be covered by Medicare, and instead will be a burden on Medicaid programs and families.

As private costs increase, they may create economic hardships for greater numbers of families, creating a demand to expand Medicare coverage of chronic conditions and end-of-life care. However, the magnitude of the costs also suggests a greater difficulty in financing them publicly.

THE FUTURE: A DISTANCE TO GO

Forecasts of the future generally take the form of multiple scenarios—some grim, some rosy—and suggest possible different outcomes. Given that the ultimate death of every individual is an absolute certainty, the future of how people die in America is really an issue of continuum rather than of alternative possibilities. Specifically, the way we care for people who are dying and their families could remain essentially the same—mostly dreadful. Or, depending on a host of factors, could improve a little or a lot.

In the case of “a little,” certain aspects of death and dying could improve; for example, there could be more pervasive and effective treatment of physical symptoms associated with the dying process.

⁴³Hoover, D.R., Cantor, J., Kumar, R., Sambamoorthi, U., Crystal, S. *Elderly Medicare and Non-Medicare End of Life Expenditures in the Medicare Beneficiary Survey from 1992–1996*. Presented at Annual Meeting of the American Public Health Association, Boston, MA, November 2000.

In the case of “a lot,” end-of-life care would more closely approximate the gold standard and become the rule rather than the exception.

Predicting the future is a matter of describing the types of improvements likely, the speed with which they might occur, and the degree to which they will become entrenched and broadly available. The following are some thoughts about the opportunities and challenges that will determine the type of improvements in care and caring near the end of life that are likely to occur, their probable speed, and their reach and durability.

THE FUTURE AS AN OPPORTUNITY

The greatest potential of the future is its flexibility and our conviction that we can change it. Some facts must be acknowledged because they are contextual. And some surprises or “wild cards,”⁴⁴ being unpredictable, may have enormous impact. However, aside from the givens and the wild cards, how the future materializes is largely dependent on how the field brings its collective intellect and passion to bear to identify leverage points and apply pressure strategically. In that way, we have choices about where on the continuum of improvement in end-of-life care, from none to the gold standard, we will find ourselves, and whether we help create the future that will match our vision.

In support of the likelihood that we will make effective use of leverage points to improve end-of-life care, discussions and interviews with key informants (see Appendix 1) indicate that people working on end-of-life issues tend to be quite optimistic about the future of end-of-life care and caring. They are optimistic because end-of-life issues are clearly on the table. Baby boomers are confronting end-of-life issues for their parents and grandparents and are having an increasingly difficult time avoiding the issues for themselves. The demographics of the baby boom assure that end-of-life issues will remain an important part of our collective consciousness. In addition, we know that efforts are well under way to:

- reform the way we educate clinicians and other members of the multidisciplinary team;
- address the physical, psychological, spiritual, and social aspects of the end-of-life experience;
- create a legal and policy infrastructure that will support good end-of-life care and caring; and
- build leadership.

These seeds of change have been planted and are taking root. While it is too early to declare victory, there is much to celebrate—the numbers of people who have been trained, the textbooks that are being revised, and the attention that is being focused on the issue. The gains that have been made, while still fragile, seem unlikely to be lost. And again, the real question is not whether there will be more progress but rather how far—and how quickly—along the continuum toward our vision we will be able to advance.

⁴⁴“Wild cards” is a concept defined on page xix of the introduction to *Health and Health Care 2010* as “events that have less than a 10 percent chance of occurring, but will have a tremendous impact on society and business if they do occur. The point of wild cards is not to predict an outcome but to expand peripheral vision regarding the total range of possibilities; to offer a larger context within which to consider mainstream forecasts; and to prepare for surprises in the event they do come to pass.”

THE FUTURE AS A CHALLENGE

Noting that there is no lack of passionate, committed experts working to improve end-of-life care, experts describe their concern as one of focus and balance. They worry that we risk over-emphasizing the need for institutional and system change without sufficiently recognizing the need for public engagement and cultural change. We may envision a world in which the systems that are needed to create and sustain good end-of-life care and caring exist and professionals are better trained to provide it. But there is an inherent limit to how far professional and system change can advance us along the continuum toward the gold standard if individuals—and the public—are not sufficiently engaged in insisting that changes are made and sustained.

Social and cultural changes happen when the environment is ripe—when there is a confluence of people, events, and attitudes, supporting infrastructure, and enabling laws and policies. But more than anything, such change requires committed citizens. According to Margaret Mead, “Never doubt that a small group of thoughtful committed citizens can change the world; indeed, it’s the only thing that ever does.”⁴⁵

Sustainable change requires responsiveness at a local level—to individuals and their needs. There is an inherent tension between the focus on system change and the need to work with and engage the public at the local level. Big-picture systemic change is necessary but not sufficient. It takes work at the local level to generate the sensitivity and specificity to meet individual needs and change culture. Until and unless the public is engaged at the local level, we will fall short of being able to maximize good care and caring at the end-of-life.

The field is witness to wonderful examples of committed citizens changing the world from their communities upward. The Community-State Partnerships program and the Promoting Excellence in End-of-life Care program grantees are exemplars of what can be done at the community level. As we focus more on local activity, however, we also must maintain a bridge—a wide bridge for two-way traffic—to link those working on big-picture systemic change at the level of institutions and those advocates and activists working in their communities to assure local change responsive to individuals.

Individual activists and members of advocacy groups are often engaged as a result of personal experience. The people working to improve dying in America for the families of the future frequently became activists after first being advocates for themselves or their loved ones.⁴⁶ *TIME Magazine* reports that, “The most challenging reform may be to get patients to become their own advocates for better death. That would require frank talk about a somber subject.”⁴⁷

Together we can imagine that death would be treated differently in a culture that celebrates a quality last chapter of life as an achievement in its own right. Even more fundamentally, we can imagine the differences that would exist if we moved toward a community-spirited model of group responsibility to take care of the dying. The advocacy and activism needed are most likely to develop when Americans begin to think about the fundamental questions raised in this report. To get them

⁴⁵See <http://www.greats2000.org/parsed-data/articles/MeadMargaret.html>.

⁴⁶Refer to Dr. Ira Byock’s definitions on page 31.

⁴⁷*TIME Magazine*, Sept. 18, 2000; p.67.

to do so requires that we deal with a phenomenon noted as long ago as 1977: “Finally, in a society that emphasizes achievement and the future, the prospect of no future at all and loss of identity is an abomination. Death is seen as the destroyer of the American vision.”⁴⁸

Despite the optimism of experts about the future of care for dying individuals, so far the public is not convinced that there are some things worth doing in advance with respect to death. In the current American society, it is difficult to communicate that addressing end-of-life issues creates opportunities for growth, resolution, and closure. It is difficult to persuade people that taking advantage of these opportunities can provide meaning and context to life and may be, in and of themselves, rewards worth achieving. And most people find it hard to be “in touch with” their own values and needs in order to define what would be for them a satisfactory life closure.

PRIORITY ACTIONS

With these challenges in mind, there are nine high-priority recommendations for community- and individual-level efforts to assure that the changes that have begun will continue and flourish. To improve end-of-life care and create a future that advances universal access to a good last chapter of life, we must:

1. Strengthen community-specific efforts and focus resources on these efforts. The communities can be geographic, religious or other communities of interest, but they must be located, at least in part, at a grass-roots level and involve people committed to each other for some clear reason.
2. Respond to the challenge of the lengthening post-retirement phase of life, or the “third age.” Take specific steps to embrace the “dignity and creativity, the social importance and public significance, the self-respect and civic virtue of older people”⁴⁹ and promote ways for older people to achieve meaning during this time.
3. Recognize ethnicity. Ensure access for ethnic populations and assure sensitivity to the cultures and values of these diverse populations.
4. Respond to vulnerable populations. Ensure that the needs of vulnerable populations, particularly the frail elderly, the very poor, and those with little education, are addressed.
5. Proactively address the growing crisis in paid and family caregiving. Families pay a significant toll when there are insufficient health system and community-based supports.
6. Attend to language. Develop end-of-life initiatives that are responsive to issues of language, both to assure that translations from English are accurate and attuned to nuance and to assure that messages are meaningful in light of the culture and values of the people for whom the translation is made.
7. Promote incentives. Since facing one’s mortality appears to have a heavy price, the value and benefits that are also inherent must be made clearer. Address the age-old question: What’s in it for me? People who face the end of their lives and create good last chapters find it rewarding. Those rewards need to be better understood and promoted.

⁴⁸Feifel, Herman, *New Meanings of Death*, p.5, New York: McGraw-Hill Book Company, 1977.

⁴⁹Laslett, P. “The Third Age and the Disappearance of Old Age,” p. 10 of *Preparation for Aging*, Heikkinen, E., et al. (eds.) New York: Plenum Press, 1995.

8. Create and implement an appropriate research agenda. Change is generally expedited by data supporting its necessity and direction. The goal of the research agenda would be to identify gaps in current knowledge and address them as rapidly as possible.
9. Support durability. Efforts must be sustained at a local level by involving community leaders and by creating measurable outcomes. Success must be recognized and celebrated, but put in context, as the task will be ongoing and unlikely to be completed in our lifetime.

From a systemic point of view, implementing these recommendations requires that professional education and the education of legislators, regulators, and other policy makers must continue. Likewise, supportive legislation and policies must be assured, and issues of access must be addressed. From the perspective of professional education, training and opportunities for experience must be expanded. Barriers stemming from institutional culture must also be eliminated, and support and publicity must be given to further research. From the perspective of the public, promoting consumer recognition of and demand for good care and caring near the end of life is essential.

Implementing these recommendations, in conjunction with the changes in the health care system already under way, will move us farthest on the continuum toward universal access to the gold standard for care and caring near the end-of-life.

APPENDIX 1

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APPENDIX 2

2001 TEXTBOOK AWARD WINNERS:
"LEADING THE WAY IN END-OF-LIFE EDUCATION"

Nursing Textbook Award Winners

- Authors: Jane Ball, R.N.
Ruth Bindler, R.N.
Textbook: *Pediatric Nursing: Care for the Children*, 2nd Edition
Publisher: Prentice Hall Health
- Author: Julia Balzer-Riley, R.N.
Textbook: *Communication in Nursing: Communicating Assertively and Responsibly in Nursing*, 4th Edition
Publisher: Mosby
- Authors: Joyce Black, M.S.N., R.N.
Esther Matassarin-Jacobs, Ph.D., R.N.
Textbook: *Medical-Surgical Nursing Clinical Management for Continuity of Care*, 5th Edition
Publisher: WB Saunders
- Authors: Elizabeth Schulte, R.N., M.S.N.
Debra Price, R.N., M.S.N.
Julie Gwin, M.N., R.N.
Textbook: *Thompson's Pediatric Nursing: An Introductory Text*, 8th Edition
Publisher: WB Saunders
- Authors: Donna Wong, Ph.D., R.N.
Marilyn Hockenberry-Eaton, Ph.D., R.N.
David Wilson, M.S.
Marilyn Winkelstein, Ph.D., R.N.
Patricia Schwartz, Ph.D., R.N.C.
Textbook: *Wong's Essentials of Pediatric Nursing*, 6th Edition
Publisher: Mosby
- Authors: Judith Allender, R.N.C., Ed.D.
Barbara Walton Spradley, R.N., M.N.
Textbook: *Community Health Nursing: Concepts and Practice*, 5th Edition
Publisher: Lippincott Williams & Wilkins
- Author: Ginny Wacker Guido, J.D., M.S.N., R.N.
Textbook: *Legal and Ethical Issues in Nursing*, 3rd Edition
Publisher: Prentice Hall Health
- Authors: Suzanne O'Connell Smeltzer, Ed.D., R.N.
Brenda Bare, R.N., M.S.N.
Textbook: *Brunner & Suddarth's Textbook of Medical-Surgical Nursing*, 9th Edition
Publisher: Lippincott, Williams & Wilkins

Medical Textbook Award Winners

Authors: Richard Behrman, M.D.
Robert Kliegman, M.D.
Hal Jenson, M.D.

Textbook: *Nelson Textbook of Pediatrics*, 16th Edition
Publisher: BPR Publishers

Author: John Noble, M.D.
Textbook: *Textbook of Primary Care Medicine*, 3rd Edition
Publisher: Mosby

Author: Judith Tintinalli, M.D.
Textbook: *Emergency Medicine: A Comprehensive Study Guide*, 5th Edition
Publisher: McGraw-Hill Medical Publishing Division

Medical Textbook Publisher Award Winner

Lippincott Williams & Wilkins

Pharmacy Textbook Award Winner

Author: Rebecca Finley, Pharm.D.
Textbook: *Concepts in Oncology Therapeutics*
Publisher: American Society of Health-System Pharmacists

1999 AWARD RECIPIENTS

End-of-Life Care Content in Nursing Textbooks

Best Overall Nursing Textbook with End-of-Life Care Content

Textbook: *Cancer Nursing: A Comprehensive Textbook*, 2nd Ed.
Publisher: WB Saunders
Authors: Ruth McCorkle, Ph.D., FAAN.
Marcia Grant, DNSc., FAAN
Marilyn Frank-Stromborg, Ed.D., J.D., ANP, FAAN
Susan B. Baird, M.P.H., M.A., R.N.

Outstanding Specialty Book

Textbook: *Toward Healthy Aging: Human Needs and Nursing Response*
Publisher: Mosby
Authors: Priscilla Ebersole, Ph.D., R.N., F.A.A.N.
Patricia Hess, Ph.D., R.N., G.N.P.-C.S., N.A.P.

Textbook: *Psychiatric-Mental Health Nursing: Adaptation and Growth*
Publisher: Lippincott
Author: Barbara Schoen Johnson, Ph.D., R.N., C.S.

Textbook: *Pediatric Nursing: Caring for Children*
Publisher: Appleton & Lange
Authors: Jane Ball, R.N., C.P.N.P., Pharm.D.
Ruth Bindler, R.N.C., M.S.

Best Nursing Fundamentals Textbook

Textbook: *Fundamentals of Nursing: Concepts, Process, and Practice*, 5th Ed.
Publisher: Addison-Wesley
Authors: Barbara Kozier, R.N., M.N.
Glenora Erb, R.N., B.S.N.
Kathleen Blais, R.N., Ed.D.
Judith M. Wilkinson, R.N.C., M.A., M.S.

Textbook: *Fundamentals of Nursing: Concepts, Process, and Practice*
Publisher: Mosby
Authors: Patricia A. Potter, R.N., B.S.N., M.S.N.
Anne Griffin Perry, R.N., B.S.N., M.S.N., Ed.D.

End-of-Life Care Content in Medical Textbooks**Best General Textbook with End-of-Life Care Content**

Textbook: *Family Medicine*, 4th Ed.
Publisher: Springer-Verlag
Editor: Robert Taylor, M.D.

Best Chapter with End-of-Life Care Content in a Medicine Textbook

Textbook: *Textbook of Family Practice*, 5th Ed.
Publisher: W.B. Saunders
Editors: Robert Rakel, M.D.
Porter Storey, M.D.

Best Specialty Textbook with End-of-Life Care Content

Textbook: *Principles and Practice of Pediatric Oncology*, 3rd Ed.
Publisher: Lippincott-Raven
Editors: Philip Pizzo, M.D.
David Poplack, M.D.

Best Chapter with End-of-Life Care Content in a Specialty Textbook

Textbook: *Cancer: Principles and Practice of Oncology*, 5th Ed.
Publisher: Lippincott-Raven
Author: Frank Brescia, M.D.
Editors: Vincent DeVita, Jr., M.D.
Samuel Hellman, M.D.
Steven Rosenberg, M.D., Ph.D.

Most Committed to Excellence in Changing End-of-Life Care Content in Medical Textbooks

Textbook: *Merck Manual of Diagnosis and Therapy*, 17th Ed.
Publisher: Merck Research Laboratories
Editors: Mark Beers, M.D.
Robert Berkow, M.D.

APPENDIX 3

SELECTED WEB-SITE LISTING*

(current as of January 12, 2001)

Note: Since it is not possible to list every site that would be of interest to people facing end-of-life issues, this listing is intended to provide a helpful sample.

ORGANIZATION NAMES & WEB-SITE DESCRIPTIONS

About.Com on death and dying (click on “d” and then “death and dying”: www.about.com	Extensive offering of information about various aspects of death and dying. Clicking on a topic results in sub-lists of both articles and related Web sites. Also offers access to bookstore, video store, newsletters, and special “spotlight” articles selected by the site’s guide.
Agency for Healthcare Research and Quality http://www.ahrq.gov/	Government agency designed to perform research and report its results on various health care issues. Long-term care and the elderly are two of its focal points. Web site reports on various research topics and provides news releases on some of the findings.
Aging with Dignity www.agingwithdignity.org	Site offers ordering information for Five Wishes Advanced Directives packet that can be used in 33 states. Also provides information on organization’s other projects.
Alzheimer’s Association www.alz.org	Site of the Alzheimer’s Association offers a great deal of information and news.
Alzwell www.alzwell.com	Created for caregivers who take care of people with Alzheimer’s or other patients with dementia. Contains numerous personal stories as well as links to other eldercare resources. The Growth House database can be searched from this site.
American Academy of Hospice and Palliative Medicine www.aahpm.org	Has information on the Academy as well as brochures and other publications that can be ordered online. It has a comprehensive set of links and resources. The Growth House database can be searched from this site.
American Academy of Pain Management www.aapainmanage.org	Has information for both professionals and consumers. It offers directories of accredited physicians and programs as well as articles on pain management. The National Pain Data Bank, which contains tools for assessment of various treatments, is included. Past issues of the organization’s newsletter are available along with information about CME programs.
American Association of Retired Persons www.aarp.org	Offers extensive, detailed, easy-to-understand information for consumers about many aspects of EoL care. Subjects range from coping with grief to finding an estate planner to funeral arrangements. Also offers member benefits such as personalized counseling. Various articles from their member magazines are also available online and highlight current news and events in the field of EoL care.

*This listing was prepared by Laura Nodelman while working as a Program Analyst at Partnership for Caring.

American Hospice Foundation <i>www.americanhospice.org</i>	Numerous full-text articles on hospice care and bereavement as well as information on substantive publications and in-house training programs that are available through the organization. A good list of related links including links to lesser-known sites.
American Pain Society <i>www.ampainsoc.org</i>	This is the official site of this membership organization. Aimed at professionals, although there are some articles suitable for the general public. Good resource/link list and database of pain facilities also made available. Some of the organization's position statements and specially developed tools and guides for professionals are also on the site.
Americans for Better Care of the Dying <i>www.abcd-caring.org</i>	Focused mostly on policy issues and includes tools for consumers and professionals who want to get involved in the movement to improve EoL care. ABCD Exchange, the ABCD newsletter reporting improvement and reform activities is available in full text. Links to an online email information exchange through the Inter-Institutional Collaborating Network on End-of-Life Care.
American Society of Law, Medicine and Ethics <i>www.aslme.org</i>	Membership organization that deals primarily with issues of medical ethics, pain management, and under-treatment of pain. Organization publishes two journals. Web site presents access to some of these articles as well as information on the organization's research projects and publications.
Band-Aids & Blackboards <i>http://funrsc.fairfield.edu/~jfleitas/contents.html</i>	Divided into sections each for adults, teenagers, and children. It offers information on coping mechanisms and strategies for growing up with a medical problem. There is a large database of stories and information sent in by parents and their ill children. Not so much an end-of-life resource site, but one that is a good jumping off point for related children's issues.
Before I Die <i>http://www.wnet.org/archive/bid/index.html</i>	Set up to accompany a 1997 PBS series on death and dying, this site contains a set of real life stories detailing death with dignity issues as well as articles surrounding those issues. Extensive list of helpful short summaries, links, and resources to help introduce readers to EoL issues. Also provides information and resources to begin a community discussion group.
Bereavement and Hospice Support Netline <i>www.ubalt.edu/www/bereavement</i>	Provides directory of resources to state and national organizations that provide bereavement support and counseling. Provides name and contact information for most of the organizations listed as well as information about their conferences and meetings.
Care Counsel, LLC <i>www.carecounsel.com</i>	Private company offers access to Memorial Sloan-Kettering doctors who, for a fee, will review a patient's medical records and give them a care plan. Service offers a second opinion from top cancer-care doctors in the country. Site also offers articles on getting health records and second opinions as well as other links that may be helpful to patients and their families.
Caregiver.com <i>www.caregiver.com</i>	Helpful, short articles on many different issues confronting caregivers. There is also a care directory with helpful names and numbers as well as a discussion forum and chat site.
Caregiver Zone <i>www.caregiverzone.com</i>	Contains very informative guides on many different aspects of care giving. Visitors can shop online or visit discussion forums as well.

Careguide.com
www.careguide.com

For-profit company that offers various care management programs for a fee. Available on the site FREE are helpful articles and extensive resources for legal and financial questions as well as links to information for problems such as creating a safe environment and getting help with household chores.

Catholic Health Association of the U.S.
www.chausa.org

Operated by the CHA, this page provides access to many articles and links related to health care and religion. Search tools to locate local ethicists, Catholic hospitals, etc. Updates on current policy and legislation affecting group.

Center to Advance Palliative Care
www.capcmssm.org

Informational site funded by RWJF provides articles about what palliative care is and how hospital administrators can institute a program. Also gives links to EoL sites and some information on various current events in the field (e.g., Moyers on Dying.) Various pamphlets and guides are also available online.

Center to Improve Care of the Dying
www.medicaring.org

Provides the support for quality improvement and policy-related research offered by the RAND Center to Improve Care of the Dying, in conjunction with the Institute for Healthcare Improvement. It includes an automated referral system to locate other resources, practical tips on quality improvement, downloads of research findings, and links to online communications through the Inter-Institutional Collaborating Network on End-of-Life Care.

Children's Hospice International
www.chionline.org

Contains information about the movement to extend hospice services to children. It has information on hospice and various other services specific to the care of children as well as information on new projects being undertaken to improve care in this field.

Compassion in Dying
www.compassionindying.org

Has information about the organization's goals and projects. Also provides consumer tools, such as a sample letter to a doctor and Internet resources for end-of-life care organizations. Testimonials, newsletters, and press releases are also available. Information on local affiliates.

Counseling for Loss and Life Changes
www.counselingforloss.com

Extensive offering of articles on grief and bereavement, FAQ's, discussion groups, memorials, weekly advice columns, and local and national resources. A separate section for children is also available.

David Baldwin's Trauma Information Pages
<http://www.trauma-pages.com/index.phtml>

Extensive resource with information on psychological trauma and its treatment. Includes numerous journal articles as well as research aids and links to trauma sites and other mental health sites. Some general bereavement and loss information is also available.

Death and Dying Grief Support
www.death-dying.com

Many resources for people who have a terminal illness or have recently lost a loved one. Message boards, discussion groups, newsletters, and articles are all available, as well as a special area for kids and teens. Also provides information on a range of state laws and online legal forms. Various information and links on general health matters and relaxation, etc.

Decision Aids
<http://www.lri.ca/programs/ceu/obdec/default.htm>

Part of the Loeb Research Center, this page has various tools available for professionals and patients to use in serious medical situations, including EoL care. Helps patients decide the right treatment for them depending on their conditions. Guides can be downloaded. Other publications are also available, as well as information on current research projects.

Directory of Web Sites on Aging <i>http://www.aoa.dhhs.gov/aoa/webres/craig.htm</i>	Immense site, maintained by the Administration on Aging, links to sites related to elder care. Site organized by location, type, and other subheadings.
Doctor-Assisted Suicide <i>http://web.lwc.edu/administrative/library/suic.htm</i>	Comprehensive text-based site with materials on PAS. Includes lists and links to books, journal articles, newspaper articles, and transcripts from NPR broadcasts. Also includes texts of various court decisions and model legislation for PAS programs in various states. Growth House can be searched from here.
Dying Well <i>www.dyingwell.com</i>	Dr. Ira Byock's site in support of and supported by information in his book, <i>Dying Well</i> . Site provides access to articles about palliative care and pain management from various medical journals and newspapers as well as information on various projects and organizations dealing with EoL care. Includes a link to Growth House site.
Edmonton Palliative Care Program <i>www.palliative.org</i>	Site has a wealth of information on palliative care procedures and tools developed by professionals in this organization. Headings link to specific articles with ability to link to other archived articles. Also available are extensive lists of links to other Web sites. The Growth House database can be searched from this site. Some consumer information on palliative care is available through their articles and links, but it is not primarily designed for consumers.
Education for Physicians on End-of-Life Care (EPEC) <i>http://www.ama-assn.org/ethic/epec/index.htm</i>	Project Web site of the EPEC program. Information on the program's objectives is detailed. There is also access to a resource list and a sign-up for the EPEC Discussion Group.
Eldercare Web <i>www.elderweb.com</i>	Large site consisting of many Web links and informational resources for various aspects of elder care. Site is very clear and easy to navigate. Topics include caregiving, financial concerns, living arrangements, and health care. There is also a large section on news events that covers current legislation regarding Medicare, etc.
End-of-Life Nursing Education Consortium (ELNEC) <i>www.aacn.nche.edu/elneec</i>	Project, funded by RWJF and co-managed by the American Association of Colleges of Nursing and the City of Hope Medical Center, seeks to develop a core of expert nursing educators and to coordinate national nursing efforts in EoL care. Site provides information on the program, the curriculum, some guides, and application information. Contact information and outside resources are also listed online.
End-of-Life Physician Education Resource Center (EPERC) <i>www.eperc.mcw.edu</i>	Program, run through Medical College of Wisconsin and supported by RWJF, seeks to assist physician educators in locating educational training materials on EoL care. Site, parts of which are password-protected, provides access to the training materials as well as books, videos, funding resources, and a discussion section.
Family Caregiver Alliance <i>www.caregiver.org</i>	Clearly organized with a tremendous amount of information. Site has information about various illnesses as well as general caregiver topics. Informative fact sheets, reading lists, policy statements, current events, human-interest articles, information for the media, and publications that can be ordered by the public are all available. The group offers information and referrals through its email service.

Final Thoughts
www.finalthoughts.com

Information on many aspects of end-of-life care including estate planning and funeral arrangements, etc. Also features various chat rooms and message boards as well as expert-led discussions. New and innovative services are also available, such as after-death email services for friends and family.

Grief and Loss Resource Center
http://www.rockies.net/~spirit/grief/grief.html

Extensive set of links and articles about grieving and loss. Christian religious emphasis. Access to various discussion groups and newsletters.

Griefnet
www.rivendell.org

Site contains access to 35 support/discussion groups for all different types of situations. Also memorial site, bookstore and resource links. The Growth House database can be searched from this site.

Growth House
www.growthhouse.org

Extensive resource with focus on links to the majority of relevant EoL sites. Also provides merit ratings of sites and links to book reviews. Summaries of topic headings are general. Site is clearly organized and "cross-referenced" throughout. Host of the Inter-Institutional Collaborating Network on End-of-Life Care (IICN) that links major organizations internationally. The IICN offers health care professionals over 70 mailing lists and online education features as well as chat rooms for the general public.

Health A to Z
www.healthatoz.com

Comprehensive site offers all types of general health information. Searches performed on terms like "end-of-life care" and "living wills" returned multiple articles. Proper search terms must be known to maximize information collection.

Health Care Financing Administration
www.hcfa.gov

Official site of the HCFA, agency that administers Medicare and other government financing programs. A number of HCFA quality-of-care improvement programs are detailed on the site. Site primarily includes reports on government-funded activities.

Healthcare and Elder Law Programs Corporation
www.help4srs.com

Nonprofit site has information and tools for elderly Americans looking on estate planning, insurance, advance directives and other topics. Site uses California law as its reference point.

Healthfinder
www.healthfinder.gov

Government-controlled meta-site provides Web resources and informational sheets about various topics, including death and dying, hospice, and advanced directives. Good list of links and informative articles can be accessed with the appropriate search terms. Information is not directly referenced on home page.

Hemlock Society
www.hemlock.org

Web site of the Hemlock Society, the oldest right-to-die organization, provides detailed articles, newsletters, legal information, and information on its local affiliates geared to those strongly supporting assisted dying.

Hospice Cares
www.hospice-cares.com

Site created by Hospice of North Central Florida with both local and national information. Site introduces hospice concepts, including bereavement and children's hospice, and provides access to numerous articles and links. Site features large bookstore, chat/discussion rooms, information on hospice employment, and volunteer positions.

Hospice Foundation of America <i>www.hospicefoundation.org</i>	Site provides information for consumers on concept of hospice, what it costs and how to find a local hospice. Also bereavement support and information on upcoming conferences and press releases from HFA. Extensive resource list on related topics—caregiving, etc. The Growth House database can be searched from this site.
Hospice Homepage <i>www.scu.edu/hospice</i>	Site is created and administered by Dr. Dale Larson. Various stories and caregiving ideas for the hospice professional are posted, as well as links to other sites. The site is very well organized, but not as comprehensive as some of the other hospice Web sites.
Hospice Net <i>www.hospicenet.org</i>	User-friendly text-based site with information about hospice and text articles written for specific readers and situations. Major headings are bereavement, caregivers, services, and patients. Links are provided to various other sites.
Hospice and Palliative Nurses Association <i>www.hpna.org</i>	Membership organization's Web site provides information about the organization as well as current general information on hospice and palliative nursing, certification, and upcoming conferences. Also lists other nursing-related links and information.
HospiceWeb <i>www.teleport.com/~hospice</i>	Consumer-focused information on hospice. Provides general information and FAQs about the service as well as links to some related sites and a state-by-state directory of hospices.
Innovations in End of Life Care <i>www.edc.org/lastacts</i>	Bimonthly online journal that focuses on innovative projects in EoL care. Site provides access to archived editions and other resources for professionals seeking new programs in EoL care. Online discussion forum offered for leaders in end-of-life care.
Institute for Healthcare Improvement <i>www.ihl.org</i>	A non-profit group addressing quality improvement in health care, one of IHI's foci is improvement in EoL care. Web site offers numerous guides and studies, the organizational newsletter and links to other resources.
Julie's Place <i>www.juliesplace.com</i>	Dedicated to children and teenagers who have lost a sibling. Offers discussion groups and bulletin boards as well as activity ideas and stories. Resource list and links are also available.
Last Acts <i>www.lastacts.org</i>	Has an enormous amount of information about EoL projects and activities including those of the <i>Last Acts</i> Partner Organizations. Electronic newsletter, current and archived press releases and journal articles, and grant information are available. Page provides direct links to all Partner Web sites.
Massachusetts Compassionate Care Coalition <i>www.massccc.com</i>	Coalition working to improve EoL care. Site has various links to other resources. Also provides an e-mail question sheet and offers response within two days.
The Mayday Pain Project <i>www.painandhealth.org</i>	Site categorizes various pain Web sites by topic. Goal is to increase awareness and provide objective information to both pain sufferers and their families and caregivers. Includes much information which is not related to EoL care.
Medical College of Wisconsin Palliative Medicine Program <i>www.mcw.edu/pallmed</i>	Develops, implements and educates professionals about various programs and studies to improve EoL care. Site provides information on current projects as well as ordering information for materials and lists of links and resources.

Medicare/Medicaid Hospice Services www.bcfa.gov/medicaid/ltc2.btm	Informational page, found through Growth House, that is maintained by HCFA and offers information on the Medicare benefit for hospice care. It has general requirements and restrictions as well as contact information.
Mediconsult www.mediconsult.com	General health site with a great deal of information for consumers on chronic pain issues and palliative care. Advertised as a completely independent site, it offers many news/journal articles, live support networks, chat rooms, and Q&A services. Extensive information on specific conditions.
Midwest Bioethics Center http://www.midbio.org	Site provides list of publications and articles on topics around improving EoL care. Information on <i>Community-State Partnerships</i> , <i>Compassion Sabbath</i> and <i>Caring Conversations</i> is also included on the home page. Current events information and discussion groups are also highlighted.
National Alliance for Caregiving www.caregiving.org	Provides information, resources, and support for family caregivers and the professionals who serve them. Useful advice and tools in an easy-to-use format. Research and studies can be downloaded. Site offers lists of books and publications as well as online links.
National Center for Advanced Illness Coordinated Care www.coordinatedcare.net	Site describes efforts to integrate advanced illness coordinated care in mainstream medical practice and to bridge the gap between good theory and practice. A section called Walking the Road is a roadmap for adjusting to advanced illness.
National Family Caregivers Association www.nfca.org	Membership organization offers tips and articles for caregivers as well as access to printed publications. Full-text articles and news briefs are online as well as membership information.
National Hospice Foundation www.hospiceinfo.org	A good starting place for general information on hospice care. Provides online access to long Q&A brochures on hospice care, communicating EoL wishes and the Medicare Hospice Benefit. Also provides information on the organization's current and past projects. Informational brochures can be ordered in hard copy. User can link to NHPCO for directory of national hospices.
National Hospice & Palliative Care Organization www.nhpco.org	Site offers information both to professionals and the public about hospice care. A hospice care locator and downloadable research and statistical reports are available as well as information on professional conferences and recent news articles and press releases. Some information is provided by the National Hospice Foundation site. Other information for members is accessed through a login screen.
National Institute for Healthcare Research www.nihcr.org	Organization's goal is to encourage professional collaboration to advance the understanding of health and spirituality through educational programs and research. Site offers long articles on various topics as well as a range of contact information and a speakers bureau section.
National Viatical Association www.nationalviatical.org	Association's goal is to help fund and promote the needs of people coping with terminal illness. Site provides information describing viatical settlements and lists contacts for more information and related end-of-life links.
Nolo.com www.nolo.com	Consumer-based legal site offers tools and information on many different areas of the law. Elder care site has advice column, legal encyclopedia, calculators, tools, and downloadable guides and software for many different aspects of estate planning, elder law, retirement, and Medicare.

On Our Own Terms—Moyers on Dying
www.pbs.org/onourown/terms

Site based on the PBS series, “On Our Own Terms” and the outreach that has followed. Well-organized and contains user-friendly tools and resource guides.

Pain.com
www.pain.com

Large Web site. Divided for use by professionals and consumers. For professionals, site offers online continuing medical education programs and a large database of articles, journal studies and professional directories. For consumers, site contains informational resources as well as Q&A and discussion sections. Significant list of links and resources for both professionals and consumers.

Partners against Pain
www.partnersagainstpain.com

Site, operated by Purdue Pharma, has professional and consumer sections. For professionals, abstracts of journal articles, downloadable patient brochures, and tools to gauge pain and prescribe medications. For consumers, tools and explanations regarding pain as well as news articles and support group information and links.

Partnership for Caring
www.partnershipforcaring.org

Advocates for the rights of dying patients, provides legal and educational information regarding EoL decision-making and offers counseling and resources related to advance directives and other end-of-life issues. Site allows users to download free, state-specific advance directive and living will forms.

Pediatric Oncology Group
www.pog.ufl.edu

Part of the U.S. National Cancer Institute, a cooperative clinical trials group of over 100 centers working to treat cancer among children and teens. Site offers information about treatments, news and other oncology resources.

Pediatric Pain
<http://is.dal.ca/~pedpain/pedpain.html>

This site is dedicated to pain management in children. It offers subscriptions to its newsletter and listserv as well as abstracts of various publications and articles. Assessment tools for professionals and researchers working on children’s pain issues are also available. Site offers published sourcebook and some links.

Project on Death in America
www.soros.org/death

PDIA is a special long-term project to improve EoL care. Site tells of project’s progress and goals. It has an extensive list of links.

Promoting Excellence in End-of-Life Care
www.promotingexcellence.org

National program office of RWJF to foster long-term changes in health care institutions to improve care for the dying. Site offers information on the program’s goals and objectives as well as access to a number of discussion forums, resources and links and information on the organizations awarded grants.

Safe Crossings
<http://www.providence.org/safecrossings>

Local hospice site is dedicated to helping children and teens deal with grief and EoL issues. It is divided into sections devoted to children, families, and professionals. Provides activities, tools, resources, and links for each section.

Stoppain.org at Beth Israel Medical Center
www.stoppain.org

Excellent information source for consumers and professionals on pain management, palliative care, and specific conditions. Resource lists, fact sheets, online conferences, clinical trial information, and programs at Beth Israel are all detailed.

Supportive Care of the Dying
www.careofdying.org

Coalition comprises 13 health care organizations and the Catholic Health Association with goal of improving EoL care. Site provides resource lists as well as measurement tools for patients, professionals, and caregivers. Also provides newsletters and information on the coalition’s focus groups and research.

University of Baltimore Center for Clinical
Ethics and Humanities in Health Care
www.ubalt.edu/www/bereavement

Informative articles on various ethical issues in health care including EoL care. Lots of information on advance directives and other tools for consumers. Provides access to various journal articles as well as legal cases. Extensive resource and link lists, including EoL care sites, university sites, and bioethics sites. Site was last updated on January 20, 1998.

University of Ottawa Institute
of Palliative Care
http://www.pallcare.org/

Site with updates on Institute's projects. Sections for both professionals and consumers. New features include an online educational center, educational slide shows on grieving, and a "downloads" page. Also available are newsletters and discussion groups and a large link/resource list. Pamphlets can be ordered online and there is a section of FAQs.

U.S. Living Will Registry
www.uslivingwillregistry.com

Service collects notarized living wills and makes them available to any hospital that requests a copy. A free service. Site is very clear, user-friendly and offers links to other EoL sites that focus on living wills. Information available in English and Spanish.

University of Washington Ethics
in Medicine
http://eduser.v.bscer.washington.edu/bioethics/index.html

Bioethics site maintains a variety of articles on various ethical issues and EoL care. Provides simple step-by-step guides for professionals in the field as well as informative articles on advance directives and other legal and ethical issues likely to arise. Site also includes various case studies, useful links, and an online discussion forum.

The Viatical and Life Settlement
Association of America
www.viatical.org

General information and resources on viatical settlements. Information and links to viatical companies as well as legal documents. Q&A section posted as well as code of ethics followed by all members of the Association.

Viatical Settlements
http://www.ftc.gov/bcp/online/pubs/services/viatical.htm

A straightforward Q&A style paper about estate planning and viatical settlements. Includes information on other resources. Excellent explanations.

Web of Care
www.webofcare.com

Multifaceted site includes information on a variety of serious medical conditions as well as tips for caregivers and discussion rooms. Many advertising banners dot the site. Also special reports on medical studies and findings that may be relevant to some users. Extensive resource list for life insurance policy information.

University of Wisconsin Comprehensive
Cancer Center: Pain & Policy Studies Group
www.medsch.wisc.edu/painpolicy

Site details projects being undertaken by the group as well as guides for both professionals and consumers on issues regarding pain and pain policy. Site contains numerous articles related to the study of how public policy affects pain management. Project is connected with World Health Organization cancer pain project. WHO newsletter available on the site.

Last Acts[®]

*A national coalition to improve care
and caring near the end of life*

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