Means to a Better End:

A Report on Dying in America Today

November 2002

A Vision for Better Care at the End of Life

Death and dying are not easy to deal with. Perhaps you or someone you love is facing an illness that cannot be cured. Few of us are really ready for the hard choices that may have to be made at the end of life. It can be hard for everyone involved—the dying person, their family and loved ones, and health care providers, too.

But there is a way to ease pain and make life better for people who are dying and for their loved ones. It is called *palliative care.* Palliative care means taking care of the whole person—body, mind, spirit—heart and soul. It looks at dying as something natural and personal. The goal of palliative care is that you have the best quality of life you can have during this time.

Some health care providers—doctors, nurses, social workers, pharmacists, clergy and others—have learned how to give this special kind of care. But all health care providers should know how to give good palliative care or to help you find someone who can.

FIVE PRINCIPLES OF PALLIATIVE CARE

The following Five Principles of Palliative Care describe what care can and should be like for everyone facing the end of life. Some of these ideas may seem simple or just common sense. But all together they give a new and more complete way to look at end-of-life care.

1. **Palliative care respects the goals, likes and choices of the dying person. It . . .**
   - Respects your needs and wants as well as those of your family and other loved ones.
   - Finds out from you who you want to help plan and give you care.
   - Helps you understand your illness and what you can expect in the future.
   - Helps you figure out what is important.
   - Tries to meet your likes and dislikes: where you get health care, where you want to live and the kinds of services you want.
   - Helps you work together with your health care provider and health plan to solve problems.
2. **Palliative care looks after the medical, emotional, social and spiritual needs of the dying person. It . . .**
   - Knows that dying is an important time for you and your family.
   - Offers ways for you to be comfortable and ease pain and other physical discomfort.
   - Helps you and your family make needed changes if the illness gets worse.
   - Makes sure you are not alone.
   - Understands there may be difficulties, fears and painful feelings.
   - Gives you the chance to say and do what matters most to you.
   - Helps you look back on your life and make peace, even giving you a chance to grow.
3. **Palliative care supports the needs of the family members. It . . .**
   - Understands that families and loved ones need help, too.
   - Offers support services to family caregivers, such as time off for rest, and advice and support by telephone.
   - Knows that caregiving may put some family members at risk of getting sick themselves. It plans for their special needs.
   - Finds ways for family members to cope with the costs of caregiving, like loss of income, and other expenses.
   - Helps family and loved ones as they grieve.

continued on inside back cover

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ACKNOWLEDGMENTS

The development of this *Last Acts* report was an inspiring group project. Many people contributed to this effort, which we hope will spark public discussion about the state of dying in America today. From the first brainstorming session held by the *Last Acts* Committee Conveners to the report's publication, drafts found their way into over 40 pairs of capable hands. We are grateful to all of the conveners and other experts who guided us so carefully. Special thanks to Jim Towey for "birthing" the idea that led to the report and his initial stewardship of this project. In designing specific measures, we particularly benefited from the expertise of Ira Byock, M.D., Stephen Connor, Ph.D., Elliott S. Fisher, M.D., David Joranson, M.S.S.W., Diane Meier, M.D., Christina Puchalski, M.D., Charles Sabatino, J.D., Joan Teno, M.D., and John Wennberg, M.D.

Carolen Collins and the Midwest Bioethics Center were instrumental in developing our "Momentum for Change" section. Peg Metzger developed and wrote the Action Guide which serves as a companion piece to this report. The "Islands of Hope" features describe some of the past winners of the American Hospital Association's Circle of Life Award, *www.hospitalconnect.com/aha/awards-events/circle_of_life/index.html*. Many thanks also to Jean and Dick Atcheson and Margaret Trejo, our editorial and design experts, who brought an extraordinary amount of energy, creativity and dedication to this process.

As always, the *Last Acts* team members provided helpful suggestions and quick "turn around" when needed—especially Mollie Katz, Karen Long, Jane Koppelman, and our program officer at The Robert Wood Johnson Foundation, Vicki Weisfeld. Sheila Gaskins' unflappable good cheer helped us through many a draft. And, last but not least, there would be no report without the tireless and continuous efforts of Tricia Nitsche, our *Last Acts* Research Associate.

How we die says a lot about our society. We hope this report fuels a much larger discussion of why and how America must grapple with improving the care of people nearing the end of their lives.

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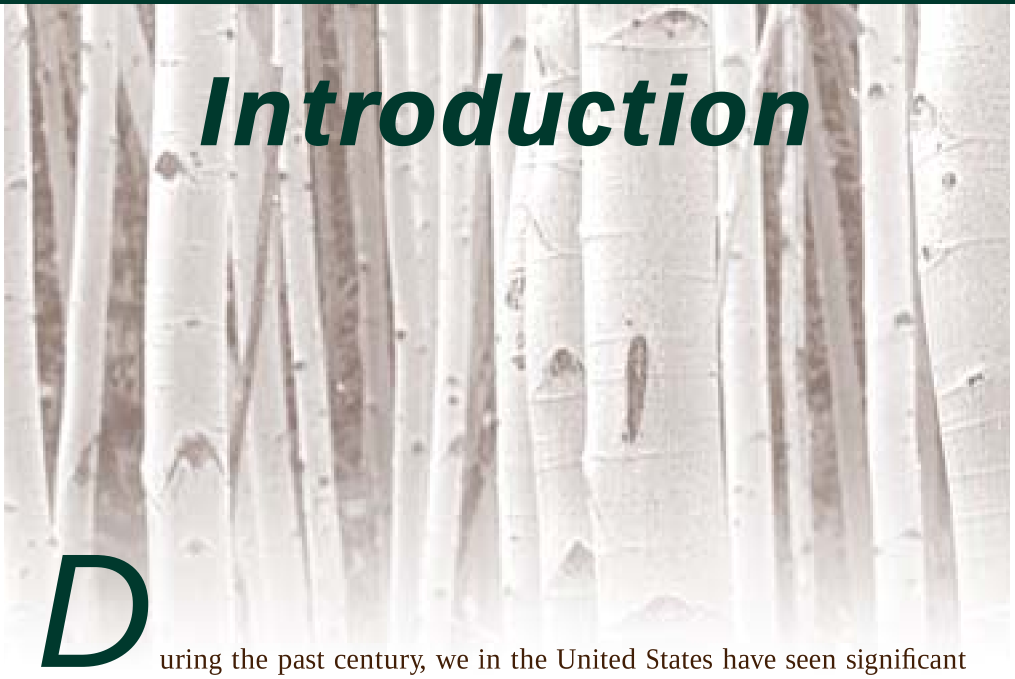
Introduction



During the past century, we in the United States have seen significant changes in the way we experience illness and death. A hundred years ago, people usually died from an injury or sudden illness. Farm work, factory work—even childbirth—were risky. Today, with medical and other advances, people live longer and can expect to live several years with an illness that may eventually kill them. Ultimately, many will reach a point where medical technology may be able to keep them alive but can neither restore their health nor even improve their condition. In truth, more treatment may be merely prolonging dying. At that point, patients and families face difficult choices about the kind of care they want.

While opinion polls reveal that most Americans would prefer to die at home, free from pain and with their loved ones, the reality is vastly different. Americans often die alone in hospitals or nursing homes, in pain and attached to life support machines they may not want. And this happens despite modern medicine's ability to ease most pain, the existence of good models of delivering supportive care, and the increasing availability of excellent end-of-life care through hospice and palliative care programs. All these services, however, are underused—in large part because in our death-denying culture, many Americans don't want to discuss death and dying, or because many Americans don't know about these options for good end-of-life care and thus don't ask for them.

Many Americans don't know about these options for good end-of-life care and thus don't ask for them.

The last decade saw an evolution in the way Americans think about death and dying. The debate over physician-assisted suicide, coupled with pioneering studies about patterns of end-of-life care, launched a national dialogue about how we die. In November 1995, the *Journal of the American Medical Association* published initial results from SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments), the largest, most widely publicized research project examining end-of-life care in the United States to date.[1] SUPPORT documented what the public had suspected: Dying in America was unnecessarily painful and isolating, physicians did not understand patients' wishes, and it was costly. In 1997, an Institute of Medicine report, *Approaching Death in America: Improving Care at the End of Life*, underscored that "people have come to both fear a technologically over-treated and protracted death and dread the prospect of abandonment and untreated physical and emotional stress."[2]

On the heels of SUPPORT, The Robert Wood Johnson Foundation launched *Last Acts*, a multiyear, multimillion-dollar national campaign to promote improvements in care and caring near the end of life. Since 1996, *Last Acts* has been communicating with policymakers, groups representing health care professionals, and consumer organizations about the need to make sure that seriously ill and dying patients receive the best care possible and have the fullest possible understanding of the kinds of care available.

FAST FACT

Approximately 2.5 million people die each year—55,000 of them are children and 80 percent of them are Medicare beneficiaries.

The need for serious efforts to figure out how best to care for dying people and their loved ones is becoming more urgent every day. A large aging population, increases in the incidence of chronic disease, and the reduced availability of paid and unpaid caregivers, among other factors, must soon focus more attention on ways to improve the care we offer individuals nearing the end of their lives.

Experts—and the public—generally agree that the best end-of-life care treats the whole person—body, mind and spirit. This is called *palliative care*. Palliative care works aggressively to relieve pain and other physical symptoms; it also offers emotional and spiritual support to the patient and family, while respecting their culture and traditions. Care for people near the end of life is largely financed and delivered through Medicare and Medicaid—programs that were not designed to provide comprehensive palliative care.

Palliative care is often contrasted with curative care, but the lines between cure and the relief of suffering are blurry. In fact, palliative care may be needed for many years after diagnosis of a serious illness and not just near the end of life. Palliative care can complement other therapies and can be delivered in many settings—hospitals, nursing homes, other long-term-care facilities and hospices. Although palliative care has broad applications, this report focuses on palliative care near the end of life.

In 1997, *Last Acts* published its *Precepts of Palliative Care*, which describe for health professionals five areas that are key to delivering high-quality end-of-life care.[3] Briefly stated, these core areas are:

- Respecting patient goals, preferences and choices.
- Providing comprehensive caring.
- Utilizing the strengths of interdisciplinary resources.
- Acknowledging and addressing caregiver concerns.
- Building systems and mechanisms of support.

A Vision for Better Care at the End of Life, a version of the *Precepts* for the public, appears as the endpapers of this report.

SPARKING A PUBLIC DISCUSSION

In this report, *Last Acts* rates each of the 50 states and the District of Columbia on eight criteria as a basis for assessing the state of end-of-life care in this country. Despite many recent improvements in end-of-life care and greater public awareness about it, this report shows that Americans at best have no better than a fair chance of finding good care for their loved ones or for themselves when facing a life-threatening illness. In most states, too few patients are accessing hospice and palliative care services, there are too few professionals trained in pain management and palliative care, and there are too many patients dying in hospitals and nursing homes—in pain—rather than at home with their families.

Our ratings suggest a statistical portrait of access to some facets of good end-of-life care—they are far from a perfect measuring tool. For several important aspects of end-of-life care—such as whether emotional or spiritual needs are addressed or awareness of the differences in the kind of care desired by people from different cultural backgrounds—state-by-state data simply do not exist. (Some notes on the importance of spirituality and cultural issues in health outcomes and health care decision-making are presented on pages 4 and 5.) All the data need some explanation about their strengths and weaknesses and what they are really telling us. We hope that this report will stimulate efforts to improve the availability and quality of the data needed to understand end-of-life care in this country, but meanwhile we hope to spark a public discussion that cannot wait until more refined data are developed.

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Key Issues

SPIRITUALITY

Over time Western medicine has separated physical care from patients' spiritual needs. Increasingly, however, there is recognition of the importance of spirituality in the care of dying people.[4,5] *Numerous studies have been done that support the important role spirituality plays in patient care.*[6,7] *When medicine confronts life-limiting illness, in particular, and when cure becomes less likely, it is of paramount importance to help patients cope with their suffering and eventual dying.*

As people near death they often wrestle with questions such as "Why me?" or "What will happen to me?" or "What has my life meant?" These are inherently issues of the spirit, not only of biology or chemistry. Physicians and other health care providers increasingly recognize that good care of dying people is as much or more about these questions as it is about the relief of pain and other symptoms. Spirituality is an expression of how people relate to a larger whole—something greater than themselves—and how they find meaning in the midst of their suffering. A person's purpose and meaning in life can be expressed in different ways—through specific religious traditions, a deep regard for nature, connections to family, nature, art and music, or in some other way that is uniquely personal.[8,9,10,11]

Many hospitals recognize the role of spiritual caring in their provisions for chaplains and religious services and the inclusion of chaplains or other religious advisers on hospital palliative care teams.[12] *Hospice has long recognized the critical importance of involving pastoral professionals on interdisciplinary teams and always makes this service part of the total package of care available to all patients and their families.*

Increasingly, medical schools are realizing that addressing spirituality can be an important and useful part of patient care and doctors' own well-being. More than 70 medical schools now include some teaching about spirituality and medicine.[13] *While some doctors may hesitate to tread on spiritual ground, it seems that Americans* want *their doctors to ask them about spiritual concerns. In 1996,* USA Today *reported that 63 percent of people surveyed believe it is good for doctors to talk to patients about spiritual beliefs.*[14] *The American College of Physicians has convened two consensus conferences, which concluded*

In a country where so much research is conducted it is remarkable that this should be the first attempt to offer a comprehensive report on a situation that ought to interest every single American. Its importance is as obvious as its urgency. Our elderly population is increasing, and as our family members and friends grow ill and die, the experience becomes vivid to every one of us. What do we know about death in this country? What are our expectations for our own care at the end of our lives? Or would we rather not think about it?

Last Acts offers this report to help every interested American start to understand how disturbing the current situation is and, at the same time, what the elements of good end-of-life care are. It is a reminder that thinking ahead about the kind of care we want for ourselves and our families, and where we might turn to find it, is critical in averting crises when an incurable illness strikes. Thinking ahead is essential in making the end of life as peaceful as possible.

MORE INFO

See "Spirituality and End-of-Life Care" in *Innovations in End-of-Life Care*, 1(6), Nov.–Dec., 1999, and "Palliative Care in African American Communities" in *Innovations in End-of-Life Care*, 3(5), Sept.–Oct., 2001, at *www2.edc.org/lastacts/*

that physicians are obligated to address the spiritual and existential suffering of their patients.[15,16] A spiritual assessment tool was developed that many medical schools and hospitals are now using routinely.[17]

In another recent survey, 45 percent of respondents indicated that spiritual or religious beliefs would influence their treatment decisions if they were seriously ill.[18] A 1997 Gallup survey, which addressed needs people would have at the end of life, showed that the top concern of the American public was having their spiritual needs addressed.[19] In fact, seriously ill patients and bereaved family members have rated attention to spirituality among their most important concerns at the end of life.[20,21]

DIVERSITY

People from different backgrounds have different beliefs about and approaches to almost any important issue. The challenges and dilemmas that surround serious illness and death are no exception. Increasingly, doctors, nurses and counselors are being urged to identify and respect the unique needs, wishes and views about end-of-life issues of dying patients and their families.

In recent years, the diversity of our population's preferences with respect to end-of-life care has received some long-overdue attention. Results of one study of Caucasian, African, Korean and Mexican Americans suggest that ethnicity is strongly related to attitudes toward and personal wishes for the use of life support.[22] Another study found that African Americans are consistently more likely than whites to prefer aggressive treatment during the terminal phase of an illness. African Americans are one-third as likely as Caucasians to have living wills and one-fifth as likely to have Do Not Resuscitate (DNR) orders. Hispanics are about one-third as likely as Caucasians to have DNR orders and are equally likely to have living wills.[23] Even though certain beliefs and practices may be more common in particular ethnic or cultural groups, we cannot presuppose another individual's beliefs, desires or motives based on superficial knowledge or stereotype.

The Last Acts *Diversity Committee has published a* Statement on Diversity and End-of-Life Care*, which is accompanied by several case studies that depict the kinds of issues that arise when patients from various backgrounds deal with end-of-life decisions.[24]*

HOW *LAST ACTS* PREPARED THIS REPORT

In May 2001, *Last Acts* brought together a group of national experts in palliative care, spirituality, pain management and the U.S. health care system. (Please see page 86 for a complete listing of the conveners' names and affiliations.) They were there to produce something that did not exist—a way to describe the status of end-of-life care in every state. Much discussion of possible means of measuring the state of care eventually focused on eight important questions:

1. Do state policies support good advance care planning?
2. What proportion of the state's deaths occur at home?
3. Is hospice care widely used in the state?
4. Do hospitals in the state offer pain and palliative care services?
5. How many elderly people spend a week or more in intensive care units during the last six months of life, meaning that they may have received over-aggressive care?

6 How well do the state's nursing homes manage their residents' pain?
7 Do state policies encourage good pain control?
8 Does the state have enough physicians and nurses who are trained and certified in palliative care?

The answers to these questions can be found in the *State Report Card Measures*—the heart of this report. We describe each measure in turn, say why it is important and how it was developed and show a map indicating state performance—A, B, C, D or E. (A much more detailed description of the data behind each measure, by state, is in the Appendix.) With each measure, we include a brief case study illustrating how this measure affects real people, in real situations, every day. We follow this section with a set of *Recommendations for Action*.

Although the *State Report Card Measures* are discouraging and show tremendous shortfalls in care, there is good news, too. In a later section of this report, titled *Momentum for Change*, we describe how state coalitions composed of diverse professional and consumer groups have recognized the serious problems with care of the dying in their states and are working actively to try to fix them. Already some of their efforts have resulted in substantial progress, described on pages 53–66. And, recently, *Last Acts* established a new project, called *Rallying Points*, to help some 350 local coalitions work to improve end-of-life care at the community level. Details about where these coalitions are located and what they are doing can be found on the project's Web site, *www.rallyingpoints.org*.

The answers to these questions can be found in the State Report Card Measures.

State Report Card Measures

See the Appendix, pages 67–85,
for the actual data, charted by state,
on which these measures are based.

? Do state policies support good advance care planning?

People use advance care planning documents (living wills and medical powers of attorney) in an attempt to determine the type of care they want if they cannot speak for themselves. These documents explain the extent to which people want life-sustaining medical treatments, and appoint someone to make those decisions for them if they cannot. Experts and consumers alike believe that honoring a terminally ill patient's treatment preferences is a critical element of high-quality end-of-life care.[25]

Although advance directive policies are determined primarily at the state level, in 1991, Congress enacted the Patient Self-Determination Act (PSDA). This act requires that all health care facilities receiving Medicare or Medicaid reimbursements must inform patients of their right to make choices about the treatment they receive and to prepare advance directives.

Advance Directive **is a general term used to describe two types of documents—living wills and medical powers of attorney.** *Living wills* **(sometimes called medical directives) are written instructions for care in the event that a person is not able to make medical decisions for him- or herself. Currently, 47 states and the District of Columbia have laws authorizing living wills. Massachusetts, Michigan and New York do not.[26]**

As an additional guide to patients' treatment wishes, most health care facilities, including nursing homes and rehabilitation centers, are required to have a Do Not Resuscitate (DNR) order policy in place if they wish to be accredited by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO). There are also some people living at home for whom resuscitation is not appropriate or is unwanted. In order to protect them from resuscitation efforts (which are mandatory if emergency personnel are called), many states have authorized "non-hospital" (or out-of-hospital) DNR orders. These are orders signed by a physician that can be presented to emergency medical personnel, which allow them *not* to begin resuscitation. Currently 44 states and the District of Columbia have authorized the use of non-hospital DNR orders.

Despite the PSDA's requirement that health care providers tell patients about advance directives, surprisingly few Americans actually complete these documents. A study published in 2002 estimated the overall prevalence of advance directives to be 15 to 20 percent in the general population.[27] Rates of completion are also low in the populations that most need them. A 2002 study of nursing home residents found that only 20 percent of them had living wills, and 48 percent had DNR orders.[28]

How we rated state advance directive policies

For this report, we looked at the extent to which five aspects of state policies conform to key elements of the Uniform Health Care Decisions Act,[29] plus one aspect reflecting the existence of state DNR order policy. Except where indicated, the sources of these data are the legislative tracking charts produced by the American Bar Association's Commission on Law and Aging.[30] According to the Uniform Act, states should:

- Recommend a single, comprehensive advance directive, which reduces confusion (1 point).
- Avoid mandatory forms or language for medical powers of attorney or combined living wills/medical powers of attorney, giving residents the freedom to express their wishes in their own way (1 point).
- Give precedence to the agent's authority or most recent directive over the living will, recognizing that an agent has the advantage of being able to weigh all the facts and medical opinions in light of the patient's wishes at the time a decision needs to be made (½ point).[31]
- Authorize default surrogates (typically next of kin) to make health care decisions, including decisions about life support if the patient has not named someone (1 point).
- Include "close friend" in the list of permissible default surrogates, recognizing that "family" in today's world often extends beyond the nuclear family (½ point).
- Have a statewide *(non-hospital)* DNR order protocol for Emergency Medical Service personnel, to ensure that the wishes of terminally ill patients in the community can be followed by EMS personnel (1 point).[32]

This report placed states into five groups according to their overall score, which could range from 0.0 to 5.0. States receiving an A scored 4.5 to 5.0 overall, those receiving a B scored 3.5 to 4.0, and so on.

A *medical power of attorney* **(sometimes called a health care power of attorney) is a document that appoints a particular person (health care proxy or health care agent) to make health care decisions for a patient who is unable to do so for him- or herself (not just during a terminal illness). All 50 states and the District of Columbia have laws recognizing health care powers of attorney. Currently 28 states and the District of Columbia specify the types of decisions that health care proxies can make.**

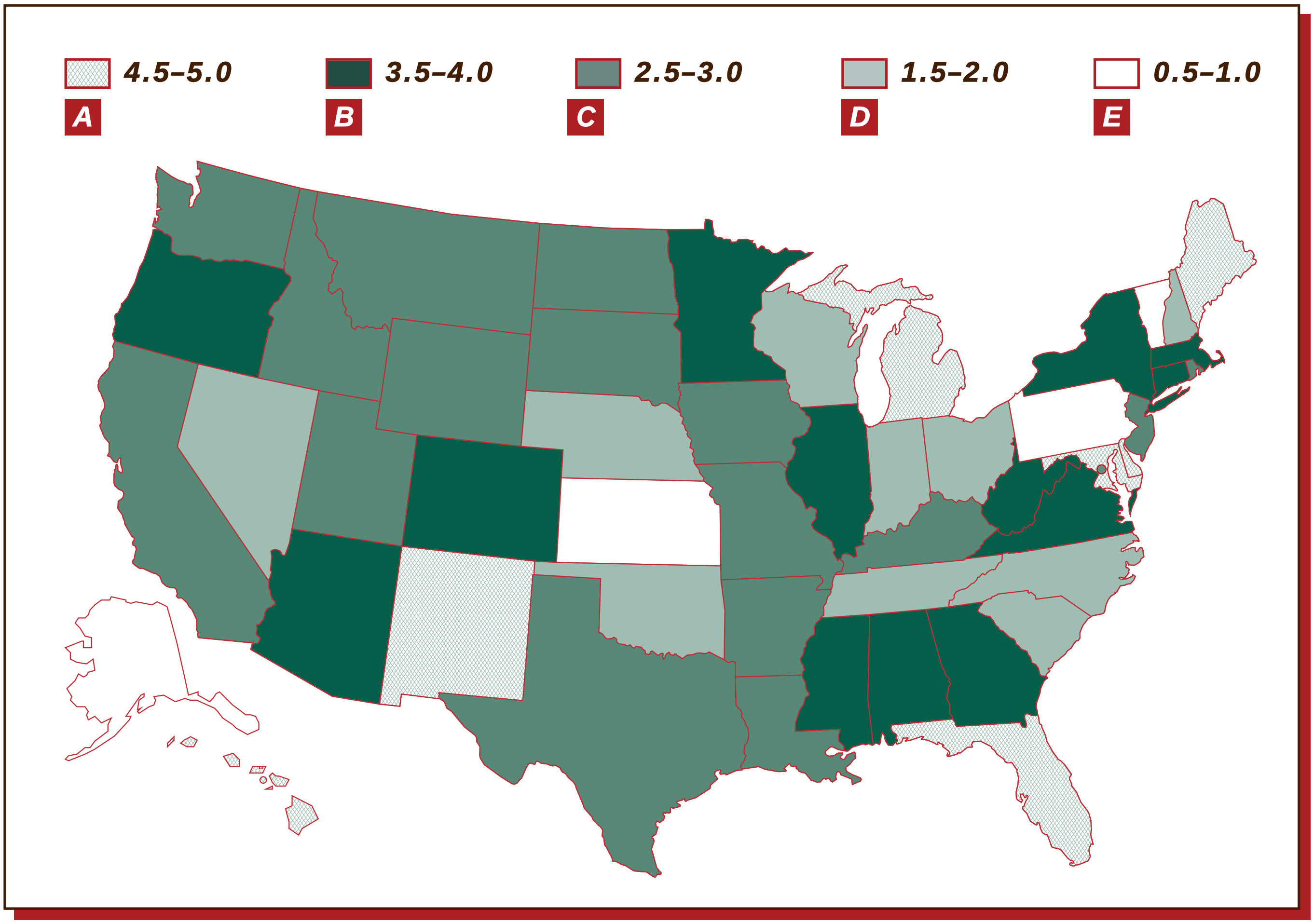
ISLAND OF HOPE

Fairview Health Services • Minneapolis, Minnesota

Fairview Health Services includes seven hospitals, three physician networks, 75 clinics, three nursing homes, and 14 senior residences. All patients are asked upon admission who should make decisions for them if they become incapacitated. At one of Fairview's rural sites, advance directives and care plans are reviewed whenever patients have a history and physical exam. Patients keep the original form, as they go from setting to setting, and a copy goes into each chart.

Quality of state advance directive laws, 2002

Range 0.5 – 5.0



A	**B**	**C**	**D**	**E**
Delaware	*Alabama*	*Arkansas*	*Indiana*	*Alaska*
Florida	*Arizona*	*California*	*Nebraska*	*Kansas*
Hawaii	*Colorado*	*District of Columbia*	*New Hampshire*	*Pennsylvania*
Maine	*Connecticut*	*Idaho*	*North Carolina*	*Vermont*
Maryland	*Georgia*	*Iowa*	*Ohio*	
Michigan	*Illinois*	*Kentucky*	*Oklahoma*	
New Mexico	*Massachusetts*	*Louisiana*	*Nevada*	
	Minnesota	*Missouri*	*South Carolina*	
	Mississippi	*Montana*	*Tennessee*	
	New York	*New Jersey*	*Wisconsin*	
	Oregon	*North Dakota*		
	Virginia	*Rhode Island*		
	West Virginia	*South Dakota*		
		Texas		
		Utah		
		Washington		
		Wyoming		

Source: American Bar Association, Commission on Law and Aging. *State Health Decisions Legislative Update, 2002, www.abanet.org*; Sabatino, CP. "The Legal and Functional Status of the Medical Proxy: Suggestions for Statutory Reform." *Journal of Law, Medicine & Ethics*, 27: 552–68, 1999; Sabatino, CP, "Survey of State EMS-DNR Laws and Protocols." *Journal of Law, Medicine & Ethics*, 27: 297–315, 1999.

CASE STUDY

Planning for care makes the end of life easier

In 1998, when Margaret Lazarz was 80, she sat down with trusted relatives to orchestrate a critical stage in her life—her final medical care. With two cardiac surgeries and a pacemaker behind her, and congestive heart failure a near certainty, she knew that a time would come, not far in the future, when she would need her loved ones to act on her behalf. She created a power of attorney for health care, designating her sister-in-law, Rosella Lazarz, and her niece, Janet Aide, as her representatives in making decisions. If her breathing and heart stopped, she did not want doctors to attempt cardiopulmonary resuscitation (CPR) unless she had a good chance of survival. Her wishes were put down in writing.

Some time later, Margaret was taken to the hospital because her poorly functioning heart allowed her lungs to fill with fluid and she was unable to breathe. There she was asked whether she wanted to be resuscitated if her symptoms advanced further. Margaret's personal doctor was met with a list of questions from the family representatives: How bad was her heart? What could she expect for the future? If her breathing stopped, would CPR be successful? Would her treatment be top quality if she did not choose CPR? Could a plan be made to ensure she was comfortable, no matter what happened?

Gently, the doctor explained to Margaret that CPR would not help extend her life with any quality, if it worked at all. She then agreed to let her written directive stand. In just a few weeks, her breathing and heart began to fail again. Hospice helped make her more comfortable, and she died the following day. Her advance directive, well understood by her family, had been respected.

"It was a big relief to have a plan," said Rosella Lazarz, who is confident that she abided by her sister-in-law's last wishes.

Adapted from Partnership for Caring

What proportion of the state's deaths occur at home?

About 50 percent of Americans 65 and older die in hospitals, often after stays in intensive care units, visits to multiple physicians in the months before death, and expensive life-prolonging treatments. Another 20 to 25 percent die in nursing homes, and this proportion is growing. Only 24.9 percent of Americans die at home, although more than 70 percent say that is their wish.[33]

Certainly, not all people with life-threatening illnesses can die at home. Sometimes a hospital or nursing home is the most appropriate place for people whose conditions require advanced medical technology or when home care is difficult or not desired. Still, most patients who die in hospitals and nursing homes would not require institutional care if support were available for them at home.[34] That, coupled with the large proportion of people who want to die at home, suggests that the 24.9 percent rate of home deaths easily could be higher.

Only 24.9 percent of Americans die at home, although more than 70 percent say that is their wish.

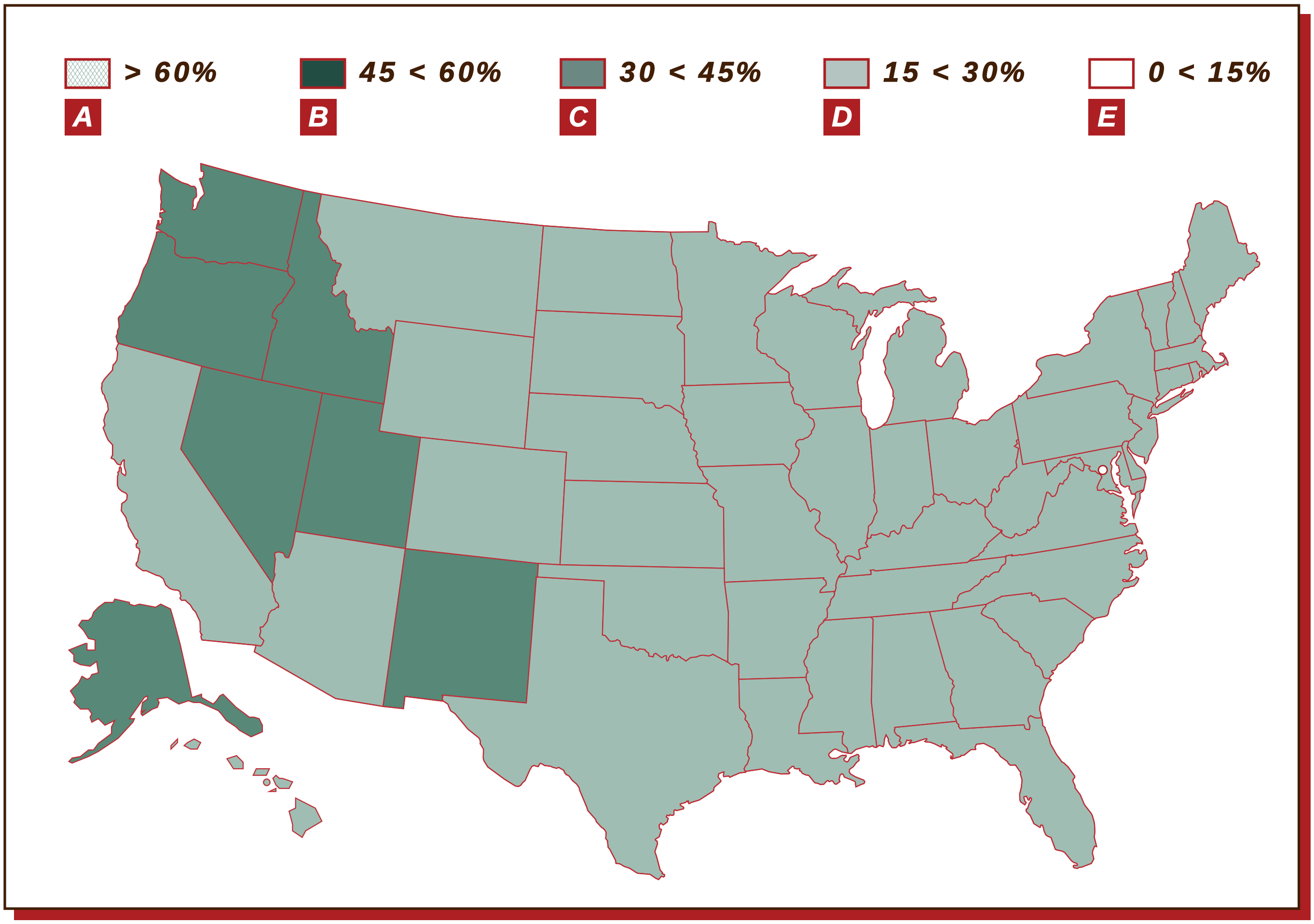
Where people die—and what kind of end-of-life care they receive—may be less a reflection of their wishes and more influenced by local doctors' practice habits, the availability of hospice services and the proportion of open hospital beds in the community.[35] People use hospice services earlier in their course of illness if they live in areas that have more hospital beds, more hospice services and more general practitioners.[36] They are less likely to die in hospitals if they live in areas where nursing homes and hospices are more available. Patients' preferences often are not the deciding factor in where they die.[37]

How we rated the states regarding proportion of at-home deaths

We gave states one of five grades, with the top grade reserved for states where more than 60 percent of deaths occurred at home, a level below the expressed desire of more than 70 percent of Americans. No state receives an A on the map on page 14.

Deaths at home, 1997

Range 14.7% – 35.8%   Mean 24.9%



A —

B —

C
Alaska
Idaho
New Mexico
Nevada
Oregon
Utah
Washington

D
Alabama
Arizona
Arkansas
California
Colorado
Connecticut
Delaware
Florida
Georgia
Hawaii
Illinois
Indiana
Iowa
Kansas
Kentucky
Louisiana
Maine
Maryland
Massachusetts
Michigan
Minnesota
Mississippi
Missouri
Montana
Nebraska
New Hampshire
New Jersey
New York
North Carolina
North Dakota
Ohio
Oklahoma
Pennsylvania
Rhode Island
South Carolina
South Dakota
Tennessee
Texas
Vermont
Virginia
West Virginia
Wisconsin
Wyoming

E
District of Columbia

Source: Brown University Center for Gerontology and Health Care Research, *www.chcr.brown.edu/dying/forresearcherssod.htm*.

CASE STUDY

A family-centered death at home

For 11 years, Ruth Wolf waged a fierce battle against cancer. At the age of 58, she had gone through chemotherapy, attended cancer support groups, researched new cancer treatments, challenged her oncologist's decisions, and endured both a double mastectomy and a bone marrow transplant. When the cancer spread to her brain, she decided it was time to die.

Ruth wanted to exert as much control over the course of her death as she had over her disease, and dying at home was paramount to that wish. With the help of hospice, her two extremely supportive daughters and her husband, she was able to do just that. Ruth had her hospital bed and oxygen tank placed in her living room, so that her many friends would feel more comfortable visiting than if she were in her bedroom. "She wasn't hiding," recalled her daughter, Dagny. A multitude of friends came through—friends from childhood, from her college days, and from her cancer support group. "They had time to talk with her," Dagny said. "In fact, people would come and camp out in our house." For the two months before her death, the house was constantly filled with the sounds of laughter, talking and ringing phones, just as Ruth had wanted.

"Mom had collected dozens of scarves to cover her head while she was in chemotherapy," Dagny said. "She had us drape the scarves over the furniture, and asked each visitor to take a scarf to have something to remember her by. When they chose a scarf, she told a story that went along with how she had bought that particular one. It's tragic that she died so young, but if we could all die like she did, we'd be fortunate. I take great pride in the fact that we helped her have the death that she wanted, and that she was able to do it at home."

Adapted from an interview with Ruth Wolf's daughter, Dagny

? Is hospice care widely used in the state?

Hospice is a philosophy of care that considers the dying patient and family as one unit and focuses on relieving symptoms (palliation) rather than attempting to cure underlying disease. This kind of palliative care can be provided wherever the patient calls home—a private residence, a nursing home, assisted living or a hospice facility. The care is multifaceted, attending not only to physical symptoms, but also to psychological, emotional and spiritual needs. Support for family members continues after the patient's death—one-year bereavement services are a standard hospice benefit.

Over the years, Americans have increasingly turned to hospice. Enrollment has risen from about 1,000 per year in 1975, when hospice care was introduced in the United States, to 700,000 in 2000.[38] This increase in enrollment was made possible in large part by congressional approval of hospice care as a separate Medicare benefit in 1982. Since Medicare covers almost every American 65 and older, and since 75 percent of Americans who die are in that age group, hospice then became a covered benefit for the vast majority of dying Americans. To qualify, a patient must have a life expectancy of six months or less and must forgo curative treatments. Medicaid also pays for care near the end of life, largely through funding of long-term-care services for low-income people. Medicaid's role in paying for hospice is small and follows Medicare's rules.

Many end-of-life care experts, as well as patients and families, consider hospice to be the "gold standard" in end-of-life care—in terms of both quality and cost-effectiveness.[39] Most people equate end-of-life palliative care with hospice care, but it can also be effectively delivered in hospitals, nursing homes and other long-term-care facilities. Family members consistently report the quality of hospice care to be excellent.[40] Compared to traditional care for the terminally ill, hospice care and the use of advance directives such as living wills and medical powers of attorney could save up to 10 percent of the cost of care in a

ISLAND OF HOPE

Hospice of the Florida Suncoast • Largo, Florida

This award-winning organization provides high-quality end-of-life care for 4,700 people each year, and in its Pinellas County region it is "the place to go" for support when death touches life. HFSC reaches out to many segments of the community—police officers, employers and doctors' office staff, as well as families—with bereavement counseling services. "They helped me get myself together and prepare for the future," said one widow whom HFSC aided.

patient's last year of life, 10 to 17 percent in the last six months, and 25 to 40 percent in the final month.[41] Traditional end-of-life care seriously affects family income and savings.[42]

Experts agree that patients need to be enrolled in hospice for at least 60 days to maximize its benefits, in terms of pain and symptom management and psychological and spiritual support.[43] Unfortunately, the average length of stay in hospice has dropped over the years, from 70 days in 1983 to 36 days more recently. In 1998, 28 percent of hospice patients were enrolled for one week or less before dying.[44]

The average length of stay in hospice has dropped . . . from 70 days in 1983 to 36 days more recently.

☑ *How we rated the use of hospice care*

This report measures hospice use in two separate ways: How many state residents who die receive hospice care, and for how long? For each, we placed each state into one of five groups, A through E.

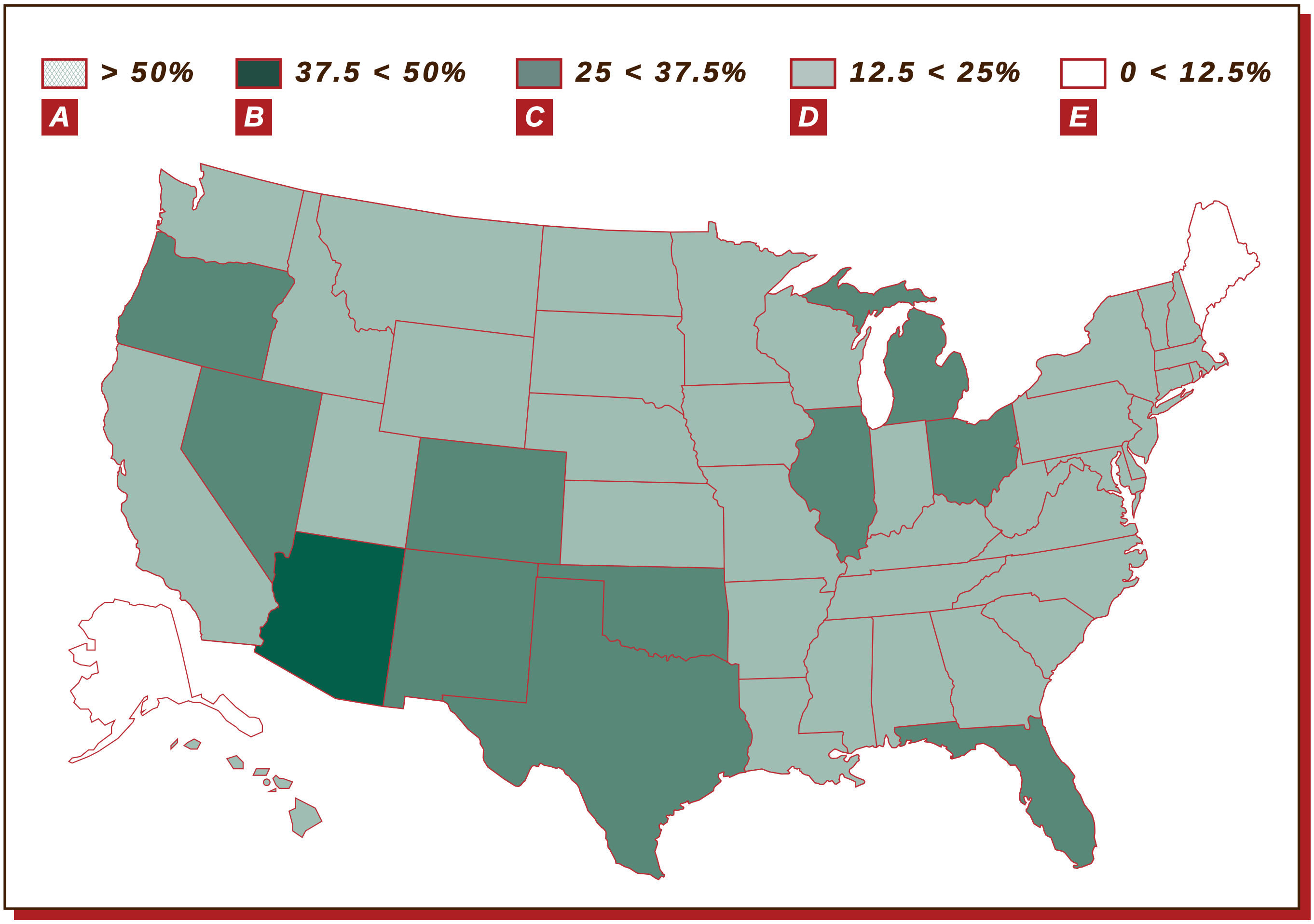
For the percentage of residents who obtain hospice care, states receiving an A would be those where more than 50 percent of people over 65 used hospice in their last year of life. For the length of hospice care, states in the A group would have median patient stays of at least the recommended 60 days. The remaining four grades were set at equal intervals. Data for the hospice care measure are from 2000; data for length of stay are from 2001. Note that no state gets an A, and only one achieves a B.

Hospice Use

3

People over 65 who used hospice in the last year of life, 2000

Range 4.9 – 42.0%   Mean 21.5%



A —

B Arizona

C
Colorado
Florida
Illinois
Michigan
Nevada
New Mexico
Ohio
Oklahoma
Oregon
Texas

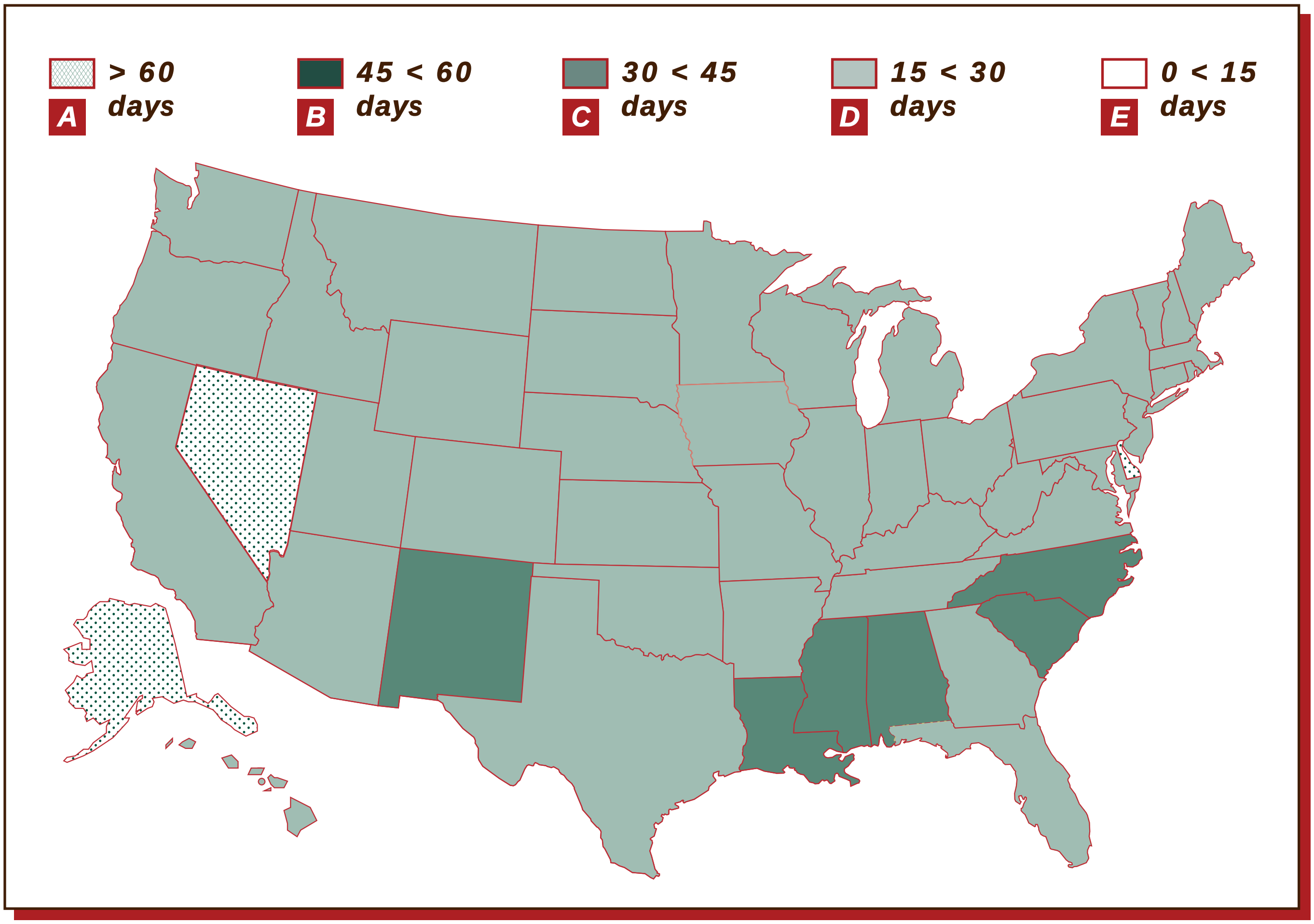
D
Alabama
Arkansas
California
Connecticut
Delaware
District of Columbia
Georgia
Hawaii
Idaho
Indiana
Iowa
Kansas
Kentucky
Louisiana
Maryland
Massachusetts
Minnesota
Mississippi
Missouri
Montana
Nebraska
New Hampshire
New Jersey
New York
North Carolina
North Dakota
Pennsylvania
Rhode Island
South Carolina
South Dakota
Tennessee
Utah
Vermont
Virginia
Washington
West Virginia
Wisconsin
Wyoming

E
Alaska
Maine

Source: Special analysis by the research team for the *Dartmouth Atlas of Health Care*, Web site *www.dartmouthatlas.org*.

Median number of days in hospice, 2001

Range 13.7 – 42.9 days   Mean 25.3 days



A —

B —

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Alabama
Louisiana
Mississippi
New Mexico
North Carolina
South Carolina

D
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Arkansas
California
Colorado
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Florida
Georgia
Hawaii
Idaho
Illinois
Indiana
Iowa
Kansas
Kentucky
Maine
Maryland
Massachusetts
Michigan
Minnesota
Missouri
Montana
Nebraska
New Hampshire
New Jersey
New York
North Dakota
Ohio
Oklahoma
Oregon
Pennsylvania
South Dakota
Tennessee
Texas
Utah
Vermont
Virginia
Washington
West Virginia
Wisconsin
Wyoming

E
Rhode Island

▨ ***Data not available***
Alaska
Delaware
District of Columbia
Nevada

Source: National Hospice and Palliative Care Organization.

CASE STUDY

Hospice care allows comfort and closure

A round of chemotherapy had produced less than promising results for Tom Bradshaw, 61. Doctors said that his esophageal cancer had grown, and new cancers had appeared in his liver and stomach. Tom decided that he did not want to spend his final days in a losing battle with a rapidly advancing and very painful disease. He preferred to be as comfortable as possible and at home.

Tom and his wife, Mimi, contacted a local Miami hospice organization that helped them set up the range of services Tom would need through what turned out to be his final two months of his life. The hospice assigned a nurse and a physician to Tom's case. Then hospice staff trained Mimi, their friends and family, in administering Tom's pain medications and using tiny ice chips to help him cope with an extremely dry throat and mouth. The hospice nurse also taught Mimi how to tell when Tom's pain was increasing, so that he could be given a higher dosage of morphine to bring him comfort.

In addition, Tom received visits from a family psychologist to discuss death, and how to make peace with his son, with whom he had a strained relationship. In his last meeting with the psychologist, Tom said, "I don't want to die, but it seems to be my time. It'll be okay."

When the hospice nurse estimated that Tom would probably die in about two days, she told Mimi to alert family and friends who lived at a distance, so that they would have time to visit with him and say goodbye. In those two days, Tom was surrounded by a round-the-clock vigil of those who loved him.

Later, many said they felt good about the way Tom died. They were grateful for the opportunity to be part of a courageous, peaceful and graceful death in the comfort and familiar surroundings of Tom's home. A social worker from the hospice kept in touch with Mimi for a year after Tom's death, helping her to cope with her feelings of loss.

Adapted from an interview with Tom Bradshaw's son, Keenan

? Do hospitals in the state offer pain and palliative care services?

Although the proportion of deaths occurring in hospitals is declining in America, about half of all deaths still take place there. All hospitals should offer critically ill and dying patients the palliative care services they need. A self-reported survey conducted by the American Hospital Association (AHA) in 2000 found that only 42 percent of U.S. hospitals reported offering a formal pain management program, and 23 percent and 14 percent offered formal hospice or palliative care programs, respectively. These services are defined by the AHA as follows:

Only 42 percent of U.S. hospitals offered a formal pain management program.

a) **Pain Management:** A formal program that educates staff about how to manage chronic and acute pain based on accepted academic guidelines.

b) **Hospice:** A program providing palliative care and supportive services that address the emotional, social, financial and legal needs of terminally ill patients and their families. This care can be provided in the hospital or at home under the auspices of the hospital.

c) **Palliative Care Program:** A program providing specialized medical care, drugs or therapies to manage acute or chronic pain and/or control other symptoms. The program, run by specially trained physicians and other clinicians, also provides services such as counseling about advance directives, spiritual care and social services to seriously ill patients and their families.

While the number of organized palliative care programs in hospitals is increasing, they are not yet the norm and do not easily fit into the coverage and payment policies of Medicare and other insurers. Funding for these programs often depends on cobbling together resources from different departments and funding streams, including short-term grants. Their continuation is jeopardized whenever any of these resources disappear.

How we rated the availability of end-of-life care services in hospitals

As with any self-reported survey, the data depend on the accuracy of reporting by many individuals. While such a method is less reliable than a special study, the AHA has conducted this survey for many years, and it is a reasonably trustworthy snapshot of the nation's approximately 6,000 hospitals.

Each service was considered separately. States were placed into one of five equally distributed groups, with the better states having the most hospitals that offer formal end-of-life care services. No state would earn an A in any of the three services.

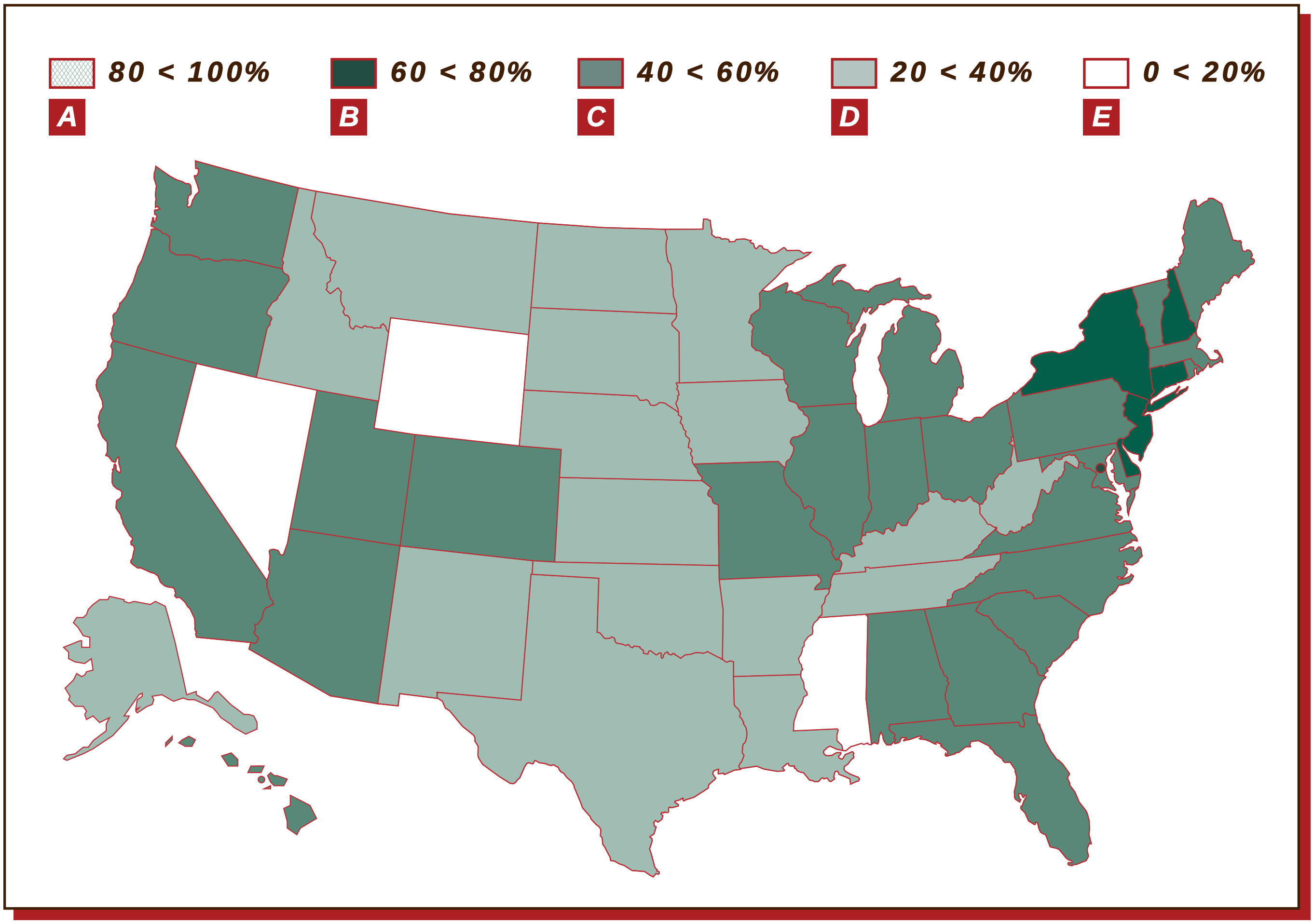
ISLAND OF HOPE

Beth Israel Medical Center • Manhattan

"We create a system around the patient," says Russell K. Portenoy, M.D., describing the comprehensive services of Beth Israel's Department of Pain Management and Palliative Care. It offers patients and families—early in the trajectory of a serious illness—a broad range of services, including intensive pain and symptom management, but also inpatient consultations, case management and community-based services. This successful program is becoming integral to patient care, teaching and research programs throughout the institution.

Hospitals reporting pain management programs, 2000

Range 4.9 – 72.7%   Mean 42.3%



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Illinois
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Maine
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Pennsylvania
Rhode Island
South Carolina
Utah
Vermont
Virginia
Washington
Wisconsin

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New Mexico
North Dakota
Oklahoma
South Dakota
Tennessee
Texas
West Virginia

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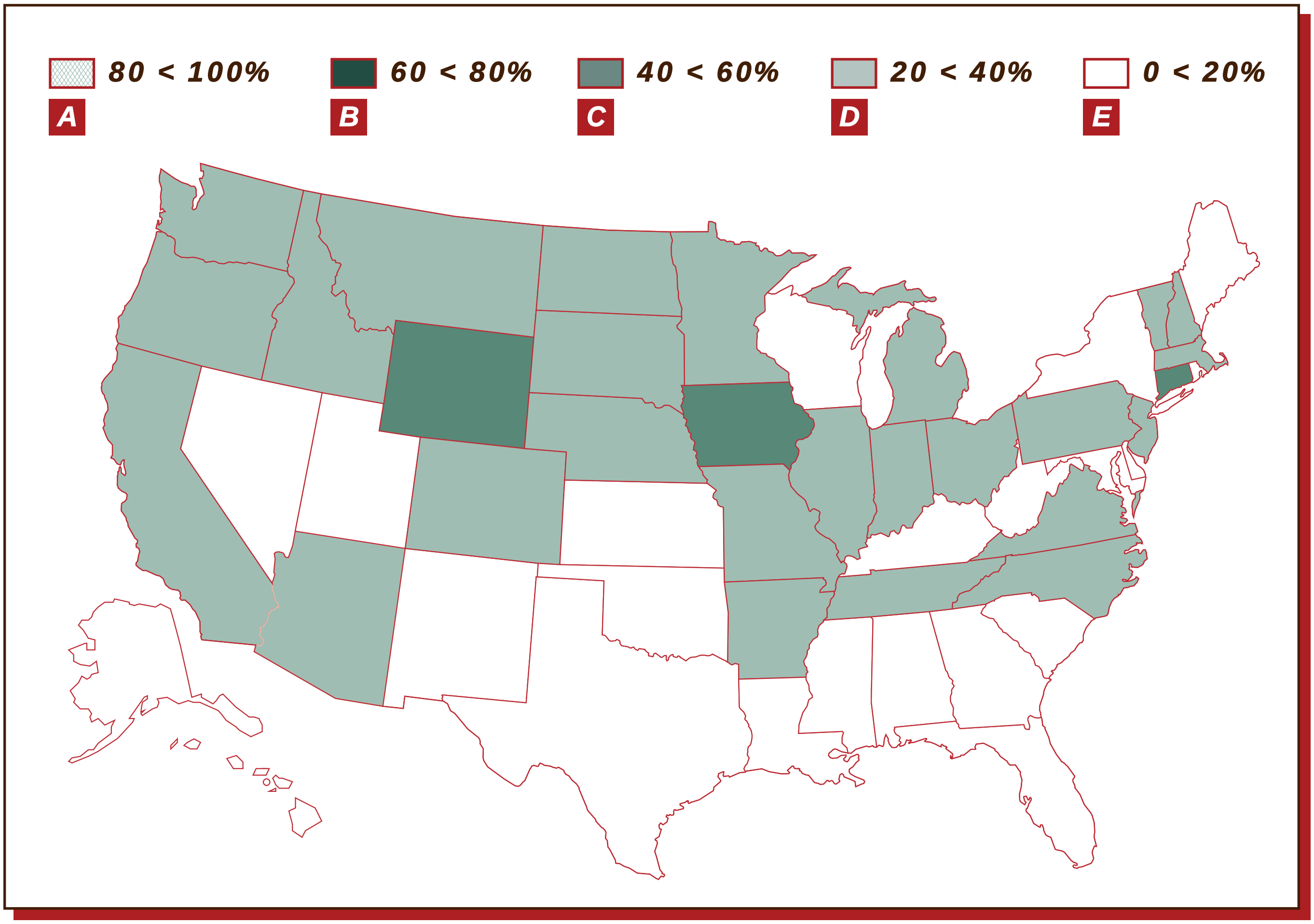
Mississippi
Nevada
Wyoming

Source: *Hospital Statistics*. American Hospital Association, 2000 data.

Hospitals reporting hospice programs, 2000

Range 5.0 – 57.5% Mean 23.5%



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Oregon
Pennsylvania
South Dakota
Tennessee
Vermont
Virginia
Washington

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Louisiana
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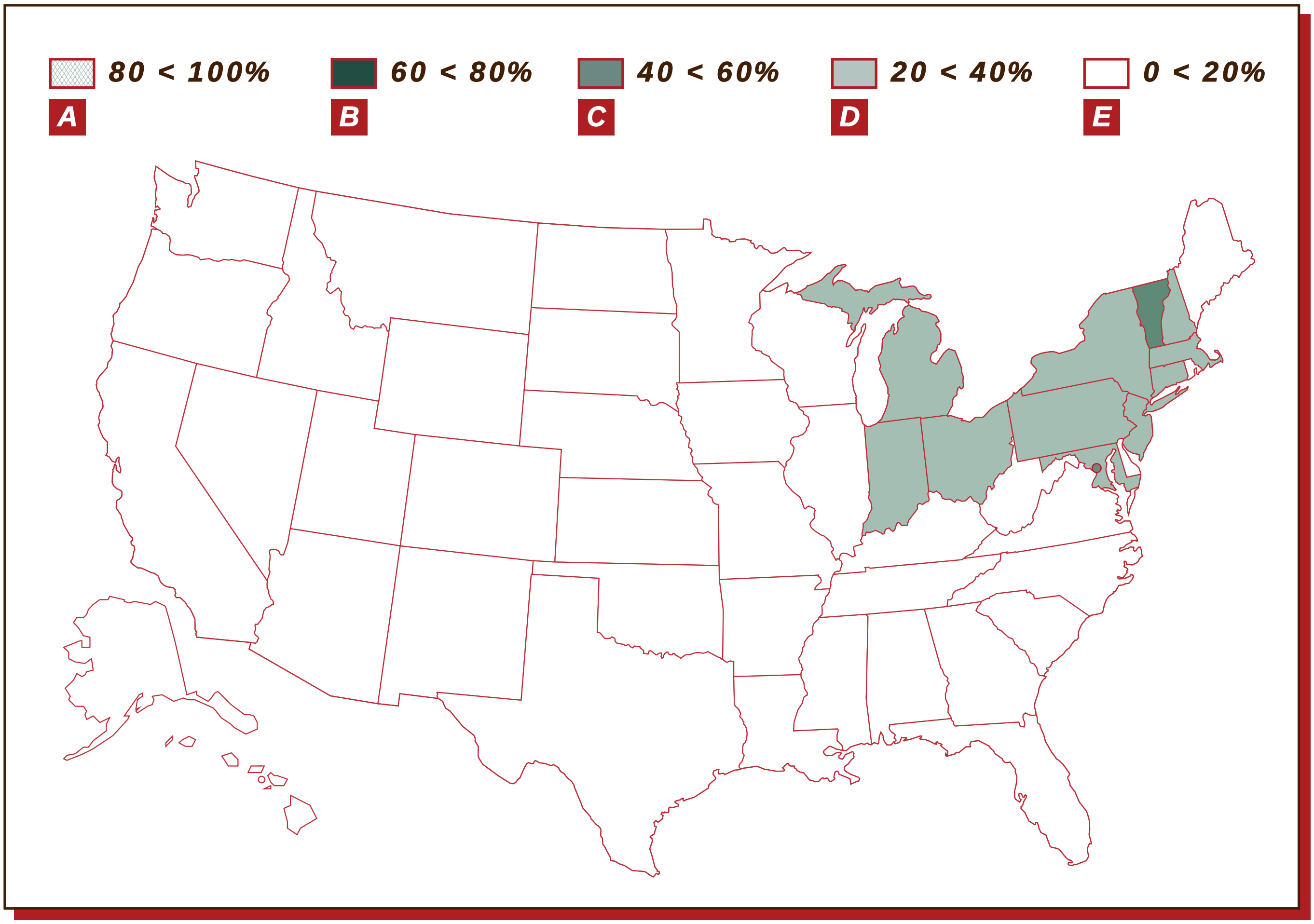
Mississippi
Nevada
New Mexico
New York
Oklahoma
Rhode Island
South Carolina
Texas
Utah
West Virginia
Wisconsin

Source: *Hospital Statistics*. American Hospital Association, 2000 data.

Hospitals reporting palliative care programs, 2000

Range 0 – 54.5%   Mean 13.8%



A —

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District of Columbia
Vermont

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Connecticut
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Massachusetts
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New Hampshire
New Jersey
New York
Ohio
Pennsylvania

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Alaska
Arizona
Arkansas
California
Colorado
Delaware
Florida
Georgia
Hawaii
Idaho
Illinois
Iowa
Kansas
Kentucky
Louisiana
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Nebraska
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North Carolina
North Dakota
Oklahoma
Oregon
Rhode Island
South Carolina
South Dakota
Tennessee
Texas
Utah
Virginia
Washington
West Virginia
Wisconsin
Wyoming

Source: *Hospital Statistics*. American Hospital Association, 2000 data.

CASE STUDY

An integrated hospital-based palliative care program

One of the nation's premier hospital-based palliative care programs functions at Mount Sinai Hospital in New York City's Lilian and Benjamin Hertzberg Palliative Care Institute. A consultation team (a nurse, 10 attending physicians, some rotating fellows and a few residents in training) advises hospital physicians who care for seriously ill patients on topics such as pain and symptom management, when to use comfort care and how to talk about treatment options with patients and family members.

The program also includes a four-bed inpatient unit for patients with difficult emotional and physical symptoms and for those who need help adjusting to and planning a course of care for their terminal illness. The unit is staffed by nurses, social workers, interns and residents, and works closely with the consultation team.

A home care program staffed by Mount Sinai's Certified Home Health Agency and Mount Sinai's "Visiting Doctors" program cares for seriously ill patients who are able to return home. Finally, a palliative care program trains new physicians, using bedside teaching, clinical rotations and lectures. Mount Sinai requires that all oncology and geriatrics fellows complete a one-month clinical palliative care rotation.

According to program director Diane Meier, M.D., an increasing number of hospital physicians are using the consultation team, and they are seeking the team's advice earlier in a patient's care. About half of the patients for whom the team consults are able to leave the hospital to go home, usually with hospice care, or to a nursing home. In hospitals without these palliative care services, such sick patients would probably die in the hospital.

Adapted from the Mount Sinai School of Medicine Web site, www.mssm.edu/geriatrics/hertzberg.shtml

? *How many elderly people spend a week or more in intensive care units during the last six months of life, meaning that they may have received overaggressive care?*

Hospital intensive care units (ICUs) and critical care units (CCUs) are where patients with acute, life-threatening illnesses or injuries receive specialized around-the-clock medical and nursing care, such as mechanical ventilation and invasive cardiac monitoring. Each year more than 4 million patients are admitted to U.S. intensive care units,[45] and about 500,000 of them die there.[46]

Many Americans fear spending their final days in intensive care "connected to machines." ICU care is often uncomfortable and unwanted. For example, a recent study of cancer patients being treated in the ICU found that 55 to 75 percent had moderate to severe pain, discomfort, anxiety, sleep disturbance or unsatisfied hunger or thirst.[47] Another study of ICU cancer patients established that their treatment choices—as expressed by their advance directives—did not affect whether life-support efforts were begun.[48]

Data in this report show that the percentage of people who died who spent a week or more in an intensive care unit during the last six months of life ranged from 3.4 percent in Oregon to 17.3 percent in New Jersey. As with many of our measures, substantial variation exists within states. Some communities within the state will be well below the state average, while other communities will be above it.

MORE INFO

Data at the level of specific communities are available from the *Dartmouth Atlas of Health Care* at *www.dartmouthatlas.org*

How we rated each state's proportion of ICU deaths

End-of-life care in ICUs and CCUs has only recently gained the attention of researchers. New initiatives are focusing attention on the type of care given in the ICU, communication with patients and their families, and the amount of time that terminally ill patients spend in an ICU. As yet, there is no consensus on what percentage of people *appropriately* spend seven or more days in an ICU in the last six months of life.

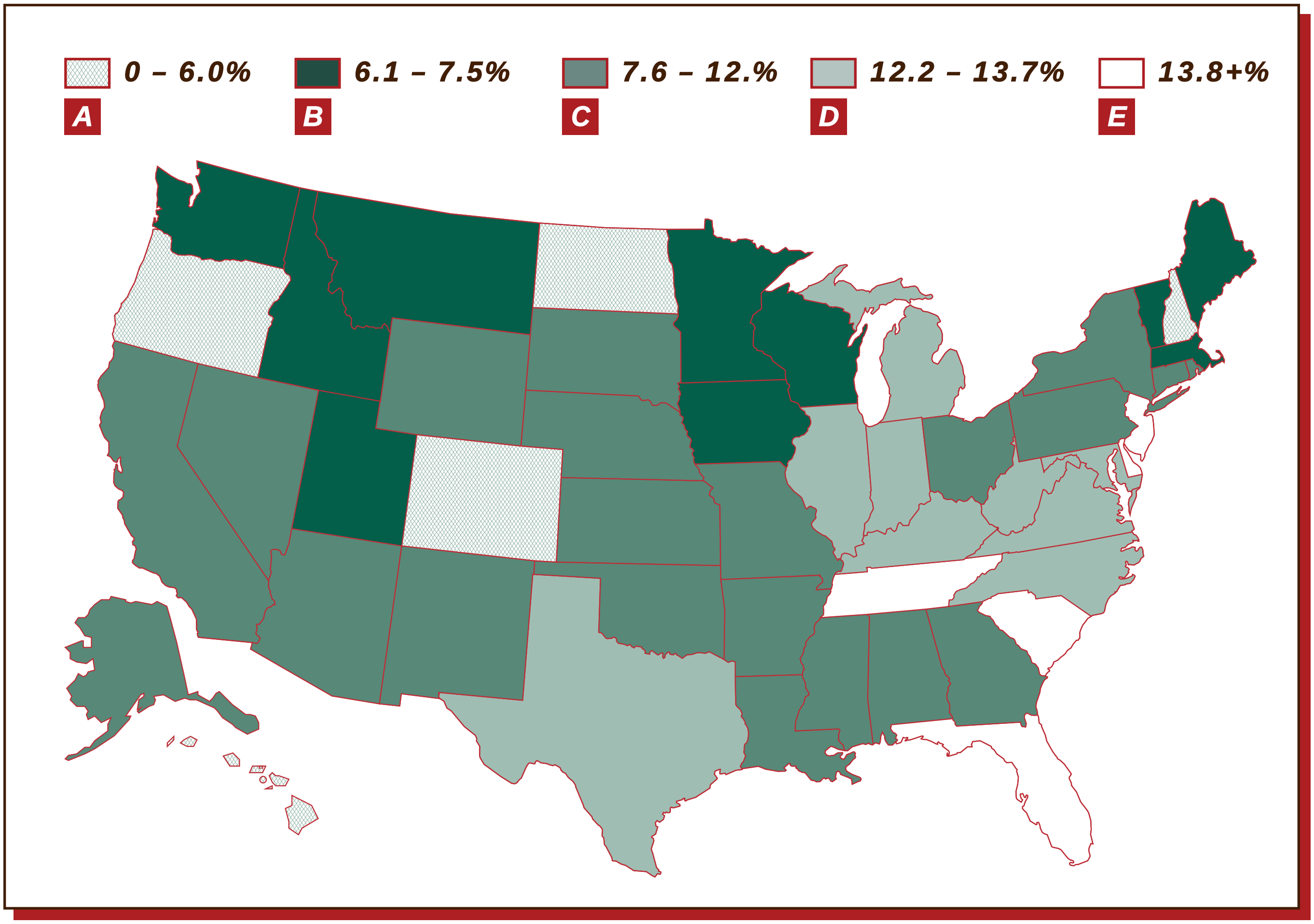
We therefore rated the states on a “curve” for this measure. The five states with the *lowest* percentage of decedents who spent a week or more in the ICU in their last six months of life received an A. The ten next lowest were given a B, and so on.

MORE INFO

For more information on initiatives promoting palliative care excellence in intensive care, see *www.promotingexcellence.org*.

People over 65 with 7 or more ICU days during the last 6 months of life, 2000

Range 3.4 – 17.3% Mean 10.1%



A
Colorado
Hawaii
New Hampshire
North Dakota
Oregon

B
Idaho
Iowa
Maine
Massachusetts
Minnesota
Montana
Utah
Vermont
Washington
Wisconsin

C
Alabama
Alaska
Arizona
Arkansas
California
Connecticut
Georgia
Kansas
Louisiana
Mississippi
Missouri
Nebraska
New Mexico
New York
Nevada
Ohio
Oklahoma
Pennsylvania
Rhode Island
South Dakota
Wyoming

D
District of Columbia
Illinois
Indiana
Kentucky
Maryland
Michigan
North Carolina
Texas
Virginia
West Virginia

E
Delaware
Florida
New Jersey
South Carolina
Tennessee

Source: Special analysis by the research team for the *Dartmouth Atlas of Health Care, www.dartmouthatlas.org*.

CASE STUDY

A difficult death in intensive care

Joann's mother, Violet, had surgery to remove a second brain tumor, and in the years that followed the procedure she repeatedly told her family that if anything were to happen, she did not want to endure "that sort of thing" again. "She would say, 'I'm tired. I've had enough. If anything else comes up, I don't want any more,' " Joann said. Violet never signed an advance directive, but her family felt that her wishes were clear. Then, quite suddenly, she had a heart attack and was rushed to the hospital. Facing a medical emergency, with no clear instructions on what to do, the doctor put her on life support in the intensive care unit. She remained there, semicomatose, for a week, and then died.

Joann said later that there had been no room for intimacy or conversation in the ICU, and physical contact with her mother was all but impossible. During the rare moments when Violet was alert, she was alarmed to find herself in the hospital. "Because of all the tubes and this and that, you felt like you couldn't physically help," Joann said, "and it's hard to stroke someone or be near them. You can't even imagine saying goodbye because it's like they are not even there. You're an observer. It was the equivalent of being at a wake."

If anyone had ever talked with Violet about what she meant by "nothing extraordinary" and "I've had enough," and then had discussed her wishes with the doctor, perhaps he would have known not to intubate her. Had the family known more about the medical system and the options available, and what their mother wanted and didn't want, perhaps they would have asked that the ventilator be removed so that her dying would not have been prolonged and so that they could have said goodbye to her in peace.

From Virginia Morris, Talking About Death Won't Kill You *(New York: Workman Publishing, 2001). Reprinted with permission.*

? How well do the state's nursing homes manage their residents' pain?

About 1.6 million Americans live in nursing homes and according to national surveys, if they are in pain, it is not likely to be assessed or adequately treated. These findings are sobering, given that many nursing home residents have chronic conditions, and more than 20 percent of residents die there—a figure projected to double by 2020. Adequate pain management for seriously ill and dying nursing home residents is essential to achieving high-quality end-of-life care in a state.[49]

According to a comprehensive national study conducted in 1999, nearly one-sixth of nursing home patients are in daily pain, and more than 40 percent of residents who were in pain at their first pain assessment were still in severe pain 60 to 180 days later.[50] Another recent study found that many dying nursing home residents who are in daily pain receive either inadequate pain treatment or none at all.[51]

✔ How we rated each state on how well its nursing homes manage patients' pain

The percentage of patients who are considered to be in persistent pain was calculated by finding the percentage of patients in pain, when first asked, who were still in pain when asked again, 60 to 180 days later. States where fewer than 25 percent of nursing home residents have persistent pain would have received an A. (None qualified.) The remaining four groups were placed at 10 percent intervals, with states where rates of persistent pain are more than 55 percent receiving an E.

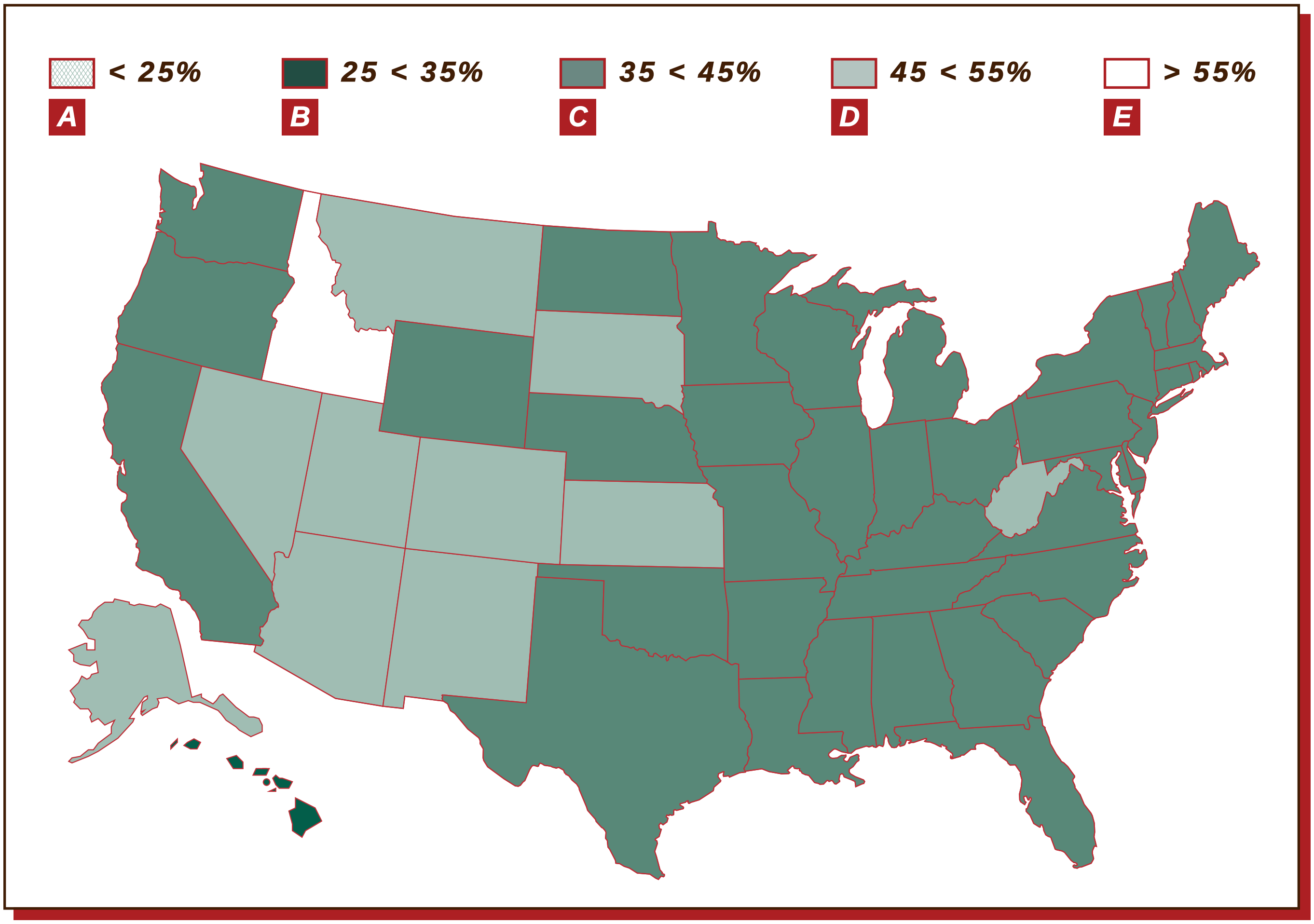
ISLAND OF HOPE

St. Joseph's Manor • Trumbull, Connecticut

In 1997, when St. Joseph's Manor started an institution-wide effort to improve end-of-life care, staff recognized that "dying is a sacred time, a life event that should be supported in special ways," says Karin Tomsic, director of pastoral care and mission. An angel placed on a dying resident's door signals that additional support is needed, that it is time to say goodbye, and that routine events, such as equipment maintenance, should be set aside.

Nursing home residents in persistent pain, 1999

Range 33.3 – 54.9%   Mean 42.2%



A —

B *Hawaii*

C
Alabama
Arkansas
California
Connecticut
Delaware
District of Columbia
Florida
Georgia
Illinois
Indiana
Iowa
Kentucky
Louisiana
Maine
Maryland
Massachusetts
Michigan
Minnesota
Missouri
Mississippi
Nebraska
New Hampshire
New Jersey
New York
North Carolina
North Dakota
Ohio
Oregon
Oklahoma
Pennsylvania
Rhode Island
South Carolina
Tennessee
Texas
Vermont
Virginia
Washington
Wisconsin
Wyoming

D
Alaska
Arizona
Colorado
Kansas
Montana
Nevada
New Mexico
South Dakota
Utah
West Virginia

E *Idaho*

Source: Brown University Center for Gerontology and Health Care Research, *www.chcr.brown.edu/dying/forreessearcherspsp.html*.

CASE STUDY

Unnoticed pain, unnecessary suffering

One year ago, Robert Wagner, 81, moved to a nursing home after a stroke impaired his speech and paralyzed his right side. Robert found it awkward and embarrassing to communicate. He struggled to complete a sentence and was ashamed to gesture because of his immobilized right arm. He seemed to avoid talking, even when his wife and friends were there. Whenever nurses and physicians asked him how he felt, he routinely answered, "Fine."

One day, Robert's occupational therapist noticed that he was frowning and blinking often. Although he said, as usual, that he was fine, the therapist consulted with a physician who referred him to an ophthalmologist. During the eye exam, the ophthalmologist inadvertently leaned against Robert's left leg. Robert let out a cry, and tears welled up in his eyes. The ophthalmologist then realized that Robert was in pain. Further testing revealed a cancer in his right femur.

Robert's pain would not have gone unnoticed if the staff in his nursing home had been properly trained to identify pain in their patients—even in those who cannot communicate. Providers qualified to prescribe medications are experienced in selecting the right pain medication at the right dosage, and nursing home staff would have checked Robert's comfort level frequently, knowing that pain can flare up unpredictably.

Adapted from the Partners Against Pain *Web site, www.partnersagainstpain.org*

? Do state policies encourage good pain control?

Medical experts agree that at least 90 to 95 percent of all serious pain can be safely and effectively treated, yet at least half of dying patients report being in pain.[52] For the patient, unrelieved pain is oftentimes crippling; it triggers a range of problems that include depression, social isolation, disturbed sleep, decreased mobility, falls, difficulty in thinking clearly, and loss of appetite. Unrelieved pain is costly to society in both direct and indirect ways, and it can ruin the quality of life of patients and their families.[53]

Serious pain can be effectively treated, yet at least half of dying patients report being in pain.

Many factors contribute to inadequate pain treatment, but for most of them state-level data do not exist. One factor we are able to assess is state policy relating to pain management. State policy can have an impact on what doctors know about pain management, their ability to prescribe adequate doses of pain medication, and their fears of being sanctioned for overprescribing.

FAST FACT

"Opioids" are strong pain medications derived from opium, or synthesized to behave like opium derivatives. Examples of opioids include morphine, codeine, oxycodone, methadone and fentanyl.[54]

All states have laws addressing controlled substances, such as opioids, which are primarily aimed at decreasing the chance that these drugs will be misused. Some of these state policies are useful and effective; some create formidable barriers to good pain management. For example, certain laws would sanction a doctor based on the number of doses in a prescription or the prescription's duration, both of which standards have no clinical basis and do not take into account the very high doses that some patients may need.[55]

In July 2000, the American Bar Association recognized the numerous legal barriers to good pain management and adopted a resolution urging state, federal and territorial governments to remove legal barriers to high-quality pain and symptom management, and to support the right of all patients to receive effective pain and symptom evaluation, management and ongoing monitoring, as part of basic medical care.[56]

☑ How we rated state pain policies

We assessed pain policies using six criteria and assigned a point value to each:

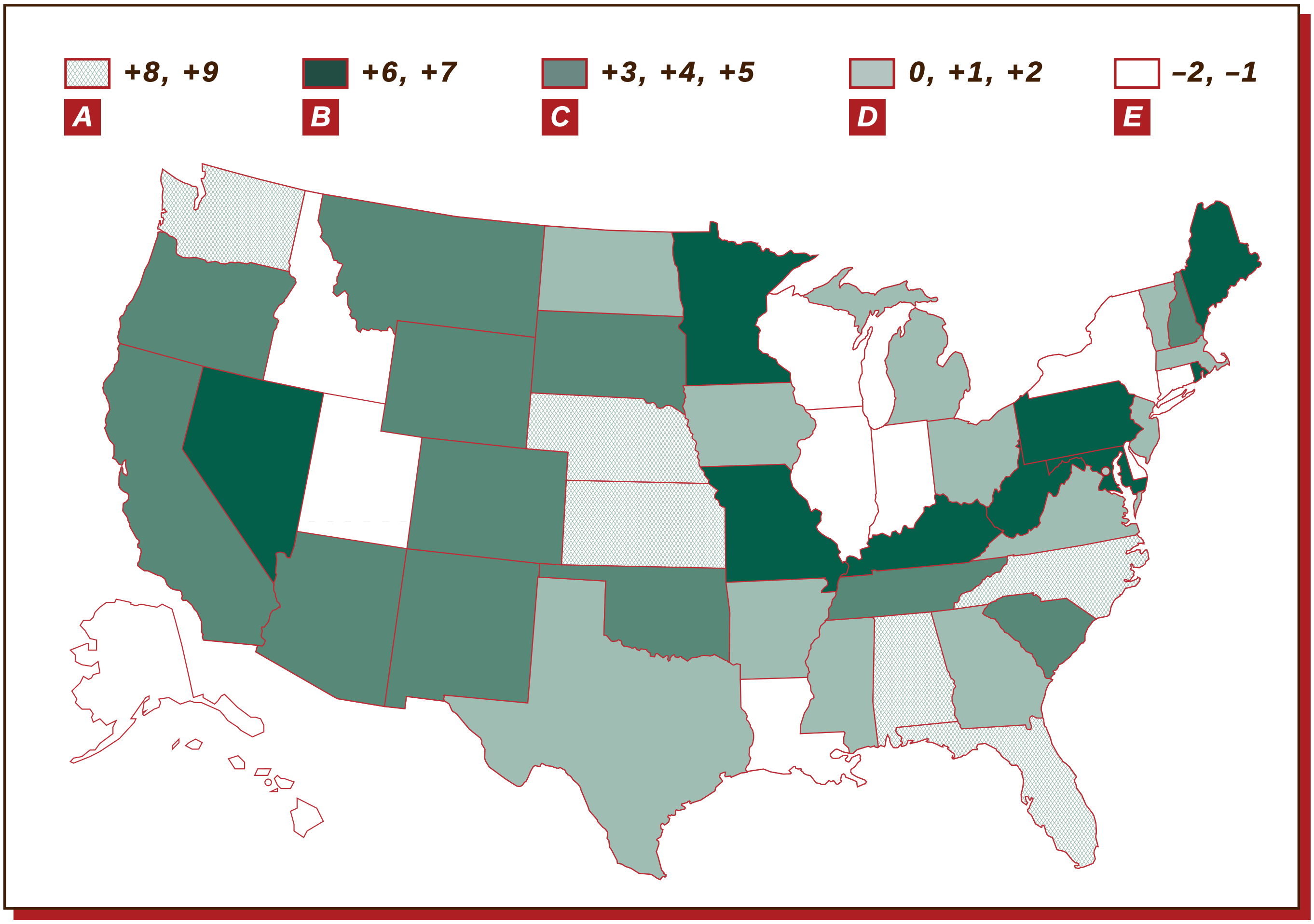
1. State policy explicitly addresses the needs of terminally ill patients (1 point).
2. The state has a comprehensive pain management policy or has adopted the model pain treatment guidelines issued by the Federation of State Medical Boards (0 = no or none of the guidelines adopted; 1 point = adopted one or two of the guidelines; 2 points = adopted several guidelines; 3 points = adopted most or all).
3. State policy includes provisions that have the potential to impede prescribing pain medication, particularly restrictions on medical decision-making that could affect dying patients (–1 to –3 points, with –1 point = only a few negative provisions; –2 points = several; –3 points = significant restrictions).
4. State policy reassures physicians that they can treat pain with opioids without undue regulatory scrutiny (1 point).
5. State policy defines what constitutes good medical practice for pain management (2 points).
6. State policy expresses concern about the undertreatment of pain (1 point).

States were given grades, according to their overall score, which ranged from –2 to +9. States in the A group scored +8 to +9 overall, those in the B group scored +6 to +7, and so on.

7

Strength of state pain policies, 2001

Range –2 – +9



A
- Alabama
- Florida
- Kansas
- Nebraska
- North Carolina
- Utah
- Washington

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- Kentucky
- Maine
- Maryland
- Minnesota
- Missouri
- Nevada
- Pennsylvania
- Rhode Island
- West Virginia

C
- Arizona
- California
- Colorado
- Montana
- New Hampshire
- New Mexico
- Oklahoma
- Oregon
- South Carolina
- South Dakota
- Tennessee
- Wyoming

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- District of Columbia
- Georgia
- Iowa
- Massachusetts
- Michigan
- Mississippi
- New Jersey
- North Dakota
- Ohio
- Texas
- Vermont
- Virginia

E
- Alaska
- Connecticut
- Delaware
- Hawaii
- Idaho
- Illinois
- Indiana
- Louisiana
- New York
- Wisconsin

Source: Based on *Achieving Balance in Federal & State Pain Policy*, dated July 2000, and updated in the *Annual Review of State Pain Policies 2000* (published February 2001) and *Annual Review of State Pain Policies 2001* (published February 2002) from the Pain and Policy Studies Group of the University of Wisconsin's Comprehensive Cancer Center, Madison, Wisconsin. More recent information may be available at the group's Web site: *www.medsch.wisc.edu/painpolicy*.

CASE STUDY

Undertreatment of pain sparks legislative change

At age 85, William Bergman was dying of lung cancer. He was admitted to Eden Medical Center in northern California in February 1998, complaining of intolerable pain. During a five-day hospital stay in which he was treated by an internal medicine specialist, nurses charted Mr. Bergman's pain level at 10—the worst rating on their pain intensity scale. Despite his family's intention that his pain be addressed, Mr. Bergman's internist sent him home—still in agony—with inadequate medication. Ultimately, his family contacted another physician who took a more aggressive approach, and Mr. Bergman died at home soon afterward.

This case inspired the California legislature to pass Assembly Bill 487, signed into law October 4, 2001. The new law requires that physicians who fail to prescribe, administer or dispense adequate pain medication be charged with unprofessional conduct and be investigated by the California Medical Board's Division of Licensing. Physicians found guilty of undertreating pain must complete a pain-management education program.

Adapted from a story that appeared in Last Acts Quarterly, *Summer 2001*

? Does the state have enough physicians and nurses who are trained and certified in palliative care?

Appropriate care for dying people requires a team of health professionals trained in end-of-life care. While certification in palliative care is now available for physicians and nurses, few who offer this care have specialty training. For both physicians and nurses, certification programs in palliative care help to set standards of quality care and provide clinicians who can serve as change agents and leaders in the field of end-of-life care and within their institutions.

Since 1996, the American Board of Hospice and Palliative Medicine (ABHPM) has offered physicians certification in palliative care. As of March 2002, 917 U.S. doctors had passed the board's examination. Certification is an acknowledgment of a physician's knowledge, attitudes and skills as they apply to good palliative care. According to a recent study, certified physicians are more likely than their noncertified peers to believe themselves adequately prepared to provide palliative care (70 percent versus 38 percent); however, only 39 percent of physicians providing palliative care are certified.[57]

Only 39 percent of physicians providing palliative care are certified.

As of January 2002, 7,623 U.S. nurses were certified in hospice and palliative care as CHPN ("Certified Hospice and Palliative Nurse"). The Hospice and Palliative Nurses Association (HPNA) has provided this certification since 1994. To be certified, CHPNs must demonstrate both knowledge and competency in hospice and palliative nursing. Large hospice programs are beginning to acknowledge the benefits of having certified nurses on their staffs. Several programs and state hospice organizations sponsor review courses and provide financial assistance to nurses interested in certification; others offer certified nurses higher salaries.[58]

While accreditation standards for medical schools now include the mandate to cover end-of-life care, the requirement contains no clear standards for that instruction.[59] As the Accreditation Council for Graduate Medical Education does not yet accredit palliative medicine residencies or fellowships, a limited number of these programs currently exist.

Several excellent programs do exist for practicing health care professionals. One of these is the Education for Physicians on End-of-Life Care (EPEC) project, which trains physicians both to provide such care and to train others to do so. EPEC is designed to educate physicians about the essential clinical competencies required to provide quality end-of-life care. As of February 2002, the EPEC project had trained 863 physicians and other health care professionals.[60] A study of physicians and hospitals providing palliative care found that the EPEC program "plays a key role in educating physicians on palliative care."[61]

ELNEC (End-of-Life Nursing Education Consortium) is a program to train a core of expert nurse-educators and to coordinate national nursing efforts in end-of-life care. ELNEC began in February 2000 and will continue for three and a half years. The program involves three-day courses for baccalaureate and associate-degree faculty, who then can facilitate the integration of end-of-life nursing care into basic nursing curricula. The eighth course, scheduled for January 2003, is for state board of nursing representatives to strengthen their commitment to encouraging end-of-life care education and practice initiatives.[62] As of April 2002, there were 937 ELNEC trainers in the United States.

Other efforts are under way to incorporate palliative care and end-of-life care into the medical school curriculum. Studies demonstrating a lack of end-of-life material in medical textbooks have sparked a response by publishers.[63] In addition, educators and students are establishing new end-of-life curricula in medical education.[64,65]

FAST FACT

Nearly 40 million Americans will be 65 or older by 2010. The baby boomers—those born between 1946 and 1964—will start turning 65 in 2011. Their numbers will drive an elder boom.[66] By 2030, one-fifth of the U.S. population, more than 70 million people, will be over the age of 65.[67]

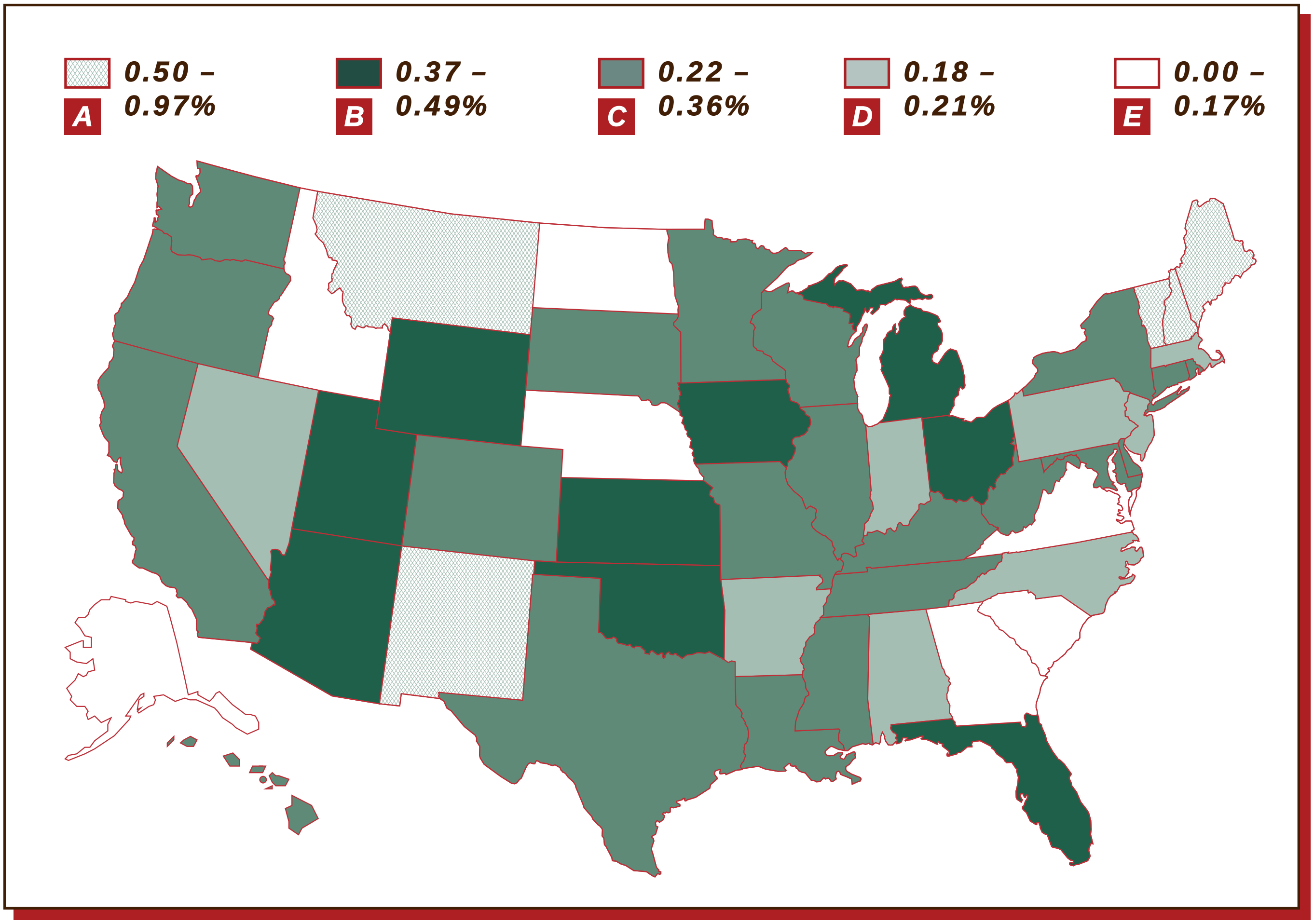
✓ How we rated the supply of palliative care-certified physicians and nurses

This report compares states on the percentage of physicians or nurses who are certified in palliative care. Our measure considers data for physicians and nurses separately, in part to emphasize the need for progress in both fields. In practice, however, palliative care should be a collaborative effort, involving a team of practitioners rather than a doctor or nurse working alone. Nurses spend more time with dying patients and families than do any other health care professionals and are intimately involved in all aspects of end-of-life care.[68]

Since an "ideal" percentage of certified palliative care health care practitioners has not been established, we rated states on a "curve" for this measure. The five states with the highest percentage of palliative care certified physicians or nurses are in the A group. The B group contains the 10 states with the next highest percentages, and so on.

Percentage of general primary care and primary care subspecialty physicians who are certified in palliative medicine, 2000

Range 0.00 – 0.97%   Mean 0.33%



A
- *Maine*
- *Montana*
- *New Hampshire*
- *New Mexico*
- *Vermont*

B
- *Arizona*
- *Florida*
- *Iowa*
- *Kansas*
- *Michigan*
- *Ohio*
- *Oklahoma*
- *Utah*
- *Wyoming*

C
- *California*
- *Colorado*
- *Connecticut*
- *Delaware*
- *District of Columbia*
- *Hawaii*
- *Illinois*
- *Kentucky*
- *Louisiana*
- *Maryland*
- *Minnesota*
- *Mississippi*
- *Missouri*
- *New York*
- *Oregon*
- *Rhode Island*
- *South Dakota*
- *Tennessee*
- *Texas*
- *Washington*
- *West Virginia*
- *Wisconsin*

D
- *Alabama*
- *Arkansas*
- *Indiana*
- *Massachusetts*
- *Nevada*
- *New Jersey*
- *North Carolina*
- *Pennsylvania*

E
- *Alaska*
- *Georgia*
- *Idaho*
- *Nebraska*
- *North Dakota*
- *South Carolina*
- *Virginia*

Source: American Board of Hospice and Palliative Medicine; *www.abhpm.org*. American Medical Association. *Physician Characteristics and Distribution in the US*, 2002–2003 Edition (Chicago: American Medical Association Press, 2002).

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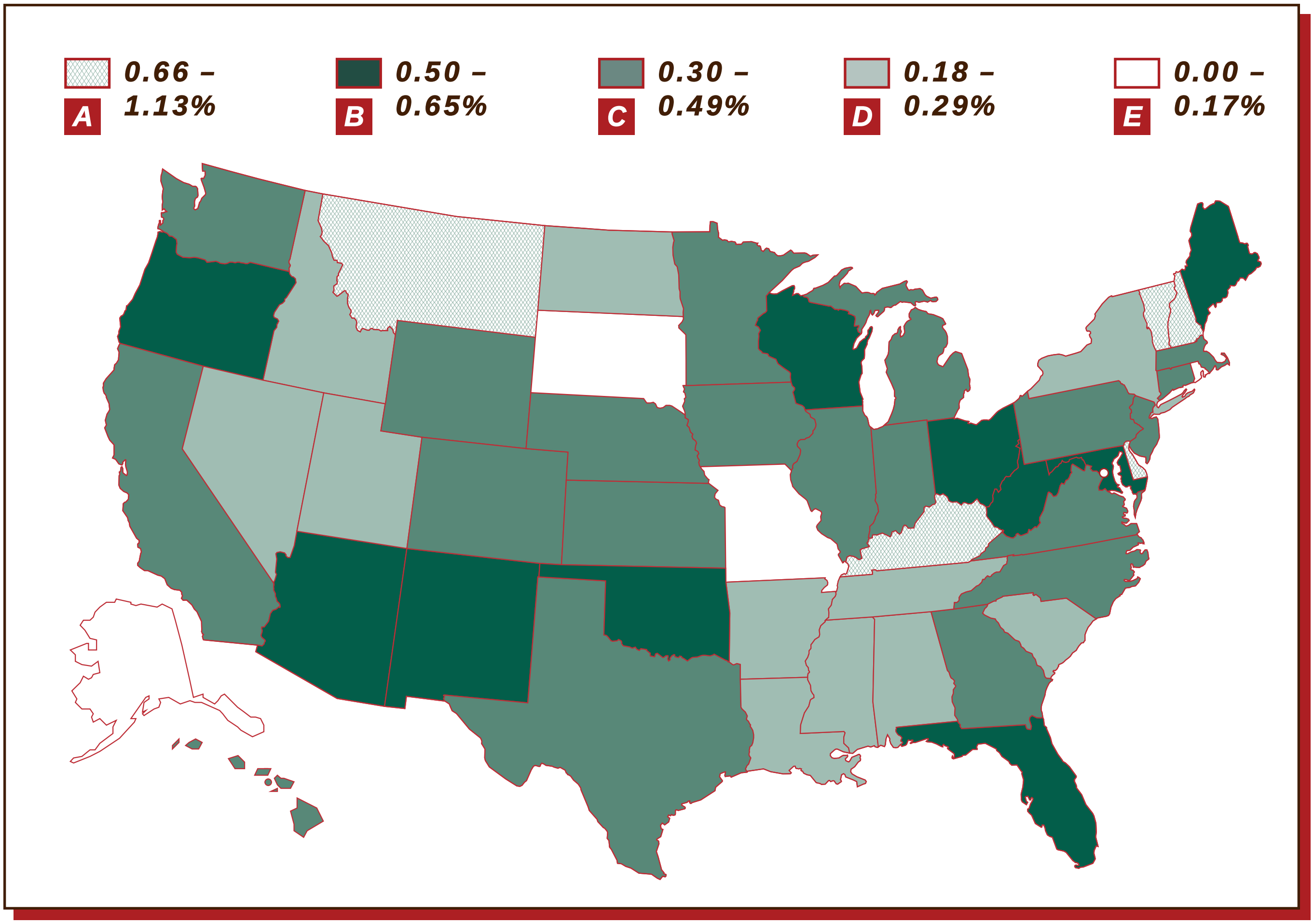
Percentage of full-time-equivalent nurses (estimated) who are certified in palliative care, 2000

Range 0.09 – 1.13%   Mean 0.41%



A
Delaware
Kentucky
Montana
New Hampshire
Vermont

B
Arizona
Florida
Maine
Maryland
New Mexico
Ohio
Oklahoma
Oregon
West Virginia
Wisconsin

C
California
Colorado
Connecticut
Georgia
Hawaii
Illinois
Indiana
Iowa
Kansas
Massachusetts
Michigan
Minnesota
Nebraska
New Jersey
North Carolina
Pennsylvania
Texas
Virginia
Washington
Wyoming

D
Alabama
Arkansas
Idaho
Louisiana
Mississippi
Nevada
New York
North Dakota
South Carolina
Tennessee
Utah

E
Alaska
District of Columbia
Missouri
Rhode Island
South Dakota

Source: Hospice and Palliative Nursing Association; *www.hpna.org/*. HRSA, Division of Nursing. The National Survey of Registered Nurses, March 2000: Preliminary Findings February 2001.

CASE STUDY

Doctors fear end-of-life decisions, too

A doctor was treating a patient whose cancer had spread to 11 different areas of the brain. Chemotherapy and radiation no longer held any promise; it was time to focus on comfort. And yet, according to one colleague, the doctor kept softening anything he said with words like "yet" or "at this time." So the family kept asking, "Is it time for more chemo yet?" The doctor admitted privately that he was hoping the patient would decide against further chemotherapy, which would end the discussion and put the weight of the decision on the patient's shoulders, rather than on his or the family's.

This scenario could have been avoided had the doctor been properly trained in end-of-life care. He could have been more direct and honest in telling the patient and family that more treatment would be senseless. He could have discussed care options (including hospice) to ensure that the patient's remaining days would be spent as comfortably as possible. At the very least, he could have informed the patient and family that death was approaching, allowing time for everybody to say goodbye.

From Virginia Morris, Talking About Death Won't Kill You *(New York: Workman Publishing, 2001). Reprinted with permission.*

Recommendations for Action

Recommendations for Action

As the data in this report indicate, Americans' likelihood of receiving good end-of-life care varies widely, depending on where they live, what they know about quality end-of-life care services and the type of care they choose. Even though some aspects of care may be better in some states than in others, in general, care for dying Americans is no better than mediocre. This is true despite years of research, improved professional education and training, the excellent record of hospice, innovation among hospitals and some nursing homes, grassroots advocacy and millions of dollars of private philanthropy—all directed at advancing the understanding and availability of good palliative care near the end of life.

In general, care for dying Americans is no better than mediocre.

Last Acts believes that the United States is at a crossroads. The state-by-state data we have gathered and analyzed here depict a nation that is coping poorly with critically ill and dying people *right now*. As we noted, there were no available data on spiritual and cultural issues at the end of life that could be tracked by state; however, there is no reason to believe that these matters are being well addressed nationwide. Meanwhile, demographers forecast a constantly growing number of elderly people and ever higher burdens of chronic illnesses. Much more must be done to make dying a more compassionate and caring experience, both for the patient and for the family, in America.

Last Acts recommends the essential steps that follow.

☑ *Actions for Public Policymakers*

General

1. Make quality end-of-life care a priority for national health policy.
2. Make end-of-life care a special priority in aging policy.
3. Support public/private initiatives to meet the needs of family caregivers.
4. Encourage policies to enhance consumers' knowledge of the options for quality care near the end of life.

Decision-Making

5. Promulgate policies that encourage advance care planning and out-of-hospital Do Not Resuscitate programs.
6. Ensure that in the absence of advance directives, family surrogacy is recognized and used in the best interests of dying people.

Professional Capacity

7. Set state targets for the numbers of doctors and nurses with palliative care training needed to care for the state's critically ill and dying patients, and work with state-funded educational institutions to achieve them.
8. Encourage requirements for continuing medical and nursing education about end-of-life care.

Service Delivery

9. Establish good pain management policies that tackle the problem of undertreatment of pain.
10. Encourage coordination of health services programs used by dying people of all ages, to promote continuity of care.
11. Require that hospitals and nursing homes establish palliative care services—using appropriately trained multidisciplinary teams, meeting quality standards and encouraging contracting with hospice—as a condition of their participation in Medicare and Medicaid.
12. Reassess the rules and regulations that apply to nursing homes (where rehabilitation is the mission) and allow greater flexibility in caring for dying residents.
13. Support the provision of hospice services in government-run institutions—prisons, jails, mental hospitals, and so on.
14. Change the Medicare hospice eligibility criteria to allow Medicare beneficiaries to qualify for the Hospice benefit by diagnosis rather than an estimate of a six-month prognosis of terminal illness.

Research and Financing

15. Support large-scale demonstrations of promising models of coordinated end-of-life care that are likely to show both better quality of life for patients and families, and cost savings.
16. If these demonstrations warrant, revise Medicare and Medicaid benefits to cover the clinical, counseling and support services essential to high-quality end-of-life care.
17. Collect data to assess quality, cost and access to end-of-life care in a variety of settings.
18. Develop evidence-based palliative care clinical protocols.

☑ *Actions for Health Care Leaders*

1. Work to establish multidisciplinary palliative care services in hospitals—particularly in intensive care units—and nursing homes for seriously ill patients who have symptoms that are difficult to handle or painful treatments, or who are likely to die.
2. Include hospice or palliative care service rotations in physician, nurse, social work and pharmacy training.
3. Encourage the capacity of end-of-life teams to be culturally competent.
4. Expand the relevant training and role of social workers—particularly about advance care planning, recognizing cultural issues and the need for family support.
5. Convey the expectation of good pain and symptom management to clinical staff in hospitals, nursing homes and other settings.
6. Work with clinicians on key communications skills: breaking bad news and setting realistic treatment goals. Currently, few know how to do this well.
7. Support practicing physicians who seek training in palliative care.
8. Engage in ongoing clinical and process improvement efforts.
9. Advocate tirelessly for the comfort and support of dying patients and their families.

☑ Actions for Everyone

1. Learn what constitutes good end-of-life care.
2. Don't be afraid to insist that your loved one, friend or neighbor receive it.
3. Join others in your state or community who are trying to make positive changes.
4. Ask your employer to have policies in place to help seriously ill employees, those caring for a seriously ill family member, and those who are bereaved.
5. Complete your own advance directive and discuss it with your family, health care proxy and physician. Update it every five years or when your health changes.
6. Encourage your spiritual leader to help your congregation explore the spiritual aspects of illness and death, and organize to help seriously ill members and their families.
7. Learn practical ways to help friends and family who are grieving.

Americans have successfully avoided the unpleasant topic of death and dying for two or three generations. But now, as we begin to experience a rapid increase in the number of elderly citizens, our denial comes at a price we cannot afford—the risk of leaving more and more Americans without good, supportive, affordable care as their lives come to a close.

The data brought together in this report represent the best statistics currently available regarding end-of-life care in America. We ardently wish that they will inspire better, more thorough and complete documentation of progress at the national, state and local levels. The many people who aided *Last Acts* in compiling this report share the hope that it will raise public awareness, spur both the expectation and demand for good end-of-life care, and help everyone who cares about our future to make a clear and factual case for reform.

Momentum for Change

Momentum for Change

Statewide coalitions and partnerships in 30 states are working to build a diverse constituency for improving the quality of end-of-life care. Through them, significant numbers of community, professional and policy stakeholders are able to identify common obstacles, create comprehensive strategies, and carry out mutually agreed-on policy and educational initiatives. There are four main goals for their activities:

- To improve advance care planning.
- To improve pain management.
- To improve the quality of care and care coordination.
- To increase both the demand for and access to high-quality end-of-life care.

Statewide coalitions and partnerships in 30 states are working to . . . improve the quality of end-of-life care.

The groups vary considerably in terms of management structure, type of lead organization and mechanisms for carrying out initiatives. A handful grew out of state end-of-life commissions that gathered data and set reform agendas. Others were formed from well-established hospice, bioethics, health care decision-making or pain policy organizations. A few have been in existence for more than a decade; others have formed since 1998, or even more recently.

Many of the coalitions began by gathering information about serious barriers to good end-of-life care, which they have used to inform their respective statewide plans of action. Typically, the groups:

- Create consumer education tools that empower patients to plan and advocate for themselves and their loved ones at the end of life.
- Help public agencies, associations of faith leaders, state nursing groups and others identify end-of-life care as a critical agenda item.
- Launch coordinated community outreach efforts around programs such as Bill Moyers' four-part PBS series, *On Our Own Terms*.

- Obtain media coverage that raises the public's expectation of excellent care.
- Spotlight cultural, ethnic, social and economic diversity issues to ensure that excellent end-of-life care is available to underserved and vulnerable people as well as those who can afford it.
- Organize training sessions for practicing physicians, nurses, pastoral care professionals and other members of palliative care teams using tested educational programs such as the Education for Physicians on End-of-Life Care (EPEC) curriculum.
- Conduct model quality improvement projects focused on advance care planning and pain management in nursing homes and other care settings.
- Organize state licensing boards to adopt joint pain policy standards or issue interpretations of laws and regulations.
- Educate policy leaders on how to revise existing state policies and create new policies related to end-of-life care.

FAST FACT

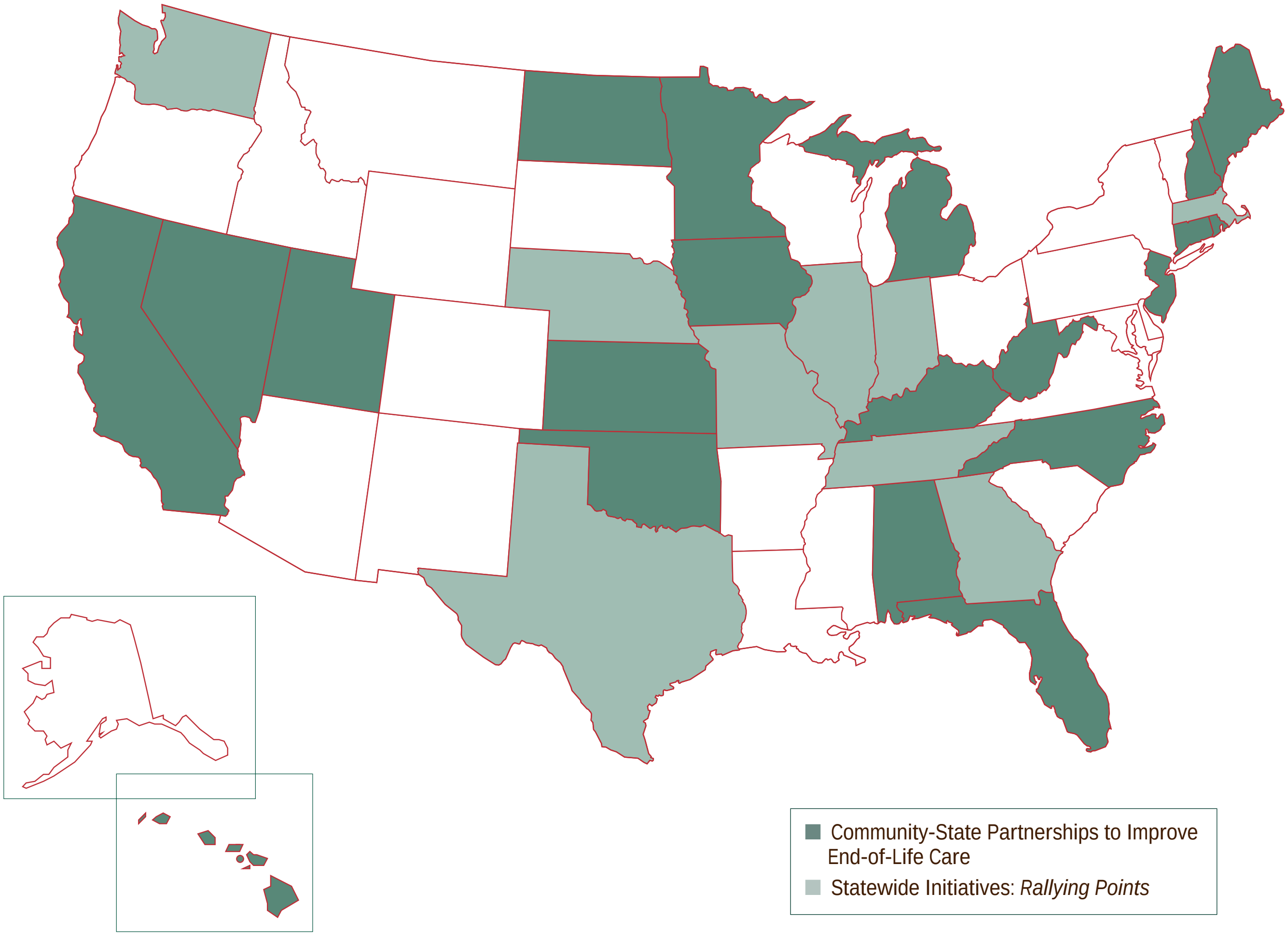
Largely through the work of statewide coalitions, 160 separate legislative acts were passed in 23 states between 1999 and 2001.

Overall, the statewide end-of-life care initiatives have proved their ability to overcome the competition and dissension that sometimes keep natural allies from collaborating and promoting the common good. They help states create a whole that is greater than the sum of its parts.

• • •

The map opposite shows the 30 existing statewide coalitions and partnerships and is followed by brief descriptions of each one with complete contact information.

Statewide End-of-Life Care Initiatives



■ Alabamians for Better Care at Life's End
■ California Coalition for Compassionate Care
■ Connecticut Coalition to Improve End-of-Care—*Better Endings*
■ District of Columbia Partnership to Improve End-of-Life Care
■ The Florida Partnership for End-of-Life Care
□ Georgia Collaborative to Improve End-of-Life Care
■ Hawaii Kokua Mau
□ Illinois Coalition for Improving End-of-Life Care
□ Indiana Hospice & Palliative Care Organization
■ Iowa Partnership for Quality Care in Dying with Dignity
■ Kansas LIFE Project—Living Initiatives for End-of-Life Care
■ Journey's End—A Kentucky Partnership for Quality End-of-Life Care
■ Maine Center for End-of-Life Care
□ Massachusetts Compassionate Care Coalition
■ Michigan Partnership for the Advancement of End-of-Life Care
■ Minnesota Partnership to Improve End-of-Life Care
□ Missouri End-of-Life Care
□ Nebraska Coalition for Compassionate Care
■ Nevada Center for Ethics and Health Policy
■ New Hampshire Partnership for End-of-Life Care
■ New Jersey Comfort Care Coalition
■ North Carolina: The Carolinas Center for Hospice and End-of-Life Care
■ North Dakota *Matters of Life & Death* Project
■ Oklahoma Alliance for Better Care of the Dying
■ Rhode Island: Improving Quality of Care for Our Most Vulnerable Population
□ Tennesseans End-of-Life Partners
□ Texas Partnership for End-of-Life Care
■ Utah Partnership to Improve End-of-Life Care
□ Washington State End-of-Life Consensus Coalition
■ West Virginia Initiative to Improve End-of-Life Care
■ Community–State Partnerships to Improve End-of-Life Care

Source: National Conference of State Legislatures; Community-State Partnerships; *Rallying Points*.

Alabamians for Better Care at Life's End

Formed in 1999, the partnership is focused on improving access to end-of-life care for the most disadvantaged Alabamians. The partnership is working to build professional and lay education opportunities through nursing curriculum reform and a palliative care rural scholars program. It is also working to implement pain as a fifth vital sign at the University of Alabama at Birmingham Hospital and eventually at other institutions; to create a clergy education program; and to liberalize Medicaid regulations. The group recently co-sponsored an interdisciplinary one-day Intensive Palliative Care Introduction/Review Course. Contact: Kay Johnson, R.N., M.P.H., University of Alabama at Birmingham Palliative Medicine Program, 1801 Building, 1530 Third Avenue South, Birmingham, AL 35294-0023. Phone: (205) 975-9815. E-mail: kayjohns@uab.edu.Web: *www.abcle.org*.

California Coalition for Compassionate Care

The California program is carried out by a 35-member partnership formed in 1998. The coalition has three major initiatives: (1) end-of-life care guidelines for skilled nursing facilities; (2) advance care planning tools in English and Spanish; and (3) professional education efforts that include EPEC training for practicing physicians. The group is highly regarded as an educational resource on end-of-life issues by California policymakers. A recent initiative is the establishment of several Latino advisory committees that are working together to guide community outreach efforts directed at Spanish-speaking Californians. Contact: Marge Ginsburg, Executive Director, Sacramento Health Care Decisions, 10540 White Rock Road, Suite 135, Rancho Cordova, CA 95670. Phone: (916) 851-2828. E-mail: marge.shd@quiknet.com. Web: *www.finalchoices.calhealth.org*.

Connecticut Coalition to Improve End-of-Life Care—Better Endings

The Connecticut coalition is a statewide not-for-profit organization that addresses a comprehensive array of end-of-life care issues. Its six task forces are: Public Education, Professional Education, Law and Ethics, Services and the Continuum, Research, and Arts and Humanities. Focused on public, professional and policymaker education, the task forces engage in projects related to community outreach and focus group research, advance care planning, best practices in end-of-life care, professional education for medical students, development of consumer education materials and caregiver support. Contact: Karen Weingrod, Director, Connecticut Coalition, 300 Research Parkway, Meriden, CT 06450. Phone (203) 237-4556. E-mail: kweingrod@canpfa.org. Web: *www.canpfa.org/endoflife/index.htm*.

District of Columbia Partnership to Improve End-of-Life Care

This District-wide program is guided by a community advisory board whose members represent many cultures and ethnic groups within the city. Initiatives have four focus areas: Professional Education, Public Education, Public Policy, and Research. All areas utilize the combined expertise of a broad array of professionals, health care organizations, professional schools and community organizations to effect systematic, sustained reform of care for residents of the D.C. metropolitan area who are facing life-limiting illnesses. Contact: Joan Panke, M.A., A.P.R.N., Executive Director, D.C. Partnership, c/o District of Columbia Housing Authority, 1250 Eye Street, N.W., Suite 700, Washington, DC 20005. Phone: (202) 289-6231. E-mail: jpanke@dcha.org. Web: *www.dcha.org/EOL/eol.htm*.

The Florida Partnership for End-of-Life Care

Based on the recommendations of a state end-of-life work group, state partnership initiatives have included a statewide network of community-based coalitions, the State's first-ever pain management training program for pharmacists, a DNR order demonstration project, an end-of-life care education program for EMS providers, public education campaigns involving the statewide aging network, ethics educational materials for diverse populations, and professional end-of-life care educational programs with special sessions for attorneys and clergy. Contact: Robyn Chase, Coordinator, Florida Partnership, 1616 Metropolitan Circle, Suite D, Tallahassee, FL 32308. Phone: (850) 878-2632. E-mail: flpartners@nettally.com. Web: *www.floridapartnership.org*.

Georgia Collaborative to Improve End-of-Life Care

The focus of the Georgia collaborative is educating nurses, physicians and health facility surveyors. The partnership works collaboratively to present ELNEC training for nurses and social workers in the state. Contact: Glenn Landers, Georgia Collaborative, c/o Georgia Health Policy Center, One Park Place South, Atlanta, GA 30303. Phone: (404) 463-9562. E-mail: mail@gaeolcare.org.

Hawaii Kokua Mau

Kokua Mau, which means continuous care, builds on four key recommendations that emerged from a statewide planning process conducted by Governor Ben Cayetano's Blue Ribbon Panel on Living and Dying with Dignity. Hawaii's multicultural, multiracial citizens face a unique and complex challenge in finding quality end-of-life care in the setting of their choice. Therefore, the Kokua Mau project focuses on providing culturally appropriate practical resources to the clergy; running a speaker's bureau and conducting a statewide public awareness campaign; piloting a pain as a fifth vital sign demonstration project; and providing updated information to policymakers and health care regulatory boards. Contact: Joanna Crocker, Ph.D., Project Coordinator, Executive Office on Aging, No. 1 Capitol District, 250 South Hotel Street, Suite 406, Honolulu, HI 96813-2831. Phone: (808) 586-7285. E-mail: jcrocke@mail.health.state.hi.us. Web: *www.kokuamau.org*.

Illinois Coalition for Improving End-of-Life Care

The Illinois coalition has several priority activities that include providing education on end-of-life issues such as pain management and use of advance directives to both professional and community groups. Contact: Mickey Stanley, Executive Director, Illinois Coalition for Improving End-of-Life Care, 200 West Third Street, Suite 704, Alton, IL 62002. Phone: (618) 275-4336. E-mail: Stanley@shawneelink.com.

Indiana Hospice & Palliative Care Organization

The organization (IHPCO) provides a statewide consumer helpline on family caregiving, manned by a social worker. The organization recently developed a public education campaign, “Say You Care: Start the Conversation,” which features conversation starters, a workbook for families, a family caregiving information sheet, a video and a public service announcement featuring basketball star Larry Bird. The group also serves as a clearinghouse for professionals on end-of-life issues and advocates on behalf of the terminally ill and their loved ones. Contact: Harriet O’Connor, President and CEO, IHPCO, 1720 Market Tower Building, 10 West Market Street, Indianapolis, IN 46104. Phone: (317) 464-5145. E-mail: inhospiceorg@att.net.

Iowa Partnership for Quality Care in Dying with Dignity

The Iowa partnership has 108 members and more than four dozen community coalitions. Four work groups address specific issues related to enhancing the quality of end-of-life care. These work groups (1) promote Iowans’ end-of-life care awareness and knowledge; (2) distribute the partnership’s *Implementing Pain as a Fifth Vital Sign* manual throughout Iowa health care institutions; (3) develop guidelines for EMS agency and personnel for out-of-hospital DNR orders and promote related legislation; and (4) increase access to oral health care at the end of life. The partnership also plans to pilot a faith community initiative. Contact: Tanya Uden-Holman, Ph.D., M.A., Assistant Professor (Clinical Track), Institute for Quality Healthcare, University of Iowa, 5229 Westlawn Building South, Iowa City, IA 52242-1100. Phone: (319) 335-8708. E-mail: tanya-uden-holman@uiowa.edu. Web: *www.public-health.uiowa.edu/EndOfLife/*.

Kansas LIFE Project—Living Initiatives for End-of-Life Care

The Kansas LIFE Project is a collaborative effort of more than 70 agencies and organizations including governmental agencies, professional associations, licensing boards, academic institutions, medical providers, media, consumer action groups and a Caring Communities program. The shared mission of the LIFE Project Partners is to help Kansans live with dignity, comfort and peace as they near the end of life. The project's strategic initiatives are focused on impacting three arenas—public policy, professional education and systems change, and public engagement and awareness. Contact: Stacie Ogborn, Project Manager, LIFE Project Foundation, 1901 University, Wichita, KS 67213. Phone: (316) 263-6380. E-mail: stacie@lifeproject.org. Web: *www.lifeproject.org*.

Journey's End—A Kentucky Partnership for Quality End-of-Life Care

The centerpiece of the Kentucky Partnership is establishment of a new Legislative Taskforce on End-of-Life Care chaired by State Sen. Julie Denton. The partnership also recently learned that the University of Louisville is supporting its proposal for a new center for research in end-of-life care. The partnership has a number of other initiatives under way. They include: (1) education of practicing professionals using the EPEC curriculum; (2) a toll-free peer resource help line for professionals staffed by five board-certified palliative care physicians and initiated July 2000; (3) development of pain management and advance care planning guidelines to be piloted in five long-term-care facilities; and (4) implementation of a coordinated case management service to support a wide array of interdisciplinary palliative care services for a Medicaid partnership, called Passport. Contact: Jennifer Scharfenberger, Project Coordinator, KHA Center for Nursing and Allied Health Professions, 2501 Nelson Miller Parkway, Louisville, KY 40223. Phone: (502) 426-6220. E-mail: JScharfenberger@kyha.com. Web: *www.journeysendky.org*.

Maine Center for End-of-Life Care

The newly created Maine Center for End-of-Life Care builds on the work of the Maine Consortium for Palliative Care & Hospice and the 18-year-old Maine Hospice Council. The partnership has developed a resource directory; a hospice/palliative care rotation for second-year medical students at the University of New England; and an interfaith manual on end-of-life care. An important aspect of the project is the involvement of health care insurers and affiliates and other health care organizations in development of an ideal services package that includes universal access to hospice and end-of-life care. The center currently supports five regional coalitions and is working with the state long-term-care association on standards of best practice and employee retention. Contact: Kandyce Powell, R.N., M.S.N., Maine Hospice Council, 16 Winthrop, P.O. Box 2239, Augusta, ME 04338-2239. Phone: (207) 626-0651. E-mail: kpowell@saturn.caps.maine.edu. Web: *www.mcpch.org*.

Massachusetts Compassionate Care Coalition

MCCC is a voluntary collaborative of organizations, agencies, institutions and individuals who seek to enhance care for people affected by life-limiting illnesses. The group works closely with the Massachusetts legislature's Commission on End-of-Life Care. MCCC has been engaged in a variety of public outreach projects: promoting community conversations on advance care planning and developing several theater and visual arts projects. The coalition sponsors regular networking breakfasts that bring professionals and consumers together. MCCC co-sponsored a seminar on "Ethics and The Health Professions in End-of-Life Care" with Brandeis University in October 2002. Contact: Carol Wogrin, Executive Director, MCCC, 53 Langley Road, Suite 260, Newton Center, MA 02459. Phone: (617) 964-1196. E-mail: cwogrin@ mountida.edu.

Michigan Partnership for the Advancement of End-of-Life Care

The Michigan Partnership for the Advancement of End-of-Life Care strives to increase the quality of, accessibility to, and timeliness of referrals to palliative and end-of-life care in Michigan. The partnership has a number of accomplishments over the past three years. Educators from medicine, nursing, pharmacy, social work and pastoral care developed competencies for end-of-life care and promoted those standards and available resources within their institutions and disciplines. Members of the partnership helped the state's regulatory agency develop and adopt statewide pain management and end-of-life indicators for use by long-term care facilities and surveyors. Focusing on diverse communities and end-of-life care decision-making, the partnership developed a well-received community education training program and supporting materials. Contact: Bradley McKinney, M.P.H., M.S.W., Project Director, Michigan Partnership, 6015 West St. Joseph Highway, Suite 104, Lansing, MI 48917. Phone: (517) 886-6667. E-mail: bradhospice@aol.com.

Minnesota Partnership to Improve End-Of-Life Care

The Minnesota partnership began in 1997 when representatives from three large health insurers began discussing a joint project to improve end-of-life care for Minnesotans. The partnership also staffed a 26-member state commission to identify and address public policy barriers to good care, with a focus on state funding, education and licensure. While the partnership is in transition to refine its mission and search for a new host agency, board chair Mary Lou Irvine is the contact: mary.l.irvine@healthpartners.com.

Missouri End-of-Life Coalition

The Missouri coalition was formed in 1998 to foster cooperation, education and research to promote high-quality care for the dying. It develops and promotes public awareness projects that educate health care providers, students, policymakers and the public regarding optimal care; fosters collaborative research efforts; and promotes advance care planning that enables dying persons, loved ones and caregivers to express their needs and expectations. The coalition has two current projects: work with the state Emergency Medical Services Bureau to implement local EMS unit policies that honor out-of-hospital DNR order requests; and collaboration on an end-of-life care manual to guide policies and procedures in nursing facilities. Widespread distribution will be followed by regionalized training. Contact: Cindy Baird, Executive Director, Missouri Hospice & Palliative Care Association, 3905 Stonewall Avenue, Independence, MO 64055. Phone: (816) 350-7702. E-mail: cindy@mohospice.org.

Nebraska Coalition for Compassionate Care

The Nebraska coalition has a number of educational, awareness and coalition-building efforts aimed at physicians, nursing home residents and the general public. Two priority activities are: promotion of a new publication, *An Educational Guide on End-of-Life Care Law and Public Policy in Nebraska*, which explains how health care professionals can offer the best care without violating applicable state laws; and a joint project with the Nebraska Hospice Association to launch an initiative that will measure quality of life and satisfaction with care, and monitor health care dollars spent on end-of-life care. Contact: Greg Schleppenbach, Operations Board Chair, NCCC, P.O. Box 94714, Lincoln, NE 68509-4714. Phone: (402) 477-0204. E-mail: gregschlepp@alltel.net. Web: *www.nebrccc.org*.

Nevada Center for Ethics and Health Policy

The Nevada Center for Ethics and Health Policy carries out activities initiated by the State's Attorney General and outlined in the statewide plan, "Death with Dignity and Caring in the State of Nevada." Housed at the University of Nevada, Reno, the program trains teams of clinicians drawn from underserved areas of Nevada; carries out statewide campaigns focused on advance care planning; staffs continuing education programs for community health nurses; works with licensure boards, professional associations and other institutions to integrate end-of-life policies that reflect recent changes in Nevada law; and organizes interdisciplinary conferences for doctors and nurses on pain relief practices and what it means to have a dignified death. Contact: Noel Tiano, Th.D, Executive Director, Nevada Center for Ethics and Health Policy, University of Nevada/339, Reno, NV 89557-0133. Phone: (775) 327-2309. E-mail: noel@unr.edu. Web: *www.unr.edu/ncehp*.

New Hampshire Partnership for End-of-Life Care

The New Hampshire partnership is driven by findings from a 1998 statewide study, "Death in New Hampshire: A Review of Medical Charts." The centerpiece of its activity is a series of regional education initiatives across the state to help patients and families engage in advance care planning and complete directives. A public information campaign promotes the importance of talking about treatment preferences and reinforces the local education initiatives. Workshops and quality improvement efforts inform health care professionals, insurers and others about best practices related to advance care planning. Related efforts are designed to encourage health and spiritual care providers to talk about advance care planning. Contact: Shawn LaFrance, M.S., M.P.H., Vice President, Foundation for Healthy Communities, 125 Airport Road, Concord, NH 03301. Phone: (603) 225-0900. E-mail: slafrance@nhha.org. Web: *www.fhconline.org*.

New Jersey Comfort Care Coalition

Housed at New Jersey Health Decisions, the coalition has 30 participating organizations. The group has created interdisciplinary training for health professions students and clinicians, new models to finance care, and a comprehensive campaign for public education and dialogue. The coalition recently co-sponsored an intensive ethics conference with the New York Citizens' Committee on Health Decisions, "In the Wake of Devastation: Dealing with Trauma, Stress and Grief." Contact: Stephanie G. Levy, Project Manager, New Jersey Health Decisions, 13 Rockland Terrace, 1st Floor, Verona, NJ 07044. Phone: (973) 857-5552. E-mail: stevilevy@aol.com.

North Carolina: The Carolinas Center for Hospice and End-of-Life Care

The Carolinas Center has developed an infrastructure for statewide community outreach that includes 35 local end-of-life care coalitions, 30 advance care planning (ACP) instructors, and numerous statewide organizations to which it provides consultation, networking and resources. Certified ACP instructors have trained more than 450 health care professionals and community leaders and distributed more than 20,000 ACP educational materials to help consumers plan and communicate their wishes. A comprehensive Web site includes an end-of-life resource locator as well as online resources. A quality improvement project provides intensive education in pain management and end-of-life care for staff in nursing homes. Contact: Gwynn Sullivan, R.N., M.S.N., Director of NC Community Outreach, The Carolinas Center, 2400 Weston Parkway, P.O. Box 4449, Cary, NC 27519-4449. Phone: (919) 677-4117. E-mail: gsullivan@carolinasendoflifecare.org. Web: *www.carolinasendoflifecare.org*.

North Dakota Matters of Life & Death Project

The *Matters of Life & Death* Project is a coalition of more than 50 organizations, individuals and agencies in North Dakota working together on initiatives to improve care at the end of life. Initiated in 1999, the project has implemented interdisciplinary strategies in four key areas: professional education; services and access to end-of-life care; public education; and advance care planning. The project strives to create a more supportive environment that encourages advance planning and provides early access to excellent care that addresses the physical, psychological, spiritual and social needs of dying people and their family. Contact: Bruce Levi, J.D., Project Director/Director of Legal Affairs, North Dakota Medical Association, Box 1198, Bismarck, ND 58502. Phone: (701) 223-9475. E-mail: blevi@ndmed.com. Web: *www.ndmed.com*.

Oklahoma Alliance for Better Care of the Dying

The alliance (OkABCD) has collected data from focus groups and town hall meetings in several cities to document citizens' experiences with end-of-life care. OkABCD focuses on several key initiatives: (1) a public awareness campaign that encourages older adults to talk with their loved ones and physicians about their care preferences; (2) a speaker's bureau that shares information on various end-of-life issues; (3) interdisciplinary workshops that meet the professional education needs of physicians, nurses, nursing home administrators, social workers, physician assistants, pharmacists, emergency medical technicians, clergy and other concerned professionals; and (4) meetings with directors of nursing homes, state regulators and surveyors to resolve misunderstandings about hospice care in nursing homes, pain assessment and other regulatory topics. Contact: Linda Edmondson, L.C.S.W., Executive Director, Oklahoma Association for Healthcare Ethics, 228 Robert S. Kerr Boulevard, Suite 300, Oklahoma City, OK 73102-5201. Phone: (405) 236-2280. E-mail: leokabcd@swbell.net.

Rhode Island: Improving Quality of Care for Our Most Vulnerable Population

The Rhode Island program has experienced success in two key areas: advance care planning and pain management. The Attorney General's office has put together a legal steering committee to examine current advance directive forms and explore standardization of their use in long-term care facilities and by emergency medical health providers. The Pain Management/Public Policy/Professional Education task force has supported a Brown/Rhode Island Continuous Quality Improvement Pain Management project, which is collecting data from participating nursing homes. The Rhode Island Department of Health initiated a statewide "Pain Awareness Week" in cooperation with the Attorney General's Health Care Advocate. Contact: Debra DeSilva, Project Coordinator, Brown University, Box G-H Hemisphere Building, LL, 167 Angell Street, Providence, RI 02912. Phone: (401) 863-9628. E-mail: debra_desilva@brown.edu. Web: *www.chcr.brown.edu/commstate/homepagewithframes.htm*.

Tennesseans End-of-Life Partners

The coalition (TELP) focuses on defining and promoting best practices in end-of-life care. TELP has implemented a statewide survey of physicians regarding their perceived competencies and concerns in providing optimal end-of-life care. In collaboration with the State Health Department, TELP worked with the Board for Licensing Healthcare Facilities to amend its Rules & Regulations to address end-of-life care and pain management for all licensed health care facilities, including hospitals, nursing homes, ambulatory surgery, residential hospice and home care organizations. The group also conducted training sessions on pain management and end-of-life care at the State Surveyors annual meeting. Contact: Norma Lindsey, TELP, c/o St. Mary's Medical Center, 900 East Oak Hill Avenue, Tower 2, Knoxville, TN 37917. Phone: (865) 545-7166. E-mail: nlindsey@stmaryshealth.com.

Texas Partnership for End-of-Life Care

The Texas partnership (TxPEC) has launched 12 local and regional partnerships serving Texans in 20 cities. The organization regularly offers educational opportunities to health care and social service professionals as well as the faith community. It has sponsored EPEC training, developed a clergy project, held conferences and conducted consumer polls on end-of-life attitudes in five communities. Regional task forces are addressing such issues as service coordination in nursing homes, grief and bereavement training, bilingual staff recruitment, and development of residential hospice facilities. The partnership is planning a conference in 2004 to promote diversity and cultural exchange. Contact: Suze Miller, Executive Director, TxPEC, 3710 Cedar Street, Box 22, Suite 275, Austin, TX 78705. Phone: (512) 453-9600. E-mail: info@txpec.org. Web: *www.txpec.org*.

Utah Partnership to Improve End-of-Life Care

The Utah partnership has four major goals: (1) to increase public awareness of end-of-life issues; (2) to improve professional practices; (3) to provide educational assistance on policy that affects end-of-life care; and (4) to conduct meetings that bring together care providers and the loved ones of people who have died. The partnership's Web site is widely used by consumers seeking information on end-of-life care. The group also is participating in an ad hoc committee that is developing a form like Oregon's POLST (Physician Orders for Life-Sustaining Treatment). Future efforts may include promoting palliative care for children and involving the clergy. Contacts: Maureen Henry or Kim Segal, Co-Project Managers, HealthInsight, 348 E. 4500 South, Suite 300, Salt Lake City, UT 84107. Phone: (801) 892-0155. E-mail: mhenry@healthinsight.org. Web: *www.carefordying.org*.

Washington State End-of-Life Consensus Coalition

The Washington coalition has hosted numerous conferences and workshops across the state and supported the creation of multidisciplinary clerkships. Currently the group is working in three areas: (1) to create an interdisciplinary continuing medical education pilot program for the Washington State Medical Association's annual meeting, which will focus on communication and symptom management to provide comfort to patients and their families; (2) to help create a pain management resource for health care professionals; and (3) to host an end-of-life coalition meeting in 2003. The coalition engages policy leaders in addressing the regulatory barriers to honoring advance directives. Contact: Graham Short, Communications Coordinator, Washington State Medical Association, 2033 Sixth Avenue, Suite 1100, Seattle, WA 98122. Phone: (206) 441-9762. E-mail: gfs@wsma.org.

West Virginia Initiative to Improve End-of-Life Care

The West Virginia program uses a multidisciplinary approach and strong public participation to improve end-of-life care for all state residents. Current activities include a plan to initiate a series of community discussions, "Dispelling the Myths about Pain," to be held with civic and community groups in senior centers, churches, public libraries and other public locations. A minority issues task force has begun to work on planning a possible conference for African-American clergy. The group is also seeking funds to film a documentary about the end-of-life care experiences of African Americans in West Virginia. The policy task force is working on minor changes to the DNR order and to the West Virginia Health Care Decisions Act that would include wording about the use of the POLST form. The palliative care nurse-educators group continues to provide palliative care education and consultation with nursing homes and rural hospitals throughout the state. The professional education task force hopes to develop a social work track at the West Virginia University School of Social Work Summer Institute on Aging. Contact: Jim Keresztury, L.C.S.W.,

Physician Orders for Life-Sustaining Treatment ***(POLST) is a one-page, two-sided document designed to help health care providers honor the end-of-life treatment desires of their patients. The document is a physician order form that follows patient wishes and treatment intentions and thereby enhances the appropriateness and quality of patient care. It is not intended to be completed by the patient or the patient's family. It is not an advance directive, which in Oregon must follow statutory wording.***

The POLST form is easily recognized because of its bright pink color and standardized format. It uses language to convey physician orders about specific medical treatment that is understandable to nursing home staff, home health/hospice personnel, covering physicians, emergency medical services and loved ones of the patient.

A.C.S.W., M.B.A., Project Manager/Associate Director, West Virginia University Center for Health Ethics and Law, 1195 Health Sciences North, P.O. Box 9022, Morgantown, WV 26506-9022. Phone: (304) 293-7618. E-mail: jkeresztury@hsc.wvu.edu. Web: *www.wvinitiative.org*.

Community-State Partnerships to Improve End-of-Life Care

National Program Office, Midwest Bioethics Center, 1021 Jefferson Street, Kansas City, MO 64105. Phone: (816) 221-1100. Contacts: Myra Christopher, National Program Director. E-mail: myra@midbio.org. Jacqueline Talman, M.S.W., L.C.S.W., Deputy Director. E-mail: jtalman@midbio.org. Web: *www.midbio.org*.

Appendix

Appendix

METHODOLOGY

The idea for this report came out of a 2001 discussion among the end-of-life care experts who serve as conveners of *Last Acts*' 11 committees. Jim Towey, at that time co-convener of the *Last Acts* Family Committee, volunteered to steer the process to produce it. Jim consulted and received comments and suggestions from many experts in the end-of-life field who helped develop initial measures for rating the states. They recommended that the criteria be quantifiable, and that each should represent an important aspect of end-of-life care. Staff did an initial search for data sources and presented draft measures and potential data to the *Last Acts* committee conveners. (Listings of both groups appear on pages 86 and 87.) Based on their suggestions and the advice of additional experts and reviewers, staff revised criteria and, in some cases, located new data sources.

The data ultimately used, although accurate and as up-to-date as possible, do not adjust for variations in public programs and morbidity factors, nor can they show very real local differences in care *within* states. Data were obtained primarily from publicly available sources (e.g., Web sites, published books and special projects).

The following sections describe the data sources and special considerations for each measure used.

1 STATE ADVANCE DIRECTIVE POLICIES

The ratings are based on an analysis done by Charles Sabatino, J.D., in 2002 that looked at six aspects of state statutes. We placed each state in one of five possible groups according to its overall score (range of possible scores was 0.0–5.0).

*MA, MI & NY have only proxy statutes but are treated as comprehensive statutes because health care instructions may be included in any directive.

**As MA, MI & NY have only proxy statutes, precedence to agent's authority is inherent in the statutory structure.

Source: American Bar Association, Commission on Law and Aging. *State Health Decisions Legislative Update, 2002, www.abanet.org*; Sabatino, CP. "The Legal and Functional Status of the Medical Proxy: Suggestions for Statutory Reform." *Journal of Law, Medicine & Ethics*, 27: 552–68, 1999; Sabatino, CP, "Survey of State EMS-DNR Laws and Protocols." *Journal of Law, Medicine & Ethics*, 27: 297–315, 1999.

Quality of state advance directive laws, 2002

State	Encourages single, comprehensive AD statute	Avoids mandatory forms or language (in proxy or combined proxy/living will)
Alabama	•	
Alaska		
Arizona	•	•
Arkansas		•
California	•	•
Colorado		•
Connecticut	•	•
Delaware	•	•
District of Columbia		•
Florida	•	•
Georgia		•
Hawaii	•	•
Idaho		•
Illinois		•
Indiana		
Iowa		•
Kansas		
Kentucky	•	
Louisiana		•
Maine	•	•
Maryland	•	•
Massachusetts	•*	•
Michigan	•*	•
Minnesota	•	•
Mississippi	•	•
Missouri		•
Montana		•
Nebraska		•
Nevada		
New Hampshire		
New Jersey	•	•
New Mexico	•	•
New York	•*	•
North Carolina		•
North Dakota		•
Ohio		
Oklahoma	•	
Oregon	•	
Pennsylvania		•
Rhode Island		•
South Carolina		
South Dakota		•
Tennessee		•
Texas		
Utah		
Vermont		
Virginia	•	•
Washington		•
West Virginia		•
Wisconsin		
Wyoming		•

AD statute gives precedence to agent's authority or most recent directive over LW	***Statute authorizes default surrogates for health care decisions, including life support***	***Default surrogates include "close friend"***	***Has statewide EMS-DNR protocol in place***	***TOTAL Shaded columns count ½ point***
•	•		•	*3.5*
			•	*1.0*
•			•	*3.5*
	•		•	*3.0*
			•	*3.0*
	•	•	•	*3.5*
	•		•	*4.0*
•	•	•	•	*5.0*
	•		•	*3.0*
•	•	•	•	*5.0*
•	•		•	*3.5*
	•	•	•	*4.5*
	•		•	*3.0*
•	•	•	•	*4.0*
	•		•	*2.0*
•	•			*2.5*
			•	*1.0*
	•		•	*3.0*
	•		•	*3.0*
•	•	•	•	*5.0*
	•	•	•	*4.5*
•**			•	*3.5*
•**			•	*4.5*
•			•	*3.5*
•	•			*3.5*
		•	•	*2.5*
	•		•	*3.0*
•				*1.5*
	•		•	*2.0*
•			•	*1.5*
			•	*3.0*
•	•	•	•	*5.0*
•**			•	*3.5*
			•	*2.0*
•	•	•		*3.0*
	•		•	*2.0*
			•	*2.0*
	•	•	•	*3.5*
				1.0
•			•	*2.5*
	•		•	*2.0*
•	•			*2.5*
			•	*2.0*
•	•		•	*2.5*
•	•		•	*2.5*
•				*0.5*
	•		•	*4.0*
	•		•	*3.0*
•	•	•	•	*4.0*
•			•	*1.5*
	•		•	*3.0*

2 LOCATION OF DEATH

Data are from 1997 and were analyzed by the Brown University Center for Gerontology and Health Care Research.[69] The center used data from the Mortality Files compiled by the National Center for Health Statistics to demonstrate where chronically ill Americans died in 1997. We report percentages of deaths occurring at home, in a hospital, and in a nursing home.

Deaths at home, in a hospital, and in a nursing home, by state, 1997

State	**Deaths at home in 1997 (%)**
Alabama	*29.2*
Alaska	*35.8*
Arizona	*25.5*
Arkansas	*25.0*
California	*26.9*
Colorado	*29.0*
Connecticut	*21.3*
Delaware	*27.7*
District of Columbia	*14.7*
Florida	*27.4*
Georgia	*19.3*
Hawaii	*22.7*
Idaho	*32.3*
Illinois	*19.5*
Indiana	*23.1*
Iowa	*20.9*
Kansas	*23.2*
Kentucky	*24.6*
Louisiana	*21.0*
Maine	*23.8*
Maryland	*26.7*
Massachusetts	*22.4*
Michigan	*25.6*
Minnesota	*23.7*
Mississippi	*21.5*
Missouri	*23.2*
Montana	*27.7*
Nebraska	*18.8*
Nevada	*31.7*
New Hampshire	*23.6*
New Jersey	*26.9*
New Mexico	*32.1*
New York	*21.2*
North Carolina	*23.9*
North Dakota	*18.4*
Ohio	*23.1*
Oklahoma	*24.1*
Oregon	*35.1*
Pennsylvania	*23.2*
Rhode Island	*20.9*
South Carolina	*25.1*
South Dakota	*19.3*
Tennessee	*19.8*
Texas	*23.3*
Utah	*34.1*
Vermont	*29.6*
Virginia	*24.9*
Washington	*30.0*
West Virginia	*26.5*
Wisconsin	*24.5*
Wyoming	*26.6*

Source: Brown University Center for Gerontology and Health Care Research, *www.chcr.brown.edu/dying/forresearcherssod.htm.*

Deaths in a hospital in 1997 (%)	Deaths in a nursing home in 1997 (%)
56.5	14.3
43.5	20.7
42.8	31.7
55.1	19.9
48.4	24.7
40.6	30.4
48.0	30.7
46.4	25.9
71.9	13.4
51.7	20.9
63.7	17.0
64.7	12.6
37.0	30.7
57.7	22.9
47.4	29.5
48.6	30.4
49.3	27.6
55.5	19.9
65.1	13.9
43.0	33.0
49.4	23.9
48.8	28.8
49.7	24.8
38.6	37.7
65.8	12.7
49.0	27.9
41.6	30.7
45.8	35.4
51.8	16.5
48.5	27.9
56.9	16.2
46.7	21.3
61.8	17.0
53.3	22.8
48.3	33.2
48.8	28.1
53.4	22.5
32.5	32.4
49.1	27.7
45.8	33.3
56.5	18.4
45.8	34.9
61.5	18.7
57.3	19.4
38.9	27.0
38.4	31.9
54.0	21.0
35.7	34.3
58.0	15.5
40.3	35.2
42.8	30.6

3 HOSPICE USE

The first measure represents the percentage of Medicare-eligible non-HMO patients who were receiving hospice care at the time of their death. The second measure is the median length of stay in hospice.

Data for the hospice care measure are based on a special analysis by the research team for the Dartmouth Atlas of Health Care Working Group and are for the year 2000. The length of stay data are from 2001 and were obtained from the National Hospice and Palliative Care Organization's membership database. The data included in the length of stay measure are from states with five or more reporting hospice agencies.

People over 65 who used hospice in the last year of life, by state, 2000

State	Deaths with hospice stays (%)
Alabama	23.5
Alaska	4.9
Arizona	42.0
Arkansas	18.8
California	24.2
Colorado	36.8
Connecticut	19.4
Delaware	24.4
District of Columbia	13.8
Florida	35.3
Georgia	24.2
Hawaii	19.1
Idaho	20.8
Illinois	25.0
Indiana	18.8
Iowa	23.1
Kansas	22.5
Kentucky	20.8
Louisiana	19.7
Maine	9.1
Maryland	20.5
Massachusetts	18.3
Michigan	28.2
Minnesota	21.8
Mississippi	17.6
Missouri	22.0
Montana	17.5
Nebraska	20.0
Nevada	28.8
New Hampshire	17.9
New Jersey	18.7
New Mexico	29.6
New York	15.8
North Carolina	18.9
North Dakota	18.1
Ohio	26.9
Oklahoma	28.4
Oregon	31.1
Pennsylvania	21.2
Rhode Island	18.3
South Carolina	19.3
South Dakota	12.8
Tennessee	15.4
Texas	28.4
Utah	24.9
Vermont	14.9
Virginia	18.1
Washington	24.1
West Virginia	16.6
Wisconsin	19.5
Wyoming	14.5

Source: Special analysis by the research team for the *Dartmouth Atlas of Health Care*, *www.dartmouthatlas.org*.

Median number of days in hospice, by state, 2001

State	Median length of hospice stay
Alabama	42.9
Alaska	—
Arizona	27.7
Arkansas	26.0
California	23.6
Colorado	22.5
Connecticut	21.5
Delaware	—
District of Columbia	—
Florida	18.2
Georgia	25.4
Hawaii	26.6
Idaho	25.1
Illinois	18.8
Indiana	26.7
Iowa	27.9
Kansas	25.4
Kentucky	27.5
Louisiana	33.2
Maine	27.4
Maryland	20.5
Massachusetts	18.1
Michigan	26.2
Minnesota	23.2
Mississippi	37.0
Missouri	24.1
Montana	25.2
Nebraska	25.4
Nevada	—
New Hampshire	20.8
New Jersey	21.1
New Mexico	35.2
New York	18.9
North Carolina	32.2
North Dakota	20.9
Ohio	17.5
Oklahoma	25.9
Oregon	23.9
Pennsylvania	24.3
Rhode Island	13.7
South Carolina	34.1
South Dakota	26.8
Tennessee	23.6
Texas	25.0
Utah	19.3
Vermont	27.0
Virginia	24.9
Washington	23.6
West Virginia	29.4
Wisconsin	18.0
Wyoming	15.2

Source: National Hospice and Palliative Care Organization.

4 HOSPITAL END-OF-LIFE CARE SERVICES

These measures show the percentage of hospitals self-reporting end-of-life services—specifically defined as pain management, hospice or a palliative care program. Data on hospitals that offer these services are from the 2000 American Hospital Association annual survey of all U.S. hospitals; the response rate for this survey in 2000 was 84 percent.[70] Each service was considered separately.

Source: *Hospital Statistics*. American Hospital Association, 2000.

Hospitals reporting pain management programs, hospice programs, and palliative care programs, by state, 2000

State	Number of hospitals reporting
Alabama	78
Alaska	16
Arizona	50
Arkansas	91
California	244
Colorado	64
Connecticut	40
Delaware	6
District of Columbia	11
Florida	201
Georgia	171
Hawaii	20
Idaho	36
Illinois	200
Indiana	106
Iowa	125
Kansas	144
Kentucky	99
Louisiana	123
Maine	40
Maryland	62
Massachusetts	86
Michigan	149
Minnesota	116
Mississippi	102
Missouri	143
Montana	58
Nebraska	80
Nevada	19
New Hampshire	29
New Jersey	75
New Mexico	41
New York	193
North Carolina	112
North Dakota	34
Ohio	158
Oklahoma	111
Oregon	56
Pennsylvania	198
Rhode Island	16
South Carolina	77
South Dakota	56
Tennessee	100
Texas	476
Utah	41
Vermont	14
Virginia	90
Washington	70
West Virginia	66
Wisconsin	137
Wyoming	26

Hospitals with pain management program (%)	Hospitals with hospice program (%)	Hospitals with palliative care program (%)
41.0	16.7	6.4
37.5	6.3	18.8
46.0	20.0	12.0
33.0	25.3	7.7
42.6	20.5	13.1
50.0	20.3	17.2
62.5	57.5	32.5
66.7	16.7	16.7
72.7	9.1	54.5
53.7	17.9	12.9
40.4	14.6	10.5
40.0	5.0	10.0
38.9	30.6	8.3
53.0	32.0	17.5
54.7	34.9	21.7
32.0	44.8	16.0
20.1	14.6	16.0
35.4	15.2	11.1
30.9	10.6	10.6
45.0	17.5	15.0
59.7	19.4	25.8
57.0	20.9	23.3
53.0	30.2	20.1
25.0	39.7	8.6
4.9	12.7	0.0
46.9	27.3	2.1
24.1	34.5	15.5
23.8	30.0	5.0
10.5	5.3	5.3
62.1	34.5	34.5
68.0	25.3	24.0
24.4	19.5	14.6
61.1	19.2	20.2
50.0	24.1	14.3
32.4	38.2	5.9
53.8	29.1	22.8
27.0	17.1	10.8
41.1	39.3	19.6
57.6	30.3	21.7
56.3	6.3	6.3
42.9	14.3	1.3
28.6	39.3	5.4
35.0	21.0	12.0
30.9	10.5	9.2
46.3	19.5	14.6
42.9	35.7	42.9
56.7	27.8	17.8
40.0	22.9	17.1
28.8	16.7	18.2
58.4	15.3	1.5
19.2	42.3	11.5

5 CARE IN ICUs AT THE END OF LIFE

Data are from 2000 and were a special analysis of state-level data prepared by the Dartmouth Atlas of Health Care Working Group.[71] The group established the percentage of Medicare beneficiaries who had had an ICU or CCU hospitalization during their last six months of life, and the length of the stay on a day rate basis per beneficiary who had died. Finally, the ICU days were totaled across all hospital admissions during the last six months of life, based on Medicare claims data. Note that states received a grade for the third set of data only.

People over 65 with 7 or more ICU days during the last 6 months of life, by state, 2000

State	Beneficiaries with an ICU or CCU stay (%)	ICU/CCU stay day rate per decedent	Decedents with 7 or more ICU/CCU days (%)
Alabama	32.7	2.5	11.5
Alaska	29.3	2.4	11.7
Arizona	22.2	1.7	8.3
Arkansas	31.2	2.2	9.9
California	23.8	2.3	10.8
Colorado	17.3	1.0	4.7
Connecticut	25.2	2.0	9.0
Delaware	37.0	3.2	15.7
District of Columbia	32.0	2.9	12.8
Florida	32.2	3.0	14.9
Georgia	32.7	2.5	12.0
Hawaii	18.1	1.3	5.8
Idaho	23.6	1.4	6.6
Illinois	33.8	2.8	13.7
Indiana	34.3	2.7	13.3
Iowa	25.0	1.6	7.5
Kansas	27.3	1.9	9.0
Kentucky	33.1	2.6	12.7
Louisiana	30.2	2.3	11.3
Maine	25.5	1.7	7.2
Maryland	31.5	2.7	12.3
Massachusetts	22.0	1.6	7.0
Michigan	33.3	2.6	12.5
Minnesota	21.3	1.4	6.2
Mississippi	31.1	2.4	11.4
Missouri	31.0	2.5	11.7
Montana	25.4	1.5	6.7
Nebraska	26.2	2.1	9.3
Nevada	25.3	2.1	10.7
New Hampshire	21.6	1.4	5.9
New Jersey	37.2	3.8	17.3
New Mexico	25.3	1.7	8.3
New York	26.0	2.3	10.2
North Carolina	33.9	2.7	12.5
North Dakota	22.2	1.3	5.5
Ohio	30.9	2.5	12.1
Oklahoma	27.5	1.9	9.0
Oregon	15.2	0.8	3.4
Pennsylvania	29.3	2.4	11.5
Rhode Island	21.2	1.8	8.0
South Carolina	37.1	3.2	15.6
South Dakota	24.1	1.7	7.9
Tennessee	35.4	3.1	14.9
Texas	33.2	2.7	13.6
Utah	24.2	1.5	6.8
Vermont	23.7	1.5	6.3
Virginia	33.8	2.9	13.5
Washington	24.0	1.5	7.0
West Virginia	31.6	2.6	12.5
Wisconsin	24.9	1.6	6.9
Wyoming	25.9	1.8	8.4

Source: Special analysis by the research team for the *Dartmouth Atlas of Health Care, www.dartmouthatlas.org*.

Nursing home residents in persistent pain, by state, 1999

State	Patients in persistent pain in nursing homes (%)
Alabama	37.3
Alaska	45.8
Arizona	46.6
Arkansas	41.9
California	44.4
Colorado	47.2
Connecticut	38.1
Delaware	41.7
District of Columbia	42.9
Florida	42.5
Georgia	44.4
Hawaii	33.3
Idaho	54.9
Illinois	41.9
Indiana	42.1
Iowa	37.2
Kansas	45.4
Kentucky	40.6
Louisiana	43.0
Maine	41.3
Maryland	38.5
Massachusetts	38.1
Michigan	39.2
Minnesota	39.7
Mississippi	38.0
Missouri	41.0
Montana	48.4
Nebraska	36.8
Nevada	51.1
New Hampshire	41.9
New Jersey	37.2
New Mexico	45.1
New York	37.1
North Carolina	40.4
North Dakota	43.8
Ohio	44.4
Oklahoma	42.3
Oregon	39.6
Pennsylvania	38.8
Rhode Island	41.4
South Carolina	37.7
South Dakota	45.3
Tennessee	42.6
Texas	42.4
Utah	51.7
Vermont	44.2
Virginia	39.1
Washington	44.3
West Virginia	46.9
Wisconsin	40.8
Wyoming	43.1

6 PAIN AMONG NURSING HOME RESIDENTS

Data are from 1999 and were analyzed by the Brown University Center for Gerontology and Health Care Research.[72] The center analyzed data from the Minimum Data Set, the nursing home resident assessment instrument that all nursing homes are required to complete. Rates of persistent severe pain were calculated by using the number of residents reported to be in moderate daily or episodic excruciating pain at a first assessment and again at a second assessment 60 to 180 days later, divided by the total number of people reporting pain at the first assessment, to achieve the percentages shown here.

Source: Brown University Center for Gerontology and Health Care Research, *www.chcr.brown.edu/dying/forresearcherspsp.htm*.

7 STATE PAIN POLICIES

We developed a scoring system that was used to score the data in *Achieving Balance in Federal & State Pain Policy*, prepared by the Pain and Policy Studies Group of the University of Wisconsin.[73] The range of possible scores was –3 to +9. (In the chart at right 0 = no policies found; doesn't apply.) Note that while this criterion is a measure of the pain policy environment in a state, it is not a measure of the actual practice of pain management.

Strength of state pain policies, 2001

State	**Policy explicitly addresses needs of terminally ill patients (1 point)**	**State has a comprehensive pain management policy (1 point = few provisions, 2 = some, 3 = most/all)**
Alabama	*1*	*3*
Alaska	*0*	*0*
Arizona	*0*	*2*
Arkansas	—	—
California	*1*	*2*
Colorado	*1*	*0*
Connecticut	*0*	*0*
Delaware	*0*	*0*
District of Columbia	*0*	*0*
Florida	*1*	*3*
Georgia	*0*	*0*
Hawaii	*0*	*0*
Idaho	*0*	*0*
Illinois	*0*	*0*
Indiana	*0*	*0*
Iowa	*0*	*1*
Kansas	*1*	*3*
Kentucky	*2*	*3*
Louisiana	*0*	*1*
Maine	*1*	*2*
Maryland	*1*	*1*
Massachusetts	*1*	*0*
Michigan	*1*	*0*
Minnesota	*1*	*3*
Mississippi	*1*	*0*
Missouri	*1*	*3*
Montana	*0*	*0*
Nebraska	*1*	*3*
Nevada	*1*	*3*
New Hampshire	*1*	*2*
New Jersey	*1*	*0*
New Mexico	*0*	*0*
New York	*1*	*1*
North Carolina	*1*	*2*
North Dakota	*0*	*0*
Ohio	*0*	*0*
Oklahoma	*0*	*1*
Oregon	*1*	*0*
Pennsylvania	*0*	*3*
Rhode Island	*1*	*2*
South Carolina	*0*	*3*
South Dakota	*0*	*3*
Tennessee	*0*	*2*
Texas	*0*	*0*
Utah	*1*	*3*
Vermont	*0*	*0*
Virginia	*0*	*0*
Washington	*1*	*2*
West Virginia	*1*	*1*
Wisconsin	*0*	*0*
Wyoming	*0*	*0*

Source: Based on *Achieving Balance in Federal & State Pain Policy*, July 2000, and updated in the *Annual Review of State Pain Policies 2000* (published February 2001) and *Annual Review of State Pain Policies 2001* (published February 2002) from the Pain and Policy Studies Group of the University of Wisconsin's Comprehensive Cancer Center, Madison, Wisconsin. More recent information may be available at the group's Web site: *www.medsch.wisc.edu/painpolicy*.

Includes “discouraging” provisions (*minus* 1 to 3 points, with –1 few, –2 some, –3 significant restrictions)	**Reassures physicians on their ability to prescribe opioids for pain management (2 points)**	**Describes the steps in good medical practice for pain management (2 points)**	**Expresses concern about the undertreatment of pain (1 point)**	**TOTAL**
0	*2*	*2*	*0*	*8*
–1	*0*	*0*	*0*	*–1*
–1	*2*	*2*	*0*	*5*
–1	*2*	—	—	*1*
–3	*2*	*2*	*1*	*5*
–1	*2*	*2*	*1*	*5*
–1	*0*	*0*	*0*	*–1*
–1	*0*	*0*	*0*	*–1*
0	*0*	*0*	*0*	*0*
–1	*2*	*2*	*1*	*8*
–1	*0*	*2*	*0*	*1*
–1	*0*	*0*	*0*	*–1*
–1	*0*	*0*	*0*	*–1*
–1	*0*	*0*	*0*	*–1*
–2	*0*	*0*	*0*	*–2*
–1	*0*	*2*	*0*	*2*
0	*2*	*2*	*1*	*9*
–2	*2*	*2*	*0*	*7*
–2	*0*	*0*	*0*	*–1*
0	*2*	*2*	*0*	*7*
0	*2*	*2*	*1*	*7*
–1	*0*	*0*	*1*	*1*
–2	*2*	*0*	*0*	*1*
0	*2*	*0*	*0*	*6*
–1	*0*	*0*	*1*	*1*
0	*2*	*0*	*0*	*6*
–1	*2*	*2*	*1*	*4*
0	*2*	*2*	*1*	*9*
–1	*2*	*2*	*0*	*7*
–1	*0*	*2*	*0*	*4*
–2	*0*	*2*	*0*	*1*
0	*2*	*2*	*0*	*4*
–3	*0*	*0*	*0*	*–1*
0	*2*	*2*	*1*	*8*
0	*2*	*0*	*0*	*2*
0	*0*	*0*	*0*	*0*
0	*2*	*2*	*0*	*5*
–1	*2*	*0*	*1*	*3*
–1	*2*	*2*	*1*	*7*
–2	*2*	*2*	*1*	*6*
–2	*2*	*0*	*1*	*4*
0	*0*	*0*	*0*	*3*
–3	*2*	*2*	*0*	*3*
–2	*2*	*0*	*0*	*0*
–1	*2*	*2*	*1*	*8*
–2	*0*	*2*	*1*	*1*
0	*0*	*2*	*0*	*2*
0	*2*	*2*	*1*	*8*
0	*2*	*2*	*1*	*7*
–1	*0*	*0*	*0*	*–1*
0	*2*	*2*	*0*	*4*

8 PALLIATIVE CARE-CERTIFIED PHYSICIANS AND NURSES

This measure approximates the availability of palliative care-certified physicians and nurses using the percentage of clinicians who are certified in palliative care. Data on the number of palliative care-certified physicians and nurses are from the American Board of Hospice and Palliative Medicine's Web site[74] and the Hospice and Palliative Nursing Association's Web site, respectively.[75] Data on the number of primary care physicians are for 2000 and are from the American Medical Association.[76] Data on the number of registered nurses are *estimated* for the year 2000 and are from the U.S. Department of Health and Human Services, Health Resources and Services Administration.[77]

While this measure approximates the percentage of palliative care-certified physicians and nurses statewide, it does not capture the actual availability at local levels.

Percentage of general primary care and primary care subspecialty physicians who are certified in palliative medicine, 2000

State	Total number of physicians
Alabama	9,887
Alaska	1,362
Arizona	12,250
Arkansas	5,711
California	97,213
Colorado	11,692
Connecticut	13,279
Delaware	2,099
District of Columbia	4,488
Florida	46,013
Georgia	19,324
Hawaii	3,887
Idaho	2,370
Illinois	35,943
Indiana	13,461
Iowa	5,927
Kansas	6,486
Kentucky	9,468
Louisiana	12,207
Maine	3,598
Maryland	23,449
Massachusetts	28,886
Michigan	25,209
Minnesota	14,257
Mississippi	5,399
Missouri	14,061
Montana	2,188
Nebraska	4,300
Nevada	4,025
New Hampshire	3,438s
New Jersey	27,462
New Mexico	4,565
New York	78,524
North Carolina	21,118
North Dakota	1,603
Ohio	30,229
Oklahoma	6,565
Oregon	9,312
Pennsylvania	39,603
Rhode Island	3,814
South Carolina	9,689
South Dakota	1,708
Tennessee	15,360
Texas	46,904
Utah	5,041
Vermont	2,318
Virginia	20,362
Washington	16,693
West Virginia	4,442
Wisconsin	13,954
Wyoming	1,013

Source: American Board of Hospice and Palliative Medicine; *www.abhpm.org*. American Medical Association. *Physician Characteristics and Distribution in the US*, 2002–2003 Edition (Chicago: American Medical Association Press, 2002).

Total primary care plus primary care subspecialty physicians	Physicians certified by the American Board of Hospice and Palliative Medicine	Certified doctors as % of total primary care + subspecialty physicians
4,264	9	0.21
634	1	0.16
4,560	17	0.37
2,476	5	0.20
37,624	96	0.26
4,672	16	0.34
5,207	12	0.23
833	3	0.36
1,679	5	0.30
16,545	69	0.42
8,064	11	0.14
1,600	5	0.31
926	0	0.00
15,426	46	0.30
5,627	11	0.20
2,359	9	0.38
2,653	12	0.45
3,884	11	0.28
4,908	11	0.22
1,408	11	0.78
9,233	28	0.30
11,092	20	0.18
10,353	44	0.43
6,217	18	0.29
2,236	5	0.22
5,698	14	0.25
828	8	0.97
1,863	3	0.16
1,592	3	0.19
1,334	12	0.90
11,498	21	0.18
1,874	17	0.91
31,414	72	0.23
8,604	16	0.19
717	1	0.14
12,405	51	0.41
2,690	11	0.41
3,611	13	0.36
15,357	29	0.19
1,576	4	0.25
4,001	7	0.18
748	2	0.27
6,453	17	0.26
19,096	64	0.34
1,944	8	0.41
939	6	0.64
8,382	14	0.17
6,688	20	0.30
1,856	6	0.32
5,809	21	0.36
420	2	0.48

Percentage of full-time-equivalent nurses (estimated) who are certified in palliative care, 2000

State	***Estimated full-time-equivalent registered nurses***
Alabama	*30,987*
Alaska	*4,264*
Arizona	*28,575*
Arkansas	*17,147*
California	*154,002*
Colorado	*26,556*
Connecticut	*26,407*
Delaware	*6,024*
District of Columbia	*8,877*
Florida	*112,735*
Georgia	*49,746*
Hawaii	*7,516*
Idaho	*6,765*
Illinois	*87,457*
Indiana	*38,780*
Iowa	*25,897*
Kansas	*21,204*
Kentucky	*30,064*
Louisiana	*34,510*
Maine	*10,936*
Maryland	*38,291*
Massachusetts	*59,884*
Michigan	*66,452*
Minnesota	*37,357*
Mississippi	*19,652*
Missouri	*47,337*
Montana	*6,327*
Nebraska	*13,826*
Nevada	*9,320*
New Hampshire	*9,446*
New Jersey	*56,868*
New Mexico	*10,295*
New York	*136,663*
North Carolina	*62,427*
North Dakota	*5,779*
Ohio	*84,188*
Oklahoma	*19,684*
Oregon	*21,498*
Pennsylvania	*104,392*
Rhode Island	*9,389*
South Carolina	*25,877*
South Dakota	*7,463*
Tennessee	*43,757*
Texas	*116,252*
Utah	*10,940*
Vermont	*4,596*
Virginia	*43,602*
Washington	*33,486*
West Virginia	*13,831*
Wisconsin	*38,498*
Wyoming	*3,417*

Source: Hospice and Palliative Nursing Association; *www.hpna.org/*. HRSA, Division of Nursing. The National Survey of Registered Nurses, March 2000: Preliminary Findings February 2001.

Number of nurses certified by the Hospice and Palliative Nursing Association	***Certified nurses as % of full-time-equivalent/registered nurses***
82	*0.26*
6	*0.14*
175	*0.61*
44	*0.26*
548	*0.36*
94	*0.35*
127	*0.48*
42	*0.70*
8	*0.09*
676	*0.60*
165	*0.33*
24	*0.32*
15	*0.22*
288	*0.33*
132	*0.34*
124	*0.48*
83	*0.39*
208	*0.69*
64	*0.19*
60	*0.55*
194	*0.51*
202	*0.34*
306	*0.46*
168	*0.45*
44	*0.22*
79	*0.17*
56	*0.89*
60	*0.43*
23	*0.25*
79	*0.84*
225	*0.40*
53	*0.51*
388	*0.28*
222	*0.36*
14	*0.24*
546	*0.65*
102	*0.52*
112	*0.52*
480	*0.46*
15	*0.16*
46	*0.18*
9	*0.12*
78	*0.18*
442	*0.38*
21	*0.19*
52	*1.13*
205	*0.47*
155	*0.46*
76	*0.55*
192	*0.50*
14	*0.41*

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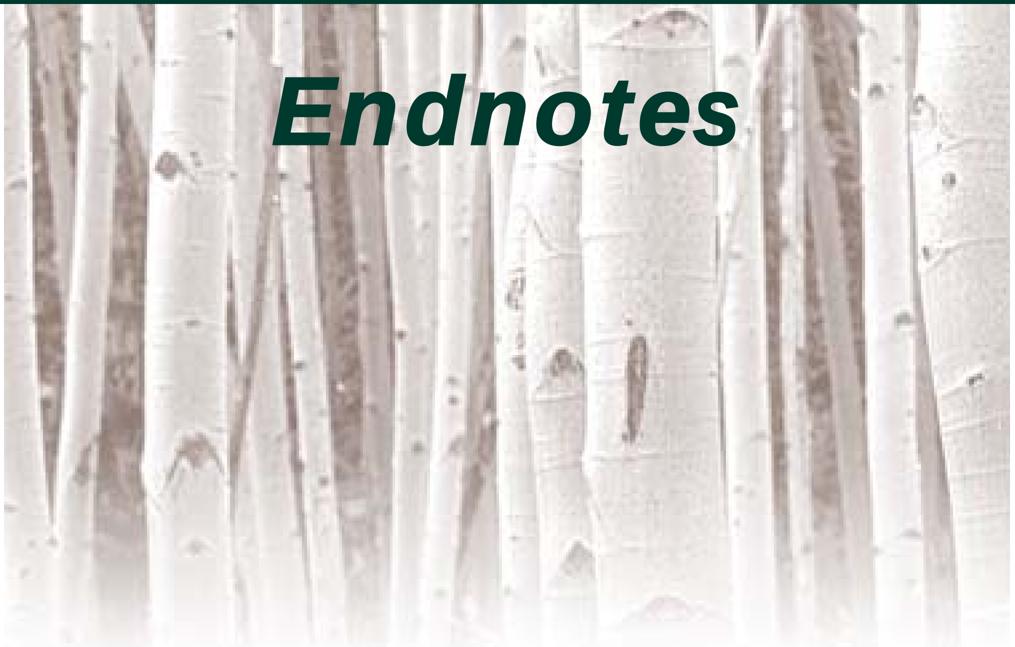
Endnotes



Endnotes

1. SUPPORT 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.
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4. **Palliative care helps gain access to needed health care providers and appropriate care settings. It . . .**
    - Uses many kinds of trained care providers, doctors, nurses, pharmacists, clergy, social workers and personal caregivers.
    - Makes sure, if necessary, that someone is in charge of seeing that your needs are met.
    - Helps you use hospitals, home care, hospice and other services, if needed.
    - Tailors options to the needs of you and your family.
5. **Palliative care builds ways to provide excellent care at the end of life. It . . .**
    - Helps care providers learn about the best ways to care for dying people. It gives them the education and support they need.
    - Works to make sure there are good policies and laws in place.
    - Seeks funding by private health insurers, health plans and government agencies.

The Five Principles are a vision for better care at the end of life. They were developed for people who are dying, their families and their loved ones by the *Last Acts* Task Forces on Palliative Care and the Family. *Last Acts* is a coalition of more than 900 organizations representing health care providers and consumers nationwide.

The organizations involved in *Last Acts* believe that everyone can make a difference in the care given to dying people and their families. We need to work together toward a health care system that offers all Americans, when they are dying:

- The services that meet their individual needs.
- Health plans that cover such care.
- Health care providers who are well trained in palliative care.

That would make the Five Principles of Palliative Care a reality.

WHAT YOU CAN DO

You and your family should expect to get good care at the end of life. You can improve the likelihood that you and your family will get the care you want if you:

- Share this document. Discuss the care you want with your family, friends, physician and other health care professionals, and your spiritual adviser. Don’t wait until you are seriously ill!
- Learn about your options for care. Make a list of questions to ask, to find out whether your doctor can provide the care you want near the end of life. There is a list of sample questions on the *Last Acts* Web site, *www.lastacts.org*.
- Check with your local hospitals, nursing homes and home health agencies about the special services (palliative care) they offer for dying patients and their families. Examples: Are there physicians, nurses, social workers and spiritual counselors trained in end-of-life care who can talk to you and your family about your concerns? Do they have experts who can manage pain and other physical discomforts? Do they offer bereavement services?
- Find out about local hospice services.
- Think about important decisions *now*. Prepare a living will and appoint someone to make decisions for you if you are not able (a health care proxy).
- Look into community support groups and educational programs for seriously ill patients and their families (often offered by church groups, community centers, libraries and other organizations).

For more information about *Last Acts*, visit our Web site at *www.lastacts.org*.

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