

State Initiatives in End-of-Life Care

Issue 20, November 2003

Hospice Care—Part III

Maine's Legislative Approach to Expanding Hospice Access

A poor and largely rural state, Maine seemed destined to remain at or near rock bottom nationally for hospice utilization—until the spring of 2001 when bold action by the state legislature laid a foundation for change.

In 1995, Maine's Medicare hospice referral rate of 6 percent of all eligible patients was indeed the lowest in the country. Its 2000 hospice utilization rate of 9 percent still compared unfavorably with the national rate of 25 percent, earning it the lowest possible hospice utilization grade in the Last Acts national report card, *Means to a Better End: A Report on Dying in America*.

These low utilization rates were symptomatic of many different problems, including inadequacies in hospice benefits, facilities, and public awareness. As recently as 2000, Maine was one of only five states in the country without a Medicaid Hospice Benefit for low-income residents under 65. More affluent residents who did not qualify for the Medicare Hospice Benefit because they were under 65 often had nominal or no hospice benefits in their employer-based private insurance programs. Even residents who had benefits could not always get care because there were no inpatient hospice facilities for those who could not receive care at home.



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Pictured the year before his death is Joseph Mayo, then clerk emeritus of Maine's House of Representatives, and his assistant, Rita Melendy. Mayo's power and courageous public struggle with Lou Gehrig's disease helped win bipartisan support for Maine's Statute to Improve End-of-Life Care (story on page 3).

And the public knew little about the nature and value of hospice care. Two different surveys commissioned before legislative action suggested that nearly 50 percent of residents were unfamiliar with hospice.

The state's 2001 Statute to Improve End-of-Life Care has begun to change this picture by expanding hospice access substantially and sketching with broad strokes an institutional and research infrastructure to guide future improvements in end-of-life care. The state's hospice awareness gap has also narrowed thanks to an extraordinarily successful educational campaign occasioned by a referendum on physician-assisted suicide (PAS) and by the terminal illness of one of the state's most visible and beloved public officials (above).

This issue of *State Initiatives* offers a brief analysis of Maine's Statute to Improve End-of-Life Care and the remarkable process by which it was developed and enacted. ■

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The Statute's Major Provisions

Hospice is generally regarded as the gold standard of end-of-life care because it focuses on improving the quality of life rather than aggressively pursuing unattainable cure. Hospice fosters the kind of death most Americans say they want, according to a 1999 National Hospice Foundation study: individualized pain control; a choice of care options; a team of professionals to carry out their choices; and psychological, emotional, and spiritual support for themselves and their families. A majority of Americans who die under hospice care are able to die where they wish to die: at home or in homelike settings in the embrace of family.

The most far-reaching of the statute's hospice access provisions requires that this gold standard of care be extended to all employees covered by state-regulated private insurance plans—slightly less than half of Maine's current workforce. Though federally regulated ERISA plans are now exempt, Karen Bell, MD, MMS, medical director of Anthem Blue Cross Blue Shield—the state's largest private payer—believes the benefit mandate makes good sense and may ultimately be voluntarily adopted by ERISA employers. "From a quality perspective, I do feel it's prudent to supply hospice benefits, and from a payer perspective, costs of care are lower. ERISA employers may support the intent of the law. I suspect they will be on the bandwagon."

Readers interested in more information on hospice issues may request issues 11 and 17 of the *State Initiatives* series, using information provided on page 6.

The Maine Hospice Legislation in Brief

Hospice-Related Provisions

- Increases the Medicaid hospice per diem from \$106 to \$130 per day for the last six months of life (Medicare plus 23 percent).
- Mandates comprehensive hospice coverage for the last 12 months of life in private insurance policies for all non-ERISA employers.
- Provides an appropriation of \$50,000 in each biennial budget to be divided among Maine's voluntary hospice programs.
- Encourages a study to foster the development of an inpatient hospice facility.

Broader End-of-Life Care Provisions

- Mandates the creation of the Maine Center for End-of-Life Care (now a program of the Maine Hospice Council) to serve as a center for leadership, education, research, and advocacy, and to develop a strategic plan for improving care statewide.
- Requires basic research on the current status of end-of-life care, including a survey and assessment of relevant state entry-level and professional requirements, as well as a study of baseline data and standardized assessment tools from databases within the Maine Health Data Organization.

The statute also raised reimbursement under the state's initial Medicaid Hospice Benefit, which was widely regarded as inadequate. Originally \$106 per day, the benefit is now \$130 per day (the Medicare benefit plus 23 percent). This is the highest routine home care reimbursement rate under Medicaid in the country, according to Kandyce Powell, executive director of the Maine Hospice Council (MHC). State officials estimate that this will increase the number of annual beneficiaries by approximately 400. The projected 2002–2003 cost for this coverage expansion was \$186,750 in state funds and \$372,046 in federal funds.

The statute also includes two other smaller-gauge hospice provisions. Starting in 2001, each biennial budget will contain a special \$50,000 appropriation to be divided evenly among all voluntary hospice entities in Maine. Powell expects this money

to be used for technology updates and small initiatives such as training and children's grief programs. The statute also encouraged but did not specifically mandate a study to foster the development of an inpatient hospice facility.

In crafting the bill, legislators were clearly looking beyond hospice benefit expansion to the long-term challenge of improving the quality of end-of-life care statewide. The rationale for this action is captured succinctly by Laurel Coleman, MD, a geriatrician who actively advocated for the statute: "End-of-life care is often poor in nursing homes, and palliative care has a way to go even in hospices."

To address this challenge, the legislature mandated—but did not have the money to fund—the development of the Maine Center for End-of-Life Care. The center, officially an initia-

The Power of Stories

In Memory of Joseph W. Mayo, 1959–2002

tive of the MHC, will become the focus of leadership, advocacy, provider and public education, service, and research aimed at raising the level of care statewide. As part of its research mission and statutory mandate, the center will complete a study of the current status of end-of-life care in Maine, determine major barriers to establishing an inpatient hospice facility, and prepare the strategic plan for improving state care in the state. The center will also consult with units of government engaged in other mandated research activities. “Any state needs to build a data infrastructure to make forward progress,” says Powell, who is leading center development. “Information is a very powerful policy tool.”

An update on progress toward establishing the center and fulfilling other statute mandates appears on page 6. ■

“You must approach fellow legislators on a very personal basis. Ask yourself, ‘Who’s gone through the death of a loved one?’ Everyone brings a different story to the table.”

David Madore, a leading sponsor of the statute while serving as Maine State Representative (R-Augusta)

“The universe is made of stories, not of atoms,” says poet Muriel Rukeyser in “The Speed of Darkness”—a useful reminder of the power of stories to shape individual lives as well as governmental policies.

The story of Joseph Mayo’s courageous public struggle with Lou Gehrig’s disease (ALS) and his leadership in the end-of-life care statute’s development and passage while serving as clerk (and clerk emeritus) of the Maine House of Representatives provide a dramatic example of this power. “He brought to his legislative colleagues on a daily basis the story of Joe Mayo—a friend and advisor—living and dying with his disease,” says MHC’s Powell.

The facts of his early rise to public prominence and of his prodigious legislative skill form the backdrop of this story: son of a well-known Maine legislator, dynamo of a legislative operative himself, first as a Democratic representative and majority whip in the Maine House of Representatives, and later as clerk of the House, supervising the legislative process with an organizational genius that did not antagonize, say his colleagues, and coaching with fierce fairness legislators of both parties in the nuts and bolts of making laws. He also developed a national reputation as an expert on parliamentary procedure.

“Joe was a champion, a person with a long reputation of being honest, kind and forthright,” says State Senator Marge Kil Kelly (D-District 16). “It would have been easy to take the news of the diagnosis and go into the security of home and hearth but he saw he had a bully pulpit to promote quality end-of-life care and use his challenge as a example of what was needed.”

He knew what was needed from personal experience. First there was the story of his mother’s brave struggle with cancer, her terror of dying in a hospital, and the dignified death at home that hospice provided her. Then his own hospice experience. “Something about the hospice visits gave him energy,” says Rebecca Wyke, Mayo’s wife of 20 years and Maine’s commissioner of finance and administration. “He and his hospice worker had a mutual love of JFK and current events. She started reading Carolyn Kennedy’s new book to him.”

And there were the stories of other ALS patients he met and helped. “Joe saw other ALS sufferers didn’t have the support we had,” says Wyke. “Their employers were pushing them out the door. So Joe asked, ‘What can I do to make others get what I got?’”

What he did was work until three weeks before his death. Though this meant enduring tube feeding and suctioning in full view of all the state’s legislative leaders, he continued to take a public stand on the hospice legislation, encourage and advise statute advocates, buttonhole colleagues, and offer critical testimony before the State Banking and Insurance Committee: “We all have an obligation to ensure that those facing terminal illness do so with our comfort and aid. More importantly, we must help the health care community understand what people enduring terminal illness need. With the advances in modern medicine, no one has to die in pain.”

“By working, Joe reminded legislators what someone who is dying can do,” says Wyke, “and what someone who is dying deserves.” ■

How the End-of-Life Care Statute Became Law

A remarkable coincidence of events, savvy strategic decisions, political skill, and strong hospice advocacy resources made statute passage possible.

A Referendum on Physician-Assisted Suicide (PAS) Becomes a Teachable Moment

Referenda on legalizing PAS are now commonplace. Most recently, members of the Vermont Medical Society are preparing to vote on whether to oppose or remain neutral regarding PAS, in anticipation of a possible state legislative debate in 2004. Maine is a veteran of such controversy. Early in 2000, coalitions for and

wart in her role as MHC head. NO’s strategic decisions to conduct rigorous public opinion polling and to emphasize public education on the need for better end-of-life care laid the groundwork for referendum defeat and set the stage for statute passage.

NO’s strategy had two thrusts: dramatizing perceived dangers in the proposed PAS Act (e.g., lack of state supervision to prevent abuse) and dispatching credible doctors and hospice experts to convince legislators and the public that end-of-life care was itself in critical condition and had to be fixed. This meant shifting the debate from helping people die to

Other messages enumerated the benefits of good hospice care. Powell herself acted as a spokesperson in an ad that assured citizens that MHC was working on the concerns of the terminally ill and that the pain feared by so many dying patients could be successfully controlled through good pain management. Slogans like “Your pain can be managed to ensure your comfort” drove home this message. The campaign also walked audiences through real cases, showing how good hospice and palliative care could have made for better deaths.



There are alternatives.

Maine Citizens Against the Dangers of Physician-Assisted Suicide believes that “death with dignity” is not about promoting physician-assisted suicide. Instead, we believe that “death with dignity” is really about promoting hospice care, palliative care, and effective pain management. And we believe it’s about living one’s final moments surrounded by family and friends.

This section from a NO On 1 brochure illustrates how the anti-PAS referendum campaign redefined “death with dignity”—the Pro-PAS referendum slogan—to mean promoting good hospice and palliative care.

against the state’s sixth referendum on physician-assisted suicide were gearing up for a November vote. Mainers for a Dignified Death (MDD) was pushing hard for a yes on the measure, and polls indicated that approximately 71 percent of the population supported its position. The No On 1 campaign (NO), launched by a secular coalition called Maine Citizens Against the Dangers of Physician-Assisted Suicide, had only six months to shift public opinion, says Powell, a NO stal-

looking at the way many people were dying—alone and without resources. NO’s overarching message was, “We need to fix the problem, not kill the patient.” More specific messages were aimed at persuading voters of the need for universal access to hospice, better insurance benefits for hospice, and inpatient hospice facilities, says Gordon Smith, JD, executive vice president, Maine Medical Association, whose organization supported the NO cause.

A New Coalition of “Winners” and “Losers”

In just six months, NO had closed the education gap, and Maine voters defeated the referendum 52 to 48 percent, a gain of 26 percentage points. NO had also succeeded in shifting the terms of public debate about death and dying, created a momentum for change, raised legislators’ consciousnesses, and effectively promised the public legislative action to improve care. To capitalize on these successes, NO invited the leadership of MDD

How the End-of-Life Care Statute Became Law*Continued from page 4*

to take part in a new coalition to advance reform legislation. MDD's leader, Kate Roberts, explains the new coalition's compelling common ground: "We all agreed the system was terrible, and we never disagreed about the need for good end-of-life care and a better Medicaid hospice benefit."

That both sides were able to transcend referendum partisanship and help craft new draft hospice legislation made for both a better bill and favorable attention from the legislature. "It was a big key to the success of this legislation," says State Representative Christopher O'Neil (D-District 15), House chair of the Joint Standing Committee on Banking and Insurance, the committee that conducted the public hearing on the statute. An equally important key to measure passage was House Clerk Joe Mayo, who became the new coalition's chief strategist and the statute's most visible and powerful advocate (see page 3 story).

A Positive Policy Climate and Legislative Skill Ensure Statute Passage

MHC had in 1997 partnered with some 50 other organizations to form the Consortium for Palliative Care and Hospice. The Consortium's subsequent annual reports to the legislature had repeatedly defined hospice access barriers and potential solutions. Consortium recommendations were widely accepted as credible and ultimately formed the core of the statute. In 1999 the Consortium received a \$450,000 grant from The Robert Wood Johnson Foundation as part of its Community-State Partnerships to Improve End-of-Life Care initiative. The grant provided new resources for a number of projects, including education for both the public and legislators.

Legislative skill also gave the bill support at four turning points:

1. The education that informed statute passage was adept. Spokespeople were able to demonstrate that the actual costs of acute care were greater than those of hospice. "We did the math," says State Senator Lloyd LaFountain

III (D-District 32), Senate chair of the Joint Standing Committee on Banking and Insurance, "and we figured the measure would save money or at least not create increases." This led legislators to bypass a potentially time-consuming actuarial review by the Bureau of Insurance.

2. Speaker of the House Michael Saxl (D-Portland) spearheaded a House-Senate coalition that got the measure wrapped into the budget bill to make it "unassailable."

3. Mayo read the bill word for word before final action and caught an inadvertent but significant drafting error before support could unravel.

4. The budget bill was passed late at night; by then lobbyists from the insurance industry had gone home. ■

"We all have an obligation to ensure that those facing terminal illness do so with our comfort and aid."

Joseph W. Mayo

Ten Tips for Enacting End-of-Life Care Legislation

1. See "right-to-die" controversies as golden opportunities to educate the public on the value of good end-of-life care.

2. Conduct audience research to gauge public sentiment and knowledge.

3. Craft positive messages that clarify what hospice and palliative care have to offer rather than attack perceived "rights."

4. Pull together strong bipartisan coalitions that include unlikely bedfellows such as sanctity-of-life advocates and their usual opponents.

5. Develop comprehensive, authoritative data on costs, including what the absence of legislation will cost.

6. Continuously educate legislators and the public on the importance and value of hospice and palliative care; use personal experiences and feature real stories.

7. Utilize the leadership skills and intellectual capital of seasoned hospice associations and end-of-life care coalitions.

8. Shoot for all you want but make clear that "limited wins" have real value as a foundation for future work.

9. Don't assume that budget problems make progress impossible.

10. To protect against negative votes, consider wrapping hospice access legislation into budget bills.

Updates and Next Steps

The hospice legislation has passed the first test of longevity. “Although the legislature is currently facing a \$1.2 billion shortfall and re-projected the budget four times in the last session, it did not touch the hospice statute,” says Powell. “This is a testament to the educational efforts since 1999 to help legislators understand the importance of these issues. We have educated legislators one person at a time, and it has served us well.” MHC has also retained all its state funding.

A freestanding hospice facility remains a hope for the future, but three major projects are moving along, Powell says, with two poised to begin significant capital campaigns. At least two hospitals are also considering developing palliative care units that could serve as hospices.

Research on statute costs and benefits is stalled for lack of funds to complete a comprehensive study. Anecdotal evidence suggests that hospice referrals have increased 20 percent in mid-coast Maine since the PAS campaign and legislative reform, says Juliana L’Heureux, BS, RN, MHSA, executive director, CHANS Home Health Care.

As an unfunded mandate, the center’s first order of business has been an intense fund-raising effort. Foundations have already made two grants, and other proposals are in the works; several corporations are helping to create a business plan. Though new staff are not yet in place, Powell and

others have begun to fulfill the statute’s requirement to gather baseline data on where and how people in Maine are dying—through focus groups with hospices and retrospective reviews of closed charts in a state veterans’ home.

There is general agreement that the statute’s main benefit—beyond extending hospice coverage—was expanding public awareness about end-of-life care both for legislators and consumers.

Influencing the quality of care at the bedside is a much tougher nut to crack. “We have not yet dramatically improved care for the terminally ill,” says Smith. “The statute is better than nothing, but for people to get hospice, doctors must refer to hospice, and we have to have patients who are knowledgeable about hospice, so we are still in our infancy about care for the terminally ill.”

Helping doctors become knowledgeable and supportive of hospice care will be a major challenge. “So many doctors in our state think palliative care isn’t relevant,” says Lauren Michalakes, MD, interim director, Hospice of Southern Maine. “We need to mobilize their interest.” While some believe marketing is the solution, Michalakes calls for more: “Doctors learn by being shown and supported (‘seeing one, doing one, teaching one’). We need to find opportunities to get to the bedside if we are to reach doctors.” ■

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State Initiatives in End-of-Life Care

Information about the Series

“Hospice Care—Part III: Maine’s Legislative Approach to Expanding Hospice Access” is the twentieth in a series of briefs profiling promising policies and practices in end-of-life care, and the third and final issue in a miniseries about hospice care.

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