

State Initiatives in End-of-Life Care

Issue 9, January 2001

Focus: Policy Leaders and End-of-Life Care—Part I

How End-of-Life Care Can Be a Positive Issue for Policy Leaders

There is no doubt that America is getting older. Currently, the American elderly population stands at 34.5 million—up more than 10 percent in the past decade. In some states—such as Florida, the state with the largest per-capita population of seniors—the elderly population is increasing at nearly twice the rate of the general population. Longer life expectancies, even for those with life-limiting illnesses, are one result of advances in medical technology. “We are getting to a point at which medical science can keep us alive in terrible shape,” says U.S. Rep. Nancy Johnson (R-Conn.), just one of many legislators working to remove legal barriers to good pain management (see p. 6).

Political Leaders Rethink End-of-Life Policy

A recent Gallup Poll showed 90 percent of Americans wish to die at home, but the reality is that only 10 to 15 percent will die there, with the rest spending their final days among strangers in a hospital or nursing home. Dying people feel such loss of control keenly; fear of pain and loss of control over one’s last days contribute to depression and anxiety as death approaches. State policy makers working to improve care near the end of life believe that addressing these problems and establishing a supportive climate for palliative care would help insulate their states against efforts to secure a right to assisted suicide. “People have to feel confident that the health care



David Fujitt

A dying woman at home, cuddling her grandson. Leading policy makers are helping a greater number of Americans fulfill their wishes to die at home among family, with their pain and other symptoms managed.

system will take good care of them when they are dying,” says Assemblywoman Helen Thomson (D-Calif.—see p. 4). “Lack of faith in that system is what moves people to demand desperate measures.”

More and more policy makers are dedicating their own time and visibility and the resources of their offices to creating new policy, revising existing policy, and interpreting laws and regulations for physicians and families, who often feel unsure of how their

states govern their choices and actions. This issue is the first in a mini-series that will profile leaders with impressive track records in end-of-life care policy. This issue features three leaders, with briefer profiles on several others whose work bears watching. Clearly a political leadership exists that has found end-of-life care a positive issue with virtually no political downside, because every single constituent in these leaders’ districts benefits from good end-of-life-care policy.

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J. Joseph Curran: Providing Good Advice to Maryland's Providers and Families

Maryland Attorney General J. Joseph Curran has been working actively to improve end-of-life care in his state since 1987, primarily by interpreting how existing state laws and regulations apply to the care of dying Marylanders. Practitioners have come to rely on his office for guidance when they are uncertain about how the law applies to their treatment choices.



withdrawal or refusal of artificial feeding devices when the patient was terminally ill or permanently unconscious. He and his Chief Counsel on Opinions and Advice, Jack Schwartz, crafted a 40-page opinion that reassured patients, families, and practitioners that there was no legal or public policy justification for distinguishing between refusing to start a feeding tube and removing one

- whether doctors can decline to perform CPR on a patient when they judge it inadvisable (they can)
- what the differences are between “informed consent” and the creation of an oral advance directive
- what the process is for enacting do-not-resuscitate (DNR) orders in nursing homes.

“Working to improve end-of-life care is important because it benefits *every single person*, without exception, in my state.”

Attorney General J. Joseph Curran (D-Maryland)

www.oag.state.md.us/Healthpol/index.htm

In the past five years Curran and Schwartz have reassured physicians they will not be prosecuted for prescribing opioid analgesics appropriately. “He’s really been in the forefront there, setting a precedent for other states in promoting pain management and protecting prescribers who need to use the tools available to them,” says Michael Gloth, M.D., President of Hospice Network of Maryland. “As a result, in Maryland, we’re seeing an improvement in opioid use.”

Asked how he would respond to a colleague who was debating taking on end-of-life issues, Curran replies, “I would tell them that working to improve end-of-life care is important because it benefits *every single person*, without exception, in my state. . . . I don’t see one political drawback.”

Schwartz concurs, adding that while policy makers might fear that working on end-of-life issues could embroil them in the debate over physician-assisted suicide, it need not be so. Curran’s clear and consistent message has never resulted in his being drawn into this controversy. “Joe’s been working on this issue for a dozen years now, and I don’t think anyone—not from the right-to-life movement, not from the Hemlock Society, no one—has perceived him as biased or politically motivated,” Schwartz says. “He has clarified his position and crafted consistent messages that the advocates and the general public can understand.”

“Joe is rare in this era for taking a nonpartisan, nonpolitical, higher-ground stance about end-of-life care,” says Ruth Gaare Burnheim, J.D., M.Ph., Executive Director of the Institute for Practical Ethics and assistant professor of medical ethics at the University of Virginia School of Medicine. “Physicians who work with him learn that he listens carefully and that they can trust his reasoned understandings and policy decisions on complex medical issues. He has a very balanced and thoughtful judgment about the care that is needed at the end of life.”

Curran’s policy work on the issue began in 1987, when the state Office on Aging asked him to interpret whether Maryland law permitted the

already in place. “This opinion is accepted medical practice today, but at the time it was highly controversial,” says Schwartz, Curran’s right hand on end-of-life care issues. Their leadership has spurred the creation of a new End of Life Care Working Group of the National Association of Attorneys General. The Working Group so far includes AGs from 15 states.

Since issuing the 1987 opinion, Curran’s office has issued a half-dozen formal opinions and scores of less formal letters of clarification and support on a gamut of end-of-life-care issues, including

- whether families can consent to a do-not-resuscitate order when a heart attack renders a patient “terminally ill” (they can)

Gema Hernández: Promoting “Cultural Competence” in Caring for Florida’s Dying

Gema Hernández was appointed Secretary of Florida’s Department of Elder Affairs (DOEA) in January 1999 to spearhead a comprehensive, culturally sensitive educational program about death and dying for a state with the fourth largest population in the country and the largest population of elderly residents. As DOEA Secretary, Hernández is heading an End-of-Life-Care Workgroup that is studying the ways Florida’s different cultures respond to and deal with death and the dying process and ways to educate people—practitioners, providers, and the general public—about how to become “culturally competent” about death and dying. As part of its legal mandate, the workgroup is also identifying barriers to better end-of-life-care in existing law, crafting model advance-directive and DNR forms, and developing an advance directives website.

“In American culture we believe we have control over our illness and death,” Hernández says. “We are individualized and independent in our values system. [At DOEA], we are trying to prevent those values from being indirectly imposed on others who do not share them.”

Though Florida may be perceived as having a largely Cuban population, the state is in fact a melting pot for cultures from all over the world, including the cultures of African Americans, older retired Americans from western and northeastern states, and immigrant Haitians, Vietnamese, and Russian Jews. “Seventeen languages are spoken by the elementary school children of Miami-Dade County,” Hernández asserts.

DOEA staff are conducting random telephone polls of elderly residents with questions that include the extent of end-of-life decision-making indi-



“We need to inform and communicate to the general public the different ways cultures approach the end of life, so that providers and individuals see there can be many different ways, all equally valid.”

Secretary of Elder Affairs
Gema Hernández (R-Florida)

www.state.fl.us/doea

viduals have engaged in and the ways their culture influences their attitudes toward pain management and other palliative-care service. Staff will report back to the workgroup, which hopes to distill and report the findings by December 2000. The report’s release will kick off an end-of-life educational program mandated by state law. The DOEA hopes to target the report toward physicians and providers to urge them toward cultural sensitivity in end-of-life care.

“We want to make the practitioners aware that their way of thinking is not the only one,” says Hernández. “When practitioners become culturally competent, their changed attitudes

will affect caregiving institutions, and end-of-life-care will improve. . . . With the general public, we want to identify critical mechanisms that will allow us to tap into the communities.” As examples, she notes that the DOEA will most likely educate Latino/Hispanic communities about end-of-life-care options through Catholic Churches, African American communities through Baptist and African Methodist Episcopal churches, Jewish communities through synagogues, and Vietnamese communities through identified spokespeople or elders with credibility.

Growing up in a Cuban American community gives Hernández insight into the issue of cultural competence. With advanced degrees in public policy and cultural anthropology and more than 10 years of experience in studying end-of-life care policy, she is enthusiastic about carrying out this new state policy.

“Gema almost invented ‘cultural competence’ in Florida,” says Mimi Walzer, MBA, Fiscal Director of the Channelling Project at the Miami Jewish Home and Hospital for the Aged. “She certainly started the cultural sensitivity around this issue.” Hernández facilitated the agency’s support groups for caregivers of elderly people facing death. “She understands how language and cultural issues affect the way services—including care at the end of life—are delivered.”

“She understands the issues and she’s willing to bring them up in political venues,” says Samira K. Beckwith, CHE, LCSW, President of Florida Hospices and director of The Robert Wood Johnson Foundation-sponsored Florida Partnership for End-of-Life Care. “We’re thrilled she is championing the policy issue of cultural com-

Helen Thomson: Legislating Better End-of-Life Care for Californians

California State Assemblywoman Helen Thomson's work in end-of-life-care policy is relatively recent, but she is viewed in her state as a strong and dedicated health policy reformer.

Thomson's experience as a founding board member of Yolo Hospice in her district and "her experience as a registered nurse made her an obvious person to participate in this effort. Her knowledge of health-care policy pervades her career," says Assemblymember Carol Migden (D), who in 1997 asked Thomson to join the Select Committee on Palliative Care that Migden was chairing.

In the past two years Thomson wrote and secured Migden's co-sponsorship of two state laws to improve end-of-life care. The first, which took effect Jan. 1, 2000, addressed pain management by

- requiring inclusion of pain management and end-of-life care in all California medical school curricula beginning June 1, 2000
- requiring all health facilities—including all hospitals and nursing homes—to assess pain

as the fifth vital sign (the four vital signs typically assessed are pulse, temperature, respiration and blood pressure).

"Hundreds of physicians in America graduate every year with no training in pain management or end-of-life care, so making pain management and end-of-life care courses mandatory in California medical schools is a major policy achievement," Thomson says. "And making sure that every health-care facility will measure pain as the fifth vital sign ensures patients will get better care."

Thomson's second bill—signed into law Aug. 31, 2000—reduces some of the red tape for patients and physicians caused by triplicate prescription forms for opioid pain medication. California law requires prescriptions for morphine and other related drugs to be written on a three-copy form issued by the Department of Justice (DOJ). The new law allows physicians' employees to fill out the forms, amending the former law's requirement that all triplicate forms be handwritten personally by the physician. The

new law allows physicians to receive an unlimited number of triplicate forms from the DOJ (formerly, each physician could receive only 100 per month).

Finally, the law allows pharmacists to fill prescriptions for controlled substances containing an error if the pharmacist notifies the physician of the error.

"Requiring a patient to return to his or her physician because the date on the form is wrong is ridiculous," Thomson says. "For patients who are in pain, who live far from their physician, or who have trouble obtaining transportation, these regulations create an unnecessary hardship."

"It takes courage to stand up and advocate for the things Helen Thomson has advocated for," says Scott Fishman, M.D., Chief of the Division of Pain Medicine at University of California–Davis, a nationally known pain expert who testified during Thomson's hearings on her bills. "She stood up and said the triplicate system isn't in the best interests of those who are in pain. This law is a step forward that we would never have had without Helen Thomson." ■



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Assemblywoman Helen Thomson (D-California)

Policy Leaders to Watch

Sharon Bulova

Fairfax County Supervisor
(D-Virginia)

With a district in close proximity to the nation's capital, Sharon Bulova eagerly agreed when the Bill Moyers staff asked her to spearhead Northern-Virginia outreach efforts on behalf of his television series, *On Our Own Terms: Moyers on Dying*. Bulova uses forums, community outreach, and press coverage to lay the groundwork for policy development. Her office organized a public forum



Sharon Bulova and Bill Moyers

on “Death as a Spiritual Journey,” which attracted a standing-room-only audience of pastoral counselors, community nurses and others ministering to the spiritual needs of the dying. The forum received major feature treatment from the *Washington Post*; Bulova's other end-of-life-care events—including town hall meetings, a bar-association-sponsored seminar on legal issues, and a workshop for caregivers on the benefits of music therapy at the end of life—have been covered in community newspapers. Bulova's office is now fielding calls from state assembly members following up on her office's efforts in the policy arena. “I think we've now made the ground fertile for these issues to be introduced into the General Assembly,” Bulova says.

Susan Collins

U.S. Senator (R-Maine)

A member of the Senate Special Committee on Aging, Collins has made end-of-life care a top item on her legislative agenda. Collins would like to see Medicare cover orally self-administered pain medications for the relief of chronic pain in life-threatening illnesses—currently, Medicare covers no self-administered pain medication except that delivered by pump, a cumbersome and expensive method. She also would like to see models for end-of-life care developed for Medicare patients who do not qualify for the hospice benefit but who have illnesses that are ultimately fatal. At present, a patient must have six months or less to live to receive the Medicare hospice benefit.



“About one-fourth of Medicare funds are spent on care at the end of life that is geared toward expensive, high-tech interventions and ‘rescue’ care despite the fact that many Americans would prefer palliative care in the comfort of their own homes surrounded by their loved ones,” Collins says. “Clearly, there is more we can do to relieve suffering, respect personal choice and dignity, and provide opportunities for people to find meaning and comfort at life's conclusion.”

Frankie Sue Del Papa

Attorney General (D-Nevada)

During her three terms, Frankie Sue Del Papa has found that “the single most requested service for law advocacy from seniors is advice about advance-care plan-



ning and advance directives.” So in 1996 Del Papa's office led the “Death with Dignity and Caring in Nevada” project. In 1997 the project produced an action-plan consisting of 15 objectives designed to help Nevadans negotiate the dying process with less complication and more compassion. The plan's recommendations, which are now being implemented, include measuring pain as the fifth vital sign; requiring health care professionals to obtain educational credits in palliative care and pain management; developing an advance directives kit for use by all primary care physicians; and reaching out to the news media. “I would encourage policy makers to approach this issue by including important stakeholders; for example, I'd never dream of going out on this issue without the help of my state medical society,” Del Papa says. “And the payoff is, you are providing public education about a sensitive issue that's going to touch *everyone* in your state.”

www.ag.state.nv.us/deathwithdignity

Charles Fogarty
Lieutenant Governor
(D-Rhode Island)

Upwards of 38 percent of Rhode Island's residents die in nursing homes. In an effort to provide more public information about health-care facilities' quality of care, Lt. Gov. Charles J. Fogarty sponsored legislation that instituted the Health Quality Performance Measurement and Reporting Program. This 1998 law required the state department of health to assess and begin to report



publicly the quality of care in its 13 acute-care facilities and its 107 nursing homes. Fogarty's legislation made Rhode Island the first state to call for comprehensive statewide assessment and public reporting of patient satisfaction, core clinical measures (quality of care), and administrative data for all licensed health care facilities. Quality-of-care reports will be formulated for use by consumers, providers, payers, purchasers, and health plans.

"Our goal is to get information out about quality in a responsible way, in order to help consumers make better decisions. Ultimately, as a result of this law, we hope that every piece of the long-term-continuum—from visiting nurses to nursing facilities—will provide higher quality care," Fogarty says.

Nancy Johnson
U.S. Representative (R-Connecticut)

Nancy Johnson's end-of-life care efforts have focused on putting physician oversight into the hands of physicians' peers, as an alternative to permitting criminal or judicial agencies to have access to physicians' records. She also supports keeping end-of-life decision-making in the hands of patients, their families, and their physicians, rather than governmental agencies. "Now is the time to make sure people retain the power to decide how much medical care they want at the end of life," Johnson says.

Johnson this year coauthored a bill that would have required peer-review organizations to oversee physicians'



opioid prescribing practices and educate doctors about better pain management. The bill also proposed making palliative care more available to families by creating a set of community-based family support networks in palliative care, as well as a national pain-guidelines website, a Pain Advisory Committee, a Surgeon General's Report on Pain, and a National Institutes of Health Conference on Pain. While the bill did not pass, it still received bipartisan support, and Johnson intends to keep advancing the bill's priorities in future congressional sessions. ■

Information About the Series

"Policy Leaders and End-of-Life Care—Part I: How End-of-Life Care Can Be a Positive Issue for Policy Leaders" is the ninth in a series of briefs profiling promising policies and practices in end-of-life care, and the first in a mini-series about policy leaders working to improve end-of-life care.

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Last Acts is a coalition of more than 500 national and local organizations dedicated to improving end-of-life care. For more information about the Last Acts campaign, contact

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