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Campaign 2008

He's turning end-of-life care into a political issue

Doc wants candidates to talk about death

By MEG HECKMAN
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When would-be presidents talk about health care, Dr. Ira Byock wants to ensure they consider the needs of frail elders and the people who care for them.

Byock, the head of palliative medicine at Dartmouth-Hitchcock Medical Center, has spent the last several months gathering opinions about death, dying and end-of-life care from hundreds of New Hampshire residents. Through a new nonprofit called Reclaiming the End of Life, he'll use the data to educate presidential candidates and voters about an often unsettling, but important, aspect of health care: death.

Many hospitals and elder care providers offer progressive end-of-life care, but the programs are small and often strapped for resources. As a result, Byock says, too many people die in pain or alone, and too few spend their last days at home. The consequences are financial as well as emotional: Nearly 400,000 American families go bankrupt each year because of medical expenses, including those associated with the end of life.

Voters, Byock says, must demand that candidates develop plans to improve access to healthcare, nursing home conditions and the availability of proper pain management. How will politicians ensure that health care workers understand the needs of dying patients? Or provide services that allow people to die at home? Or increase the number of seniors who have access to hospice care?

"Without this effort it's unlikely that these questions and this level of discussion would happen," he said. "It seems so depressing, so complex, so daunting that (candidates) change the subject."

Already, more than 90 percent of nursing homes have too few workers to care for patients, according to a 2002 Congressional study. Hospitals also struggle to hire and retain staff. The Institute of Medicine says many health care professionals lack the training to care well for dying people. Demand for such services is about to increase dramatically: By 2030, the number of Americans 65 and older will nearly double to 71.5 million. Many will have, or develop, chronic illnesses that require long-term care.

"Their voices are often not heard by the body politic," Byock said. "They are too ill, too frail or too overwhelmed."

New Hampshire is aging more rapidly than the rest of the nation. It's also home to the first presidential primary. Both factors spurred Byock to create Reclaiming the End of Life. To collect data - and begin educating voters - the organization hosted eight forums throughout the state.

At the meetings, participants responded to an exhaustive list of questions using handheld computers that resemble jumbo remote controls. Topics included medical billing methods, health care availability, the importance of prayer, what services the government should subsidize and how respondents imagine their own deaths.

Participants have included health care workers, elder care providers, seniors and baby boomers who don't want to repeat their parents' deaths.

"My father died in excruciating pain," said Jeanne Childs, who lives in Hanover and attended a forum early this week. Byock's "care for end of life is where have to go. He's doing something about it."

Preliminary results show that, of the 463 New Hampshire residents who responded, 47 percent believe America's health care system is in a state of major crisis. An additional 49 percent say it has "major problems." When envisioning their final days, the vast majority said pain control, the ability to communicate and being at home were important.

Most also responded that they would want help tying up loose ends and making medical decisions that are true to their values. More than 80 percent said it is important that they do not die alone.

Byock plans to distribute the data, as well as other end-of-life training material, to presidential campaigns. Then he and a growing corps of volunteers will make sure candidates pay attention.

"We won't grade them, that would be lobbying," Byock said. "We won't tell them what to say. We will pay attention and make it obvious who's listening."

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