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Doctor says there is not much time left

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If America fails to stanch the downward spiral in quality end-of-life care, 2007 will be looked back on as the "good old days," a prominent physician and professor at Dartmouth Medical School says.

Dr. IRA BYOCK

"We will be nostalgic for 2007 because the baby boomers are aging but the pool of adult care-givers continues to shrink: nurses, nurses' aides, geriatricians (who almost don't exist)," said Dr. Ira Byock, professor of anesthesiology and community and family medicine at DMS and director of palliative medicine at Dartmouth-Hitchcock Medical Center.

He added: "For the first time ever in our history there's going to be more old than young people. It's happening to us all. This is an almost silent public epidemic."

Byock said there's plenty of research that shows we are not prepared as a society to deal with how people age and how they die.

He said we have stopped teaching geriatrics -- the practice of medicine for aged people -- in medical schools.

There are also health care financing issues that focus on the disease rather than on the person living with the disease, Byock said.

"Medicare pays better for doing something to the disease than to help them live with the disease or cope with the problems of loss of mobility or eyesight," he said.

In addition, people at the end of their lives frequently deal with pain.

"And we don't teach pain management much in medical school," he said, noting: "Our reimbursement system should be encouraging support of conversations between patients and doctors about planning for a time of frailty and the end of their lives."

To get hospice care, he said, "... Medicare requires that you agree that you are dying and that you be willing to give up some types of treatment to get hospice care for your quality of life. Good data now shows that requirement costs society money."

Byock said there also have been multiple academic and private studies showing staffing levels in nursing homes are not sufficient to meet the basic needs of the people there.

"All of us are responsible," Byock said. "We should be demanding more staff in nurses. And if it means more taxes, well, damn it, what are taxes for but for the well-being of our parents and grandparents?"

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Elinor Ginzler is director of livable communities for AARP, a national advocacy organization for senior citizens.

"We often address illness as an opportunity to cure," Ginzler said. "That's how our medical model is built. But there comes a time when cure will not be the most helpful approach. It could be more humane to ask what is the setting you want to be in for your remaining time."

The greenhouse model

For those who don't want to spend their last days in their own home or in a nursing home, a recent alternative is the greenhouse.

"The greenhouse is a fascinating new model of care," Ginzler said, "that takes the home setting and recognizes that you might need skilled nursing care." Greenhouse homes may welcome visits from pets and are set up to enable residents to be as independent as they can be. Several models exist, one in Tupelo, Miss., another in Lincoln, Neb., others in California. Some are certified as a Medicare- or Medicaid-approved facility.

Ginzler says New Hampshire is one of a group of states working this year to try to expand home- and community-based services and to do that by "reshuffling" more dollars away from institutional care to community care.

New Hampshire Commissioner of Health and Human Services John A. Stephen recently moved $3 million from a surplus in the state's nursing home budget to home- and community-based care.

Stephen initiated the Granite Care program in the early days of his term. The program focuses on enabling people facing end of life to remain in their homes.

The state's longterm care ombudsman, Don Rabun, is personally responsible for the safety and well-being of 12,000 long-term care residents, and for resolving their complaints and problems.

"We look to broaden the range of options for people because many want to maintain as much independence as possible," Rabun said.

People of any age, but particularly when approaching the end of their lives, may file an advance directive, which includes a living will and their choice of someone with power of attorney if they are incapable of making decisions having to do with their health. The directive instructs the hospital staff which life support systems to continue using and which to discontinue under specific circumstances.

Sometimes, a physician or someone with power of attorney may attempt to go against the instructions in the directive, and that's a major concern for Rabun.

"Our view is as long as they can give a coherent response, the patient's wishes should be listened to," Rabun said.

Help for caregivers

While advocating for home- and community-based end-of-life care, Commissioner Stephen believes alternative living services are also important.

"I have met a number of nursing home employees that each and every day give quality of life, and quality of care to every life," Stephen said. "But the nursing care industry has to look to a changing culture. Nursing homes should look to alternative ideas like assisted living."

Rockingham County has more than 50 beds that are designated independent assisted living beds. "We are paying an assisted living rate that is very close to the market value," Stephen said.

"I would love to see that some of the beds in nursing homes are used for more independent care of living, something that provides respite for care-givers, for instance. We actually have a task force looking at the respite idea."

State Sen. Joseph D. Kenney, R-Wakefield, intends to submit a bill that would seek federal approval for Medicaid reimbursement for short-term nursing stays for seniors who receive subsidized care in their home.

"When the family takes a vacation or goes on a business trip, the mom or dad they are caring for needs a place to go," he said. "We want to explore some of the nursing home beds for seniors who may require this respite care."