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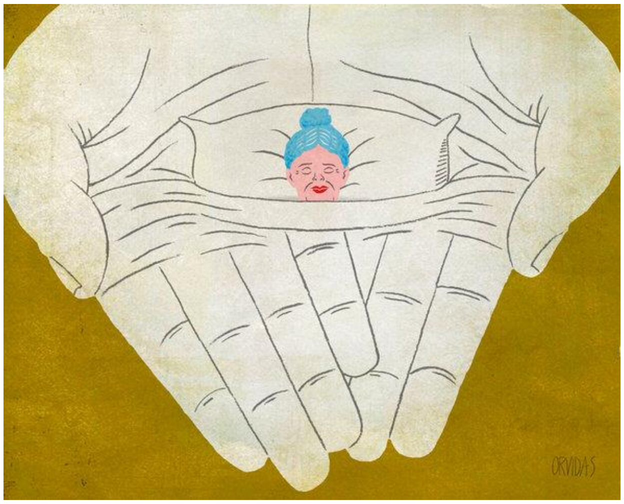
Seeking a ‘Beautiful Death’

By JANE E. BRODY | FEBRUARY 9, 2015



Virgie Divinigracia had the kind of death last month that most Americans say they want: at home, relieved of physical and mental pain, surrounded by those she loved, “a beautiful death” as those present described it. Alas, this is true for too few Americans. Most still die in costly medical facilities tethered to machines, often unable to communicate, in a futile attempt to prolong their lives.

Dr. Angelo E. Volandes, the author of an enlightening new book, “The Conversation,” said that although Americans received some of the best health care money could buy, “they also experience some of the worst deaths in the developed world,” mainly because people failed to articulate what they wished for at the end of life, and doctors failed “to recognize that fixing specific problems may not fix the whole patient.”

Mrs. Divinigracia’s experience is illustrative. At 88 and in need of full-time care after 10 years with Alzheimer’s disease, she developed acute kidney failure. Her doctor suggested dialysis.

But after a clearheaded review of her prospects, her devoted husband and primary caregiver, Paul, and their son and daughter acknowledged that, had she been able to say so, she would not have chosen aggressive medical treatment that would only further diminish the quality of her remaining days.

And so she lived to have an 89th birthday celebration with her family before deteriorating health prompted a call to hospice for help.

By now, most people are aware of advance directives — living wills that detail the treatments wanted or not wanted when life hangs in the balance, and assignment of health care agents to speak for patients when they cannot speak for themselves. But as of 2010, only 26.3 percent of American adults had prepared such a document, according to a nationally representative survey of 7,946 participants.

Even those who have done so don’t necessarily understand what they have signed up for, nor have they discussed these matters with their doctors and had the document included in their health record.

“An advance directive is just a piece of paper — that’s not enough,” said Dr. Joan M. Teno, a health policy expert at Brown University School of Public Health. “The doctor or nurse practitioner should talk with the patient and family about the goals of care and the patient's wishes and preferences, then put a plan of care in place to insure that those preferences will be honored."

Doctors should be sure patients understand their prognosis, and should anticipate the problems likely to arise and "have the right medications and services in place" so patients nearing the end of life are not automatically shipped off to an intensive care unit and placed on ventilators, feeding tubes or dialysis, Dr. Teno said.

As Dr. Atul Gawande put it in his new book, "Being Mortal," "We pay doctors to give chemotherapy and to do surgery but not to take the time required to sort out when to do so is unwise."

Dr. Volandes, a staff physician at Massachusetts General Hospital in Boston, noted that "in the abstract, fighting every second of the way and pursuing aggressive life-prolonging interventions sounds admirable." But he wants doctors, patients and families to consider the likely outcome of the fight and how much suffering it will involve.

He recognizes that "there are no right and wrong decisions about medical care at the end of life" but insists that all decisions should be fully informed. To ensure that patients and families understand the options, he has developed a video tour of what medical interventions like ventilation, CPR or placement of a feeding tube look like, which often prompts a change of heart. As one patient put it, "It looks so different on television."

The video, produced by ACP Decisions, a nonprofit group devoted to advanced-care planning, is licensed to health care providers and insurers who can show it to patients and families to facilitate shared decision making in planning for care at the end of life.

In a randomized trial of the video's effectiveness among 50 patients with advanced brain cancer, a quarter of patients in the control group who had only a verbal discussion about end-of-life care with their doctors chose life-prolonging care, half opted for limited medical care and only one-quarter chose comfort care. But none of those who saw the video opted for life-prolonging care, a handful chose limited medical care, and 92 percent decided on comfort care, Dr. Volandes reported. After watching the video, patients said they had a better understanding of their choices.

However, even just a discussion with their doctors about goals for end-of-life care can often make a huge difference. The one-third of patients in a 2008 national Coping With Cancer study who had such a discussion were less likely to undergo CPR, be put on a ventilator or be placed in an intensive care unit. Most enrolled in hospice, suffered less and were in better physical shape and better able to interact with others and for a longer time.

Their survivors, too, fared better; six months after the deaths, they were markedly less likely to experience major depression.

Options regarding end-of-life care should be discussed well before an emergency — or for those with dementia, during the early stages of mental decline. “The absolute worst time to contemplate decisions about medical care is when one is critically ill and in the hospital,” Dr. Volandes writes.

The kinds of questions doctors should be asking:

- What gives your life meaning and joy?
- What are your biggest fears and concerns?
- What are you looking forward to?
- What goals are most important to you now?
- What trade-offs or sacrifices are you willing to make to achieve those goals?

Whoever is chosen as health care agent must understand the patient’s priorities and agree to honor them, regardless of what that person might want for himself. A strong backbone is needed to assure that the agent will advocate the patient’s wishes even if doctors or family members disagree.