

## **KEEP YOUR VOICE, EVEN AT THE END OF LIFE**

*From a NY Times article By Jane E. Brody, January 18, 2011*

The specter of “death panels” was raised yet again this month, prompting the Obama administration to give in to political pressure a second time in its effort to encourage end-of-life planning.

Of course, the goal of this effort was not to make it easier to “pull the plug on grandma” in order to save the government’s money, as some opponents would have it. The regulation in question, which was withdrawn just days after it took effect on Jan. 1, simply listed “advance care planning” as one of the services that could be offered in the “annual wellness visit” for Medicare beneficiaries.

The widespread misconceptions about the regulation were exemplified in a letter to the editor published Dec. 29 in The New York Times.

“Death panels,” the writer said, would have denied her 93-year-old mother colon cancer surgery that has given her the chance to live “several more years.”

But that is not at all what the regulation would have done. Instead, “by providing Medicare coverage for end-of-life planning with a physician, it would have encouraged doctors to talk to their patients about their wishes and made it far easier and more likely for these important conversations to take place,” said Barbara Coombs Lee, president of Compassion & Choices, an organization that helps people negotiate end-of-life problems.

With payment schedules that limit doctor visits to a mere 15 minutes or so, it is unreasonable to expect physicians to spend 30 or more unreimbursed minutes discussing with patients the many decisions that can arise at the end of life.

Encouraging such conversations might indeed save money in the long run. Doctors and hospitals are paid only for treating living patients, so there is always a possibility that financial incentives, conscious or unconscious, would prompt many expensive if futile life-extending measures – efforts that many patients would veto if they could.

In a study of patients with advanced cancer published in March 2009 in Archives of Internal Medicine, the costs of care during the last week of life were 55 percent higher among those who did not have end-of-life discussions with their doctors.

At least as important, the quality of life in their final days was much worse than among those who did have such discussions. Countless studies have shown that extensive medical interventions can make the last weeks of life an excruciating experience for patients and those who care about them.

### **An Individual Decision**

Although talk about end-of-life options has often emphasized avoiding unwanted, intrusive and futile care, that does not mean everyone would or should make that choice. Many patients, especially younger ones, might be inclined to ask that every conceivable measure be taken.

Dr. Josh Steinberg, a primary care physician in Johnson City, N.Y., routinely discusses end-of-life desires with very ill patients. He told me about an AIDS patient who was down to 77 pounds and had no strength, no appetite and failing kidneys. But the man refused hospice care, saying he wanted to go home and live as well as possible for as long as possible.

“Though we didn’t think he’d last more than a day or two, we got lucky,” Dr. Steinberg said. “We stumbled on a new treatment, he rallied, and he’s home doing well right now.”

For other patients, hospice care is the right decision. Studies have found that terminally ill patients are likely to live longer, with better quality of life, when they choose hospice over aggressive treatment to the bitter end.

The point is that end-of-life care is an individual decision that should be thoroughly discussed with one’s family and physicians. Studies have shown that when doctors don’t know a patient’s wishes, they are inclined to use every possible procedure and medication to try to postpone the inevitable. More often than not, this shortens patients’ lives and prolongs bereavement for the survivors.

In an interview on the syndicated news program “Democracy Now!” on Jan. 5, the writer and surgeon Dr. Atul Gawande said that patients with terminal cancer who discuss end-of-life choices with their doctors “are less likely to die in the intensive care unit, more likely to have a better quality of life and less suffering at the end, do not have a shorter length of life, and six months later their family members are markedly less likely to be depressed.”

### **Plan While You Still Can**

For many more of us these days, the end does not come swiftly via a heart attack or fatal accident, but rather after weeks, months or years battling a chronic illness like cancer, congestive heart failure, emphysema or Alzheimer’s disease. When doctors do not know how you’d want to be treated if your heart stopped, or you were unable to breathe or eat and could not speak for yourself, they are likely (some

would say obliged) to do everything in their power to try to keep you alive.

A year ago my husband was given a diagnosis of Stage 4 cancer. As his designated health care proxy, I had agreed long before he became ill to abide by the instructions in his living will. If he was terminally ill and could not speak for himself, he wanted no extraordinary measures taken to try to keep him alive longer than nature intended.

Knowing this helped me and my family avoid agonizing decisions and discord. We were able to say meaningful goodbyes and spare him unnecessary physical and emotional distress in his final weeks of life.

Preparing these advance directives should not wait until someone develops a potentially fatal disease. Patients in the throes of terminal illness may resist discussions suggesting that death may be imminent, and close family members may be reluctant to imply as much.

Indeed, judging from national studies and people I know (including a 90-year-old aunt), most Americans regardless of age seem reluctant to contemplate the certainty that one day their lives will end, let alone discuss how they'd want to be treated when the end is near.

A study published in January 2009 in The Journal of the American Geriatric Society showed that 40 percent of people questioned had not yet thought about advanced-care planning and 90 percent hadn't documented their wishes for end-of-life care.

Ideally, everybody over 18 should execute a living will and select a health care proxy – someone to represent you in medical matters.

[Compassion & Choices has an excellent free guide and "tool kit" to help people prepare advanced directives. Click here to download from the organization's Web site, or call \(800\) 247-7421 for a free hard copy of the documents.](#)

