

Spelling out your views for end-of-life care is a 'spiritual' act

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November 27, 2013

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(RNS) At Thanksgiving family reunions this week, many adult children traveling home are in for a rough surprise: Mom or Grandpa is more frail, more confused, maybe more ill, than they realized.

Now what? Does anyone know what medical treatment they would want if they could no longer speak for themselves? Is it in writing? Where?

Holiday visits may be the only opportunity for months, if not years, to get a conversation about end-of-life wishes started before it's too late.

The Pew Research Center's new survey on end-of-life treatments found that most people (72 percent) have given at least some thought to what they might want or refuse. And nearly half (47 percent) have known someone in the last five years who was dealing with a life-threatening illness or in a coma.

However, far fewer — just 35 percent — of all adults say they've written down their end-of-life treatment wishes in any form of advance directive. Another 31 percent say they've talked about this with someone, but one in three Americans have said or done nothing to spell out what should be done if a time comes when they cannot speak for themselves.

"It hurts their hearts to think about this," said Sandy Silva, the vice president of education at the Center for Practical Bioethics, in Kansas City, Mo.

Silva meets frequently with community groups and religious congregations to introduce them to the center's "Caring Conversations Workbook" to get them thinking about the issues. It's not always easy.

“It’s a sad conversation and it’s a scary conversation. We human beings are, by our very nature, hopeful. We are reluctant to face the fact that we are just not going to live forever,” she observed.

Many factors can play into people’s reluctance to talk about or write down values or set limits on aggressive treatment when they are too ill to speak for themselves:

- * The view that one’s family should make such decisions.
- * The belief that the end of one’s life is God’s call, not one’s own, to make.
- * Hope that new cures or treatments will one day be available.
- * Concern that doctors will not heed one’s wishes at the critical moment.

Even when people know what they want, they may not know which paperwork will make those wishes clear and effective. Is a health care power of attorney, authorizing someone to make decisions, enough? What about a living will or an advance directive? What do MOLST or POST or TPOPP even mean?

The umbrella term “advance directives” includes:

- * A living will: It can spell out your overall desires but it may be too vague to be useful, Silva said. “It may say you don’t want any ‘extraordinary measures,’ but what does that mean to you? Many people will say they don’t want to be ‘on machines’ but if you have a reversible condition, maybe you really will want a ventilator for a while,” said Silva. “Right away, people are confused.”
- * A durable power of attorney of health care (or health care proxy): It gives an agent you select the legal power to make medical decisions for you when you no longer can. It requires careful communication to be sure your values are clear. But physicians may not be able to reach the agent and “sometimes people are shocked because no one told them they were the agent,” said Silva.

Forms available through the American Bar Association and the Caring Conversations Workbook and MyDirectives.com guide people through several scenarios for consideration so an agent would be better prepared.

- * Transportable Physician Orders for Patient Preferences. In Kansas and Missouri, the form goes by TPOPP. But the idea started 20 years ago in Oregon, where it is known as “Physicians Orders for Life-Sustaining Treatment” (POLST). It has been adapted state by state with similar names, such as MOLST in Maryland.

This addresses some of the shortcomings of the other formats, said Silva, who directs the TPOPP project at the center. First, it is designed for “people who already have a life-threatening diagnosis that could limit the length or quality of their life.”

It requires the patient and his or her agent to verify that “this is what a person wants now, not what they said years ago when they were healthy or just beginning treatment,” she said. People who want aggressive treatment that never quits can specify that, or they can elaborate on the circumstances when they would want to reject or withdraw from treatment.

Unlike other types of directives, a physician signs a TPOPP type form after a conversation with the patient. That makes it a doctor’s order, effective across all levels of care — from the ambulance crew to the emergency department all the way to the intensive care unit and hospice.

Silva sees a spiritual value to urging people to think about their end-of-life wishes, talk about them and write them down. She calls these actions of autonomy and self-respect.

“Throughout all of our lives, we are constantly trying to make sense of the beyond, whatever that may be. It’s an honor and a responsibility to participate in such conversations in this world so we make that transition in a way that reflects how we lived our lives,” she said.