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How to Make Your Wishes for End-of-Life Care Clear

New Concerns Arise About How Well Patients and Doctors Understand Advance Directives

By Laura Landro

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As acceptance of end-of-life planning grows in the U.S., new concerns are emerging about how well patients and their doctors understand the forms they are signing about the care they want in their final days.

In September, the Institute of Medicine's "Dying in America" report called for a national effort to improve medical and social services for end-of-life care, both to improve quality of life and to help reduce the outsize costs of unwanted care at the end of life.

Some health plans are reimbursing doctors who help with advance care planning, and the federal government is weighing doing the same for doctors who talk to Medicare patients about options. A growing number of states are starting programs known as Physician Orders for Life Sustaining Treatment, or Polst, a form offered to patients who might die within a year so they can document their wishes in a medical record, signed by the doctor.

But while the "death panels" controversy has faded, some experts say there is much education still to be done on advance directives such as living wills and do-not-resuscitate, or DNR, orders.

Clarity or Confusion?

Living wills are recommended for healthy adults, to document the kind of care they wish to receive if they are no longer competent or are in a persistent vegetative state, and to appoint a legal health representative. In contrast, a DNR directs medical providers not to intervene with cardiopulmonary resuscitation if patients have no pulse or aren't breathing, but doesn't address withdrawing or withholding any medical care other than resuscitation.

A continuing series of studies known as Triad, for The Realistic Interpretation of Advance Directives, concludes that there is confusion among doctors about living wills and DNR orders, which could lead to limiting or delaying lifesaving treatment in cases that aren't terminal or where there is hope for survival with a good quality of life.

Though few living wills contain DNR orders, doctors may mistakenly assume that a living will is the same as a DNR. And when a patient has signed a DNR order, doctors may assume that means not to provide treatment at all, according to Ferdinando Mirarchi, lead investigator of the Triad studies and medical director of the department of emergency medicine at UPMC-Hamot in Erie, Pa., part of the University of Pittsburgh Medical Center system.

"The risk is that you don't receive the necessary and standard-of-care treatment for a critical illness such as a heart attack, which could lead to death or permanent disability, whereas the standard-of-care treatment could save your life," says Dr. Mirarchi.

Sending a Clear Message

If you are going into the hospital for a medical procedure and have made plans:

◆ Tell the medical provider you have a living will, do-not-resuscitate order or Physician Orders for Life Sustaining Treatment (Polst).

◆ Be clear with the medical provider what your intentions are regarding treatment in the face of such a document or order:

- Do you seek aggressive treatment or comfort care?
- Be clear to ascertain if this is a terminal condition despite sound medical treatment versus a critical illness.
- Be clear to ascertain possible prognostic outcomes.

◆ Communicate and coordinate with family members to ensure all are on the same page about the treatment plan.

◆ Discuss next steps. For example:

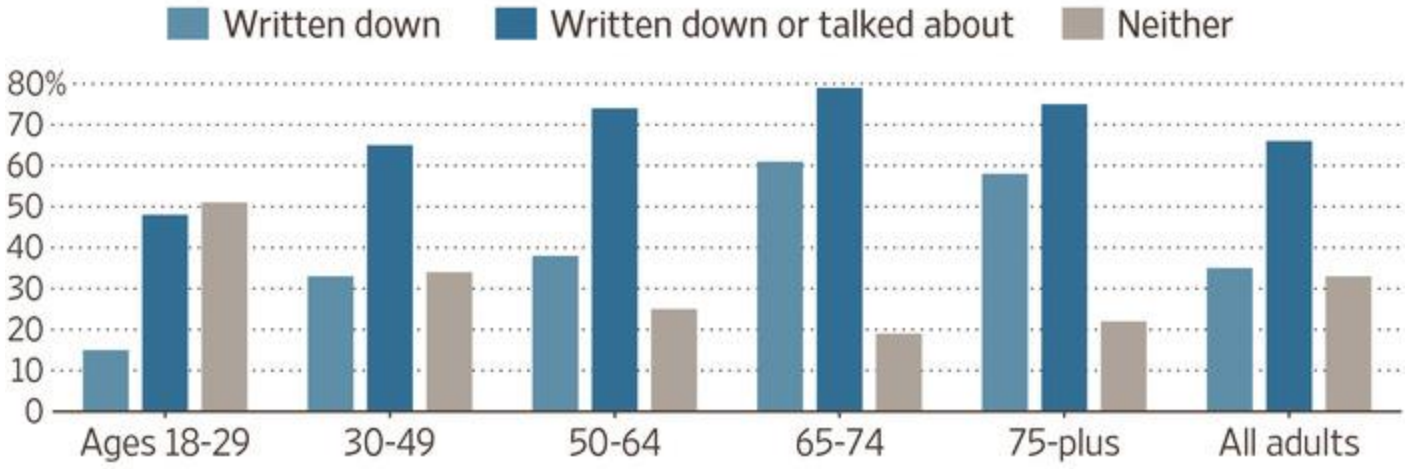
- My mother is critically ill. What do we do next for her? Can we give her a trial of life-sustaining care for 48 to 72 hours, and then if there is no benefit can we withdraw life-sustaining treatment and provide comfort?

◆ Look into palliative care and hospice if you decide not to pursue aggressive care or are considering withdrawing life-sustaining care.

Source: Ferdinando Mirarchi, "Understanding Your Living Will," via the University of Pittsburgh Medical Center

A Final Bow

When asked if they have written down or talked with someone about their end-of-life wishes, the following percentages of surveyed adults said:



Source: Pew Research Center telephone survey of 1,994 adults age 18 and older, March-April 2013; margin of error: +/- 2.9 percentage points

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Take a Moment

The research led to the creation of a "resuscitation pause" at UPMC-Hamot, which allows doctors to talk with patients or their representatives, using a series of questions to clarify the intent of an advance directive or Polst and make sure they honor their wishes.

Dr. Mirarchi, who is also the author of "Understanding Your Living Will," advises, "If you enter a hospital and they ask if you have a living will, you should say 'Yes, but I am full code,' " which means to provide all treatment. That can be revisited if the patient's condition changes—such as slipping into a persistent vegetative state—to trigger the living will's provisions.

Patients should also respond "yes" if asked whether they want to be treated if they are in cardiac arrest, unless they have a known terminal illness and would not want extreme measures. If they answer "no," the hospital may create a DNR for them, sometimes without their knowledge or consent, but with far-reaching consequences. "Answering that question as no and having a DNR order impacts every phase of your care and treatment in a negative fashion," Dr. Mirarchi says. Studies have shown that DNR orders result in fewer medical interventions such as transfer to an intensive-care unit, blood transfusions and aggressive critical-care procedures.

Scott Henry, a gastroenterologist in Erie affiliated with UPMC-Hamot, says many of his patients have DNR orders, but before they are sedated for a procedure, he will discuss what their wishes are in different scenarios. Often, he finds, "people haven't discussed their true desires with their doctors, and doctors sometimes don't understand all the differences themselves."

When he explains that if they stop breathing during a surgical procedure they can likely be revived, almost all change the order to a "full code."

Erik Dansk, 69, says before he was sedated recently for an endoscopy to treat ulcers, Dr. Henry asked him about the DNR in his file. Mr. Dansk told the doctor, "I don't want to come out of this worse than when I came in, or end up hooked up to a machine." But given his age and physical status, Dr. Henry said there was no reason to think he would. They reversed the DNR order.

Talk to the Doctor

UPMC-Hamot's Dr. Mirarchi also raises concerns about Polst forms, which require a signature by both doctors and patients after a discussion of the patient's wishes. But that discussion may take place with non-physicians who might not be the most qualified to explain to patients what conditions might benefit from treatment.

A typical Polst form has three sections for patients to express their wishes. Section A asks patients whether they want CPR if they have no pulse and aren't breathing. Section B offers a choice of preferences if they have a pulse and are breathing: comfort measures only to relieve pain and suffering; limited additional interventions such as antibiotics and fluids; or full treatment. Section C covers preferences on tube feeding. There are six possible combinations of the A and B sections.

The journal Resuscitation in January published a study of Polst forms in Oregon, which developed the program. The analysis found most patients chose one of three combinations that were easy for health providers to interpret: DNR and comfort measures; DNR and limited interventions; or attempt resuscitation/full treatment. But about 10% of forms had combinations that were less easy to interpret or logically inconsistent.

Susan Tolle, an author of the study and director of the Center for Ethics in Health Care at Oregon Health and Science University, says it is important to avoid contradiction or confusion, and educate health professionals about how to have conversations with patients. But she says there is a growing body of evidence that the Polst model is effective in conveying patient preferences.

By offering clear documentation of patient wishes, Dr. Tolle says, Polst forms decrease the likelihood of overreliance on DNR orders, and are "the best way to honor patient preferences for or against life-sustaining treatments as they approach the end of life."