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How Doctors Can Approach End-of-Life Conversations

It's important that doctors talk to their patients. But it's also important that they do it right.

Doctors need to set aside enough time for an uninterrupted session in a quiet place so that the focus is on the patient. *PHOTO: MANON ALLARD/ISTOCK/GETTY IMAGES*

By BARBARA SADICK
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In 2016, after years of controversy, Medicare plans to begin reimbursing doctors for having discussions with patients about what type of medical care they want and don't want near the end of their lives.

Private insurers are likely to follow, some experts say, meaning voluntary end-of-life counseling could soon become a part of standard medical care.

For many in the medical community, it's a much-needed change. Most researchers and physicians agree that too many people in the U.S. receive treatments they never would have wanted or that don't align with their values as they near death. Indeed, although most people if given a choice would prefer to spend their final days at home, surrounded by loved ones, about 70% of people die in hospitals, nursing homes and long-term care facilities, according to the Centers for Disease Control and Prevention.

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"It's better to work through end-of-life issues while people are still alive so that [family members] can look back and feel that they did it right," says Ira Byock, a palliative-care expert who leads the Providence Institute for Human Caring in Torrance, Calif.

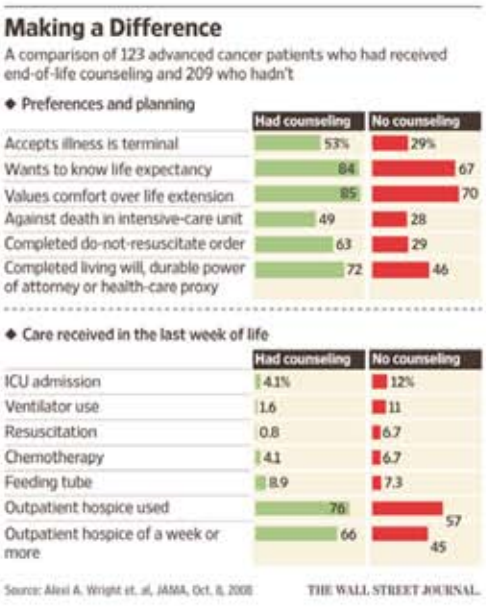
Although most people say they are open to having end-of-life conversations with loved ones, only 27% actually do, according to surveys conducted by the Conversation Project, an initiative founded by journalist Ellen Goodman to encourage people to make their wishes known. Some people avoid these conversations out of fear, she says, while others think they will have time to do it later.

Yet studies show clear benefits when patients are given a chance to speak up. Research by Alexi Wright, a population scientist and medical oncologist at Dana Farber Cancer Institute in Boston, has found that cancer patients who have conversations about end-of-life issues are more likely to die at home or in a comfortable setting, instead of a hospital intensive-care unit. And survivors are able to cope better with death and experience less anxiety and doubt later.

Here are what physicians and other experts say works—and doesn't work—when it comes to having effective end-of-life conversations.

Timing matters

These days, most end-of-life conversations take place after a patient has been diagnosed with a serious illness. Experts say that this is a big mistake, and that the talks should begin well before a person becomes ill because it can be difficult for both patients and their families to think clearly once a health crisis hits.



Indeed, what others call end-of-life conversations are actually continuing conversations about a person's values, preferences and priorities, Dr. Byock says. They should be initiated well before a person is sick and revisited periodically, he says.

Diane Meier, director of the Center to Advance Palliative Care at Mount Sinai Medical Center in New York, hopes to see advance-care planning become an integral part of routine adult primary medical care in the same way that discussions about smoking, weight and vaccines are.

Crucial times to revisit a plan, Dr. Meier says, are when the diagnosis of a disease has been made, as a disease progresses, and before a risky procedure or surgery. A patient's circumstances and beliefs can change as he or she ages, or as death approaches, so it's important to make sure that decisions made earlier still stand.

Who takes the lead

In some places, doctors are taught to take the lead in initiating and guiding discussions about end-of-life care. Elsewhere, physicians leave it up to patients to take the lead. But most experts agree that a shared approach is best, with patients laying out their preferences and priorities, and doctors helping them understand the risks and benefits associated with them.

Regardless of the approach taken, doctors need to set aside enough time for an uninterrupted session in a quiet place so that the focus is on the patient.

While there is no standard script for end-of-life conversations, doctors need to be careful not to inject their personal opinions and biases into the discussion to avoid stoking fears that they are trying to coerce patients. It is also important that doctors pay attention to what patients say and to be alert to body language and other nonverbal cues that may indicate fear or stress.

"When cues are missed, that's a missed opportunity to show empathy," says Angelo Volandes, an internist at Massachusetts General Hospital.

For critically ill patients, a physician may lay out the options if treatments don't work—for instance, whether the patient prefers hospice care or to continue to be treated and kept alive in a hospital intensive-care unit.

But it's best to avoid jargon such as DNR, for "do not resuscitate," and DNH, for "do not hospitalize," because such terms may be mysterious to many people.

Instead, experts recommend that doctors ask patients and their families what they want medical teams to do or not to do and then explain what those decisions mean.

Visual aids can help. An initiative called ACP (Advanced Care Planning) Decisions, co-founded by Dr. Volandes, uses videos to help patients grasp concepts that often seem abstract; one, for example, shows the insertion of a feeding tube.

However, the videos are designed to supplement end-of-life conservations, not replace them, Dr. Volandes says.

Going deep

End-of-life conversations aren't just about the mechanics of terminal care; they are about uncovering what a patient truly values. Is he or she religious? Is quality of life more important to the patient than its length?

"Instead of focusing on CT scans and tests, part of our job as physicians is to get people to pause and reflect upon what's most important to them," says Mount Sinai's Dr. Meier.

In one model for end-of-life conversations that was developed at Gundersen Health System in La Crosse, Wis., patients are asked about their experiences with those who are sick or dying and what they have learned from those experiences. They also are asked what a good day looks like—which helps patients determine what is important to them. Finally, patients are asked to reflect deeply upon whether they have any strongly held values and beliefs that might influence how decisions should be made.

Most people need time to absorb and become comfortable with their decisions, experts say. Once that happens, the patient's wishes should be committed to paper and stored where doctors and families can easily find them.

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