

July 25, 2019 -- Patty Webster heard her mom talk about death. A lot. So often that she and her sisters sometimes had to stop their mother from bringing it up. Her message got through, though.

Before her mom died of a stroke in 2016 at age 73, a previous stroke had already robbed her of her ability to communicate. But her family knew what she wanted at the end of her life because she had made it plain to them. That allowed them to share her wishes with her doctors and others so that she could die as she chose.

“We were her voice,” Webster says. “I didn’t know what a gift all of those talks had been until then.”

Webster works for the Conversation Project, an initiative of the Boston-based Institute for Healthcare Improvement. Founded in 2010, it encourages people to become comfortable talking about the type of care they want -- and don’t want -- at the end of their lives. A survey the group conducted in 2018 found that 95% of Americans are open to discussions about their wishes. But only about 1 in 3 have talked about what they would want. Five years earlier, however, that number had been closer to 1 in 4. More people, it seems, are talking about how they want to die. Some more than others.

“My family is tired of me talking about it,” Webster says, laughing.

But Webster wants those discussions to continue, and she wants the number of people having them to keep growing. She also wants to clarify: “Don’t talk about death but about how you want to live.”

Expressing your wishes for the end of your life and having them respected: Some call it “a good death.” Others may refer to it as “successful dying.” Ira Byock, MD, prefers “dying well.” A palliative care specialist and chief medical officer of the Institute for Human Caring at Providence St. Joseph Health in Gardena, CA, Byock is also the author of *Dying Well: Peace and Possibilities at the End of Life*.

“Every one of us as adults should be having this conversation,” he says.

In fact, Byock and his colleagues talk to high school seniors about advanced care planning: “We want to normalize this and make it a part of growing up.”

In a paper published in 2016, researchers reviewed 36 previously published studies to determine the “core themes” of a good death. They looked at the question from three perspectives: the person dying, the family, and health care providers. While 11 themes emerged, all three groups ranked three themes as most important:

- Deciding how they wanted to die, including who would be with them and having their treatment preferences and funeral plans prepared
- Approaching death without pain
- Being emotionally well, meaning their psychological and spiritual well-being has been addressed

States Adapt to Change

In some parts of the country, the conversation includes drugs that end your life. Oregon became the first state to enact the Death with Dignity Act, which voters approved in a 1994 referendum. After years of court challenges, the law took effect in 1998. It allows residents who are terminally ill, have 6 months or less to live, and are deemed mentally able to make their own decisions to end their lives. Ten years would pass before another state, Washington, would approve its own version. Maine became the most recent state to pass a version of the law. Gov. Janet Mills signed it on June 12. These are the other states where doctor-aided dying has been made legal and when the laws took effect:

- California (2016)
- Colorado (2016)
- District of Columbia (2016/2017)
- Hawaii (2018/2019)
- New Jersey (2019)
- Vermont (Patient Choice and Control at the End of Life Act, 2013)
- Montana (Although no Death with Dignity law exists in Montana, the state’s Supreme Court ruled in 2009 that the practice was legal.)

The laws have sparked opposition. In Maine, for example, the state legislature passed the law by only four votes. In California, the law was overturned in court last year, but an appeals court put a hold on that ruling, and the state's Supreme Court chose not to review the case. That leaves the law, known as the End of Life Option Act, in effect, though its future remains uncertain.

Between 2009 and 2017, the most recent year for which statistics are available, 1,364 people in Washington had used the law to end their lives. Last year, in California, 337 people chose to die under the state's End of Life Option Act. In Oregon, 2,217 terminally ill people have received life-ending drugs over the past 2 decades. Nearly two-thirds used those drugs, while the rest opted not to take them.

"That's been the case year after year," says Peter Lyon, MD, medical director of End of Life Choices Oregon, a Portland-based organization that helps Oregonians navigate the Death with Dignity Act and other final decisions. "Some people just like to know that the medicine is there and available if their pain becomes too severe or their condition worsens a great deal."

On average, says Lyon, people do not reach out to his organization until they have about 3 to 4 weeks left to live. One reason: It's so difficult for many people to think about, let alone talk about.

"Talking about death is the hardest conversation that families can have," he says.

More Than a Medical Decision

How you want to die is only partly about medical issues, Byock says. It's also highly personal. And it will mean something different to you than it will to your spouse, your parents, your children, and others. To reach your own definition, Byock advises you take stock.

"Ask yourself, 'If I'm seriously ill, what would matter most to me?'" he says. "For the vast majority of us, it's other people. We are hard-wired to matter to one another."

Your conversations, of course, should address practical matters, like life insurance information, how to access your safe deposit box, how to close your bank account -- and your Facebook account -- and more. Byock recalls how much that meant to him after his mother's death.

“She lived alone, we found that she kept a wooden box next to her phone with all the documents we needed,” he says. “Mom was still taking care of us.”

You will also need to make decisions about key medical concerns. For example, do you want to be kept alive as long as possible, even if treatment causes great discomfort? Or do you prefer care that may allow you to enjoy better quality of life, though your death may come sooner?

“Some people might worry that they’re not going to get enough treatment, while others might be afraid that they’ll get overly aggressive care,” says Kate DeBartolo, who directs the Conversation Project.

Another crucial consideration: Who will speak for you if you are not able to voice your wishes? For many people, that may be a loved one, such as a family member, but it does not have to be.

“I try to encourage my patients to think about who knows them best on their good days and bad days and who is readily available,” says palliative care doctor Christian Sinclair, MD, of the University of Kansas Health System in Kansas City.

DeBartolo agrees: “I would love to expand the idea that it doesn’t have to be a traditional family member. Ask yourself: Who would you trust, and who do you think could really speak for you?”

Such a person, known variously as a health care proxy or surrogate or agent, can be given power of attorney to make treatment decisions for you when you can’t make them for yourself. You also can --and should -- put your wishes in writing. Legal documents, such as advance directives and living wills, are an alternative or may be used along with a proxy to make clear what you want.

Sinclair, a co-author of the Institute of Medicine’s 2014 report *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, says that over the last 15 years or so, conversations between patients and providers about end-of-life care have become more common as more doctors have been trained for such discussions.

“Research shows that when these conversations happen and patients and clinicians are on the same page, there’s more likelihood that those patients will actually get the care that they want,” says Sinclair. “Having a good death is about making individual choices.”

[Sources](#) ^

Article: 'Good Death': Would You Choose When You Die?

Ira Byock, MD, palliative care specialist, Institute for Human Caring, Providence St. Joseph Health, Gardena, CA.

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