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End-of-life care? Start a conversation

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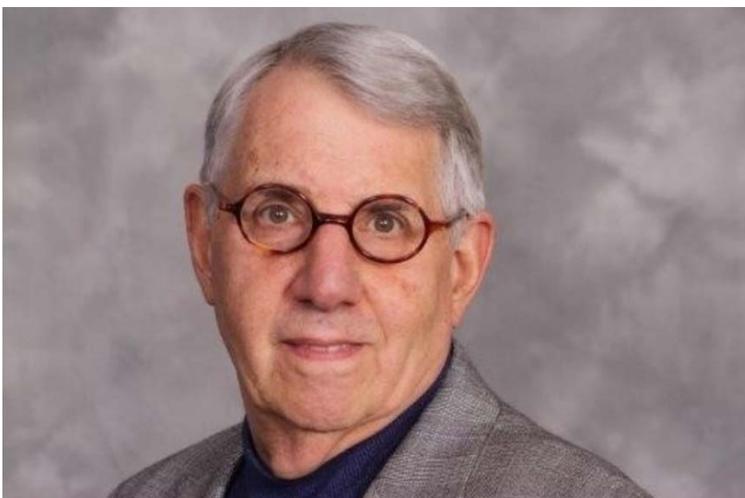


PHOTO COURTESY OF STEVE GLAZER

Fewer things make people more uncomfortable than talking about end-of-life care, but experts agree that being uncomfortable now will benefit your family later.

“It’s a hard conversation to have with parents and kids,” said Jodi Lyons, an eldercare consultant based in Virginia’s Tysons Corner. “But you have to talk about your wishes and expectations for the future, and provide your kids with the tools to make sure your wishes are honored.”

For many, decisions about advance medical directives and caregiving are confusing, unpleasant conversations, but they’re necessary and senior healthcare consultants aim to provide families with the knowledge to tackle these conversations with confidence.

Lyons specializes in assisting people with cognitive issues such as Alzheimer's disease and dementia. She works with families, whose members sometimes are spread out among several states, to put together a package that includes all of the services they'll need, as well as managing expectations.

She recalled attending a White House conference on aging in 2005, where many older adults told her they planned to move in with their children eventually.

"The kids were supposed to add on an in-law suite and take care of the parents," said Lyons. "It was not financially responsible or culturally appropriate."

More than a decade later, she said, times have changed.

First, people are living longer. The Washington-based World Bank, a global organization that works to end poverty, compiled data from the Census Bureau showing the average life expectancy for Americans increased from 70 in 1960 to 79 in 2014.

With Americans living longer, the importance for individuals to express personal end-of-life preferences, while they are competent to do so, has grown.

"An advance medical directive is something everyone who is 18 years of age or older should have," said M. Jane Markley, a healthcare executive and retired Navy nurse of 27 years based in Derwood.

An advance medical directive is a document that states the person's desires in terms of care when they are no longer able to speak, and designates a healthcare proxy. Markley said the directive is as much about a small comfort, like music preferences, as it is about major medical decisions, like the use of life support.

"As a bedside nurse, it's nice to know what the patient does and doesn't like," said Markley. "We in the healthcare system want to do what the patient wants to the best of our ability."

Markley said studies indicate that 80 percent to 90 percent of people understand they need an advance medical directive, but only 25 to 30 percent have completed one. However, those who have created a directive, haven't necessarily had a conversation with family members about their basic beliefs, values and preferences for care.

"The conversation is a gift, and it is something that needs to be a part of the completion of the documentation," said Markley.

But those conversations often bring up questions that people aren't ready to answer.

"My usual niche is the spiritual problems these people confront," said Dr. Steven Glazer, a Bethesda-based healthcare consultant who brings more than 40 years of experience as a congregational rabbi to his work.

Much of Glazer's work focuses on helping caregivers develop strategies to care for people with Alzheimer's, dementia and related conditions, but some end-of-life decisions require people to consider their personal beliefs and values.

"I'm working with a Stage IV lung cancer patient who pretty much has her ducks in order on practical [matters]," said Glazer. "But she's never really thought about God or dying, so we're exploring things like the legacy she wants to leave."

Glazer said that another aspect of his work is reminding caregivers who are relatives or friends that they must consider their own health as well as that of their loved one. He said caregivers overwork themselves, "often to the extent they become physically ill because they neglected their health or are so exhausted they can't walk."

But regardless of the client, Glazer emphasized that his job is strictly to provide information.

"I don't make decisions for anybody," said Glazer. "I empower them, by providing a broad range of information that makes it easier to deal with these complicated issues."

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