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G COVER

Making the toughest life decision

How to speak with your doctor about the way you would want to die

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MATTHEW CAVANAUGH FOR THE BOSTON GLOBE/FILE

If you woke up tomorrow in intensive care, or were told you had only months to live, would you want the most aggressive care available? Or would you accept the inevitability of death and hope for the best quality of life in your remaining time?

If you couldn't speak for yourself, which option would you want your family or friends to choose for you, and whom would you want to make that decision?

Most hospitals and doctors' groups encourage patients to think through these decisions and draw up advance directives - instructions that explain a person's wishes and designate a medical decision-maker.

But can a piece of paper signed while sitting in a lawyer's office or living room really reflect what someone might feel lying in a hospital bed hooked up to tubes and monitors?

In their book “Your Medical Mind,” published last fall, doctors Jerome Groopman and Pamela Hartzband write about the complexity of advance directives and how hard it is to predict what we will really want as our days wind down.

Care at the end of life is not about deciding “when to pull the plug,” according to Groopman and Hartzband. Rather, it’s about deciding when to shift the focus of medical care from prolonging life to protecting quality of life.

Roberta Cole Fortgang, a clinical social worker with a practice in Newton Highlands, said her parents’ advance directives were a good starting point - but not more.

Her father had wanted to live forever; he refused to talk about death, even at 96 with multiple illnesses. Knowing that, and watching him continue to flirt with his female caregivers, made it easier for her to encourage doctors to keep going with treatment well beyond what she might otherwise have thought was the end.

Her mother, who died in June at 90, had said she never wanted a tube down her throat or major surgery. But her long, slow decline from repeated heart attacks made it much harder to figure out what to do.

“I kept having to reassess and talk to the caregivers and see how far she’s going to go,” Fortgang said.

Doctors used to make all such care decisions themselves.

“In the 1960s, shared decision-making occurred when the doctor shared his decision with you,” said Dr. Ira Byock, director of palliative medicine at Dartmouth-Hitchcock Medical Center, and author of a forthcoming book, “The Best Care Possible,” about end-of-life choices.

Today, most hospitals and care centers - including the Hebrew Rehabilitation Centers where Fortgang’s parents lived - will involve families in the decision of how aggressively to approach the waning stage of life.

“Almost everyone knows someone who suffered with too much aggressive care, so people are more mindful of doing the knee-jerk, do-everything [approach],” said Jody Comart, director of palliative care for Hebrew SeniorLife, and an interfaith chaplain and licensed psychologist. “It is a family’s privilege and burden, both, to be thoughtful about this process and to influence the plan of care.”

Americans used to die quickly. In 1900, most people passed away at home after a brief illness. By 2000, most died in a hospital and were disabled for an average of two years before death, according to the Journal of the Royal Society of Medicine.

As sophisticated as American medical care may be, doctors still cannot predict who’s going to die when. Most formulas used to forecast lifespan are correct no more than 70

percent of the time, according to a January study in the *Journal of the American Medical Association*.

People also adapt to a declining quality of health, and generally want more aggressive care as they get sicker, said Dr. Terri Fried, of the Yale University School of Medicine and the Connecticut Veterans Affairs Healthcare System.

At one point, Fortgang asked her father if he didn't want to give up.

"I said 'Is this a life?' He said, 'It's my life and I'm choosing it,' " Fortgang said. Her mother wanted to live as long as she could still read novels.

Hartzband and Groopman recommend that, before deciding what they want, people consider whether they are strong believers in the power of medicine and technology, or doubters who trust nature and think medical care often does as much harm as good; maximalists who want the most care possible, or minimalists who prefer to avoid even Tylenol.

It's also helpful, they said, to ask doctors for their own mind-sets on these issues, to better understand their recommendations for care. Research by the Dartmouth Atlas Project shows that end of life care differs substantially from one hospital to another and among regions.

Usually, people's life stories will offer insights into their views of the end.

Fried spoke of a patient's family member who was unwilling to give up on aggressive care, because she wanted to give God as much time as possible to intercede with a miracle.

Fortgang's father was convinced that he had used the "right mental attitude" to survive the advanced melanoma that nearly took his life when he was in his 50s. Since it had worked for him once, he believed that his mental fortitude would protect him again, she said.

Groopman said he originally thought his mother was being a bit unrealistic when she chose to try a new therapy even after her breast cancer had spread to her bones and liver. But the treatment gave her an extra 14 months of high-quality life. After being told it wasn't working anymore, she decided not to try another new one, and died two days later.

"She had followed her mind-set and was fortunate that she had such a response" to the medication, Groopman said, "but then deeply felt that she had reached the end."

What's tricky is when patients can't choose for themselves and family members disagree about what mom or dad would have wanted - and that's when an advance directive is particularly useful, the specialists said.

Palliative medicine director Byock says he's got an advance directive to make his family's lives a little easier should catastrophe strike.

"I can help in shouldering some of that burden by giving them clear authority and telling them what I think I would want," he said. That way, "they're making decisions consistent with my wishes, even though they're going to struggle to apply what I said to the specific situations of my injury or illness."

Because every medical situation is different - and changing - Hartzband cautions that an advance directive should not lock people in to one decision or another.

"It's important for people to realize that they can change their mind," she said. "And then change it again," Groopman added.

Fortgang said she is pleased with the care her mother and father received, and feels the decisions she and the caregivers made were the right ones.

Both of her parents were given their full nine lives, Fortgang joked - even though, in making medical decisions for them, "I can't say it didn't take a few lives off mine."

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