

The Washington Post

Columnist Ellen Goodman wants families to have end-of-life talks before a crisis hits



FROM ALAN OLASIN/INSTITUTE FOR HEALTHCARE IMPROVEMENT - Writer Ellen Goodman wants adult children to talk to their parents about end-of-life issues.

December 16, 2013

By Richard Harris, E-mail the writer

It was only as her mother lay dying nearly seven years ago that Ellen Goodman began to realize she had never had a real conversation with her about her end-of-life wishes. By then, it was too late. Her mother was already suffering from dementia.

“She wasn’t really able to say what she wanted for her lunch, let alone what she wanted for health care,” the Pulitzer Prize-winning columnist says. “The only conversation I had had with my mother — and this is often true of people — is when she would see someone and say, ‘If I’m ever like that, pull the plug.’ But there was no plug to pull.”

Goodman felt so unprepared for all the decisions she was forced to make for her mother that she is now preaching one message to anyone who will listen: Have “The Conversation,” and have it early. For those who say they’re too uncomfortable to talk about end of life or say, “It’s too soon,” Goodman’s answer, born out of her own experience: “It’s too soon until it’s too late.”

And so last year she co-founded The Conversation Project with the nonprofit Institute for Healthcare Improvement to provide families with the tools to broach these often emotional and gulp-inducing discussions. Goodman says we need to treat these conversation like death itself —

something that you simply can't avoid, much as we'd like. And she hopes the tool kit makes these often difficult family discussions easier.

In a survey it commissioned, The Conversation Project found that more than nine in 10 Americans think it's important to talk about their own and their loved one's wishes for end-of-life care, but fewer than three in 10 actually engage in these conversations.

Goodman urges families to have the discussion around a kitchen table, not in an intensive care unit where emotions and the pressure of a health crisis can cloud decision-making. To help people initiate the conversation, there is a "starter kit" and guide on the group's [Web site](#). The kit, on how to talk with your family, suggests, among other things, icebreaker lines for an adult child or a parent ("I need your help with something" or "Even though I'm okay now, I'm worried and want to be prepared"). The guide offers advice on how to talk with your doctor about end-of-life care.

So far, more than 62,000 people have downloaded the information, among them Nicole Boissiere, an elementary school teacher in Woodbridge.

Boissiere's mother received a diagnosis of breast cancer five years ago, and in 2011 she learned that she had late-stage ovarian cancer. At the same time, Boissiere's mother-in-law was fighting the deadliest form of lung cancer. Boissiere said her father didn't want to acknowledge what was happening to his wife. He was in such denial that he didn't even want to go to the hospital an hour before his wife died, but Boissiere says he is glad his brother insisted on taking him to say goodbye.

Boissiere has one regret — that she couldn't grant one of her mother's wishes: to die at home. So she is determined to make sure she can fulfill her dad's vision for the end of his life. It used to be that he would ask, "What are you bringing that up for?" anytime Boissiere would raise end-of-life issues. But by using the starter kit to engage her dad in short conversations — asking him a question or two during breaks in football broadcasts — Boissiere thinks she and her 73-year-old father have been brought closer together.

'Conspiracy of silence'

Goodman says every family has a difficult end-of-life story and is hopeful that the "conspiracy of silence" — parents reluctant to worry their adult kids, and kids uncomfortable bringing up the idea of death and final wishes with their parents — is beginning to break down.

Medical technology increasingly is forcing the issue, confronting families with what can be excruciating end-of-life choices. Even though polls show that about 70 percent of people want to die at home, [nearly half of all Americans die in the hospital](#), often wired to machinery in the intensive care unit.

One-quarter of Medicare's budget is spent on treatment in the last year of life. Of that, 40 percent is spent on the [final 30 days](#). And given the coming tsunami of aging baby boomers, experts say such levels of health-care spending may become unsustainable.

Slowly, an increasing number of people are opting for palliative care and a more natural death at home or in hospice. A 2010 New England Journal of Medicine [study](#) showed that patients with newly diagnosed metastatic lung cancer who received palliative care along with their cancer

treatment suffered less depression, enjoyed better quality of life and lived three months longer than those who received standard care alone.

Until we reach immortality — and Google has a new life science start-up, [Calico](#), focused on trying to fight off aging and associated disease — Goodman remains convinced there will always be a need for The Conversation. One reason she helped launch her project, she says with a chuckle, can be summed up in the classic headline from the satirical publication The Onion: “Death rate holds steady at 100 percent.”

Goodman has taken her own advice, talking to an aunt and uncle, both in their 90s. She has also talked with her daughter and stepdaughter, both in their 40s, about her own end-of-life wishes. Her comedienne daughter’s first reaction: “Can’t we have lunch instead?”

How will Goodman know The Conversation Project has had the impact she hopes for? “Probably when the phrase ‘Have you had The Conversation?’ is so much a part of the national dialogue that everyone knows what it means.” In fact, Goodman says, her group is planning an annual day to have folks turn to each other at work, at worship, at dinner and at book groups and ask ‘Have you had the conversation?’

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