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## Opinionator

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### How to Talk About Dying

By [Ellen Goodman](#)

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I was 25 when I flew home for my father's last birthday. His cancer had returned and he would die three months later at the age of 57. What I remember most about that weekend was the large rectangular gift box he opened. My mother had bought him a new suitcase.

Photo



Credit Getty Images

I don't know if that suitcase qualifies my family for the Denial Hall of Fame. There are so many contenders for that honor. But I've carried the psychic baggage over the years. I have never forgotten that image and how we lost a chance to say goodbye. I still wonder if my father was lonely in the silence that surrounded our inability to talk about what we all knew.

Decades later my mother began a long slow decline. By then, I was a newspaper columnist, a job that I often described as "telling people what you think." I was professionally outspoken. But little had changed since my father's death.

Yes, my mother and I talked about everything — but we didn't talk about how she wanted to live toward the end. The closest we ever came to discussing her wishes was when she would see someone in dire straits and say, "If I'm ever like that, pull the plug." But most of the time there is

no plug to pull.

Gradually and painfully, my mother lost what the doctors call “executive function,” as if she were a C.E.O. fumbling with Excel spreadsheets, not a 92-year-old who couldn’t turn on the television or make a phone call. Eventually, she couldn’t decide what she wanted for lunch, let alone for medical care.

In some recess of my mind, I still assumed that death came in the way we used to think of as “natural.” I thought that doctors were the ones who would tell us what needed to be done. I was strangely unprepared, blindsided by the cascading number of decisions that fell to me in her last years.

I had to say no to one procedure and yes to another, no to the bone marrow test, yes and yes again to antibiotics. How often I wished I could hear her voice in my ear telling me what she wanted. And what she didn’t want.

When my mother died from heart failure and dementia, I began to talk with others. It was extraordinary. Everyone seemed to have a piercing memory of a good death or a hard death. Some of these stories had been kept below the surface for decades, and yet were as deep and vivid as if they’d just happened.

Too many people we love had not died in the way they would choose. Too many survivors were left feeling depressed, guilty, uncertain whether they’d done the right thing.

The difference between a good death and a hard death often seemed to hinge essentially on whether someone’s wishes were expressed and respected. Whether they’d had a conversation about how they wanted to live toward the end.

So, a small group of us — each with his or her own story — started the Conversation Project, a nonprofit, out of the belief that surely we could make this easier. Our partners at the Institute for Healthcare Improvement gathered experts frustrated at the pace of change who believed that the health care system wouldn’t change until the culture changed. So we are trying to change the culture.

There is now, finally, a real momentum for improving end-of-life care. The signs range from the Institute of Medicine’s report, “Dying in America,” to the success of Atul Gawande’s book “Being Mortal.”

There is also a growing public awareness of the need to break through the reluctance that has kept us tongue-tied for so long. A survey we did last year showed that 90 percent of Americans now think it’s important to have the conversation. But the same survey showed something else: Only 30 percent of us have actually had these conversations. So the gap remains huge.

We still need to transform the cultural norm from not talking about how we want to live at the end of life to talking about it. The real work to close the gap is not just for doctors and patients. It’s for mothers and daughters, husbands and wives, families and friends. We have to bring people to the kitchen table to talk with those they love to have the conversation. And to do this before there is a crisis. Not in the I.C.U.

In our survey, the primary reason people gave for not talking to their loved ones was “It’s too soon.” But it’s always too soon ... until it’s too late. Half of all elderly people in hospitals cannot

make decisions for themselves at the end of life. Far too many health care providers are uncomfortable and untrained in these conversations.

From all the stories shared with us, we know that what people need most is help getting started. They need a travel guide to take the first steps down an unfamiliar and difficult road. So we created a Conversation Starter Kit, which deliberately avoids being a technical medical checklist for the dying in favor of a careful discussion guide for the living.

Our starter kit asks what matters to you, not what's the matter with you. It asks what's most important to you in the last phase of your life? Who do you want to make decisions for you? Where do you want to be? Do you worry that you won't get enough care? Do you worry that you'll get overly aggressive care?

About two-thirds of the nearly 300,000 people who have come to our website download the starter kit, which is free. We've been told repeatedly that conversations that had loomed as frightening and overwhelming repeatedly turned into the most intimate and rewarding moments.

Is it important to have the health care system ready to respect and record our wishes, to have health care providers become more comfortable beginning these talks? Of course. But the hard truth is that we have to begin ourselves — by thinking about our own values, by sharing them, by bringing our own beliefs into the center of the room when decisions will be made.

In my own adulthood, the culture of birth changed. It wasn't doctors who first tossed out the stirrups and ushered in fathers and video cameras and "birthing rooms." It was parents who said, birth is not just a medical experience, it's a human experience. Now we are finally saying that dying, too, is not just a medical experience, it is also a deeply human experience.

Last winter we held a national dinner party to break bread and taboos, to eat comfort food and talk about dying. I shared the table with [Nancy Frates](#), who is known for starting the A.L.S. ice bucket challenge to honor her son Pete. "Now I understand," she told me. "The conversation is a gift to your family."

When I helped found the Conversation Project, I thought we were doing this for people who were dying. I thought of my parents. I thought of "executive function" and "baggage." What I have learned is that the conversation is also a legacy. This is the gift, maybe the last gift, we can give one another.

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