CAN WE *talk?*

The most important conversation you're not having—about end-of-life care.

by ELLEN GOODMAN

Writer Ellen Goodman

> ***"There is no more important way to care for the people we love right until the end of their lives than to honor their wishes."***

This is how I remember the last Thanksgiving of my mother's life: My family gathered across zip codes and generations to share turkey, lemon pie and a side dish of family stories. For the first time, my mother wasn't at the table. She was two miles away in nursing care, sleeping through her final days.

The next day, I raced out to get pictures printed. I thought maybe I could magically rouse—or at least comfort—my 92-year-old mother with photographs of her great-grandchildren, the ones she could no longer recognize since dementia had overcome her memory. But before I left to go to her, the phone rang and caller ID showed the name of her care facility. With a chilling premonition, I answered. Her gentle nurse told me that my mother had "passed away."

So came the end and yet not the end of my decade-long journey as my mother's caregiver. I was in my 50s when I first went from being the working mother of a growing daughter to being the working daughter of a declining mother. Slowly, imperceptibly, then relentlessly, a cascade of injuries, surgeries, breast cancer and small strokes chipped mercilessly away at her independence. One crisis at a time, I became what one friend called "the Designated Daughter."

Deciding for two

As she slid into a confusion in her late 80s, Mom was no longer able to say what she wanted for lunch, let alone for medical care, so I was faced with many decisions for which I was unprepared and uncertain. I remember feeling both painfully powerless and utterly responsible. Should she go to the hospital...again? Did she really need that spinal tap? Would morphine relieve her pain or hasten her death—or both? What comfort could I offer besides Hershey bars and being there?

I learned that in this high-tech era, death is no longer "natural" but comes with incredibly hard choices. I wondered again and again, *What would you want, Mom?*

Today, seven years after her death, I still ask myself, *How is it possible that we never talked about it?* My mom and I talked about *everything*. I once described her as a person who would talk about my problems until *I* was bored with them. Yet we never talked about how she wanted to live at the end of her life. It always seemed too soon... until it was too late.

I'd felt alone in this, but I was clearly not. Everyone I spoke to later had a story—a story of a "good" death or a particularly hard death among people they loved.

ARM & HAMMER
THE STANDARD OF PURITY

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There was the wife whose husband died in intensive care, the daughter whose dad had final and futile rounds of chemo, and my favorite, the mother who had died her own way, in hospice, eating peanut butter and butter sandwiches, talking peacefully about her life to the end.

Talking and listening

In these stories, the difference between a good death and a hard death often rested on whether people's wishes had been expressed and respected. The sense of guilt, uncertainty—even depression—among survivors often hinged on whether they knew how their loved ones wanted to live at the end of life. I began to believe that we could—and should—make this experience easier and more humane for the people we love and for ourselves.

One story led to another, and finally a small group of us who had experienced the loss of a loved one founded The Conversation Project (*theconversationproject.org*), a campaign to change the cultural reluctance to discuss end-of-life issues, so that everyone will have honest conversations about their preferences. Our goal is that these talks take place at the kitchen table *before* there is a medical crisis.

Today, surveys show that too many people are dying in ways they would not have chosen. Some 70% of people say they want to die at home, yet 70% die in hospitals and institutions. A majority of people say it's extremely important to make sure their family isn't burdened by hard decisions, yet a majority haven't shared their wishes. Parents and adult children often engage in a conspiracy of silence to "protect" each other from the reality of dying.

But now, tens of thousands of people have downloaded the Conversation Starter Kit (see box, *right*). They've brought it to their family gatherings, book clubs and church groups. They've told us that the talks they began with their loved ones were not grim and frightening at all, but among the richest and most intimate of their lives.

In my own family, too, I've had deep, emotional talks with my 94-year-old uncle about his wishes and with my 45-year-old daughter about mine, talks that have left us closer and more prepared. What better time to share this gift than when holidays bring us together?

Dying is never an easy subject, but I now know that there is no more important way to care for the people we love right until the end of their lives than to honor their wishes.

STARTING THE CONVERSATION

It's never easy to bring up this subject. What's important is to *begin*. Below, some icebreakers:

When talking to your parents

Ask for help » "Mom, I need you to help me out—I may have to make decisions for you someday and I need to know what you want."

Bring up a family story » "Remember how Aunt Julie died, on a ventilator, in ICU? Tell me how you felt about that."

Share this article » "I just read this and I'd love to talk about it."

When talking to adult children

Do the mom thing » "I don't want you kids burdened with stressful decisions about me."

Point out the upside » "I'm healthy now, but you'll be grateful we talked about this."

Persist » "I know this is hard, but it's important to me."

The conversation that follows depends on how you want to be cared for in your last years. For a complete kit on which questions to ask, visit *theconversationproject.org*