We're all going to die. Why is it so hard to talk about it?

Most of us don't fear death so much as the process leading up to it.

by Lori Erickson in the August 28, 2019 issue



It's not as if it's a big secret that we're all going to die. It's just that for many of us, most of the time, it seems like an event that's going to happen to someone else, some hypothetical me far in the future. Spiritual teachers in many traditions spend a lot of time trying to get people to see the foolishness of this perspective.

"To contemplate dying each day calls forth an instant reordering of priorities," writes Kathleen Dowling Singh in *The Grace in Aging: Awaken as You Grow Older*. "Just like a quick and deliberate shake of a kaleidoscope, it creates a whole new patterning, a whole new view." I've seen that shake of the kaleidoscope happen many times in those who've received a terminal diagnosis. Even if they've managed to avoid any serious spiritual inquiry in the years leading up to that moment, death's imminent arrival often focuses their attention. Most are able to let go of the pettiness, the anxieties, and the prickliness that may have plagued them for decades. Lifelong jerks get a little less obnoxious. Introverts start opening up. Extroverts shut up so that other people can speak without interruption. Almost everyone I've known near death becomes a little nicer, knowing they're near the exit.

It's a shock to see a body after its life force has departed, no matter how the end occurs or how emotionally close you were to the deceased. The corpse is like a piece of clothing left crumpled on the bedroom floor, fundamentally different than when it was animated by the person wearing it.

I'm grateful to have made the acquaintance of death in a variety of forms, peculiar as that may sound. In a society where dying is so removed from most people's lives, we lose the chance to become familiar with its outlines and psychic shape. Familiarity can bring understanding, and maybe a little less fear of the inevitable.

These experiences have made me rethink how I want to go. I used to think I'd like to die quickly—crushed by a falling boulder on a mountain hike, for example, or hit by a bus crossing a street. But there's a lot to be said for knowing in advance you're going to die. You have time to tie up loose ends, say good-bye, and give thanks to God and loved ones. You can remove any embarrassing items from your dresser drawers, safety deposit box, or storage unit. And if your sins are weighing heavily on your shoulders, you have the chance to get them expunged from your spiritual rap sheet.

During my tenure as a writer of Iowa ghost stories, I found it curious how many of them involved a sudden death, one that left the deceased with unfinished business of some sort. I heard numerous stories of spirits coming back to tell relatives where money is hidden or to ask forgiveness, things they didn't have the chance to do in life. It's an argument for having at least a little advance notice of your imminent demise.

Years ago, I attended a talk given by a palliative care physician about this process of getting ready to die. He began by asking us to list on a piece of paper three sets of things. First, we wrote down five possessions that gave us pleasure; second, we

listed five activities that gave us joy; and third, we named the five people we loved most in the world.

After we completed our lists, the doctor began talking about a hypothetical patient, a woman whose days were filled with the usual routines, joys, and stresses of ordinary life. But after she discovered a lump in her body, there came a cascade of medical interventions: first a biopsy, then surgery, radiation, and chemotherapy. After a year, it became clear that the treatments weren't working, and the oncologist told her that she should get her affairs in order. She entered hospice care, and gradually her world shrank to the size of her bedroom.

And throughout this story, the doctor periodically paused to ask us to cross an item off our list.

The possessions and activities went first, of course. Each was a choice—which would I hate to give up more, my laptop or my car? Biking or walking? Then it was time to start crossing off people, each decision an agonizing, *Sophie's Choice* dilemma. By now it was clear where this exercise was headed, and most of us, even the men, were borrowing tissues from the women who were organized enough to keep a packet in their purses. By the time the doctor's hypothetical patient died, all of us had gone through a similar shedding of what we held dearest, leaving us the emotional equivalent of limp noodles.

Buddhist teachers in particular seem to take great pleasure in pointing out people's inevitable deaths.

Well, not exactly *pleasure*, as my friend Scott explained to me when we met in a coffee shop after he returned from a weekend retreat during which he meditated on his own death. Yes, there are such workshops, and people are lining up to take them. "I only got in because someone else had to drop out," Scott said. (I didn't ask why.)

Not surprisingly, the weekend had been a powerful experience for Scott, beginning with a Friday evening presentation during which the leader (a Zen teacher of considerable reputation) had announced that everyone in the room would be dying on Sunday. She said they should select the form of their departure—heart attack, car accident, whatever—and then spend their weekend preparing mentally and spiritually for that event. "We did a variety of activities, including writing letters to our loved ones and deciding who should get what among our possessions," Scott said. "Our teacher led us in a life review, too, where we looked back on significant events and turning points. And we spent a lot of time in contemplation, trying to get an experiential sense for what it meant to face death on Sunday. It was intense."

"Then why did you do it?" I asked.

Scott replied by describing his work as a therapist, which includes counseling people who are dying. He has always told his clients that if you avoid something important, you invest it with a tremendous amount of energy. "If you face it, if you let in what you fear, that energy dissipates," he said. "It doesn't go away completely, but it can become manageable. That's what happened to me during the weekend."

For Scott, as for most of us, we fear not only our own deaths but also the effect our leaving will have on those we love. "In many ways, that was the hardest part to contemplate," he said. "I had feelings of fear and immense sadness. But do I walk around getting pissed off because there's gravity? Death is the same sort of immutable law."

By the end of the weekend, he said, all that was left in him was love, compassion, and forgiveness. "I don't know how to explain it in any other way," he said. "I'm not a believer in the afterlife, but still . . . by the end of the weekend, something opened in me. It's all more of a mystery to me now, what happens after we die. But most of all I keep coming back to that profound feeling of love and compassion and forgiveness."

His eyes filled with tears, and we sat in silence for several moments, while all around us flowed the conversations and clatter of the coffee shop, the everyday details of life that too often obscure the truths hidden underneath.

This stripping of possessions, status, and relationships happens to everyone as they die. Even those of us who believe death is not the final end and that we'll get the chance to see our loved ones again can't deny that in the short term, there's plenty of sadness to go around.

Spiritual teachers of many stripes, showing the kind of irrational optimism that makes them both beloved and scorned, insist that this is exactly when things get really interesting. Singh says that as we approach death, we undergo a powerful inner transformation. Even if during our lives we don't advance very far on a spiritual path, in the nearing-death experience we go through a series of spiritual stages, which include relaxation, withdrawal, radiance, silence, sacredness, transcendence, intensity, and perfection.

Singh summarizes what's most important about the nearing-death experience: "Dying is safe. . . . You are safe. Your loved one is safe. . . . Dying, remarkably, is a process of natural enlightenment, of finally coming home to our true self."

In my own time spent in hospital rooms and at the bedsides of the dying, I've come to see the truth of her words. Especially for those with a chronic illness, death often comes as a welcome release from suffering and an anticipated next step on a journey to mystery.

But getting to that point can be difficult, because what most of us fear isn't death but the process leading up to it.

Sometimes, the shortest journeys can be the most transformative. Take, for example, what happened when Dr. Angelo Volandes started taking patients who had received a terminal diagnosis on a tour of the intensive care unit at his hospital. He wanted to give them a clearer sense of the kinds of procedures that are often done on people who are critically ill. As they passed by patient rooms, they observed people on ventilators. They saw the rush of activity when someone coded and how the medical staff worked furiously to get them stabilized.

Volandes led these journeys to the ICU to give his patients a realistic picture of what end-of-life care often involves in a modern medical center, which is very different from what's typically portrayed on TV or in films. After his patients toured the ICU, all of them prepared advance care directives that spelled out their wishes in case they couldn't communicate later. Not surprisingly, most of them chose not to include the extraordinary methods that may prolong life but often at the cost of great suffering.

I was fortunate to meet Volandes when he visited my hometown at the invitation of a nonprofit organization called Honoring Your Wishes, which encourages advance care planning for everyone, not just those nearing death. I serve on the board of the organization, which has the difficult task of encouraging perfectly healthy people to think about their deaths— the equivalent of a *New Yorker* cartoon of the Grim Reaper showing up at a cocktail party, hovering over the canapés. In his book, *The Conversation: A Revolutionary Plan for End-of-Life Care*, Volandes points out a distressing paradox in how most Americans die. The majority of us want to breathe our last at home, surrounded by those we love. Instead, two-thirds of Americans die in health-care institutions, often after undergoing medical procedures that were performed because loved ones didn't know their wishes in advance and doctors needed to protect themselves from potential liability.

"Americans receive some of the best health care money can buy; they also experience some of the worst deaths in the developed world," Volandes writes.

In his presentation to our group, Volandes elaborated on those ICU visits that were so transformative for his patients. They turned out to be life-changing for him too.

I started thinking about how we could make this information available to everyone and so we put together a series of videos that explain various end-of-life options. Seeing how well these have been received around the country makes me even more convinced that everyone should have conversations about their end-of-life wishes, both with their medical providers and with their loved ones. These conversations aren't easy, but they're vitally important.

I knew the truth of Volandes's words, having witnessed firsthand the contrast between people who died at home, kept comfortable by medical professionals but not subjected to harrowing treatments that cause pain and distress, and those whose death was marked by unnecessary suffering. I was determined that my husband, Bob, and I weren't going to be in the category of people who think they'll get around to doing this paperwork eventually but not now.

So we met with a facilitator trained in advance care planning, a motherly woman who led us in a discussion of the medical interventions we'd want if we weren't able to make our wishes known. We discussed these options with our sons, who will have legal authority to make decisions for us if we're both unlucky enough to end up in comas at the same time. We signed the forms, had them notarized, and then filed them in the appropriate places. I felt virtuous and well prepared.

Then I tried to do the same process with my mother.

At this time she was still living on her own and showed no signs of the dementia that would eventually cloud her mind. I had my little speech all prepared: I'd tell her about serving on the Honoring Your Wishes board, and Dr. Volandes's visit, and how Bob and I had done our paperwork, and how I thought it would be a good thing for her to do the paperwork, too, so we'd know exactly what her wishes were should she not be able to communicate them.

I gave my presentation, using all my best techniques of storytelling, humor, and empathy. Still, my mother's face darkened. I talked faster, sounding increasingly like a door-to-door vacuum cleaner salesman who could see a purchase slipping away. I started throwing other things into the pot—ventilators, burial versus cremation, hymns at her funeral, feeding tubes, cemetery plots, do-not-resuscitate orders. Everything was met with stony silence. I finally ran out of words.

Then came the blowback. My mother, God bless her, was capable of quite an impressive head of emotional steam before she began her cognitive decline. And bringing up her death was the trigger for one of the worst arguments we'd had in years. She raised her voice, asking why I was so interested in having her die, and I felt my face get red as I struggled to keep from snapping at her. The temperature in the room dropped to arctic levels. Eventually we retreated to opposite ends of the house. "Well, that went pretty well, don't you think?" Bob offered.

Two months later, I got a phone call from my sister. "Mom signed the advance care papers when I visited this week," Julie said.

"How in the world did you get her to do it?" I asked.

"It was easy—when we met with her banker, he mentioned that she should take care of it."

"Did she argue with him?"

"Not a single word."

The somewhat tempestuous side of our relationship is a thing of the past now. When I visit my mother in the nursing home, it's a relief not to have things to argue about. Our conversations are nearly always pleasant: we talk about the weather, the food, and her work at the college. "I'm slowing down some," she says as we walk down the hallway to her room. "But I don't want to go into a nursing home, so I don't mind working."

"You'll know when it's time to quit," I say.

We sit in the lounge together, admiring the view out the floor-to-ceiling windows. It's a cold winter day, but inside the building it's toasty warm. Watching snowflakes drift to the frozen ground outside, I don't mind the tropical temperature.

"It's nice here," she offers. "People are so friendly." We talk some more about the weather, and the food, and her job at the college, and I give a silent prayer of thanks for the banker, who did what I couldn't do.

This article is excerpted from Lori Erickson's forthcoming book <u>Near the Exit: Travels</u> with the Not-So-Grim Reaper (Westminster John Knox Press). A version of it appears in the print edition under the title "We need to talk about death."