
ESSAY

Preparing for a Good End of Life

The best way to achieve a peaceful death is by planning ahead and enlisting the help of loved ones.

By Katy Butler

I recently turned 70 in Marin County, Calif., home to some of the healthiest, wealthiest and longest-lived people in the country. I swim daily, take no medications and can still hoist my roll-aboard bag into an overhead bin. But there is no denying that somewhere beyond the horizon, my death has saddled his horse and is heading my way. And I'm hoping to make that death as good as my life has been.

My wish is to die in my own bed, cared for by people I love—clean, comfortable and relatively free from pain.

I hope to have time to say my goodbyes and give my final blessings. But in our technologically advanced society—despite the billions we spend on end-of-life medical care—this simple, old-fashioned and once-inexpensive death is harder to achieve than you might think.

According to a 2017 Kaiser Foundation study, seven in 10 Americans hope to die at home. But half die in nursing homes and hospitals, and more than a tenth are cruelly shuttled from one to the other in their final three days. Pain is a major barrier to a peaceful death, and nearly half of dying Americans suffer from uncontrolled pain. Nobody I know hopes to die in the soulless confines of an Intensive Care Unit. But more than a quarter of Medicare members cycle through one in their final month, and a fifth of Americans die in an ICU.

In his final year of life, retired IBM manager Ed Walski, who had Parkinson's disease and dementia, was shuttled nine times between his assisted living apartment and hospitals and nursing homes. "The first few times I'd say, OK, we got him through this, and now he's going to get rehab and be back where he was," said his daughter Karen Randall, a veterinarian in Silver Spring, Md. "But he never came back. It was a stair step down to the basement." Despite financial resources and a devoted daughter, Walski's dying was far more chaotic and painful than it needed to be.

I don't want that to be my story.

I've spent the past three years interviewing hundreds of people who have witnessed good deaths and hard ones, and I consulted top experts in end-of-life medicine. This is what I learned about how to get the best from our imperfect health-care system and how to prepare for a good end of life.

Imagine what it would take to die in peace and work back from there. Have a vision. Some doctors assume that everyone wants to extend life until there is no joy left in the living of it. They're mistaken. In the Kaiser study, most people cared much more about not having their families financially burdened by their care or distressed by tough medical decisions; having their medical preferences honored; and dying in peace spiritually, with their loved ones around them. Living as long as possible was at the very bottom of most people's lists.

Imagine what it would take to die in peace and work back from there. Whom do you need to thank or forgive? Do you want to die under the stars or listening to a Mary Oliver poem or with Willie Nelson's "On the Road Again" playing? Any of this is possible if you face death while still enjoying life and recognize the pitfalls of modern medicine.

Advanced medicine is replete with treatments (ventilators, dialysis, defibrillators, feeding tubes, to name a few) that postpone death and prolong misery without restoring health. The default setting is often to provide them until the whole family unequivocally says "No." Get clear, long before that final panicked call to 911, on what gives your life joy and meaning. When you can no longer enjoy those things, what medical treatments would you refuse? Nobody can answer this for you. We vary widely in how much suffering we're willing to endure for more time on earth.

Talk to those you love about what a good "quality of life" means to you and put it in writing in a letter or advance directive. Appoint someone with people skills and a backbone to speak for you if you can no longer speak for yourself. The best choice for your "health care agent" isn't necessarily a close family member. In

a crisis, he or she may be too overwhelmed to let you go.

Stay in charge. If your doctor isn't curious about what matters to you or won't tell you what's going on in plain English, fire that doctor and find another. That's what Amy Berman did when a prominent oncologist told her to undergo chemotherapy, a mastectomy, radiation and then more chemo to treat her stage-four inflammatory breast cancer. This course would have destroyed her quality of life without curing her rare, and usually lethal, variant of breast cancer. "I thanked him for his time and left," said Ms. Berman, a health policy grantmaker for the John A. Hartford Foundation.

She engaged another oncologist who asked her, "What do you want to accomplish?" Ms. Berman said that she was aiming for a "Niagara Falls trajectory:" To live as well as possible for as long as possible, followed by a rapid final decline.

It has been eight years since then, and Ms. Berman is now 59. She hasn't undergone surgery or chemo, been hospitalized or gone into debt. A daily estrogen-suppressing pill slows her disease, and a one-time intense burst of "palliative radiation" eliminated pain from cancer cells that had spread to her spine. She's kept working, ridden a jet ski to the Statue of Liberty, written for the Washington Post, watched her daughter graduate from college and gone snowmobiling in Iceland. "Most doctors," she says, "focus only on length of life. That's not my only metric."

Know the trajectory of your illness. If you face a frightening diagnosis, ask your doctor to draw a sketch tracking how you might feel and function during your illness and its treatments. A visual will yield far more helpful information than asking exactly how much time

illness and its treatments. A visual will yield far more helpful information than asking exactly how much time you have left. Such predictions are as unreliable as weather forecasts, and most doctors vastly overestimate.

A sketch, on the other hand, will yield a surprising amount of actionable intelligence. It may help you, in particular, to recognize the advent of the precarious health stage that I call the “house of cards.” This fragile state is marked by needing caregivers and repeatedly returning from hospital stays worse off rather than better. At this stage, consider shifting your emphasis from cure to comfort and find an alternative to the emergency room. Look for a physician or nurse housecall service or a home-based palliative care or “serious illness management” program. All of this may be easier for people with money, but that is not the only determinant of a good decline and death. Two of the best deaths I studied involved people with little savings, and some of the worst were inflicted on people with plenty of money and rolodexes full of influential names. If funds are low, seek out government programs like PACE (the Program of All-Inclusive Care for the Elderly), which provides medical care at home, and other services that relieve burdens on family caregivers. And don’t be afraid of hospice. It won’t make you die sooner, it’s covered by insurance, and you are more likely to die well, with your family supported and your pain under control.

Find your tribe and arrange caregivers. Dying at home is labor-intensive. Hospices provide home visits from nurses and other professionals, but your friends, relatives and hired aides will be the ones who empty bedpans and provide hands-on care. You don’t have to be rich, or a saint, to handle this well. You do need one fiercely committed person to act as a central tentpole and as many part-timers as you can marshal. People

who die comfortable, well-supported deaths at home tend to have one of three things going for them: money, a good government program or a rich social network of neighbors or friends.

When my former dance teacher Stephanie Moore got ovarian cancer, she drew on the gratitude bank that she'd built over years of teaching salsa and swing. One well-organized woman created a calendar of helpers who took four-hour shifts. Her daughter was at her cottage daily. I brought dinner once a week, and my husband drove her to chemotherapy. Because commitments were widely shared, no single person was overwhelmed. When Stephanie died five months later, everyone could look back with pride on the job they had done.

So don't wait until you're at death's door to explore your passions, deepen your relationships and find your posse. It doesn't matter if you discover it among fellow quilters, folk-dancers, bridge-players, Tai Chi practitioners, or in the Junior League, the Rotary or the Christian Motorcyclists Association. You just need to get together regularly and share an activity face to face. Take command of the space. No matter where death occurs, you can bring calm and meaning to the room. Don't be afraid to rearrange the physical environment. Weddings have been held in ICUs so that a dying mother could witness the ceremony, and dogs have been smuggled onto hospital floors. In a hospital or nursing home, ask for a private hospice room or "comfort suite," get televisions and telemetry turned off and stop the taking of vital signs. You can turn a bedside table into an altar for flowers, family photographs or religious icons. Open flames are forbidden, but electric LED "candles" can create a sacred feeling.

Those who contemplate their aging, vulnerability and

mortality often live better lives and experience better deaths than those who don't. Hospital staff may help if you ask. When Liz Salmi's mentor lay unconscious on a ventilator in a dark, windowless ICU room, attended by a cacophony of hisses and electronic bleeps, she and other close friends lobbied for a better setup. All monitors but one were silenced, a doctor removed the breathing tube, and nurses and aides gurneyed her dying friend quickly into the ICU's "best room"—a sunny spot, with windows opening to the outdoors. One friend set up small speakers and cued a playlist. "Unburdened by machines," Liz wrote on her blog, *TheLizArmy*, "his body began sinking into the bed. I said, 'this is natural,' to remind myself that I was witnessing part of the cycle of life, much like a baby crying when born." Liz remembers a peaceful death, in fresh air and sunlight, with the man's favorite music playing and his closest friends holding him.

Think of death as a rite of passage. In the days before effective medicine, our ancestors were guided by books and customs that framed dying as a spiritual ordeal rather than a medical event. (One of the West's first best-selling self-help books, published in 1450 in Latin, was titled "The Art of Dying.") A spiritually mature individual was expected to contemplate it ahead of time. Without abandoning the best of what modern medicine has to offer, return to that spirit. Don't reduce the end of your life to a medical procedure or strip it of ceremony and humanity. Make sure you live and die as a full human being.

Over the years, as I've listened to hundreds of stories, I've learned one thing: Those who contemplate their aging, vulnerability and mortality often live better lives and experience better deaths than those who don't. They shape lives of comfort, joy and meaning, even as their bodies decline. They get clear-eyed about the trajectory of their illnesses, so they can plan. They

regard doctors as their consultants, not their bosses. They seek out medical allies who tell the truth and help them thrive in the face of adversity. They enroll in hospice earlier, and often feel and function better—and sometimes even live longer—than those who pursue maximum treatment. And they often die with less physical suffering, and just as much attention to the sacred, as our ancestors did.

There is a way to a peaceful, empowered death, even in our era of high-tech medicine. If you accept the reality of death and plan for it rather than fight it, you can restore dignity, community and, yes, even beauty to your final passage.

That's not to promise it will be easy. I wish I could guarantee you a vigorous old age, a short decline and a swift, painless death. I wish I could tell you that our nation routinely provides supportive, well-coordinated health care for all people, no matter what their incomes, in the often-prolonged passage from active living to active dying. But let's face it: We influence our lives, but we don't control them, and the same goes for how they end. No matter how bravely you adapt to loss and how cannily you navigate our fragmented health system, dying will still represent the ultimate loss of control.

But you don't have to be a passive victim. You retain moral agency. You can keep shaping your life all the way to its end—as long as you seize the power to imagine, to arrange support and to plan.

—This essay is adapted from Ms. Butler's new book, "The Art of Dying Well: A Practical Guide to a Good End of Life," which will be published on Feb. 19 by Scribner.

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