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## **The Ultimate End-of-Life Plan**

**How one woman fought the medical establishment and avoided what most Americans fear: prolonged, plugged-in suffering**

By

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Valerie Butler around 1990. After Ms. Butler developed heart problems, she refused surgery because of its risks. Butler family

My mother died shortly before her 85th birthday, in a quiet hospital room in Connecticut. One of my brothers was down the hall, calling me in California to say, too late, that it was time to jump on a plane. We were not a perfect family. She did not die a perfect death. But she died a "good-enough" death, thanks to choices she made earlier that seemed brutal at the time.

She slept in her own bed until the night before she died. She was lucid and conscious to the end. She avoided what most fear and many ultimately suffer: dying mute, unconscious and

"plugged into machines" in intensive care; or feeling the electric jolt of a cardiac defibrillator during a futile cardiopulmonary resuscitation; or dying demented in a nursing home. She died well because she was willing to die too soon rather than too late.



Valerie de la Harpe Butler and Jeffrey Butler as university students in 1946. The couple came to the U.S. from South Africa and had three children. Butler family

Don't get me wrong: My mother, Valerie de la Harpe Butler, loved life. She was descended from Swiss-French and Dutch Calvinist pioneers who "trekked" with their ox wagons into the dusty interior of South Africa in the mid-1800s. She and my father, Jeffrey Butler, left their African homeland in their early 20s, bursting with immigrant vigor, raised three children (all of whom ultimately moved to California) and built a prosperous life in the U.S. My father became a college professor. My mother, an amateur artist, photographed Wesleyan University faculty for their book jackets, practiced Japanese calligraphy and served tea at four without fail.

When she got breast cancer in her 40s, she did not hesitate to undergo medical treatment at its most brutal and effective. After two mastectomies and radiation, she put up her blonde-

streaked hair in its classic French twist and returned to the world as the beautiful woman she'd always been. Even as she approached 80, she hiked 2 miles a day, sewed elegant blouses on her Swiss sewing machine, weeded her garden and even stained her own deck.

She also spent six years as a family caregiver, after a crippling stroke destroyed my father's independence when he was 79 and she was 77. A hastily-inserted pacemaker forced his heart to outlive his brain, and she watched him slide year by year into dementia and misery. His medically-prolonged dying made her painfully aware of health care's default tendency to promote maximum longevity and maximum treatment. It wasn't what she wanted for herself.

She was not alone. In California, my home state, a 2012 survey by Lake Research Partners and the Coalition for Compassionate Care of California found that 70% of state residents want to die at home, and national polls have registered even higher proportions. But in fact, nationally, less than a quarter of us do. Two-fifths die in hospitals, and a tragic one-fifth in intensive care, where deaths are often harrowing. This is an amazing disconnect in a society that prides itself on freedom of choice.



The Butlers at their wedding in September 1947. Butler family

This disconnect has ruinous economic costs. About a quarter of Medicare's \$550 billion annual budget pays for medical treatment in the last year of life. Almost a third of Medicare patients have surgery in their last year of life, and nearly one in five in their last month of life. In their last year of life, one-third to one-half of Medicare patients spend time in an intensive care unit, where 10 days of futile flailing can cost as much as \$323,000. Medical overtreatment costs the U.S. health care system an estimated \$158 billion to \$226 billion a year.

Why don't we die the way we say we want to die? In part because we say we want good deaths but act as if we won't die at all. In part because advanced lifesaving technologies have erased the once-bright line between saving a life and prolonging a dying. In part because saying "Just shoot me" is not a plan. Above all, we've forgotten what our ancestors knew: that preparing for a "good death" is not a quickie process to save for the panicked ambulance ride to the emergency room. The decisions we make and refuse to make long before we die help determine our pathway to the final reckoning. In the movie "Little Big Man," the Indian chief

Old Lodge Skins says, as he goes into battle, "Today is a good day to die." My mother lived the last six months of her life that way, and it allowed her to claim a version of the good death our ancestors prized.



Valerie Butler in 1986. Butler Family

In the early spring of 2009, I discovered that my mother, then 84, could no longer walk around Wesleyan's indoor athletic "cage" without catching her breath. She had developed two perilously stiff and leaky heart valves. In a pounding rainstorm, I drove her to Boston's Brigham and Women's Hospital, a pioneer in heart-valve replacement surgery for the very old. The surgeon told her that if she survived surgery, she could live to be 90. Without it, she had a 50-50 chance of dying within two years. My mother weighed the surgery's real and often underplayed risks of stroke and dementia. Then she said no.

Her later cardiologists were disturbed by her decision. But I would discover that people of my mother's age are often like Humpty-Dumpty, seemingly vigorous until a mishap, a traumatic surgery or a hospital-acquired infection sets them on a rapid downward spiral. One

of my friends watched her 87-year-old mother die gruesomely, over three months, after exactly the surgery my mother rejected.

Still, my mother's "heart-failure management" nurse urged me to get her to reconsider. Aside from her heart, the nurse said, my mother was healthy and full of life. Torn, I called my mother's internist. "I know your mother well enough, and I respect her," he said. "She doesn't want to risk a surgery that could leave her debilitated or bound for a nursing home. I think I would advise the same decision if it was my Mom."



Ms. Butler with husband Jeffrey and daughter Katy, the author, in 1983. Even in her later years, she hiked 2 miles a day, sewed blouses on her sewing machine, weeded her garden and stained her own deck. Matt Herron

I called my mother and said, "Are you sure? The surgeon said you could live to be 90."

"I don't want to live to be 90," she said.

"I'm going to miss you," I said, weeping. "You are not only my mother. You are my friend."

That day I stopped pressuring my mother to live forever and began urging her doctors to do less rather than more. A generation of middle-aged sons and daughters are facing this dilemma, in an era when advanced medical technologies hold out the illusion that death can be perfectly controlled and timed.

This was not the world of our ancestors. From the plagues of the Black Death through the 19th century's epidemics of typhoid, childbed fever and tuberculosis, they helplessly watched people die, from youth to old age. By necessity, they learned how to sit at a deathbed and how to die.

That changed in the 1950s and 1960s, when doctors and inventors in the U.S. and Europe cobbled together astonishing new medical contraptions from washing machines, vacuum cleaners, cattle watering tubs, orange-juice cans and sausage casings. Materials invented or pressed into military service during World War II—nylon, Dacron, silicon, plastics—were put to miraculous new civilian uses.

Vaccines, antibiotics, dialysis, open-heart surgery, CPR, the 911 system, cardiac defibrillators, safer surgical techniques, pacemakers—a whole panoply of lifesaving inventions transformed medical practice and all but abolished natural death. Dying moved from the home to the hospital, obliterating Western death rituals, transforming the meaning of the body, and changing the way families, doctors, nurses—and even the dying themselves—behaved at the deathbed. Dying was transformed from a spiritual ordeal into a technological flail.



After her husband suffered a stroke, Ms. Butler spent six years as his caregiver. The couple in May 2006, here. Butler Family

Family members who once wiped the brows of the dying were restricted to visiting hours. Often there were no "last words" because the mouths of the dying were stopped with tubes and their minds sunk in chemical twilights to keep them from tearing out the lines that bound them to Earth. Months after an ICU death, family members experience high rates of anxiety, depression and symptoms of post-traumatic stress.

As the up-to-the-minute machines spread to newly prosperous countries around the world, they transformed the look of the dying body as well. "When I first started out washing and coffining corpses early in 1965, the majority of cases were home deaths," wrote the Japanese Buddhist mortician Shinmon Aoki. "[The bodies] looked like dried-up shells, the chrysalis from which the cicada had fled.

"Along with the economic advances in our country, though, we no longer see these corpses that look like dead trees," he wrote in his memoir, "Coffinman." "The corpses that leave the hospital are all plumped up, both arms blackened painfully by needle marks made at transfusion, some with catheters and tubes still dangling. There's nothing natural about the way they died, as the image of dried leaves falling in autumn would impart. This tells us that our medical facilities leave us no room to think of death."

In the 1400s, a best-selling how-to book called "Ars Moriendi," or "The Art of Dying," offered saints and sinners alike a road map to the deathbed—framed not as a place of meaningless suffering but as a mighty, transcendent battleground where angels and demons struggled for control of the soul. Family and friends gathered at the bedside and recited

prescribed prayers, giving the dying person reassurance, faith and hope. Similar guides, adapted to Protestant and Quaker theologies, stayed in print until the late 1800s. Because we do not have such pathways now, it's no surprise that relatives often panic and insist that "everything be done," even things that are torturous and futile. Any plan seems better than no map at all.

That spring my mother fixed cracked windows in her basement and threw out files for the book my father never finished writing. She told someone she didn't want to leave a mess for her kids. Her chest pain worsened, and her breathlessness grew severe. "I'm aching to garden, to tidy up the neglect of my major achievement," she wrote in her journal. "Without it the place would be so ordinary and dull. But so it goes. ACCEPT ACCEPT ACCEPT."

In July, a new cardiologist suggested inserting stents to reduce her chest pain and an experimental mitral valve replacement, performed by floating the device down a vein. "When I mentioned stroke risk," he wrote in his clinical notes, "She immediately was turned off and did not want to pursue further discussion, again desiring only palliative care."



The Japanese brush painting that she made and labeled, 'For my memorial service.' Butler family

That August, she had a heart attack. One of my brothers flew to her hospital bed while I raced to meet a work deadline. The next day I got a call from yet another cardiologist who had been handed my mother's case. The narrowing in my mother's heart vessels was in places too difficult to stent, she said. They were preparing her for heart bypass surgery and valve replacement—the very surgery she had rejected five months before.

She seemed to be heading down the greased chute toward a series of "Hail Mary" surgeries—risky, painful and harrowing, each one increasing the chance that her death, when it came, would take place in intensive care. I later discovered that the cost to Medicare would probably have been in the \$80,000 to \$150,000 range, with higher payments if she'd suffered complications.

Burning with anger, I told the astonished cardiologist that my mother had rejected surgery when she had a far better chance of surviving it, and I saw no reason to subject her to it now. I later found that in a major study, 13% of patients over 80 who underwent combined valve and bypass surgeries died in the hospital. In a smaller study, 13% died in the hospital and an additional 40% were discharged to nursing homes.

I called my mother in the hospital.

I said, "I think we're grasping..."

"—at straws," she finished my sentence. She was quiet. "It's hard to give up hope."

Four hours later she called back. "I want you to give my sewing machine to a woman who really sews. It's a Bernina. They don't make them like this anymore. It's all metal, no plastic parts."

"I'm ready to die," she went on. I could barely recognize my stoic and reserved mother. "Cherish Brian," she said, speaking of my long-term partner. "I *love* Brian. I *love* Brian for what he's done for you."

My mother was now sick enough to qualify for hospice care, and came home tethered to a portable oxygen tank. She apologized to me for not having sufficiently appreciated a loving little book I'd handcrafted in honor of her 80th birthday. She updated her will. A hospice nurse cut off her long white hair. She took digitalis and squirted morphine under her tongue to manage her intense heart pain.

She watched a moth emerge from a chrysalis and took her last photograph of its wet crumpled wings. She pulled out her Japanese ink stone and calligraphy brushes and brushed out a final one-stroke circle, what the Japanese call an enso. Below it she wrote, "For my memorial service."

I was making flight plans when she and I talked on the phone for the last time. In an outpouring, I told her how I treasured the memory of her ritual teas and regretted not having learned more of her elegance in domestic matters.

"But Katy," she said, her voice weak. "You're good at other things." Then she said, "There isn't much time."

That night she could not stop vomiting. She was taken to the inpatient hospice unit with one of my brothers following the ambulance. Once settled into her bed, she took off her hammered silver earrings and said to the nurse, "I want to get rid of all the garbage." Naked she had come into the world, and naked she would return. The next morning she told my brother to call his two siblings in California. By the time he got back, she was dead. He broke into sobs.

She died too soon for my taste. I agonized over my failure to fly in and help her. But she died the death she chose, not the death anyone else had in mind. Her dying was painful, messy and imperfect, but that is the uncontrollable nature of dying. I tell you her story that we may begin to create a new "Art of Dying" for our biotechnical age. She died a good-enough death, and she faced it head-on.

*Adapted from: Knocking on Heaven's Door, by Katy Butler. (Scribner, a division of Simon & Schuster, 2010.)*