

What Broke My Father's Heart



Photo: Eugene Richards for The New York Times. The Connecticut home of the author's parents. The photo on the wall is of her parents as a young couple.

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One October afternoon three years ago while I was visiting my parents, my mother made a request I dreaded and longed to fulfill. She had just poured me a cup of Earl Grey from her Japanese iron teapot, shaped like a little pumpkin; outside, two cardinals splashed in the birdbath in the weak Connecticut sunlight. Her white hair was gathered at the nape of her neck, and her voice was low. “Please help me get Jeff’s pacemaker turned off,” she said, using my father’s first name. I nodded, and my heart knocked.



Photo: Eugene Richards for The New York Times. Katy Butler sorting through her parents' belongings after their deaths.

Upstairs, my 85-year-old father, Jeffrey, a retired Wesleyan University professor who suffered from dementia, lay napping in what was once their shared bedroom. Sewn into a hump of skin and muscle below his right clavicle was the pacemaker that helped his

heart outlive his brain. The size of a pocket watch, it had kept his heart beating rhythmically for nearly five years. Its battery was expected to last five more.

After tea, I knew, my mother would help him from his narrow bed with its mattress encased in waterproof plastic. She would take him to the toilet, change his diaper and lead him tottering to the couch, where he would sit mutely for hours, pretending to read Joyce Carol Oates, the book falling in his lap as he stared out the window.

I don't like describing what dementia did to my father — and indirectly to my mother — without telling you first that my parents loved each other, and I loved them. That my mother, Valerie, could stain a deck and sew an evening dress from a photo in *Vogue* and thought of my father as her best friend. That my father had never given up easily on anything.

Born in South Africa, he lost his left arm in World War II, but built floor-to-ceiling bookcases for our living room; earned a Ph.D. from Oxford; coached rugby; and with my two brothers as crew, sailed his beloved *Rhodes 19* on Long Island Sound. When I was a child, he woke me, chortling, with his gloss on a verse from “The Rubaiyat of Omar Khayyam”: “Awake, my little one! Before life's liquor in its cup be dry!” At bedtime he tucked me in, quoting “Hamlet”: “May flights of angels sing thee to thy rest!”

Now I would look at him and think of Anton Chekhov, who died of tuberculosis in 1904. “Whenever there is someone in a family who has long been ill, and hopelessly ill,” he wrote, “there come painful moments when all timidly, secretly, at the bottom of their hearts long for his death.” A century later, my mother and I had come to long for the machine in my father's chest to fail.

Until 2001, my two brothers and I — all living in California — assumed that our parents would enjoy long, robust old ages capped by some brief, undefined final illness. Thanks to their own healthful habits and a panoply of medical advances — vaccines, antibiotics, airport defibrillators, 911 networks and the like — they weren't likely to die prematurely of the pneumonias, influenzas and heart attacks that decimated previous generations. They walked every day. My mother practiced yoga. My father was writing a history of his birthplace, a small South African town.

In short, they were seemingly among the lucky ones for whom the American medical system, despite its fragmentation, inequity and waste, works quite well. Medicare and supplemental insurance paid for their specialists and their trusted Middletown internist, the lean, bespectacled Robert Fales, who, like them, was skeptical of medical overdoing. “I bonded with your parents, and you don't bond with everybody,” he once told me. “It's easier to understand someone if they just tell it like it is from their heart and their soul.”

They were also stoics and religious agnostics. They signed living wills and durable power-of-attorney documents for health care. My mother, who watched friends die slowly of cancer, had an underlined copy of the Hemlock Society's “Final Exit” in her bookcase. Even so, I watched them lose control of their lives to a set of perverse financial incentives — for cardiologists, hospitals and especially the manufacturers of advanced medical devices — skewed to promote maximum treatment. At a point hard to precisely define, they stopped being beneficiaries of the war on sudden death and became its victims.

Things took their first unexpected turn on Nov. 13, 2001, when my father — then 79, pacemakerless and seemingly healthy — collapsed on my parents' kitchen floor in Middletown, making burbling sounds. He had suffered a stroke.

He came home six weeks later permanently incapable of completing a sentence. But as I've said, he didn't give up easily, and he doggedly learned again how to fasten his belt; to peck out sentences on his computer; to walk alone, one foot dragging, to the university pool for water aerobics. He never again put on a shirt without help or looked at the book he had been writing. One day he haltingly told my mother, “I don't know who I am anymore.”

His stroke devastated two lives. The day before, my mother was an upper-middle-class housewife who practiced calligraphy in her spare time. Afterward, she was one of tens of millions of people in America, most of them women, who help care for an older family member.

Their numbers grow each day. Thanks to advanced medical technologies, elderly people now survive repeated health crises that once killed them, and so the “oldest old” have become the nation’s most rapidly growing age group. Nearly a third of Americans over 85 have dementia (a condition whose prevalence rises in direct relationship to longevity). Half need help with at least one practical, life-sustaining activity, like getting dressed or making breakfast. Even though a capable woman was hired to give my dad showers, my 77-year-old mother found herself on duty more than 80 hours a week. Her blood pressure rose and her weight fell. On a routine visit to Dr. Fales, she burst into tears. She was put on sleeping pills and antidepressants.

My father said he came to believe that she would have been better off if he had died. “She’d have weeped the weep of a widow,” he told me in his garbled, poststroke speech, on a walk we took together in the fall of 2002. “And then she would have been all right.” It was hard to tell which of them was suffering more.

As we shuffled through the fallen leaves that day, I thought of my father’s father, Ernest Butler. He was 79 when he died in 1965, before pacemakers, implanted cardiac defibrillators, stents and replacement heart valves routinely staved off death among the very old. After completing some long-unfinished chairs, he cleaned his woodshop, had a heart attack and died two days later in a plain hospital bed. As I held my dad’s soft, mottled hand, I vainly wished him a similar merciful death.

A few days before Christmas that year, after a vigorous session of water exercises, my father developed a painful inguinal (intestinal) hernia. My mother took him to Fales, who sent them to a local surgeon, who sent them to a cardiologist for a preoperative clearance. After an electrocardiogram recorded my father’s slow heartbeat — a longstanding and symptomless condition not uncommon in the very old — the cardiologist, John Rogan, refused to clear my dad for surgery unless he received a pacemaker.

Without the device, Dr. Rogan told me later, my father could have died from cardiac arrest during surgery or perhaps within a few months. It was the second time Rogan had seen my father. The first time, about a year before, he recommended the device for the same slow heartbeat. That time, my then-competent and prestroke father expressed extreme reluctance, on the advice of Fales, who considered it overtreatment.

My father’s medical conservatism, I have since learned, is not unusual. According to an analysis by the Dartmouth Atlas medical-research group, patients are far more likely than their doctors to reject aggressive treatments when fully informed of pros, cons and alternatives — information, one study suggests, that nearly half of patients say they don’t get. And although many doctors assume that people want to extend their lives, many do not. In a 1997 study in *The Journal of the American Geriatrics Society*, 30 percent of seriously ill people surveyed in a hospital said they would “rather die” than live permanently in a nursing home. In a 2008 study in *The Journal of the American College of Cardiology*, 28 percent of patients with advanced heart failure said they would trade one day of excellent health for another two years in their current state.

When Rogan suggested the pacemaker for the second time, my father was too stroke-damaged to discuss, and perhaps even to weigh, his tradeoffs. The decision fell to my mother — anxious to relieve my father’s pain, exhausted with caregiving, deferential to doctors and no expert on high-tech medicine. She said yes. One of the most important medical decisions of my father’s life was over in minutes. Dr. Fales was notified by fax.

Fales loved my parents, knew their suffering close at hand, continued to oppose a pacemaker and wasn’t alarmed by death. If he had had the chance to sit down with my parents, he could have explained that the pacemaker’s battery would last 10 years and asked whether my father wanted to live to be 89 in his nearly mute and dependent state. He could have discussed the option of using a temporary external pacemaker

that, I later learned, could have seen my dad safely through surgery. But my mother never consulted Fales. And the system would have effectively penalized him if she had. Medicare would have paid him a standard office-visit rate of \$54 for what would undoubtedly have been a long meeting — and nothing for phone calls to work out a plan with Rogan and the surgeon.

Medicare has made minor improvements since then, and in the House version of the health care reform bill debated last year, much better payments for such conversations were included. But after the provision was distorted as reimbursement for “death panels,” it was dropped. In my father’s case, there was only a brief informed-consent process, covering the boilerplate risks of minor surgery, handled by the general surgeon.

I believe that my father’s doctors did their best within a compartmentalized and time-pressured medical system. But in the absence of any other guiding hand, there is no doubt that economics helped shape the wider context in which doctors made decisions. Had we been at the Mayo Clinic — where doctors are salaried, medical records are electronically organized and care is coordinated by a single doctor — things might have turned out differently. But Middletown is part of the fee-for-service medical economy. Doctors peddle their wares on a piecework basis; communication among them is haphazard; thinking is often short term; nobody makes money when medical interventions are declined; and nobody is in charge except the marketplace.

And so on Jan. 2, 2003, at Middlesex Hospital, the surgeon implanted my father’s pacemaker using local anesthetic. Medicare paid him \$461 and the hospital a flat fee of about \$12,000, of which an estimated \$7,500 went to St. Jude Medical, the maker of the device. The hernia was fixed a few days later.

It was a case study in what primary-care doctors have long bemoaned: that Medicare rewards doctors far better for doing procedures than for assessing whether they should be done at all. The incentives for overtreatment continue, said Dr. Ted Epperly, the board chairman of the American Academy of Family Physicians, because those who profit from them — specialists, hospitals, drug companies and the medical-device manufacturers — spend money lobbying Congress and the public to keep it that way.

Last year, doctors, hospitals, drug companies, medical-equipment manufacturers and other medical professionals spent \$545 million on lobbying, according to the Center for Responsive Politics. This may help explain why researchers estimate that 20 to 30 percent of Medicare’s \$510 billion budget goes for unnecessary tests and treatment. Why cost-containment received short shrift in health care reform. Why physicians like Fales net an average of \$173,000 a year, while noninvasive cardiologists like Rogan net about \$419,000.

The system rewarded nobody for saying “no” or even “wait” — not even my frugal, intelligent, Consumer-Reports-reading mother. Medicare and supplemental insurance covered almost every penny of my father’s pacemaker. My mother was given more government-mandated consumer information when she bought a new Camry a year later.

And so my father’s electronically managed heart — now requiring frequent monitoring, paid by Medicare — became part of the \$24 billion worldwide cardiac-device industry and an indirect subsidizer of the fiscal health of American hospitals. The profit margins that manufacturers earn on cardiac devices is close to 30 percent. Cardiac procedures and diagnostics generate about 20 percent of hospital revenues and 30 percent of profits.

Shortly after New Year’s 2003, my mother belatedly called and told me about the operations, which went off without a hitch. She didn’t call earlier, she said, because she didn’t want to worry me. My heart sank, but I said nothing. It is one thing to silently hope that your beloved father’s heart might fail. It is another to actively abet his death.

The pacemaker bought my parents two years of limbo, two of purgatory and two of hell. At first they soldiered on, with my father no better and no worse. My mother reread Jon Kabat-Zinn's "Full Catastrophe Living," bought a self-help book on patience and rose each morning to meditate.

In 2005, the age-related degeneration that had slowed my father's heart attacked his eyes, lungs, bladder and bowels. Clots as narrow as a single human hair lodged in tiny blood vessels in his brain, killing clusters of neurons by depriving them of oxygen. Long partly deaf, he began losing his sight to wet macular degeneration, requiring ocular injections that cost nearly \$2,000 each. A few months later, he forgot his way home from the university pool. He grew incontinent. He was collapsing physically, like an ancient, shored-up house.

In the summer of 2006, he fell in the driveway and suffered a brain hemorrhage. Not long afterward, he spent a full weekend compulsively brushing and rebrushing his teeth. "The Jeff I married . . . is no longer the same person," my mother wrote in the journal a social worker had suggested she keep. "My life is in ruins. This is horrible, and I have lasted for five years." His pacemaker kept on ticking.

When bioethicists debate life-extending technologies, the effects on people like my mother rarely enter the calculus. But a 2007 Ohio State University study of the DNA of family caregivers of people with Alzheimer's disease showed that the ends of their chromosomes, called telomeres, had degraded enough to reflect a four-to-eight-year shortening of lifespan. By that reckoning, every year that the pacemaker gave my irreparably damaged father took from my then-vigorous mother an equal year.

When my mother was upset, she meditated or cleaned house. When I was upset, I Googled. In 2006, I discovered that pacemakers could be deactivated without surgery. Nurses, doctors and even device salesmen had done so, usually at deathbeds. A white ceramic device, like a TV remote and shaped like the wands that children use to blow bubbles, could be placed around the hump on my father's chest. Press a few buttons and the electrical pulses that ran down the leads to his heart would slow until they were no longer effective. My father's heart, I learned, would probably not stop. It would just return to its old, slow rhythm. If he was lucky, he might suffer cardiac arrest and die within weeks, perhaps in his sleep. If he was unlucky, he might linger painfully for months while his lagging heart failed to suffuse his vital organs with sufficient oxygenated blood.

If we did nothing, his pacemaker would not stop for years. Like the tireless charmed brooms in Disney's "Fantasia," it would prompt my father's heart to beat after he became too demented to speak, sit up or eat. It would keep his heart pulsing after he drew his last breath. If he was buried, it would send signals to his dead heart in the coffin. If he was cremated, it would have to be cut from his chest first, to prevent it from exploding and damaging the walls or hurting an attendant.

On the Internet, I discovered that the pacemaker — somewhat like the ventilator, defibrillator and feeding tube — was first an exotic, stopgap device, used to carry a handful of patients through a brief medical crisis. Then it morphed into a battery-powered, implantable and routine treatment. When Medicare approved the pacemaker for reimbursement in 1966, the market exploded. Today pacemakers are implanted annually in more than 400,000 Americans, about 80 percent of whom are over 65. According to calculations by the Dartmouth Atlas research group using Medicare data, nearly a fifth of new recipients who receive pacemakers annually — 76,000 — are over 80. The typical patient with a cardiac device today is an elderly person suffering from at least one other severe chronic illness.

Over the years, as technology has improved, the battery life of these devices lengthened. The list of heart conditions for which they are recommended has grown. In 1984, the treatment guidelines from the American College of Cardiology declared that pacemakers were strongly recommended as "indicated" or mildly approved as "reasonable" for 56 heart conditions and "not indicated" for 31 more. By 2008, the list for which they were strongly or mildly recommended expanded to 88, with most of the increase in the lukewarm "reasonable" category.

The research backing the expansion of diagnoses was weak. Over all, only 5 percent of the positive recommendations were supported by research from multiple double-blind randomized studies, the gold standard of evidence-based medicine. And 58 percent were based on no studies at all, only a “consensus of expert opinion.” Of the 17 cardiologists who wrote the 2008 guidelines, 11 received financing from cardiac-device makers or worked at institutions receiving it. Seven, due to the extent of their financial connections, were recused from voting on the guidelines they helped write.

This pattern — a paucity of scientific support and a plethora of industry connections — holds across almost all cardiac treatments, according to the cardiologist Pierluigi Tricoci of Duke University’s Clinical Research Institute. Last year in *The Journal of the American Medical Association*, Tricoci and his co-authors wrote that only 11 percent of 2,700 widely used cardiac-treatment guidelines were based on that gold standard. Most were based only on expert opinion.

Experts are as vulnerable to conflicts of interest as researchers are, the authors warned, because “expert clinicians are also those who are likely to receive honoraria, speakers bureau [fees], consulting fees or research support from industry.” They called the current cardiac-research agenda “strongly influenced by industry’s natural desire to introduce new products.”

Perhaps it’s no surprise that I also discovered others puzzling over cardiologists who recommended pacemakers for relatives with advanced dementia. “78-year-old mother-in-law has dementia; severe short-term memory issues,” read an Internet post by “soninlaw” on Elderhope.com, a caregivers’ site, in 2007. “On a routine trip to her cardiologist, doctor decides she needs a pacemaker. . . . Anyone have a similar encounter?”

By the summer of 2007, my dad had forgotten the purpose of a dinner napkin and had to be coached to remove his slippers before he tried to put on his shoes. After a lifetime of promoting my father’s health, my mother reversed course. On a routine visit, she asked Rogan to deactivate the pacemaker. “It was hard,” she later told me. “I was doing for Jeff what I would have wanted Jeff to do for me.” Rogan soon made it clear he was morally opposed. “It would have been like putting a pillow over your father’s head,” he later told me.

Not long afterward, my mother declined additional medical tests and refused to put my father on a new anti-dementia drug and a blood thinner with troublesome side effects. “I take responsibility for whatever,” she wrote in her journal that summer. “Enough of all this overkill! It’s killing me! Talk about quality of life — what about mine?”

Then came the autumn day when she asked for my help, and I said yes. I told myself that we were simply trying to undo a terrible medical mistake. I reminded myself that my dad had rejected a pacemaker when his faculties were intact. I imagined, as a bioethicist had suggested, having a 15-minute conversation with my independent, predementia father in which I saw him shaking his head in horror over any further extension of what was not a “life,” but a prolonged and attenuated dying. None of it helped. I knew that once he died, I would dream of him and miss his mute, loving smiles. I wanted to melt into the arms of the father I once had and ask him to handle this. Instead, I felt as if I were signing on as his executioner and that I had no choice.

Over the next five months, my mother and I learned many things. We were told, by the Hemlock Society’s successor, Compassion and Choices, that as my father’s medical proxy, my mother had the legal right to ask for the withdrawal of any treatment and that the pacemaker was, in theory at least, a form of medical treatment. We learned that although my father’s living will requested no life support if he were comatose or dying, it said nothing about dementia and did not define a pacemaker as life support. We learned that if we called 911, emergency medical technicians would not honor my father’s do-not-resuscitate order unless he wore a state-issued orange hospital bracelet. We also learned that no cardiology association had given its members clear guidance on when, or whether, deactivating pacemakers was ethical.

(Last month that changed. The Heart Rhythm Society and the American Heart Association issued guidelines declaring that patients or their legal surrogates have the moral and legal right to request the withdrawal of any medical treatment, including an implanted cardiac device. It said that deactivating a pacemaker was neither euthanasia nor assisted suicide, and that a doctor could not be compelled to do so in violation of his moral values. In such cases, it continued, doctors “cannot abandon the patient but should involve a colleague who is willing to carry out the procedure.” This came, of course, too late for us.)

In the spring of 2008, things got even worse. My father took to roaring like a lion at his caregivers. At home in California, I searched the Internet for a sympathetic cardiologist and a caregiver to put my Dad to bed at night. My frayed mother began to shout at him, and their nighttime scenes were heartbreaking and frightening. An Alzheimer’s Association support-group leader suggested that my brothers and I fly out together and institutionalize my father. This leader did not know my mother’s formidable will and had never heard her speak about her wedding vows or her love.

Meanwhile my father drifted into what nurses call “the dwindles”: not sick enough to qualify for hospice care, but sick enough to never get better. He fell repeatedly at night and my mother could not pick him up. Finally, he was weak enough to qualify for palliative care, and a team of nurses and social workers visited the house. His chest grew wheezy. My mother did not request antibiotics. In mid-April 2008, he was taken by ambulance to Middlesex Hospital’s hospice wing, suffering from pneumonia.

Pneumonia was once called “the old man’s friend” for its promise of an easy death. That’s not what I saw when I flew in. On morphine, unreachable, his eyes shut, my beloved father was breathing as hard and regularly as a machine.

My mother sat holding his hand, weeping and begging for forgiveness for her impatience. She sat by him in agony. She beseeched his doctors and nurses to increase his morphine dose and to turn off the pacemaker. It was a weekend, and the doctor on call at Rogan’s cardiology practice refused authorization, saying that my father “might die immediately.” And so came five days of hard labor. My mother and I stayed by him in shifts, while his breathing became increasingly ragged and his feet slowly started to turn blue. I began drafting an appeal to the hospital ethics committee. My brothers flew in.

On a Tuesday afternoon, with my mother at his side, my father stopped breathing. A hospice nurse hung a blue light on the outside of his hospital door. Inside his chest, his pacemaker was still quietly pulsing.

After his memorial service in the Wesleyan University chapel, I carried a box from the crematory into the woods of an old convent where he and I often walked. It was late April, overcast and cold. By the side of a stream, I opened the box, scooped out a handful of ashes and threw them into the swirling water. There were some curious spiraled metal wires, perhaps the leads of his pacemaker, mixed with the white dust and pieces of bone.

A year later, I took my mother to meet a heart surgeon in a windowless treatment room at Brigham and Women’s Hospital in Boston. She was 84, with two leaking heart valves. Her cardiologist had recommended open-heart surgery, and I was hoping to find a less invasive approach. When the surgeon asked us why we were there, my mother said, “To ask questions.” She was no longer a trusting and deferential patient. Like me, she no longer saw doctors — perhaps with the exception of Fales — as healers or her fiduciaries. They were now skilled technicians with their own agendas. But I couldn’t help feeling that something precious — our old faith in a doctor’s calling, perhaps, or in a healing that is more than a financial transaction or a reflexive fixing of broken parts — had been lost.

The surgeon was forthright: without open-heart surgery, there was a 50-50 chance my mother would die within two years. If she survived the operation, she would probably live to be 90. And the risks? He shrugged. Months of recovery. A 5 percent chance of stroke. Some possibility, he acknowledged at my prompting, of postoperative cognitive decline. (More than half of heart-bypass patients suffer at least a 20 percent reduction in mental function.) My mother lifted her trouser leg to reveal an anklet of orange plastic:

her do-not-resuscitate bracelet. The doctor recoiled. No, he would not operate with that bracelet in place. It would not be fair to his team. She would be revived if she collapsed. "If I have a stroke," my mother said, nearly in tears, "I want you to let me go." What about a minor stroke, he said — a little weakness on one side?

I kept my mouth shut. I was there to get her the information she needed and to support whatever decision she made. If she emerged from surgery intellectually damaged, I would bring her to a nursing home in California and try to care for her the way she had cared for my father at such cost to her own health. The thought terrified me.

The doctor sent her up a floor for an echocardiogram. A half-hour later, my mother came back to the waiting room and put on her black coat. "No," she said brightly, with the clarity of purpose she had shown when she asked me to have the pacemaker deactivated. "I will not do it."

She spent the spring and summer arranging house repairs, thinning out my father's bookcases and throwing out the files he collected so lovingly for the book he never finished writing. She told someone that 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," she wrote in her journal. "But so it goes. ACCEPT ACCEPT ACCEPT."

Last August, she had a heart attack and returned home under hospice care. One evening a month later, another heart attack. One of my brothers followed her ambulance to the hospice wing where we had sat for days by my father's bed. The next morning, she took off her silver earrings and told the nurses she wanted to stop eating and drinking, that she wanted to die and never go home. Death came to her an hour later, while my brother was on the phone to me in California — almost as mercifully as it had come to my paternal grandfather. She was continent and lucid to her end.

A week later, at the same crematory near Long Island Sound, my brothers and I watched through a plate-glass window as a cardboard box containing her body, dressed in a scarlet silk *ao dai* she had sewn herself, slid into the flames. The next day, the undertaker delivered a plastic box to the house where, for 45 of their 61 years together, my parents had loved and looked after each other, humanly and imperfectly. There were no bits of metal mixed with the fine white powder and the small pieces of her bones.

This article is a preview of material from Knocking on Heaven's Door by Katy Butler (Scribner, a div. of S&S, etc. 2010.)