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The Long Goodbye

Katy Butler On How Modern Medicine Decreases Our Chance Of A Good Death

by SAM MOWE

SAM MOWE lives in Brooklyn, New York. His interviews have appeared in *The Rumpus*, *Tricycle*, and *Spirituality & Health*. A Buddhist for many years, he still hasn't learned a thing about nonattachment.

In 2001 journalist Katy Butler's father suffered a stroke at the age of seventy-nine. A year later a hurried decision was made to equip him with a pacemaker, which kept his heart going while doing nothing to stop his descent into dementia. In 2007 Butler's mother, exhausted from being her husband's full-time caregiver and distressed by his suffering, asked her daughter for help getting the pacemaker turned off. Butler agreed, and so began a long investigation into how modern medicine has changed the way we approach the end of life.

Born in 1949 in South Africa, Butler spent her early years in Oxford, England. When she was eight, her family moved to the suburbs of Boston, Massachusetts. Her father, a former soldier in the South African Army who lost his left arm in World War II, later became a professor at Wesleyan University, from which Butler graduated in 1971.

In the early 1970s Butler drove cross-country with three hundred dollars in her pocket to find work as a writer. After a stint at the San Francisco Bay Guardian, an alternative weekly, she worked as a staff reporter for the San Francisco Chronicle, covering healthcare, social issues, and the AIDS epidemic. After twelve years she left to freelance and has since written for such publications as The New Yorker, The New York Times, Vogue, Mother Jones, the Los Angeles Times, and The Washington Post.

Butler often employs her skills as an investigative journalist to report on subjects that are close to her heart. At the San Francisco Bay Guardian she wrote a story about midwifery that opened with her memories of her brother's home birth. A longtime Buddhist — she was lay-ordained by the Vietnamese monk Thich Nhat Hanh — Butler reported on abuses of power and sexual misconduct within Buddhist communities in the 1980s.

In 2010 she wrote about her father's death in The New York Times Magazine. The piece, titled "What Broke My Father's Heart," won awards from the Association of Health Care Journalists, the Family Caregivers' Association, and the National Association of Science Writers. It went on to become the basis of Butler's first book, Knocking on Heaven's Door: The Path to a Better Way of Death. In addition to recounting her family's experiences with her father's slow decline, the book looks at Butler's mother, who died fairly quickly a year and a half later, after refusing open-heart surgery. "Her death was totally different," Butler says. "She was continent and lucid to her end, and she died the death she chose, not the death anyone else had in mind."

Since the publication of Knocking on Heaven's Door, Butler has spent the majority of her time on the road, giving talks about overtreatment, end-of-life care, and "perverse" economic incentives in the medical industry. She's become an advocate for the growing Slow Medicine movement, which focuses on "non-rushed medical decision-making, palliative care, and comfort-giving treatment, especially as the end of life approaches," according to its Facebook group.

During this interview Butler was incisive in her analysis of economic, political, and medical issues and blunt while discussing the hard emotional tasks involved in the death of a loved one. Used to being on the other side of the microphone during her career as a journalist, she offered me tips and suggestions throughout. "Please feel free to interrupt me if I'm not going where you want me to go," she said. I seldom found it necessary.

Mowe: How has the development of modern medicine transformed our experience of death?

Butler: Death used to be a spiritual ordeal; now it's a technological flailing. We've taken a domestic and religious event, in which the most important factor was the dying person's state of mind, and moved it into the hospital and mechanized it, putting patients, families, doctors, and nurses at the mercy of technology. Nonetheless we still want death to be a sacred occasion.

Mowe: What about those who are more secular in their beliefs?

Butler: I think many of us aren't as secular as we claim. We're a society of seekers. Maybe we don't like organized religion, but we yearn to place the events of our life into a larger, more meaningful context. We want death to be about more than the end of a person's life. Death is part of an eternal pattern. Obviously if I'm dying, for me that is a major tragedy. But billions of people have died before me and have faced death with varying degrees of courage. A sacred understanding of that can help both the dying and the survivors.

Mowe: And this notion of sacredness has been undermined by modern medicine?

Butler: In the mid-twentieth century there was an explosion of postwar inventiveness: dialysis, the respirator, the ventilator, the defibrillator, the pacemaker. We invented a panoply of devices that both prevented sudden death and in some instances literally brought people back to life. But when we eliminated sudden death, we also eliminated natural death, and we lost the distinction between saving a life and prolonging a dying.

In her 1969 book *On Death and Dying*, Elisabeth Kübler-Ross describes five stages of grief. The first is denial: someone who receives a terminal diagnosis will often insist that he or she is not going to die. But by the final stage, acceptance, the person makes peace with the fact that death is approaching. Today many people remain stuck in denial, hoping for a cure right up until the end. As a result, many end-of-life tasks, such as giving your children your blessing, don't get done. It's important to leave your survivors with a sense that you love them and believe in them, and that they should go out and explore their own path. But if you're still thinking you're going to "beat this thing," you're unlikely to have that conversation. The emotional duties get neglected as a result of how excellent the medical technology is.

Mowe: But aren't we fortunate to have access to such technology?

Butler: Absolutely, when we have a decent shot at survival. If you or I were to get hit by a car tomorrow, nothing could be better than modern medical technology. But if you're in your eighties and suffering from dementia, diabetes, and colon cancer, then no. You're very *unfortunate* to have access to these technologies, which can only prolong your life beyond the point at which it holds any pleasure or meaning.

Mowe: You guided both your parents through the death process. Can you tell us about that experience?

Butler: Before I do, I want to say that I've found going over this with people more distressing than I expected. First I lived through it with my parents, then I wrote a book about it, and now I'm talking about it. Sometimes when I stand up before a group and tell my story, someone will ask, "Why didn't you just stick them in assisted living?" or something similar — as though it were that simple. But talking about it has also been a healing experience, because I feel as if my parents' suffering and the mistakes I made — and all the good things we did, too — were not for naught, because now other people can benefit from our experience.

Mowe: Where did the dying process begin for your parents?

Butler: When all this began, I was a freelance writer in California, living a full continent away from my father and my mother. I saw them once a year. They were both healthy and vigorous. So I had this unrealistic assumption, which I think is common in our culture, that they would somehow plug along at the same highly functioning level until they were suddenly struck down by some final illness, and then it would be over: nice and clean. That's how three out of my four grandparents died. But that sort of sudden death from natural causes is rare now, because we have all this machinery to prevent it. Even at the point where a natural death becomes a blessing, we don't allow people to die that way.

My father was seventy-nine when he had his stroke, and I was in my early fifties. He'd been a caring parent to me, but we were also a contentious family, and there was a sense that my siblings and I had never lived up to our parents' expectations. When I got that first phone call about his stroke, though, I was just struck dumb with love for him. I felt compelled to go home and do whatever I could to help. And during his long illness I really did fall in love with my parents all over again. I became a more mature person, less selfish.

The stroke was devastating. My father couldn't even fasten his belt. My mother was brushing his teeth, dressing him, cutting up his food — everything. Although she was a very good caregiver, it was emotionally overwhelming for her. My father had been a college professor who loved to debate, and now he couldn't

finish a sentence. My mother had never balanced a checkbook and didn't know how much money they had. He'd been the man of the house, and she'd been the überhousewife.

A year after the stroke my father developed a hernia. Because he had a slow heartbeat, the cardiologist would not clear my father for surgery to repair the hernia unless he got a pacemaker — just in case the stress of general anesthesia was too much for him. My mother was really the decision maker at that point, and she said yes. She got less information about the device than she got a year later when she bought a new Camry. The family internist and I were dubious. He was afraid that the pacemaker would prolong my father's life past a point when he had no reason to live. I had the same fear, though I felt too guilty to articulate it. I was not a player in my parents' medical decisions at that point. I was just the daughter on the opposite coast. It was only when things went farther downhill that I was given more of a role.

The pacemaker obstructed the kindest path to a natural death for my dad. It kept him going beyond the point where death would've been a mercy. We can't say exactly how long he would've lived without a pacemaker — maybe it would have made no difference at all — but his cardiologist and his family doctor both estimate that he would've died within two years of the stroke. With the pacemaker he lived another five and a half years. Those three extra years were a kind of rolling disaster in which his situation kept getting worse.

Mowe: If you don't have dementia and you get more years of life because of a pacemaker, is that such a bad thing?

Butler: Not at all! It's a question of the appropriate use of technology. When quality of life is high, the decisions are different. It's when quality of life is low and inexorably declining that you need to consider whether the cure is worse than the disease.

Mowe: What can we do to prevent death from being this sort of prolonged disaster?

Butler: We need to expand and better fund palliative care, which helps terminally and seriously ill patients make medical decisions and emphasizes quality of life rather than quantity of life. It's a team approach that provides more support for the family and for pain control and treating symptoms, and less support for what I call "Hail Mary" surgeries at the end of life, where you're just hoping for a miracle.

Mowe: What's the difference between palliative and hospice care?

Butler: Palliative care is for anyone with a chronic, incurable illness. It focuses on improving the quality of your remaining life, whether you have one year to live or fifty, and whether or not you choose to receive life-prolonging treatments. It offers practical aid and addresses how your disease is interfering with activities that give your life meaning for you.

For example, I was on a panel once with a man who was slowly dying because his heart was not pumping blood efficiently. He'd been given a defibrillator — a thirty-five-thousand-dollar device that restarts your heart by literally shocking it, which is a very painful experience.

He also had shortness of breath, which prevented him from working in his wood shop to make toys for children. Finally he asked that the defibrillator be turned off, because he preferred to die a natural death. So they turned off the device and referred him to the palliative-care unit. He told the palliative-care doctor about his shortness of breath, and the doctor put him on oxygen. With the oxygen the man could go down

to his basement wood shop and build toys for the neighborhood kids. Suddenly he wasn't so keen to die anymore.

That's palliative care. It's a relatively new specialty and is mostly funded by foundations and charities. It's very poorly reimbursed by Medicare.

Hospice offers the same benefits as palliative care but is more oriented toward the final passage to death. But Medicare pays for hospice only if you promise to forgo all life-prolonging treatments. And you can qualify only in your last six months of life.

Mowe: Do palliative care and hospice ever speed up the dying process?

Butler: No, in fact, they do the reverse. There's a *New England Journal of Medicine* study that shows that people who get palliative care and hospice live either as long as or longer than people who are receiving aggressive treatment. It's quite ironic.

Families need a palliative-care system, because it's hard to analyze all the possibilities when somebody you love is dying. When my mother made the decision at the age of eighty-four not to have heart-valve-replacement surgery, I acted as her medical researcher, but it would've been better if someone from a palliative-care program could have helped us weigh the pros and cons of what she faced. Then I could have been simply a grieving and supportive daughter.

Four different teams of cardiologists tried to get my mother to go through with the open-heart surgery, which is no small matter. The surgeon saws through your breastbone. They stop your heart temporarily with the same chemical they use in executions. She was told if she didn't have the surgery, she had a fifty-fifty chance of dying within two years, whereas if she did have the surgery and survived, she had a good chance of living to ninety.

She did the math. It was going to take her a full year to recover. She was just about to turn eighty-five and was likely to reach eighty-seven anyway. So the maximum benefit was going to be a three-year extension of her life. What was she going to risk to buy those extra three years? There was a better than 10 percent chance that she would not even make it out of the hospital alive. And there was a 40 percent chance that if she did make it out of the hospital, she would be discharged to a nursing home, unable to take care of herself. There was a 5 percent risk of stroke following the surgery and a significant chance of cognitive decline. I have talked to a number of people who had a parent who went ahead with this surgery and came out of it with major dementia. This is rarely discussed by cardiologists, who don't even do a cognitive assessment before they decide whether or not to perform this operation. Nor do they do a cognitive assessment afterward — the standard of "success" is simple survival for at least one month.

My mother didn't go through with the surgery. She was lucky, because this was a fit for her values. And she had a daughter who had been a journalist for thirty years and could help her get all the facts. Not everybody is going to be capable of doing the sort of research I did.

My advice to anyone facing major surgery after the age of eighty is to consider *all* the risks. People at that age are often like Humpty Dumpty: it doesn't take much to knock them off the wall, and then no one can put them back together again. My rules of thumb are: No general anesthesia after the age of eighty, unless there's an incredibly good reason, because of the threat of cognitive damage. And no open-heart surgery after eighty either.

Mowe: Is specialization in medicine part of the problem: the heart surgeon wants to fix the heart; the cancer doctor wants to kill the cancer, but no one is looking out for the patient as a whole?

Butler: Yes. My father's cardiologist was thinking strictly in terms of fixing my father's heart rhythm — not even his whole heart — and certainly not in terms of my father's suffering or my mother's suffering. We're not isolated atoms in space — at least, that's the way I see it as a Buddhist. We're part of a web of existence, and the "patient" is not just the patient but the family that will survive him.

Mowe: To what extent should the strain that a drawn-out death puts on a family be a factor in end-of-life decisions?

Butler: This may shock some people, because we are such an individualistic culture, but I think the whole family should be regarded as the patient.

There's really something wrong with the system we have now, in which insurance and Medicare will pay for advanced surgery to keep someone alive, but not for the caregiving that's necessary afterward. That burden falls on the family. And caregiving often negatively affects the health of the caregiver. Taking care of my father probably cut four or five years from my mother's life. I think it was criminal to extend my father's life without taking her suffering into account. What have we accomplished if we've just shifted the illness from one member of a family to another? If you're a doctor, I think you have to look at whether you're adding suffering to the family as a whole when you extend the life of an individual.

Personally I have a living will that reduces the impact my dying has on my caregivers. I don't want to outlive my brain, because it would be a tragedy for the people who have to take care of me. Even if I'm happy in my vegetative state, if it means the people I love are having to feed me and put me to bed and do this heartbreaking emotional work, I don't want my life to go on. I can't make that choice for other people, but I'm clear about it myself.

It's an interesting philosophical conundrum: Which self do we honor? The fully capable, legally responsible person I am right now, who says I don't want any artificial barrier preventing the natural death that might await me? Or the less-aware self that I might become at a later date, who might say, "No, no. Keep me alive"? I want the person I am now to count more, because I still have empathy for others and am not purely selfish, whereas at some point I may become so damaged that I won't be able to consider my family's needs.

Mowe: I was surprised to read, in a recent Pew Research Center study on end-of-life issues, that less than half of people over seventy-five have given much thought to the end of their lives.

Butler: It's stunning. I think it has a lot to do with advertising and the media. All the ads on TV show older people doing great. And if they're not doing great, they can take a drug, and then they'll be doing great, right? It's easy to get hypnotized by that promise of the quick fix. TV ads for various drugs present images of vibrant seventy-five-year-olds running marathons. You don't see images of decrepitude. The media don't hold up a mirror to the end of life.

Mowe: Are there any cultures that do deal with decrepitude well?

Butler: We dealt with it much better in this culture before the twentieth century. Back then people died at all ages of cholera, TB, fever, diarrhea — you name it. They read books called *The Art of Dying* to prepare for death. Even today the preparation for the Jewish High Holy Days involves recognizing that death can

come at any time. I think the Mexican holiday of Día de Los Muertos also helps — a day to remember the dead and celebrate them. Many cultures honor the elderly much more than we do.

Mowe: Let's talk about where we end our lives. Even though the majority of elderly people say they would prefer to die at home, almost half of them die in hospitals.

Butler: Many people don't understand that death is a pathway, not an event. They don't realize that, in order to die at home, you have to renounce the fantasy that medicine is going to have one more miracle in the bag for you. When my mother refused open-heart surgery, her doctors were shocked, because she was otherwise healthy. The fact is, people who have those Hail Mary surgeries in their eighties are often not resilient enough to recover from them, and they end up on a pathway to the Intensive Care Unit [ICU] — which, to me, is the worst possible place to die: a cold, sterile environment of beeping machines. Having a respirator tube down your throat is so painful that you are often strapped down or drugged into unconsciousness so you won't tear it out. People who survive an intensive-care stay often report hallucinations that they were being tortured in a medieval dungeon. Family members who witness these deaths suffer high rates of anxiety, post-traumatic stress, and complicated grief afterward. Twenty percent of Americans die in an ICU.

Avoiding the ICU at the end isn't a matter of your spouse or children blocking the door with your Do Not Resuscitate order in hand. The decision that keeps you out of the ICU is probably one you might make years earlier. In essence my mother decided that she preferred to die too soon rather than too late. As a result she stayed out of the ICU and had a good death, a meaningful death, on her own terms. But a lot of people who think they want to die at home still say yes to surgery near the end, partly because our society is so terrified of death and provides us with so few ways to feel safe as we approach dying.

Mowe: The frantic pace of an ICU seems particularly hostile to a calm, contemplative death.

Butler: It's more than that. It's really not fair to the ICU doctor if we dump on him or her the result of other doctors kicking the can down the road for five years or more, never having the tough conversations with patients, never telling them, "You are approaching the end of your life," because it's almost taboo to say so in this culture. The ICU lies at the end of a long series of mistakes. When an eighty-five-year-old with three different fatal conditions lands in intensive care, it means doctors have been avoiding those difficult conversations or making ill-considered recommendations for years prior to that.

What happens next is that a totally unprepared family is introduced to an intensive-care doctor they have never met. That doctor is forced by the situation to finally have a discussion with the family about death. But when he or she recommends they not overly prolong the dying process of their loved one, the family doesn't necessarily trust that advice, because it's coming from a stranger.

Mowe: Are there legal concerns that would discourage a doctor from saying, "I think we should let this patient die"?

Butler: There are both practical and legal concerns. Medicine is full of euphemisms and indirection as a result of physicians' fear of being sued. So although it's not illegal, they are unlikely to say, "I think it would be best for this patient at this stage to allow natural death," unless they have a trusting relationship with the family. It's more likely they will say it with a patient whose organs are failing, when death is just a matter of time and the patient is suffering through painful treatment with dialysis or a ventilator. But for

everyone's safety this must be phrased in terms of allowing the disease to run its natural course, and weighing the burdens and benefits of proposed treatments. There can be no mention of intentionally hastening death. That's manslaughter.

The end of life is a foggy no man's land where culture, law, and morality meet. This goes back to the Middle Ages and the teachings of Catholic theologian Saint Thomas Aquinas, who formulated the "principle of double effect," which says it's OK to do something with a harmful side effect if the primary intention is to fulfill some permitted mission. So it's OK to give someone morphine if your intention is to ease pain, even if it might hasten death.

But doctors are nervous, and understandably so. There have been many cases in which surviving family members have sued over someone being taken off life support. Even if the rest of the family is in favor of withdrawing life support, the doctor will listen to that one relative who is opposed, because that's the one who will sue.

There is no consensus in our culture, or even within families, on where to draw the line between allowing a natural death and hastening dying; between acceding to a patient's wishes for no more treatment and abetting suicide or performing euthanasia. My father's cardiologist was not clear on this. He told me that turning off the pacemaker would be like putting a pillow over my father's head, but that's not the case, legally or morally. The law is clear: a patient has the right to request the withdrawal of any medical treatment. The appointed medical proxy is empowered to carry out those wishes. If the doctor is morally opposed to the decision, he or she should refer the patient to a physician who shares the patient's values.

Mowe: You've written, of end-of-life care, "Nobody is in charge but the marketplace." What do you mean?

Butler: I mean, for example, that Medicare will not pay doctors decently for the time it takes to say, "It's not a good idea to put a pacemaker in your dad," or, "Another round of chemotherapy will not benefit you." But it will pay a fortune for drugs and devices. The financial incentives benefit the highly profitable medical-device and pharmaceutical industries, which spend enormous amounts of money promoting their wares to doctors and paying for medical studies that suggest more and more people ought to use their products. The corporate healthcare lobbies help determine what doctors get paid to do. We pay doctors very well for deploying technology and very poorly for spending time with patients. This shapes their behavior.

Mowe: So is changing how we approach death more of a financial-policy question or a spiritual question?

Butler: I think it's both. We need to restore the sacred at the end of life, but it doesn't matter how ready Americans become to face death; until we change those financial incentives, I don't think the situation is going to get better. We need to triple payments for hospice, palliative care, and other family medicine, and we need to considerably cut payments for unnecessary medical devices, chemotherapy, and so on.

When we say to doctors, "We'll pay you thousands to prescribe the expensive chemotherapy that you know will be ineffective because it's too late, but we'll pay you only fifty-four dollars to talk to your patient," we're telling them what we value. Why have we set up a system where a physician would have to be a saint to do the right thing?

Take my dad, for example. Medicare paid, without batting an eye, about twenty-two thousand dollars to put in a pacemaker and repair his hernia. And it would have paid his family doctor just fifty-four dollars to have a discussion with him about whether the pacemaker was really a good idea, given his quality of life.

Legislators tried to add a provision to the Affordable Care Act that would've paid doctors two hundred dollars to have end-of-life discussions with patients. This was distorted by the act's political opponents, who called it a "death panel," and it was stripped out of the bill.

There's a bias in the medical system against care and in favor of a cure, even when a cure is impossible. My father benefited greatly from speech therapy. It improved his quality of life. But he was limited to fifteen hundred dollars a year for it. He would've been much better off if the ten thousand dollars for his pacemaker had gone instead toward more speech therapy or to home healthcare to assist my mom, so she could have taken a yoga class or done something else to relax.

There are three powerful lobbies in Washington, D.C.: defense, finance, and healthcare. And the big players in healthcare are not the family doctors and the speech therapists. The big players are, among others, AdvaMed, which represents the makers of medical devices; the pharmaceutical companies; and specialists like interventional cardiologists, who make about half a million dollars a year. The result is that expensive, high-tech fixes are overrewarded and overpromoted. Meanwhile the hospice benefit has eroded and can't provide as many services as it used to.

A few years ago, during the Bush administration, Medicare tried to reduce the payments for certain medical devices, like defibrillators. The lobbying campaign mounted in response was so powerful that the head of Medicare just gave up.

Mowe: The patient's wishes also dictate a lot of what doctors can and can't do. Do you see a connection between the emphasis on patient autonomy and American notions about individual freedom?

Butler: I do, but first I have to say that patients' wishes are often not respected. Some doctors rip advance directives out of medical charts if they disagree with them. They argue with patients. They guilt-trip family members who are against certain treatments. Those doctors want to do what they consider best, and they do not believe patient autonomy ought to trump their recommendation.

Mowe: What are advance directives?

Butler: Advance directives are documents you sign that say, "Under such conditions, I want or do not want certain kinds of medical treatment," such as being put on a ventilator or given dialysis.

But, getting back to your previous question, I do see the link to individual freedom. In the face of this enormous marketplace machine that shapes medical treatment — I call it medical treatment, not medical care — we seem to fall back on the language of individual rights. We need a much more communitarian ethic around end-of-life issues, because I don't think it's just the individual who is affected. When I look at my father's death, I don't see it simply in terms of his right to live as long as he wanted. I see it also in terms of my mother's right not to be enslaved as a caregiver. And I see a good death as a positive legacy you can leave your kids.

One reason we have trouble talking about this is that we're working with insufficient language. Dying is a sacred experience, and if you try to characterize it in the language of individual freedom — "I have the right to do what I want with my body" — you miss what people are actually facing at the end of their lives. They don't want to assert their individual rights. They want to be held in the arms of a loving community while they and their family go through the ordeal of death.