

A Review of Katy Butler's *Knocking on Heaven's Door: The Path to a Better Way of Death* (2013)

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You are going to die. Let that sink in for a moment. Author Katy Butler hopes that all learn from her family's mistakes and triumphs in confronting mortality. Her book, *Knocking on Heaven's Door: The Path to a Better Way of Death* (New York: Scribner, 2013) exposes the ironic realities of elder care in our technology-addicted society. The analysis is a basket weave of confessional, family-history, medical-technology, and how-to-die manual. Even though it was widely praised upon publication in late 2013, several current events highlight the fact that how we deal with death will continue being a hot-button issue into the foreseeable future.

Ms. Katy Butler works through an array of themes as she exorcises her health care demons. First, medical technology may add days, weeks, and possibly months of existence, but not of a quality worth living. Second, dying impacts whole families, not just patients. Third, modern medicine has changed our culture's relationship with dying and death, perhaps not for the better. Fourth, irony abounds in "health" care. Fifth, communication with understanding in a medico-legal society is complicated by each person's unique definition of quality of life, whether they be a patient, physician, care aide, or the dreaded "cousin from Peoria." Sixth, "Slow Medicine," as espoused by proponents like Ivan Illich versus the "Fast Medicine" of most physician-specialists. Seventh, ethics of informed consent is an integral part of each theme. And through it all she wrestles with the reality of having no way to foretell which blind alley the next decision will lead down.

There is no doubt that modern medicine helps us. However, as we age, our body loses the ability to fully heal, and at about age 80 this ability diminishes exponentially. Life is more than inhale/exhale, swallow/burp, flatulate, and defecate. Yet, this is increasingly what the human body is reduced to in advanced old age. Our brains and hearts generally begin to fail at about the same time. Advances in cardiac technology go in tandem with so many elderly people who are demented. As Jeff's daughter and the author of the book, Katy, learned, stroke victims usually improve for about a year and generally live for seven years. But, since we all believe secretly that our parents are immortal, this information falls on deaf ears.

To say about one of many ironies of health care, Katy's father, Jeffrey Butler, had a stroke at 79. To regain his strength after the stroke, he was on a strict exercise regimen which caused a hernia. To repair the hernia, his heart required a pacemaker to survive the surgery. The pacemaker kept his heart pumping well after it would have stopped on its own. However, when Jeff sank into advanced dementia, the entire family encountered the moral dilemma whether removing the pacemaker would be killing Jeff.

Each person has their own unique medical history and lives within a unique family dynamic. For the Butlers, Jeff had an arm blown off in World War I, and his 21-year-old life was saved by surgeons. His wife, Val Butler, had breast cancer at 47 whose life was saved by a surgeon. Katy is a middle-aged daughter and a sister in a post-war immigrant family spread across the U.S. When the tragedy strikes, the Butlers all but totally fall apart. The raw emotions permeate every page. Some readers may find this drama unsettling, but I think that is the very point. The medical establishment has stolen our ability to determine how and when life should end, and they make us financially responsible for the problem. The chapters on the rise of the medical device and specialist industries as facilitated

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by entities like the American Medical Association (AMA), Medicare, and Medicaid are truly disturbing. There is money to be made off the elderly, and the healthcare establishment is up to their bloody elbows in reimbursements.

The author goes to great lengths to describe Slow Medicine versus Fast Medicine. Slow medicine is what humanity relied on for thousands of years. The body's ability to heal itself is primarily what keeps it alive. Most life-expectancy data show that living to 40 was average until the dawn of the 20th century and improvements were made in sanitation. Removing the high infant mortality rate from the equation bumps that number up to 50 for those who survived the first 5 years of life. Then the American modern medicine brought tremendous changes to health. Physicians were required to have licenses to practice which meant obtaining structured education. Experiments with electricity resulted in defibrillators and pacemakers. Surgical experimentation increased in kind and complexity. The first ICU opened in 1961 and the medical community declared war on death with every gadget, drug, and procedure it could. This so-called Fast Medicine increased the average lifespan well into the 70s by the century's end, but at what cost? In another example of Slow vs Fast Medicines, the author explains another irony involving her father. The Medicare program was willing to pay for his pacemaker more than for hands-on therapy by a non-physician care-provider, even though the hands-on therapy would provide tangible benefits to his feeble mind and body while the pacemaker just kept what was left of him alive.

The price that the U.S. pays for the Fast Medicine has grown at an unsustainable rate, as the author lays the blame at the feet of the collusion between the AMA and the state/federal government while running the Medicaid and Medicare programs. American citizens are living longer but not living healthier. And because health care is so expensive, it often falls on family members to take care of their own elderly. There are 29 million family caregivers in the U.S., which is roughly 9% of the population! Mostly elderly spouses and daughters, according to the author, perform this vital, untrained duty for their beloved ones on a 2/7 basis. Ironically, an elderly caregiver loses average a year of their own life for each year they care for a family member due to the physical and emotional stresses involved.

A significant portion of the book involves the legal framework and function of documents like informed consent, power of attorney, and DNR. During one poignant interview with a surgeon, the author's ill mother revealed her bright orange DNR band wrapped around her ankle. Then, the surgeon was repelled like Dracula from a cross! "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. She would spend time in recovering in intensive care. 'If I have a stroke,' my mother said, nearly in tears, 'I want you to let me go.' What about a minor stroke, the doctor said—a little weakness on one side?' It is OK my dear, the Count promises to suck out just a little bit of blood . . ."

I believe that informed consent is a terrific misnomer. The document should be required to be called an Informed Understanding Form. The medical profession hides behind too much jargon and profit potential. So often in court, a provider will blame the patient for a negative outcome because the patient either signed the form and thus admitting that they fully understood the risks, or did not follow every detail of their convalescence.

Back in the days before technology took over, say, the days of Slow Medicine, religion played such an important role. Rituals got families through life, from birth to death. A sad undertone of this book is Katy's wrestling with the importance of ritual; she moaned that her family never really had any of the rituals. In the story, we can see her mother who lived in the days of Slow Medicine, having a better grasp of life than Katy does.

The final section of the book is chock full of practical advice for "a new art of dying," and several resources for those dealing with end of life issues. This section alone is worth the price of the book many times over.