

Introduction

Death is very likely the single best invention of life. Remembering that I'll be dead soon is the most important tool I've ever encountered to help me make the big decisions in life.

—Steve Jobs

The seeds for this book were planted almost a decade ago. I was sitting in my father's sunlit apartment overlooking the vast expanse of Lake Michigan. He was eighty-eight years old and the picture of health for his age. We were discussing treatment options for a ballooned blood vessel, an aortic aneurysm, in his abdomen. His internist had recommended a surgical consult, and three separate surgeons had recommended a standard operation to permanently repair it. I expressed concern that despite his appearance of good health, such a taxing abdominal operation and the associated prolonged recovery threatened to upset his independent lifestyle. Worried about the risk of rupture and wanting him to live long enough to meet his first great-grandchild, whose birth we expected in six months, I was promoting an alternative outpatient procedure: the insertion of a strengthening stent designed to reinforce the aneurysm for up to five years.

My father stunned me with a question that crystallized many ideas that I had been pondering over the last few years of my medical practice. “Why would I want to fix something that is going to carry me away the way I want to go?” he asked. Apparently he had the generally accurate impression that if his aneurysm ruptured, he could demand pain medication, decline emergency surgery, and be dead from internal bleeding within a few hours—a day or two at the most. His message was that he did not want a lingering death, and a ruptured aneurysm held an intellectual appeal for him in that regard.

More important, his question resonated on multiple, more complicated levels. First, it demonstrated a vision of his death that we, he and his family, could use to make future end-of-life decisions. Second, it demonstrated a willingness to gain knowledge about his ailments. Third, it indicated an acceptance that death was inevitable and that having a plan—a strategy—to manage it gave him some semblance of control. Finally, his question taught me to challenge the advice physicians, including me, reflexively give patients late in life.

Ultimately, my father had the outpatient procedure I advocated, and he met his great-granddaughter soon after her birth.

A year later, I was speaking with my older sister on the phone. She was preparing to visit our dad, and concerns about his health were weighing on her mind. She was bracing herself for her role as the oldest daughter. She was preparing herself to nurse him where necessary but more likely to organize his remaining time according to his frequently stated wishes to die at home and to do everything possible to avoid a nursing home placement. “You can’t believe the wreckage in those places,” he repeated. No excessive medical care for him, thank you very much. She would create an assisted living situation in his apartment. We would protect him as best we could.

Our mother had died three years earlier. We had thought our

father would wither and die. Contrary to our expectations, he soldiered on. But now, one year after his aneurysm treatment, his rugged independence was feeling threatened, and death was on his mind. Had he experienced a premonition? He wanted to visit with his daughter.

What if-type questions poured forth from her. Channeling his willingness to forego treatment if it meant a manageable death, I answered her.

“What if he has a stroke?” she asked.

“Call me,” I replied.

“What if he gets pneumonia?”

“Call me.”

“What if he falls?”

“If he is injured or in pain, call 911; otherwise, call me.”

“What if I come in and find him dead in bed?”

“Wait until he is cold and blue, then call 911.”

“Okay, I can do that.”

Little did we know that he would live another five years.

This is a book about exit strategies. It is, indeed, another “end-of-life” book. It is not about making the end of life good. It is about making the end of life less bad. It is not about extending life. It is not even about extending “high quality” life. It is about avoiding a painful dying process and futile medical care. It is not a philosophical treatise about what makes life worth living. It is simply a practical look at declining health, old age, progressive debility, and practical choices that people can make to minimize the likelihood of the unconsidered death and to maximize the likelihood of a “better” death.

This book is not about physician-assisted suicide, medical aid in dying, or “death with dignity,” although I will mention them in

chapter 12. It is about developing a vision for a natural death—a death caused by disease or old age but not influenced by the violence of excessive medical technology.

This book is not going to dwell on ethical arguments for or against end-of-life choices, but I will state the ethical position responsible physicians take regarding life-sustaining treatments. It is the duty of the physician to sustain life and relieve suffering. When the performance of one responsibility conflicts with the other, the physician must defer to the patient's wishes.

This book is not about control. I understand that to suggest that we can control our deaths is simplistic and borders on falsehood. All deaths represent a loss of control. We can lose control to the natural history of old age and disease, or we can give up control to doctors and their therapeutic interventions. We can never keep complete control.

Finally, this book is about acceptance. That acceptance is not limited to the emotional acceptance described by Elisabeth Kübler-Ross as the fifth stage of loss and grief in her 1969 book *On Death and Dying*.¹ That emotional component is part of it, but I also encourage acceptance based on knowledge and understanding.

The goal of this book is to outline disease processes or trajectories and to emphasize choices that minimize the chances of a medicalized death and maximize the chances of a better death.

By disease trajectory, I mean the average course of illness for a given diagnosis. By medicalized death, I mean the state of a semi-conscious patient in an ICU or nursing home who is subjected to medical treatments beyond their direct wishes or beyond common sense. Therefore, the restated goal of this book is to use the knowledge of disease trajectories to choose a point in the disease process at which one considers stopping aggressive treatment and recognizes that palliative treatment is likely to offer a better outcome.

Steve Jobs's quote that "Death is very likely the single best invention of life" sounds brave. It has been used for purposes of inspiration by at least one hospice organization.² It sounds as if he really understood that all things must end. It sounds as if he accepted death. However, this is only because the quote is taken out of context; both the context of the speech and the context of his life.

The quotation was included in his commencement speech delivered to the graduating class at Stanford University in 2005. He had recently been diagnosed with a rare form of pancreatic cancer but lived six more years, dying in 2011. "Remembering that I will die soon" informed his business decisions specifically. That knowledge did not inform his medical decisions. "Steve never passively accepted end of life, nor did he have palliative care," wrote his biographer, Walter Isaacson.³

The reason I am dwelling on this is that Jobs's arrogance reminds me of my own. I recognize that it is arrogant to suggest how people should die. It is arrogant to suggest that people can control their fate. But many elderly people die while suffering excessive medical care that could have been limited if they had considered the alternative to fighting until the end.

Just a hint of philosophic perspective follows here. What makes humans forget that we are not immune to death? What makes every generation think that it will be the first generation to live much longer and much better? What makes each of us deny our illnesses and assume that we will "beat" old age or a terminal illness?

Perhaps it is the immutable will to live. Perhaps it is this century's conflation of a religious eternal life with a secular immortality. Perhaps it is a coping mechanism for an overwhelming fear of death. Perhaps it is the centuries-old confusion of science and magical thinking.

Each generation has its “immortalists.” Charlatans who sell the promise of eternal youth are everywhere. Scientists who allow the goals of their restorative or life-prolonging research to be described as “just around the corner” (instead of decades away) abound.

The current generation is obsessed with youth because youth “sells.” Diets, additives, exercise programs, and mental exercises all deny the inevitable. The beauty and fitness of our aging (but cosmetically enhanced) celebrities leap off the Photoshopped covers of glossy magazines with the promise of endless well-being.

This book is about recognizing that death is universal and will be so until this book is long out of print. This book is about recognizing the limitations of modern medicine in extending life expectancy; it is about the high physical and emotional cost of attempting to extend one’s life in the face of the inevitable; and it is about recognizing when to face death on your own terms and not someone else’s.

This book is aimed at several types of readers. First and foremost, it is written to inform the elderly and chronically ill patient who is in need of guidance at the end of life. Second, it is written to inform the families and caregivers of the elderly and chronically ill who, as agents of a patient, might be responsible for making difficult end-of-life decisions. Third, it is written for anyone who can look far enough ahead to know that death will arrive and to see that preparing for it in personal terms is better than leaving it completely to chance or in the hands of overly aggressive doctors.

Finally, it is not written for younger patients battling premature cancers or other illnesses. Such patients might take away some lessons or ideas, but I do not presume to have easy answers for their prematurely tragic circumstances. I have written it with the goal that each type of reader can see the important points from their own perspective.

The bulk of the book is devoted to informing patients and

empowering them to make informed decisions. At some point in the process of decision-making, acceptance must occur. Some readers will think that acceptance is another way of saying, “Give up.” I am not saying that. At the point of acceptance, I am saying, “Become aggressively passive.” Seize control of the decisions. Stop letting the physicians make the decisions. Review their recommendations but do not accept every one.

I understand that aggressive passivity sounds like giving up, but it is not. It is taking control of the one thing you can control: your care. It is a step taken at the point in life when you see a loss of control over everyday activities and bodily functions. It is the step to be taken when you see (with the help of this book) that you can no longer control your disease, and by fighting it you allow it to control you. Recognizing that once intensive medical treatment is initiated, its momentum and outcomes are largely out of your control, and declining such treatment puts you back in charge.

This book is broadly divided into three sections.

The first section of the book defines “a better death” and debunks aspects of the American health care system. The endless optimism of the politicians, the false hope of the advertisers, and the exaggerated promises of providers demand a reality check. Emotionally and spiritually, people have a powerful will to live, but intellectually we deny the inevitable. One of the reasons we expect to live forever is this false hope of a cure just around the corner and this false sense that American medicine is beating the odds.

The second third of the book describes disease trajectory and deathbed scenarios. In his classic work *How We Die*, Sherwin Nuland described multiple illnesses and death scenes. Using different clinical scenarios, his elegant prose grimly and honestly detailed how the body

deteriorates and life ends in the randomness and messiness of debility, disease, and death. The second section of this book dovetails with that concept and expands on it to show that, despite the differences of every clinical situation, there are also some commonalities. I describe the concepts of acute and chronic illnesses. I describe the course of illness for the six chronic diseases that cause the majority of adult deaths.

I will show that despite the randomness of illness there are recognizable patterns. Despite the unpredictability of the final act, a patient suffering from a chronic illness can take action and assert some influence on the outcome.

The final section of the book deals with practical aspects of the difficult conversations that result in responsible decisions. There are chapters on prognosis, end-of-life conversations, hospice care, and the voluntary refusal of fluid and food. A summary and a road map follow.

Finally, there is an appendix that takes a look at the details of advance directives and the unique challenges of dementia.

My father lived five years after the procedure to reinforce his aneurysm. Three of those years were good years, but two of them were not. The good years were characterized by continued activity and independence. The bad years were characterized by progressive weakness, physical limitations, and the dependence on others that my father had hoped to avoid. But by posing his original question about the wisdom of repairing his aneurysm my father informed his family and caregivers about his vision of a natural death. That vision informed all of his subsequent medical decision-making.

It is my hope that you, the reader, will enjoy the book. Doing so will help you gain a healthy skepticism of the American health care system, its marketing excesses, exaggerated promises, and the motives of its providers. I hope you will also get insight into disease trajectories,

better decisions, and, ideally, a vision that you can share with your family.

Combining the understanding of disease trajectories, an appreciation for the process of natural death, and skepticism of a system designed to treat excessively with practical end-of-life decisions will help patients have a better chance at a better death.