

A Good Death:

Learning to Live Like You Were Dying

by

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INTRODUCTION

I paused outside her closed door to catch my breath and gather my thoughts. Entering her room, I expected to find multiple family members, as on most days. Instead, she was alone.

As I shut the door behind me, the noises of a full ward faded, giving way to the gentle sounds of a humidifier and an elderly woman struggling to breathe. Her eyes were closed; an oxygen mask covered her nose and mouth. I glanced at the windowsill where multiple cards were displayed—a child’s drawing peeking out of one. Flowers on the bedside table. A family photo nearby. This was a well-loved woman.

I had witnessed her decline with each hospital visit, and it was obvious that the end was approaching. She knew it too and had requested to speak with me this day. When I sat gently on the bed, her eyes opened. Recognizing me, she gave a faint smile from underneath her mask. I reached for her hand and leaned forward so that we might hear each other.

Her hand was frail in mine, and yet her grip was tight as I began to share with her the painful truth: She was dying. Her disease had ravaged her lungs to the point that it was time to make some critical decisions.

She asked a series of straightforward and thoughtful questions, each one requiring her to gasp for air.

“So, how much time *do* I have left?”

“When I am short of breath like this, I feel terrible...will my suffering worsen?”

“You’ve witnessed the final moments of many others...what will it be like?”

“My family understands what is coming, but what exactly will they see?”

In my 30 years of medical practice—in state-of-the-art hospitals in the United States and in more nascent clinics in Rwanda—I’ve had countless end-of-life conversations. They are always soul wrenching. Typically, you can feel a heavy mixture of fear, disbelief, sorrow, and regret in the air. Sometimes, the only measure of comfort comes from a fierce embrace or a whispered prayer.

I answered her questions as clearly, honestly, and gently as possible. However, something about this particular moment—perhaps her quiet strength in the face of death, or maybe the fact that she would be terribly missed by her family—moved me unexpectedly. When I finally said, “I’m so sorry to have to tell you these things,” I began to weep.

To my surprise, my patient grabbed my other hand and squeezed even tighter.

“It’s okay,” she comforted me.” I am going to have *a good death*. Please prepare my family. I am ready.”

As I left her room, the statement, “I am going to have a good death” lodged in my mind. In the days and weeks that followed, I couldn’t shake it. Sinking into my subconscious, the phrase sometimes woke me in the night, prompting me to wonder *What does it mean to have “a good death?”* I thought about how so many people struggle mightily against our common destiny, seeing nothing about it as good. Meanwhile, others face death willingly, almost eagerly, as though arriving at a long-sought destination or getting a chance at last to become the self they knew they were meant to be.

Here’s something I know as a doctor: Persistent pain is always a signal that deeper investigation is warranted. Maybe a question that won’t go away is meant to serve the same purpose?

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Though we're always *sad*, we're never really *shocked* when death takes an elderly loved one, or when we attend the funeral of a friend or neighbor who's suffered from chronic illness or long-term debility. But then there are all those other deaths." Why?" we sob when a child dies." This isn't how life is supposed to work!" Likewise we struggle to accept the sudden passing of a young parent with small children. And how in the world are we to make sense of death when it comes via senseless acts of violence, up to and including the horrors of genocide? Perhaps you think—with good reason—that trying to find good in the wake of such evil is a fool's errand.

"A good death?" What possible good can be found in death? How in the world does anyone have "a good death"? And yet my breathless patient was genuinely peaceful as she prepared to depart this life. She seemed to possess a great secret that might benefit all those she was leaving behind. It made me wonder *If she could have "a good death," perhaps that's possible for others too?*

The more I puzzled over her odd, yet hopeful phrase, the more questions I had: Is it possible to accept the reality of death, but see it in a different light? Could we, by taking time to prepare for our eventual deaths, enhance our fleeting lives?

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It isn't a happy thought, but it's true nevertheless: The inevitable march to the grave begins with our first wobbly, toddling steps—sometimes, sadly, even before that. You don't have to be a physician to see this, but if you are a doctor, you're confronted with sobering reminders of mortality all day every day.

Professionally, I've witnessed patients receive a grim diagnosis, then fight a brave but losing battle against terminal illness. I've seen loved ones huddle in ERs following an accident to wait nervously for good news that never came. I've sat with patients, couples, and entire families as they wrestled with end-of-life decisions. I've also worked in a country—Rwanda—previously torn apart by genocide and deeply affected by the impact of the early AIDS crisis.

Personally, I have friends who have lost children and spouses. I've seen diseases like dementia, Alzheimer's, and ALS slowly and cruelly take away moms and dads, sisters and brothers. I've watched many enter the unfamiliar world of home health and hospice care so that their loved ones might live out their final weeks and days in familiar surroundings.

In all these brushes with mortality—too many sorrowful moments, painful experiences, and sudden calamities to count—I have continued to ponder that provocative phrase “a good death.” As I've interacted with the dying (both marveling at and learning from them), and as I've read eloquent books on the subject of death, I've become convinced that goodness and death are *not* mutually exclusive. Even when death comes via violence, tragedy, or unspeakable evil, I've seen how, in time, and in wholly unexpected ways, it can be the catalyst for good things. I've also discovered how doing good and being wise *now*, in life, actually prepares us for “a good death.”

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My goal in these pages is to share with you what I've learned about having "a good death."

Out of my experience as a doctor, I want to help you prepare for the unexpected difficulties that come with end-of-life realities. I want to help you plan for the future and learn how to navigate the foreign land of a hospital. I want you to understand the inevitable paradigm shifts that occur as we age...see how to care for elderly parents...grasp how to leave a legacy that matters. In these pages, I will pass on encouraging reminders (many that I learned from my dying patients), helpful checklists, and practical resources that will be of immediate use to you whether you are 40 and in great health, or 80 and reeling from a grim diagnosis. I'll even provide some important questions you'd be wise to ask your health care providers.

My goal is to share some concrete steps you can begin taking today toward "a good death" (whenever that day happens to come).

A couple of disclaimers are in order...

1. This book is intentionally short. That's because those near the end of their journey (and the ones who care for them) have little time and, typically, little warning about what lies ahead.

2. Discussions about death typically raise questions about faith, religion, and/or what comes after death. It's been my observation that when the end is near, most people tend to revisit and rethink what they believe (or why they don't believe).

In the spirit of full disclosure, let me say that I am a person of faith. I am a follower. Let me quickly add, however, that I have no intention of pushing my beliefs on anyone. This book,

while it *includes* occasional references to faith, isn't *about* faith. It isn't an exercise in proselytizing; it is about giving readers practical help for facing end-of-life medical realities.

I have many people in my life who believe deeply in God (although in very different ways). I have other dear friends who believe fiercely that God doesn't exist. These differences don't keep us from loving or learning from each other. My contention is that regardless of one's spiritual beliefs, we all need practical information and help in finding good in those fading breaths that will ultimately end with death.

Dr. Bruce Long has noted what death means to two major world religions: "There is general agreement between Hinduism and Buddhism that no human life can be filled with a sense of meaning and efficacious action unless it is lived in full acceptance of the fact of death."¹ Though I'm neither Hindu, nor Buddhist, I think Dr. Long's observation is true: Facing the reality of death and preparing for it accordingly makes for a good life. And a good life, it seems to me, leads to "a good death." (Note: If the notion of "a good death" still seems like a stretch to you, how about "a less horrible death?" Wouldn't *that* be something worth investigating?)

I'm convinced that deciding what we believe about life's ultimate questions (and why)—especially when not under duress—is helpful on the journey to the end of this life. If you're unsure of where to start in that process, may I suggest you sit and study the world around you? Use all your physical senses. Don't just look, see. Don't just hear, listen with your heart. Don't simply touch, feel. Don't merely smell, breathe in...instead of tasting, savor the wonder of life at its best.

¹ J. Bruce Long, Ph.D, "The Death That Ends Death in Hinduism and Buddhism, 1975; Essay, Kubler-Ross MD, Elizabeth, *Death: The Final Stage of Growth*, A Spectrum Book, 1975.

My faith tradition says that visible, physical realities point to invisible, spiritual realities. Perhaps then, the simple step of being still—or being mindful, as some put it—can help in your journey of discovering the “good” that’s often hard to see in life’s darkest times. Of course, if you’re not interested in taking that step right now, that’s fine too.

In the end, only you can determine whether you will have a good death. Your journey may be such that you still have many years in which to ask and answer these questions. It’s also true that none of us knows when our final day will come.

All those big mysteries and questions aside, I hope you’ll come along as we walk through some of the very basic but wise things a person can do now to prepare for “a good death.” When we’re done, I hope you’ll realize this really *isn’t* a book about death; it’s a book about life.