

## #96: Being Mortal

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#1 *NEW YORK TIMES* BESTSELLER

Atul Gawande



Being Mortal

Medicine and What Matters in the End

"Wise and deeply moving." —OLIVER SACKS

PICADOR

## Overview

A powerful look at the failure of the modern medical system to

## Book Notes

“Our most cruel failure in how we treat the sick and the aged is the failure to recognize that they have priorities beyond merely being safe and living longer; that the chance to shape one’s story is essential to sustaining meaning in life; that we have the opportunity to refashion our institutions, our culture, and our conversations in ways that transform the possibilities for the last chapters of everyone’s lives.”

Atul Gawande is an incredible writer and thinker and uniquely positioned to critique how the modern medical system has focused purely on “repair of health, not sustenance of the soul,” to the detriment of its patients. Through age or illness of ourselves or our loved ones, each of us will be forced to answer difficult questions about what gives our lives meaning, and what is necessary to retain autonomy, purpose, and dignity. Confronting this mortality is a difficult and unpleasant process. Perhaps the most reassuring part of the book is that it is no easier for a physician than it is for the layperson. Gawande chronicles his own father’s struggle with cancer (a physician himself)—even with over a lifetime of experience between father and son (and mother, also a doctor), navigating the end of his life was still full of struggle, uncertainty, and certainly, no easy answers.

Beyond the philosophical there is a lot of practical context provided around the history of elder care, the rise of nursing homes (from poorhouses) and assisted living facilities. Ultimately, this is heavy reading, but full of meaning and opportunity for reflection.

### INTRODUCTION

- *The Death of Ivan Illyich* by Tolstoy (pg. 1)
- “This is a book about the modern experience of mortality—about what it’s like to be creatures who age and die, how medicine has changed the experience and how it hasn’t, where our ideas about how to deal with our finitude have got the reality wrong. As I pass a decade in the surgical practice and become middle-aged myself, I find that neither I, nor my patients find our current state tolerable.” (pg. 9)
- “Our reluctance to honestly examine the experience of aging and dying has increased the harm we inflict on people and denied them the basic comforts they most need. Lacking a coherent view of how people might live successfully all the way to their very end, we have allowed our fates to be controlled by the imperatives of medicine, technology, and strangers.” (pg. 9)

### CHAPTER 1 - THE INDEPENDENT SELF

- “We think nostalgically, that we want the kind of old age my grandfather had. But the reason we do not have it is that, in the end, we do not actually want it. The historical pattern is clear: as soon as people got the resources and opportunity to abandon that way of life, they were gone.” (pg. 20)
- Intimacy at a distance - separation as freedom, when people age; the preferred state for aging parents (pg. 21)
  - Worldwide pattern of parents not living with children; in the US dropped from 65% to 15% between 1960’s to 1975 (parents over 65 years old).
  - Actually a sign of significant economic progress.
- “Modernization did not demote the elderly. It demoted the family. It gave people—the young and the old—a way of life with more liberty and control, including the liberty to be less beholden to other generations. The veneration of elders may be gone, but not because it has been replaced by veneration of youth. It’s been replaced by veneration of the independent self.” (pg. 22)

## CHAPTER 2 - THINGS FALL APART

- “We’re always trotting out some story of a ninety-seven-year-old who runs marathons, as if such cases were not miracles of biological luck but reasonable expectations for all. Then, when our bodies fail to live up to this fantasy, we feel as if we somehow have something to apologize for.” (pg. 28)
- Start to lose muscle mass and power around age 40 (pg. 30)
- “At the age of thirty, the brain is a three-pound organ that barely fits inside the skull; by our seventies, gray-matter loss leaves almost an inch of spare room.” (pg. 31)
- “Memory and the ability to gather and weigh multiple ideas—to multitask—peaks in midlife and then gradually declines. Processing speeds start decreasing as well before age forty. (pg. 31)
- “Leonid Gavrilov, a researcher at the University of Chicago, argues that human beings fail the way all complex systems fail: randomly and gradually. As engineers have long recognized, simple devices typically do not age. They function reliably until a critical component fails, and the whole thing dies in an instant.” (pg. 33)
- “Rectangularization of Survival” - moving from distributions of ages that look like rectangles instead of pyramids (pg. 35)

## CHAPTER 3 - DEPENDENCE

- “Old age is not a battle. Old age is a massacre.” - Philip Roth (pg. 55)
- Story of Felix, in his nineties...
  - “He felt they knew each other, and loved each other, more than at any time in their nearly seventy years together.” (pg. 56)
- Progress of Healthcare

- “For most of our species’ existence, people were fundamentally on their own with the sufferings of their body. They depended on nature and chance and the ministry of family and religion.” (pg. 69)
- “Hospitals...became the normal place for people to go with their bodily troubles, including the elderly.”
- “Pensions provided a way of allowing the elderly to manage independently as long as possible in their retirement years. But pensions hadn’t provided a plan for that final, infirm stage of mortal life.”
- Nursing homes were eventually created after hospitals overcrowded, but, “they were never created to help people facing dependency in old age. They were created to clear out hospital beds—which is why they were called ‘nursing’ homes.” (pg. 71)
- “Half of us will typically spend a year or more of our lives [in nursing homes].” (pg. 72)
- The story of his wife’s grandmother:

“All privacy and control were gone. She was put in hospital clothes most of the time. She woke when they told her, bathed and dressed when they told her, ate when they told her. She lived with whomever they said she had to. There was a succession of roommates, never chosen with her input and all with cognitive impairments. Some were quiet. One kept her up at night. She felt incarcerated, like she was in prison for being old.” (pg. 73)

#### CHAPTER 4 - DEPENDENCE

- “Your chances of avoiding the nursing home are directly related to the number of children you have, and, according to what little research has been done, having at least one daughter seems to be crucial to the amount of help you will receive.” (pg. 79)
- Laura Carstensen’s Hypothesis:
  - “How we seek to spend our time may depend on how much time we perceive ourselves to have.”
  - “As your horizons contract—when you see the future ahead of you as finite and uncertain—your focus shifts to the here and now, to everyday pleasures and the people closest to you.” (pg. 97)
- Tolstoy: “Even when a sense of mortality reorders our desires, these desires are not impossible to satisfy.” (pg. 99)
- “Our elderly are left with a controlled and supervised institutional existence, a medically designed answer to unfixable problems, a life designed to be **safe** but **empty of anything they care about.**” (pg. 109)

#### CHAPTER 5 - A BETTER LIFE

- Three plagues of a nursing home: boredom, loneliness, and helplessness; used green plants and animals to tackle some of these problems (pg. 116)

- Josiah Royce, *The Philosophy of Loyalty*
  - “We all seek a cause beyond ourselves. This was, to him, an intrinsic human need.”
  - “This dedication to a cause beyond oneself [he called] loyalty.”
  - Transcendence - above self-actualization, “the desire to see and help other beings achieve their potential.” (pg. 127)
- “Medical professionals concentrate on repair of health, not sustenance of the soul.” (pg. 128)
- Ronald Dworkin, *Autonomy and the Demented Self*
  - “The value of autonomy...lies in the schemings of responsibility it creates: autonomy makes each of us responsible for shaping his own life according to some coherent and distinctive sense of character, conviction, and interest. It allows us to lead our own lives rather than be led along them, so that each of us can be, to the extent such a scheme of rights can make this possible, what he has made himself.” (pg. 140)
  - “We want to retain the freedom to shape our lives in ways consistent with ur character and loyalties.” (pg. 141)

## CHAPTER 6 - LETTING GO

- “The insight was that as people’s capacities wane, whether through age or ill health, making their lives better often requires curbing our purely medical imperatives—resisting the urge to fiddle and fix and control.” (pg. 149)
  - “When should we try to fix and when should we not?” (pg. 149)
- “In the United States, 25% of all Medicare spending is for the the 5% of patients who are in the final year of life, and most of that money goes for care in their last couple of months that is of little apparent benefit.” (pg. 153)
- “The trouble is that we’ve built our medical systems and culture around the long tail. We’ve created a multi-trillion dollar edifice for dispensing the medical equivalent of lottery tickets —and have only the rudiments of a system to prepare patients for the near certainty that those tickets will not win. Hope is not a plan, but hope is our plan.” (pg. 172)
- “People who had substantive discussions with their doctor about their end-of-life preferences were far more likely to die at peace and in control of their situation and to spare their family anguish.” (pg. 177)
- “Our decision making in medicine has failed so spectacularly that we have reached the point of actively inflicting harm on patients rather than confronting the subject of mortality.” (pg. 178)
- “That last month...the family simply focused on being together, and it proved to be the most meaningful time they’d ever spent.” (pg. 187)

## CHAPTER 7 - HARD CONVERSATIONS

- “By 2010, 45% of Americans died in hospice. More than half of them received hospice care

at home." (pg. 193)

A monumental transformation is occurring. In this country and across the globe, people increasingly have an alternative to withering in old age homes and dying in hospitals – and millions of them are seizing the opportunity. But this is an unsettled time. We've begun rejecting the institutionalized version of aging and death, but we've not yet established our new norm. We're caught in a transitional phase. However miserable the old system has been, we are all experts at it. We know the dance moves. You agree to become a patient, and I, the clinician, agree to try to fix you, whatever the improbability, the misery, the damage, or the cost. With this new way, in which we together try to figure out how to face mortality and preserve the fiber of a meaningful life, with its loyalties and individuality, we are plodding novices. We are going through a societal learning curve, one person at a time. And that would include me, whether as a doctor or as simply a human being. (pg. 193)

- Types of doctor-patient relationships (pg. 200)
  - Paternalistic: "[Doctors] make the critical choices"
  - Interpretive: "We tell you the facts and figures. The rest is up to you."
  - Interpretive: "The doctor's role is to help patients determine what they want."
- "I am worried." - the best way to convey meaning to a patient (pg. 206)
- "This is what it means to have autonomy—you may not control life's circumstances, but getting to be the author of your life means getting to control what you do with them." (pg. 210)
- Discussing his father's cancer with his oncologist...
  - "The discussion became difficult for me or my parents to follow, despite all three of us being doctors." (pg. 218)

## CHAPTER 8 - COURAGE

- Plato's *Laches*
  - "Courage is *strength* in the face of knowledge of what is to be feared or hoped. Wisdom is prudent strength." (pg. 232)
- Two kinds of courage when aging or sick:
  - "The courage to confront the reality of mortality"
  - "The courage to act on the truth we find."
- **Kahneman's "Peak-end Rule"**
  - "An average of the pain experienced at just two-moments—the single worst moment of the procedure and the very end." (pg. 237)
- "Our most cruel failure in how we treat the sick and the aged is the failure to recognize that they have priorities beyond merely being safe and living longer; that the chance to shape

one's story is essential to sustaining meaning in life; that we have the opportunity to refashion our institutions, our culture, and our conversations in ways that transform the possibilities for the last chapters of everyone's lives." (pg. 243)

## **EPILOGUE**

- "We've been wrong about what our job is in medicine. We think our job is to ensure health and survival. But really it is larger than that. It is to enable well-being. And well-being is about the reasons one wishes to be alive."