Gawande, Atul. *Being Mortal: Medicine and What Matters in the End.* New York: Henry Holt and Company, 2014.

Atul Gawande is an American surgeon and writer from Newton, Massachusetts. Gawande is the son of Indian immigrants, both of whom were doctors. Gawande, in addition to writing for the *New Yorker* magazine, works on improving surgery globally.

1. **The Independent Self.** No medical school teaches its students about mortality. One learns to save lives, not manage the end of those lives. Gawande explores Tolstoy's Ivan Ilyich, who suffered as disease weakened him. Those attending Ilyich clung to their various hopes and illusions. Gawande tells of seeking informed consent from Joseph Lazaroff, dying of metastatic prostate cancer. Joseph chose wrongly, pursuing a medical fantasy. The hospital and medical staff let him indulge that illusion. Joseph, after a successful surgery, suffered complications in recovery. Finally, after two weeks on a ventilator, the family stopped the treatment and Joseph died. None of the medical staff spoke plainly with Joseph about his circumstance.

   Our culture has medicalized dying. Death used to come in homes. Now, most die in hospitals. We avoid death, which is unavoidable. All die. Therefore, some problem will prove beyond medicine. Medical interventions can cause pointless suffering. Heroic procedures often rob patients of comforts that are certain and available. We must speak of death, even if some are alarmed by such talk. Gawande tells of Alice Hobson, his wife's grandmother, whose health began failing. Gawande describes his immigrant father. Gawande's grandfather, in India, lived with family, and depended upon them until he died at 110 years. At that time, surviving into old age was uncommon. Now, it is not. In western cultures, children no longer care for their aged parents directly, and parents are not sad, generally, to see them go. So, Alice Hobson's teeth, eyes, and mind began to fail. She fell repeatedly. Her independence suffered.

2. **Things Fall Apart.** Before last century, death came suddenly and unpredictably. Now, we decline slowly, in a long slide, punctuated by flagging recoveries, toward ultimate death. Slowly, our parts fail. Bones and teeth soften. Blood pressures rises. Muscles weaken. In prehistory, the average life span was thirty years or less. In the Roman Empire, average life span was twenty-eight years. We die as we wear out. Our extended dying changes the human demographic range. There are now, as a percentage, more elderly people. Oddly, the study of geriatrics has declined, even as the target population grows. Gawande attended an interview between patient Jean Gavrilles and her geriatrician, Juergen Bludau. Bludau's examination focused not on Jean's probable life-threatening conditions, but on issues that would snatch from her the quality of life she retained: falling and foot care. Bludau wanted Jean to retain active engagement with the world.

   Grandmother Alice's decline began with missing the brake and finding the accelerator. Then she got scammed by a fraudulent contractor. Geriatric care improves life outcomes with no increase in mortality. It avoids dramatic interventions in favor of improved function and resilience. Geriatrics, as a medical field, is financially imperiled. It offers no popular gizmos. Gawande tells Felix Silverstone's story, himself a geriatrician. Silverstone practiced into his eighties, but quit as his wife went blind. They moved to a retirement facility. Silverstone's body failed slowly, as he cared for his wife. Both suffered problems with choking. There are too few geriatricians; the schools no longer produce enough. Felix Silverstone drove, but would have to give up his keys sometime. The old are the highest risk drivers.

3. **Dependence.** No matter how much good care one gives oneself, we eventually lose independence. Felix Silverstone's wife became totally deaf, as well as blind. She recovered some hearing, and remained, with difficulty, at home. She fell, broke both legs, and entered a nursing home. She returned home briefly, then collapsed and died.

   Alice Hobson also feared losing her ability to live at home. But she did. She moved to retirement facilities, and gave up driving.

A 1913 study of elderly poor in New York City described the plight of sixty-five aged people, all suffering diseases and living on the edge. The almshouse awaited, ill-maintained collective slums for the old. Gawande describes his experience in such a house of charity in India. Such are gone in the West, but the homes are still feared.

Alice Hobson just never felt at home in her retirement apartment. Harry Truman refused to leave his resort on Mt. St. Helens, despite knowledge of the oncoming eruption. Alice disliked the invasive safety measures of her retirement center.

This all or nothing circumstance as to the end of life began with poorhouses. These wretched institutions were replaced by hospitals. They trended then toward less expensive, but no less invasive, nursing homes.

Alice began falling. She declined from independent living to the nursing home, losing control and privacy. In nursing homes, care became unhinged from living. Safety pre-empts dignity. Nursing homes lose track of how to make life worth living for frail people.

Alice broke her hip. She chose a "do not resuscitate" order. She died in her bed.

4. Assistance. The alternatives for elderly persons are nursing homes or the care of children (mostly daughters). Lou Sander did well into his nineties, but then began falling and suffered Parkinson's disease. He moved in with his daughter, but that caused stresses. Lou grew close to his daughter's dog. Lou's daughter was burdened, and Lou kept falling. Lou's night terrors kept the family awake. He blasted the TV. He needed help with bathing, toileting, and demanded food different than the family was eating. Finally, Lou's needs overwhelmed his daughter. Lou moved to an assisted living facility.

Keren Wilson started assisted living facilities. Her concept was creating facilities that provided help but were still homes. Wilson's own mother spent a lifetime in nursing homes, consequent to a stroke. She and her spouse decided to build a different sort of place. People would have independence and not be patients. But there would be help with food, medications, care, but no one was to feel institutionalized. Tenants' health improved and the costs declined, as compared to nursing homes.

People's needs change over a lifetime. Older people seek being in the present, more than doing for the future. Laura Carstensen's research indicates that older people tend to be happier than the young. She thinks that living is a skill that takes decades to master. Older people see time more clearly, especially its limitations. At twenty-one, Carstensen suffered serious injuries in a vehicle rollover. Months in the hospital changed her values. Carstensen's ongoing studies indicated that young, healthy people value time with new sources of information or opportunity, while older people or sick people value the relationships they already have.

Assisted living mutated. Now popular, it was watered down and made a part of continuum of care facilities. Keren Wilson continues to do research into how ordinary older people can live without having to choose between neglect and institutional coddling.

Lou Sander was finally forced to move to an assisted living facility, but they seemed to care little for him. So Lou and his daughter compromised: Lou came to live with his daughter every Sunday through Tuesday.

Most assisted living caters to the elder's children, not the elders. The facilities impose limitations on our older loved ones we would never accept for ourselves.

Lou's daughter moved Lou to a nursing home as his falling worsened. She could never answer the question why safety matters more than happiness.

5. A Better Life. Physician Bill Thomas took over a nursing home. In its halls, Bill saw despair, though nothing out of the ordinary was happening. Bill decided that life itself was missing from the nursing home. He created the Eden Alternative. The three plagues of nursing homes, boredom, loneliness, and helplessness, ran rampant. So, he put in gardens and brought in dogs and cats and 100 birds, one for every room. Bill confronted cultural inertia in the nursing home. This was different. The residents organized themselves to provide care for the animals. Rabbits and laying hens joined the outside environment. The experiment worked. Deaths fell fifteen percent. Drug costs fell sixty-two percent. The animals gave

people a reason to live. Gawande believes that this experiment shows that people, even profoundly disabled people, can experience greater meaning in life.

Josiah Royce wrote *The Philosophy of Loyalty* (1908). He argued that life requires more than security. We need causes greater than ourselves to find meaning in existence. People care about what happens to the world when they are gone. We find meaning in participating in the greater prosperity of mankind, expressed in our families, communities, and world.

Medical institutions have little concern about making life meaningful. Doctors repair bodies. We have let doctors take over the last days of our lives. That has injured us. The medicalization of old age has failed. It is meaning, not safety, that is most necessary at any age.

New Bridge in Boston breaks their institution into smaller housing groups not exceeding sixteen members. The smallness reduces anxiety, and fosters friendship and staff interaction. The rules are different too. Mobility matters; people walk, though they might fall. The New Bridge philosophy is that people need privacy and community, flexibility of schedule, and friends. They brought in children regularly, and allowed pets. Peter Sanford Place emerged from a serious attempt to leave residents with choices, even poor ones. To make that work, Jacquie Carson had to battle the medical system. Her philosophy was "we will sort this out."

Beacon Hill Villages is Boston community cooperative providing assistance of all sorts to elderly people as they remain in their homes. They share the conviction with the other programs described in this chapter that needing assistance with daily living activities ought not to require one to give up personal choice and preference. All lives, not just the elderly, are interdependent and fragile. The philosopher Ronald Dworkin argues that real freedom consists in making of our lives what we imagine and fashion, to be one's own author. We resist disintegration in order to remain what we have made ourselves. Worthwhile life exceeds safety in importance.

Lou Sanders was failing when he learned of Leonard Florence Center for Living, part of the Green House movement. All rooms were single. In a Green House, life focused on food, making a home, and building friendships. Each house was ten people living together with assistants assigned to that house.

Older people do not ask much. They just want to live what life remains for them on their own terms.

6. Letting Go. Often, to make the life of an aging person better, doctors need to resist the temptation to make things better. Gawande recounts Sara Monopoli's story. Sara was thirty-four and pregnant when she learned she was dying of cancer. The couple declined treatment until their daughter was born, and then treated the inoperable metastases. Three courses of chemotherapy failed. Should treatment continue? Twenty-five percent of all Medicare monies are spent on that five percent of people who are in their last year of life. Doctors seldom know when to stop. And patients are seldom prepared for the final stage of their terminal illness. Dramatic interventions to delay dying cause, after the loved one's death, three times the number of major depressions in survivors, as compared with those who decline the interventions. Dying people want more than survival. They want little suffering, affirming relationships, being aware, not to be a burden, and finding completion to their lives.

Dying used to be precipitous. Now swift death is uncommon. Hospice provides comfort care to dying people who decline heroic final interventions. Hospice focuses attention upon making today a good day for clients. They provide comfort packs containing drugs and implements to deal with the likely problems in a person's decline. Hospice offers an alternative to the medicalization of death.

Sara Monopoli considered experimental therapies, since she had a baby and was young. Her doctor was optimistic. Research shows that sixty-three percent of doctors over-estimate how long terminal patients have to live. Many offer treatments that will not, in their professional opinions, work. Doctors participate in their patient's denial of death. Gawande tells of Sara Monopoli's lung cancer outcome. Sara fought, with Gawande's help, to the bitter end. Gawande recounts Stephen Jay Gould's essay on low-likelihood outcomes, arguing that deviation from the median happens to some on every statistical curve. Gawande hopes to offer that perspective, but to help a patient prepare for the far-more-likely median outcome.

The medical system, however, is built around the long tail, the Hail Mary. Sara could not prepare. She got pneumonia, was taken to the hospital, where she lost consciousness.

Some argue that all the end of life interventions exist because government or insurance companies pay for it, removing the person's decision-making about how to spend money. An insurance company attempted to decline improvident treatment at the end of Nelene Fox's life. Her doctors opted for experimental high dose chemotherapy followed by bone marrow transplant. Health Net declined coverage. She raised the money herself, but got the treatment later than she might have if Health Net covered. Her husband sued after Nelene's death, and was awarded $89 million. Aetna offered hospice in conjunction with hospital care. Use of hospital resources plummeted. Most doctors do not speak with patients about their goals in terminal illness. Patients in one study who had hospice conjoined with hospital care survived twenty-five percent longer. Gawande concludes that one lives longer when he stops trying to live longer.

Perhaps merely talking about death improves life. La Crosse, Wisconsin, worked to have all patients create rudimentary directives to physicians about their end of life preferences. These patients talked about death before the pressures of illness were heavy upon them. When Gawande has spoken more plainly with patients about their difficult diagnoses, some find that conversation deflating. A palliative care specialist told him that the purpose of such meetings was to alleviate anxieties about death, suffering, family, and money. One tries to learn what matters most to the ill person. If you can get clear on that, then procedures consistent with that clarity can be undertaken, others foregone. These are called "breakpoint discussions." One must include entire families. Two-thirds of patients will undergo therapies they do not want in order to satisfy loved ones. Some argue that unwanted therapies commence because the system pays doctors to do the procedures, but does not pay them to sort out which procedures to decline. The task often falls to doctors and nurses to have these discussions.

Sara Monopoli lay in the hospital. After conversations, she took antibiotics, but refused intubation. And hospice came in. Sara died.

7. **Hard Conversations.** Countries develop medically through three stages: a) most deaths occur at home, b) most deaths occur in a hospital, and c) more deaths occur at home, since resources are sufficient to provide a quality of care in that context. In 2010, forty-five percent of Americans died in hospice care. We have much to learn, but are turning from medical perspective at life's end toward preserving meaning.

Gawande's father played tennis, worked as an urologist, and did Rotary projects far into his seventies. He began to have neck pain. It proved to be a tumor inside his spinal cord. Two surgeons offered to open the spinal column and remove what of the tumor could be removed. One told Gawande senior to wait until the tumor progressed, which could be soon or late. He waited.

Gawande seeks to share decisions about treatment with his patients. He strives to be neither paternal, nor merely informative. Gawande tells of Jewell Douglass, whom he saw after her third round of chemo for ovarian cancer. Her bowel became blocked by metastases. The blockage resolved, but Gawande had a conversation with his patient about the cancer and the likelihood of recurrence of blockage. She was back soon with another blockage. She and her family decided on no further treatment. They made a trip to Florida and spent time together.

Gawande senior kept on for several years, then symptoms advanced. He quit his medical practice and reluctantly underwent the surgery, but not before completing a stint as Rotary District Governor. The surgery went well. He recovered many functions within a month. Gawande senior went on to radiation therapy to control the tumor. He responded poorly. The tumor grew into his brain. The oncologist recommended chemo, but had not seen really good outcomes from such treatment. At home, Gawande senior fell. His wife bent down to be with him, and could not get up herself. Gawande senior wanted to die, but could not. The family strategized how to care for him. He started on hospice at home. They chose a funeral home. Gawanda senior's life improved with the consistency of care.

8. Courage. Plato taught that courage is strength before known fears or hopes. Gawande asserts we must decide whether our hopes or fears matter most.

Jewell Douglass returned to the hospital after three and one-half months. Her bowel was again blocked. Her highest priority was to attend her best friend's wedding in a few days. She declined surgery, citing the risks.

People rate pain subjectively, based on its worst moment of intensity and its intensity as the cause of pain ends. People rate lives according to the story they tell. They want their own life to be meaningful as a story, to cohere, its arc punctuated by poignant moments that highlight the gist of their personal story. As in all stories, the end matters greatly.

Jewell Douglas consented to surgery, just to see if she could get a few more days. She instructed no "risky chances." So, Gawande installed two drainage tubes and sewed her up. Two weeks later, she drifted to sleep and into death.

We have some control in our endings. The medical community frequently fails to recognize that patients have purposes exceeding mere long life. They want to shape their lives. They want meaning.

How far shall we let people go in controlling the ends of their stories? We let people refuse food and medications. We remove unwanted medical devices. We give pain medications, knowing they may hasten death. Shall we end suffering if we might be terminating valued life? Gawande believes we should not seek good deaths, but rather good lives to the very end.

Gawande's daughter's piano teacher was dying of cancer. Gawande convinced her to go into hospice. She went home. A few days later, the teacher called, asking if the daughter would like a few more lessons. The teacher lived six weeks after entering hospice, teaching and even attending two student recitals. She ended her story as she wished.

Gawande's own father came to his end. He suffered much pain, and needed pain medication to live. But it made him groggy, which he hated. He fell unconscious, and his wife, panicking, called 911, not hospice. At the hospital, the family considered intubation and ICU. When Gawande senior awoke to find himself in the hospital, he was unhappy to have his preferences ignored. The family removed Gawande's father from the hospital. He lived four more days at home, and had some good hours. Then he died.

Epilogue. Medicine must be about patient well-being, not merely health and survival. Well-being concerns the meaning of one's life; it pertains to understanding, fears, hopes, compromises, and choices of actions.

Gawande's family followed his father's wishes. They cremated his body and spread his ashes as and where he asked, one part in the Ganges River. Gawande's father knew life is short and his place in it small. But he also knew his life stood as a line in the ancient and ongoing story of life.