Book Review

Being Mortal: Medicine and What Matters in the End

(Metropolitan Books, 2014)

Author: Atul Gawande
Reviewed by William J. Brisk, CELA

Should patients who are suffering the agonizing consequences of horrific illness forego lifesaving treatments to live their remaining days as authentically as possible? What role should physicians play in informing patients of their options and carrying them out? Can society afford the cost of prolonging the lives of seriously ill patients? Do we change our attitudes toward these questions as we age? Atul Gawande’s latest book, which achieved number 1 status on The New York Times nonfiction best seller list, prepares professionals as well as the general public to consider the benefits and costs of withholding or terminating treatment and even sanctioning physician-assisted suicide.

Those who know Gawande’s work will not be surprised that Being Mortal is highly readable, involving, and immensely informative as it explains medical dilemmas. For those unfamiliar with his work, Gawande is an eminent Boston surgeon who was named a Fellow by the MacArthur Foundation, an honor also known as the “genius grant.” His lucid articles appear regularly in The New Yorker, and his books apply his professional experience to how we can all cope with complications, how hospitals and other institutions can achieve better results for their patients, and how all of us can benefit by using checklists to make sure we prioritize and meet personal as well as professional goals.

Being Mortal begins with a startling confession from the author: “I learned about a lot of things in medical school, but mortality wasn’t one of them.” An hour spent discussing Leo Tolstoy’s The Death of Ivan Ilyich in a weekly seminar on doctor-patient relations was his medical school’s sole instruction on how to deal with mortality. For much of his professional life as a surgeon, he did what he could to extend the lives of patients without considering whether that always benefited the patients.

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Readers are directed to an excellent NAELA Journal article that raises and answers similar questions from a legal perspective: Katherine Hayes, Michal McDowell & Sydney Reuben, Providing Patient-Centered Care: An Examination of the Policy and Political Barriers and Proposed Options to Improve Care for Persons with Advanced Illness, 10 NAELA J. 1 (2014).

Gawande’s article on the value of coaching — in professions as well as in sports — should be required reading for NAELA members: Personal Best: Top Athletes and Singers Have Coaches. Should You? New Yorker, 44 (Oct. 3, 2011).

The Checklist Manifesto: How to Get Things Right (Picador 2011).


This classic novella, first published in 1886, begins when an unlovable 46-year-old St. Petersburg magistrate, Ivan Ilyich, develops fatal complications after falling off a stepladder. A servant provides Ilyich’s only solace as he surveys his long past and brief future.
The book draws from four principal sources: his own reflections on the different needs of his patients, particular challenges posed by his father’s illness, research into how institutionalized care (at nursing homes and assisted living facilities) became extensions of American hospitals, and his extended conversations with geriatricians and palliative care advocates, which reoriented him to emphasize care over treatment for patients facing mortality.

Gawande introduces “Joseph Lazaroff,” whose metastatic cancer has spread from his prostate to his spinal cord. Standard treatment might excise some, but not most, of the cancer. This treatment at best might prolong Lazaroff’s life a few months or so but would leave him incontinent and dependent. As Gawande explains, “We had no difficulty explaining the specific dangers of various treatment options, but we never really touched on the reality of his disease.”8 Lazaroff’s dilemma forces Gawande to consider the paradox of modern medicine, which has

profundely altered the course of human life. [While] [p]eople live longer and better than at any other time in history … scientific advances have turned the processes of aging and dying into medical experiences, matters to be managed by health care professionals. And we in the medical world have proved alarmingly unprepared for it.9]

Gawande struggles over how he as a surgeon and countless other physicians think about treatment first and only later, if at all, about care.

The waning days of our lives are given over to treatments that addle our brains and sap our bodies for a sliver’s chance of benefit. [Worse,] [t]hey are spent in institutions — nursing homes and intensive care units — where regimented, anonymous routines cut us off from all the things that matter to us in life. … 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.10

This stunning apology (which is so uncharacteristic of what we expect from surgeons) leads Gawande to consider his own family: his grandfather (living in India) and his parents (both physicians who successfully transitioned from India to the United States). Gawande notes the cultural differences. In the United States, “old age and infirmity have gone from being a shared, multigenerational responsibility [in India even today] to a more or less private state — something experienced largely alone or with the aid of doctors and institutions.”11

How did this happen? Until the 20th century, the few people who lived past 80 were venerated as guardians of tradition and wisdom. Technology, extended life expectancies, scattered

8 Gawande, supra n. 6, at 5.
9 Id. at 6. Gawande continues, “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.”
10 Id. at 9.
11 Id. at 17.
families, and communications have shaped our current society but not without cost, among them the loss of traditional privileges granted to older and wiser men and women. We live longer, but do we age better?

The second chapter (“Things Fall Apart”) traces how mortality has changed. Through most of human history, aging (mental and physical declines) arrived suddenly, with death following quickly. Today our declines resemble “less a cliff and more like a hilly road down the mountain.” Modern medicine conquers many short-term emergencies (which in the past led inexorably to death) but fails over time to restore good health when multiple illnesses accumulate. Gawande refers to Juergen Bludau, a colleague at Brigham and Women’s Hospital and the lone geriatrician on the Harvard Medical School faculty, who counsels, “The job of any doctor … is to support quality of life,” by which he meant two things: as much freedom from the ravages of disease as possible and the retention of enough function for active engagement in the world.

Gawande interviewed another eminent doctor, Felix Silverstone, who, at 82, moved with his wife to a senior community, Orchard Cove, in suburban Boston, setting the stage for one of the book’s most intriguing chapters (“Dependence”). This chapter should be required reading for all Elder Law attorneys because of its historical analysis of nursing homes in the United States. Beginning in the 19th century, charitably supported or municipal “poorhouses” provided basic housing for immigrants, alcoholics, the mentally ill, and elders without means. Couples were separated, often living in filth and decay along with debtors and criminals on furlough from prison. Towns meagerly supported such places, mainly to separate undesirables from the rest of society. An unexpected consequence of the Social Security Act, enacted in 1935, was that retired people, assured a basic income, could contribute to the cost of their housing, including in nursing homes, which were rare before 1950. Since the Act was passed, major medical advances (e.g., the discovery of penicillin and other antibiotics, drugs that control blood pressure and combat diabetes, breakthroughs in heart surgery, artificial respirators, kidney transplants) extended life expectancies by as much as 20 percent in less than 3 decades. For the first time in history, major causes of death were considered treatable. In addition, nursing homes received another boost. By 1953, hospitals began to lobby for federal funding of nursing homes to care for patients while they recuperated from hospitalization. Medicare and Medicaid, both enacted in 1965, triggered the next unintentional, but major, spurt in American nursing home growth. The problem, according to Gawande, is that reliance on nursing homes was

the consequence of a society that faces the final phase of the human life cycle by trying not to think about it. We end up with institutions that address any number of societal goals — from freeing up hospital beds

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12 Id. at 27.
13 Id. at 41. Gawande notices that Bludau checks his patients’ feet almost as often as a podiatrist. The geriatrician explains that balance is critical for standing and walking safely which, in turn, determines how much exercise his patients get as well as how well they avoid debilitating falls. Bludau’s book should be of great interest to the elder law community: Aging But Never Old: The Realities, Myths, and Misrepresentations of the Anti-Aging Movement (Praeger 2010).
14 Gawande, supra n. 6, at 270 (citing B. Vladeck, Unloving Care: The Nursing Home Tragedy (Basic Books 1980)).
to taking burdens off families’ hands to coping with poverty among the elderly — but never the goal that matters to the people who reside in [nursing homes]: how to make life worth living when we’re weak and frail and can’t fend for ourselves anymore.\textsuperscript{15}

The fourth chapter (“Assistance”) begins by defining what has become the primary alternative to nursing homes, assisted living facilities (ALFs). While we regard ALFs as “an intermediate station between independent living and life in a nursing home,”\textsuperscript{16} Keren Brown Wilson, who founded the first such facility (Park Place in Oregon in 1983) envisioned “a place that would eliminate the need for nursing homes altogether.”\textsuperscript{17} Wilson’s solution was a residence where elders could lock their doors, control their schedules, care for pets and plants, and cook for themselves when they wanted to and, as a result, had reasons to live rather than merely exist. When state officials monitored Park Place in 1988, they found that residents’ “satisfaction with their lives increased [while] their health was maintained.”\textsuperscript{18} Wilson’s idea spread rapidly so that “By 2000, the number of people in assisted living was approaching the number in nursing homes.”\textsuperscript{19} A happy ending? No, writes Gawande. “A distressing thing happened along the way. The concept of assisted living became so popular that developers began slapping the name on just about anything. The idea mutated from a radical alternative to nursing homes into a menagerie of watered-down versions with fewer services.”\textsuperscript{20} By 2003, only 11 percent of ALFs offered both privacy and supportive services.\textsuperscript{21} Gawande observes that often it is not the elder but the elder’s children who choose such facilities and thus, “visuals” such as a grand entrance enhanced with chandeliers, a spacious dining room, and even a modern gym appeal to children but not necessarily to residents. He concludes, “In the absence of what people like my grandfather could count on — a vast extended family constantly on hand to let him make his own choices — 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.”\textsuperscript{22}

Chapter 5 (“A Better Life”) introduces Bill Thomas who, in 1991, returned after receiving his MD from Harvard to the small town of New Berlin, New York, as medical director of a small nursing home. Thomas quickly recognized the “Three Plagues” of such institutions (boredom, loneliness, and helplessness) and independently discovered a prescription not unlike Keren Brown Wilson’s: pets and live plants that residents would have to care for and even a day care center for employees’ children. The impact, according to Gawande, was “shock therapy” not only for residents but also for facilities.\textsuperscript{23} It led to a national movement

\begin{itemize}
\item \textsuperscript{15} Id. at 76–77.
\item \textsuperscript{16} Id. at 87.
\item \textsuperscript{17} Id.
\item \textsuperscript{18} Id. at 92.
\item \textsuperscript{19} Id. at 101.
\item \textsuperscript{20} Id.
\item \textsuperscript{21} Id. at 102.
\item \textsuperscript{22} Id. at 108–109.
\item \textsuperscript{23} Gawande notes that researchers studying the effects of all this on residents of Chase Memorial Nursing Home, in New Berlin, New York, discovered after 2 years that residents required about half the prescriptions they earlier received, total drug costs fell to less than 40 percent of those at comparable facilities, and deaths
of the Eden Alternative (making nursing homes more resident driven) and Green Houses (new facilities organized into semiautonomous clusters housing about 20 residents each). The movement away from “warehousing” to purposeful aging is underway, but represents only a small fraction of facilities presently available to elders. Gawande praises a number of facilities in the Boston area.  

The book’s long conclusion begins with Chapter 6 (“Letting Go”), confronting the challenges of the 21st century: What do we do about mortality now that we can effectively delay it? Do we have the courage to “curb our purely medical imperatives,” which constitute an economic drain on our medical system without any apparent benefit?

What Gawande discovers along the way is that “[p]eople with serious illness have priorities besides simply prolonging their lives,” a point made to him by hospice nurse Sara Creed as he shadowed her while she conducted rounds with dying patients. He paraphrases the nurse about caring for patients in a way that is logical yet largely ignored by our present system:

> The difference between standard medical care and hospice is not the difference between treating and doing nothing . . . . The difference was in the priorities. In ordinary medicine, the goal is to extend life. We’ll sacrifice the quality of your existence now — by performing surgery, providing chemotherapy, putting you in intensive care — for the chance of gaining time later. Hospice deploys nurses, doctors, chaplains and social workers to help people with a fatal illness have the fullest possible lives right now — much as nursing home reformers deploy staff to help people with severe disabilities. In terminal illness that means focusing on objectives like freedom from pain and discomfort, or maintaining mental awareness for as long as feasible, or getting out with family once in a while . . . .”

Gawande describes how a “comfort pack” (which contains morphine to lessen pain and restore breathing, Ativan to control anxiety, Compazine to treat nausea, Tylenol to reduce fever, atropine to clear up upper-respiratory congestion, and even Haldol to treat delirium) can allow patients to self-medicate autonomously but safely.

fell by 15 percent. The explanation: “the fundamental human need for a reason to live.” Id. at 123.

24 These facilities include Orchard Cove, New Bridge on the Charles, and the Leonard Florence Center for Living, which was designed to meet Bill Thomas’ standards of a Green House (emphasizing privacy, communal meals, and other activities for groups of about 20 in each “house”). Facilities do not have to be expensive. Gawande commends a modest subsidized apartment house, Sanborn Place, managed for a fraction of the cost of other facilities. Another trend is to support elders aging in place through more than 100 “Villages,” which began with Beacon Hill Village, Boston, and have spread throughout the country. Villages enable seniors to remain in their homes, while volunteers provide transportation for medical visits as well as social and cultural events, monitor home repair specialists who keep homes comfortable and safe, and even link residents to one another during bad weather. Id. at 139.

25 Gerald F. Riley & James D. Lubitz, Long-Term Trends in Medicare Payments in the Last Year of Life, 45 Health Servs. Research 565 (2010). “[Twenty-five] percent of all Medicare spending is for the 5 percent of patients who are in their final year of life, and most of that money goes for care in their last couple of months that is of little apparent benefit.” Gawande, supra n. 6, at 153.

26 Gawande, supra n. 6, at 155.

27 Id. at 160–161.
Medicine, Gawande observes, is grounded in science, but it is not an exact science. Physicians frequently overestimate patients’ survival time and, as a result, deliver overoptimistic prognoses to patients and their families. In a counter example, Gawande tellingly refers to paleontologist Stephen Jay Gould, who, when told that he would likely die from abdominal mesothelioma within 8 months, wrote an article 3 years later indicating that his was one of a few cases that formed a statistical “long thin tail” of extended life and then lived an additional 17 years. On the other hand, Gawande explores Nelene Fox’s case, who was diagnosed with metastatic breast cancer while in her 30s and for whom surgery and chemotherapy failed. Fox was offered a radical but apparently promising treatment involving high-dose chemotherapy along with bone marrow transplantation, for which her insurer denied coverage because it considered the treatment experimental with unproven benefits. Fox raised funds to pay for the treatment but died 8 months after treatment. Her husband sued the insurer and was awarded $89 million predicated on the insurer’s denial of coverage, which resulted in anxiety as well as delay of treatment. Later research showed that the treatment, in fact, had no beneficial effect for such patients and, indeed, worsened the remaining years of their lives. Insurers today, chastened by the verdict, offer “concurrent care” (i.e., they cover the costs of hospice without requiring the patient to forego lifesaving treatment).28

Chapter 7 (“Hard Conversations”) discusses how Gawande and other physicians are trying to learn how to provide true care to their patients by honoring their autonomy and explaining real choices with realistic prognoses. He is not comfortable with what has become typical language in health care directives — asking such questions as 1) Do you want to be resuscitated if your heart stops? 2) Do you want aggressive treatments such as intubation and mechanical ventilation? 3) Do you want antibiotics? 4) Do you want tube or intravenous feeding if you cannot eat on your own?

Gawande confesses to confusion in handling his father’s last days — tacitly recognizing that this is his most personal book to date, one that explores how he functions as a son as well as a physician. Instead of asking questions about treatment, he suggests first listening intently to what is important to the patient before describing treatment choices. Gawande observes that when he prompted his father to state his goals at a critical time, his father told him that it was most important for him to complete some of his charitable work and to be present when Atul delivered a commencement address at their local Ohio college.

As his father’s condition worsened, Gawande became aware that goals change,29 calling to mind — in his final chapter (“Courage”) — Plato’s dialogue, Laches, in which two Athenian generals try to define courage, initially agreeing that courage equates with not giving in (i.e., “endurance of the soul”). Socrates questions, however, whether it is courageous to fight against all odds and whether perhaps there are times when the courageous thing to do is to retreat “to preserve one’s army to fight another day.” Upon consideration, Socrates concludes that without perfect knowledge of the alternatives and their likely outcomes, it is impossible to decide whether fighting or fleeing makes more sense. Ultimately, Gawande believes, “One has to decide whether one’s fears or one’s hopes are what should matter most.”30

The only serious deficiency in this otherwise intelligent and important book is that

28 Id. at 175–176.
29 “[J]ust as Laura Carstensen’s research on perspective suggested it would.” Id. at 209.
30 Id. at 232.
it does not attempt to predict the future of medicine. Is Ken Dychtwald right in assuming that within the next 2 decades, American centenarians will be common and, consequently, the number of years that life can be extended will impose impossible burdens on family and public resources?\textsuperscript{31} What can we expect of medicine in extending life even further or perhaps alleviating pain and decline? Will expansion of physician-assisted suicide remove incentives for improving palliative care?

This is a wise and important book that tackles issues that resonate not only with us but especially with our clients and, most notably, in public policy. Gawande’s emphasis on autonomy may disappoint some engaged in public policy who have unreasonable expectations that fiscal concerns should trump personal decisions. \emph{Being Mortal} does not have all the answers,\textsuperscript{32} but it raises questions that our clients and, indeed, we need to ask. Gawande advocates informed autonomy rather than easy answers. Gawande tells stories that make his points but also effortlessly introduces others’ research to broaden the reach of what he has so keenly observed. The book is enlightened in the true meaning of the word. It blazes a path to the wisdom we need to confront choices that humankind scarcely considered less than a century ago.


\textsuperscript{32} Some may find Gawande’s response to physician-assisted suicide to be equivocal.