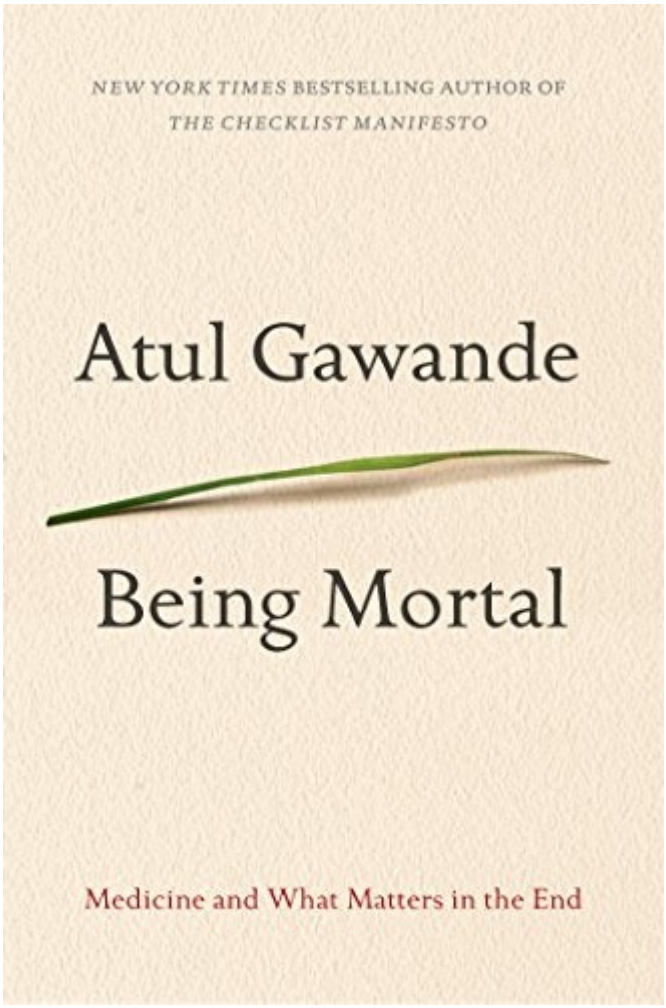
Incurable condition

by LaVonne Neff in the February 18, 2015 issue

In Review



Being Mortal

by Atul Gawande
Metropolitan

A blade of grass—a biblical symbol of life's fragility—reaches across the book jacket just above the title, which itself reminds us that we are bound to die. The introduction plunges us into a world of suffering and terminal illness. Chapter titles

like “Things Fall Apart” and “Letting Go” refuse to sugarcoat the topic. “There’s no escaping the tragedy of life, which is that we are all aging from the day we are born,” Atul Gawande intones. *Being Mortal* is not a cheery book. It will not appeal to those who want to believe that every problem has a solution.

And yet when the book was released last October, it became an instant best seller. By the end of the year it was on many people’s list of the best books of 2014, and Gawande—cancer surgeon, Harvard Medical School professor, and *New Yorker* staff writer—had appeared on *The Daily Show*, PBS’s *Frontline*, and *Charlie Rose*. I have told my daughters that before I make them agents on my health care power of attorney, they must read this book.

Being Mortal is about death. It is about our misguided approach to end-of-life care that causes unnecessary misery. It is about changes we must make in the way we treat and the way we think. Above all, it is about the need for relentless honesty, especially when we are afraid.

Gawande is an engrossing writer no matter how unsettling his topic. His previous best-selling books attest to that: *Complications* and *Better* are essay collections about the uncertainties of health care, and *The Checklist Manifesto* argues in favor of routine procedures over individual brilliance.

Like those books, *Being Mortal* abounds in human-interest stories—of the retired geriatrician who cares for his ailing wife in an assisted living center (until she falls and needs more care than he can give); the elderly widower whose daughter promises never to put him in a nursing home (until job and family demands force her to reconsider); the young mother with intractable cancer whose family refuses to let her go (thus giving her additional weeks of pain); the author’s own father, who must decide whether to have the gigantic tumor inside his spinal cord removed (and risk paraplegia); the former beauty queen with metastatic ovarian cancer who just wants to live long enough to attend a wedding.

All stories eventually end in death, of course. But when we accept our mortality, Gawande believes, we increase our chances for a peaceful ending. Tragically, most of us prefer reassuring fantasies.

“We’re always trotting out some story of a ninety-seven-year-old who runs marathons,” Gawande writes, “as if such cases were not miracles of biological luck but reasonable expectations for all.” We say we would never want to be kept alive

and miserable through pharmaceutical or medical technology, but then we beg the medical profession to fix whatever ails us. We shut our eyes to the reality that some of us (Gawande says most) “will spend significant periods of our lives too reduced and debilitated to live independently.” Yet the more we avoid such difficult truths, the more likely we are to cause suffering to those whose time is short. Not every ailment can be fixed. Not every ailment *should* be fixed.

We need to talk, Gawande says. Medical school professors need to talk to students about how best to treat the seriously ill. Doctors need to talk to patients about the probable results of any proposed intervention: Is it likely to add three weeks of life? Ten years? And what will the added time be like for this individual? Patients need to talk to health care providers and to their own family members about their hopes and fears and values. We all need to talk to one another about devising more appropriate care for those with shortened life expectancies who need help but who do not need a hospital or typical nursing home.

All of this has been said before, but Gawande says it especially well. Besides decrying the sorry state of our approach to end-of-life care, he applauds people who are doing things right. Pioneers like Keren Brown Wilson, an early developer of assisted living facilities, who wanted to find a place where her mother could feel at home after a debilitating stroke at age 55. Visionaries like physician-turned-farmer Bill Thomas, founder of Eden Alternative nursing homes, where seniors are surrounded with gardens and animal companions. Practical change agents like retired biologists Margaret and Norman Cohn, who organized a neighborhood support system that allows them to live independently in spite of Norman’s severe arthritis and Margaret’s inability to walk. We are not helpless, Gawande writes. “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.”

Palliative care is one important way to transform those last chapters. People tend to think of palliative care, often administered through hospices, as nothing more than a sign of resignation: because the patients are going to die anyway, medical treatment is suspended so they can get on with it. This is a gross misconception, Gawande maintains. Palliative care specialists actively help patients relieve anxiety, realize their hopes, and enjoy their remaining days. The results can surprise. One study showed that people enrolled in hospice “suffered less, were physically more capable, and were better able, for a longer period, to interact with others” than those who followed the traditional medical route. In another study, hospice patients

experienced less suffering and lived 25 percent longer than others.

American late-life care has begun to change. It is easier today than it was 20 years ago to find elder care that preserves independence while offering necessary assistance. The percentage of people who die at home rather than in the hospital is increasing. Hospices serve nearly half of us at the time of death. Nevertheless, we still have a long way to go. The percentage of doctors specializing in geriatrics has dropped by one-quarter since 1996. Only 3 percent of medical students take any course in geriatrics, and many geriatric services are not covered by Medicare.

It is past time for a new health care paradigm, one that favors human flourishing over technical fixes. In his passionate epilogue, Gawande addresses fellow medical professionals. “We’ve been wrong about what our job is in medicine,” he writes. “We think our job is to ensure health and survival. But really it is larger than that. It is to enable well-being. . . . Our interventions, and the risks and sacrifices they entail, are justified only if they serve the larger aims of a person’s life. When we forget that, the suffering we inflict can be barbaric. When we remember it, the good we do can be breathtaking.”