



Book Discussion Questions Being Mortal by Atul Gawande

Introduction:

Gawande writes: “I learned a lot of things in medical school, but mortality wasn’t one of them.”

Considering the cost, in money, time and resources, and the ever expanding field of research, should medical schools expand the curriculum to include end-of-life issues? Would there be trade-offs?

Why do we assume we will know how to empathize and comfort those in end-of-life stages? How prepared do you feel to do and say the right thing when that time comes for someone in your life?

Should doctors intervene if they think the patient, like Lazaroff, made a bad choice? Gawande says he should have been more honest with him. Do you agree? Would it have changed anything?

“The operation was a success – but the patient died.” This is an old joke, but can you see doctors falling into this mind set?

Interpret Gawande’s nightmares – page 7 – have you had recurring nightmares? What do you think they mean?

Doctors, and probably the rest of us, tend to define themselves by their successes, not their failures. Is this true in your life? At work, in your family, at whatever skill you have? Should we define ourselves more by our failures? Do you know people who define themselves by their failures? (Are they fun to be with?) How can doctors, and the rest of us, strike a balance?

Chapter 1, The Independent Self

Should we shield children from the realities of death? How should parents handle that?

What did Gawande learn from Kathleen and her grandmother, Alice Hobson?

How did Alice’s experience contrast with that of Sitaram Gawande? How would he have been treated in America? Do we give adequate consideration of the life’s work of those we remand to nursing homes?

Do you think most American families can care for an elderly relative? Could you?

What is your attitude, as you put it into practice, toward old age? Is it something to deny or avoid, or a state in life to be honored? Do you find that the respect given to the elderly has eroded?

As people live longer, and the once radical concept of retirement takes hold, the attitude of elders toward the young and young toward the elders has changed. What is your attitude toward the elders in your family, and theirs toward you? If you are an elder, what do you expect of your younger family members? If you are younger, what is the practicality of caring for an elder family member? Do you wish things were different – like in the “olden days”?

Chapter 2, Things Fall Apart

Gawande makes the point that sudden death is less likely than a slow decline in health and the inability to care for oneself, extending the process of dying. What are some advantages and disadvantages of each? What are the implications for the medical community and other institutions?

The story of aging – OMG Are we just falling apart?

Use the chart based on Gawande’s analysis of human decline to rate yourself, and maybe your degree of denial. Note: Not all case studies in this book involve the elderly. These symptoms are evidence of the body’s decline, or just wearing out, and can occur in people early on in life. They can also be brought on by illness at whatever age, congenital issues, nutrition, personal health and hygiene practices, as well as traumatic injury.

| Condition | OMG! | Maybe? | I’m beating the odds! |
|---|------|--------|-----------------------|
| Teeth – hard enamel wears away. Darker layers show through | | | |
| Gums pull away, teeth elongate | | | |
| Tremors due to arthritis, and small strokes | | | |
| Tooth loss | | | |
| Hardening of blood vessels, joints, muscles, heart valves, lungs | | | |
| Brittle bones | | | |
| High blood pressure | | | |
| Shortness of breath | | | |
| Loss of muscle mass | | | |
| Hand changes – less muscle, weak grip, reduced range of motion, Pain, loss of touch sensitivity, degraded handwriting, difficulty working iPhones | | | |
| Decreased lung capacity, out of breath, slow bowels | | | |
| Poor memory and planning ability | | | |
| Less ability to multitask | | | |
| Changes in vision | | | |

* The above criteria have nothing to do with appearance, although Gawande mentions graying hair and skin discoloration.

Do you think most people are in denial about their own aging? Do you find yourself drawn to books declaring “age is just a number” and “you can be young forever” mentality? Are these books helpful, or do they do more harm than good?

What can be done to encourage more doctors to specialize in geriatrics?

What is different about Dr. Bludau's examination of Jean Gavrilles? Should this method and insight be applied to every examination, regardless of the age of the patient? What has been your experience with your doctors? Do you find that your doctor hasn't the time to spend with you?

How should medical funding and priorities change? Why are there more available resources for medical equipment than quality-of-life measures for the elderly?

Do you know couples like Felix and Bella? The last days for Bella were so hard on Felix, but do you think he'd have had it any other way? Was there anything more others could have done for this couple? If you were to visit their home, what could you have contributed?

What was there about Felix that we can emulate? What allowed him to be functional for so long?

Professor Boulton said, "It's too late" for creating geriatric specialists. Do you agree? P. 51

Chapter 3, Dependence

"It is not death that the very old tell me they fear. It is what happens short of death..."
What do you fear most about the end of life?

Are you doing anything to delay the disability that comes with the end of life?
Do you feel prepared for the end?

Felix and Bella had an exceptional relationship. Who was Bella's condition hardest on? Why?
Do you think you could be as loving and strong as Felix?

How important is communication to you? When Bella lost her hearing, Felix hit a very low point. What do you think he would have done had Bella not regained her hearing?

The assistants didn't seem to understand how important routines were to Felix and Bella. What do you think they should have done? Do you think they had their own challenges?

This chapter gives new meaning to "There's no place like home." Would you be happy living in the apartment Alice chose? What would you miss most about your home?

Have we gotten rid of "poorhouses"? Is there anything that resembles them in the US today?
How much of an improvement are today's nursing homes? Why do most people dread going into them?

Medical resources have improved greatly, but there are still areas in the US where there is no hospital or even a doctor for many miles. What are the choices of people living in these areas?

How can the US ensure that everyone has access to hospitals, quality elder care or hospice, and an available doctor or medical center?

Do you think some nursing homes are still similar to prisons? How?

What are the practical challenges for institutional staff to meet the needs of the residents who want to lead meaningful lives?

If you were in a nursing home, would food be the "Hundred Years' War"? What would you insist on?

How do you think your family would react if you told them, "I'm ready"?

Chapter 4, Assistance

Shelly did the best she could for her father, but it took a toll on her and the family. Can you see yourself in that position? What conflicts did she face between her intentions and the practical needs of the family and herself?

Necessity is the mother of invention – that’s what drove Keren Brown Wilson to create what is now called the assisted living facility. What are some of the advantages, as described on Pp. 87, 88? What do you see as disadvantages? Park Place filled up immediately. Would you sign up for yourself or a family member?

How does Maslow’s “The Theory of Human Motivation” relate to assisted living facilities and elder care in general? He writes that people “give in” when their choices become narrowed and their declining abilities prevent them from doing what was most satisfying to them.

Cartensen, however, found the opposite to be true. She found that people were happier, more emotionally satisfying and stable.

With whom do you agree?

“Living is a kind of skill. The calm and wisdom of old age are achieved over time.” Do you agree with this analysis? It took Cartensen a near-death experience to learn certain lessons. What wisdom have you taken time to acquire? Do you find you can share this with others who have not had the same experiences?

Perspective matters. Are there perspectives that have formed your ideas that others may not fully understand?

Wilson’s assisted living concept was not always carried out by its imitators. It takes more than just a floor plan to make the concept work. What else is important?

Draw a floor plan and describe staff and services for your ideal living facility for the elderly or disabled. Would you go there to live? Why or why not?

Should safety still be a priority?

Chapter 5, A Better Life

Do you know anyone like Bill Thomas? Would you like him as a neighbor?

How did his lifestyle affect his plan for the disabled/elderly?

Lately, many nursing homes are including pets in residence. Thomas, it appears, went a bit overboard. Do you agree with his proposal? Do you understand why some administrators might be reluctant to have so many animals on hand?

What kind of “glorious chaos” can you envision?

How much chaos would your own pets instigate?

Why did the addition of animals trigger so many improvements among residents? What do your own animals add to your life?

There is no discussion of what happens when one of the pets dies. If you were a nurse or assistant on the floor, how would you speak to a resident who may have lost an animal friend?

In Royce’s book, The Philosophy of Loyalty, he explores the reasons why just food, safety, shelter, etc. provide an empty existence. He concludes that we all need a cause beyond ourselves.

Do you agree? What are your “causes”?

Are you part of something greater? Do you have concerns for what happens after your death?
Have you found your priorities are changing as you get older?

Is it too much to ask of doctors to not only acquire technical expertise, but to also understand human needs?
Should there be more courses in medical school?

How did the NewBridge facility better take care of human needs? Is this practical for the long-term residents whose health may be declining? Is the expense practical? What if there were not community help and philanthropic contributions?

Do you believe the concept of providing autonomy no matter what the condition is workable? Can we really be the “authors of the life we live”?

Do you like the concept of Thomas’ Green House? Could you be a member of the staff?

Chapter 6, Letting Go

Gawande speaks of “curbing the medical imperative.” P. 149
“When should we try to fix, and when should we not?”
How would you answer the same question?

In the story of Sarah and Rich Monopoli, Sara underwent excruciating treatment right to the end. What attitudes and approaches used by this couple do you admire, or agree with, and with which do you disagree?

If you were Sara’s doctors, what would you do differently?
As a family member or close friend, what conversation would you have with them, or should you just “mind your own business”?

Thinking of people you know, what would the reception be if you were to make “suggestions”?
[There is often a difference between what we say/intend and what is heard by the recipient. Example: We may suggest the family of a person with cancer look into some treatment we have read about. We mean well, but what the family may hear you saying is, “You think I’m not doing enough!”]

Often the treatments do not work. Yet our society seems to favor attempts to “fix” the problem. Gawande quotes statistics that show 25% of Medicare spending goes to the 5% of patients in the last stages of life. With catastrophic illness, the trend seems to indicate high costs during the onset of the illness, a leveling off of costs during the mid-stages, and skyrocketing costs during the last stages of life. Yet, the extreme or even experimental measures do not always improve the quality of life, or even prolong life.

Why do you think it’s so difficult for doctors and/or families to refuse or curtail treatment?
How should priorities be set?
How can we avoid ICUs that turn out to be, as one doctor commented, “a warehouse for the dying”?

What are your priorities? What criteria would you use or have your family use to determine what, if any, measures or treatments to use?

How do we build a healthcare system that will help end-of-life priorities to be accommodated?

Do you think that advancements in the medical field damage our ability to have a quality end of life?

P. 156, Gawande speaks of “dying customs.” He certainly has those customs in his family.
What dying customs exist in your family? Do you talk about this?

To what extent would you honor those customs? Gawande says he drank a few sips of water from the Ganges – but got a case of Giardia as a result!

He says these customs can appear to be dying out. “I wasn’t even sure what the word ‘dying’ meant anymore... the new difficulty for me was ‘how to die.’”

P. 159, Nurse Creed is a hospice nurse, skilled in her profession, compassionate and insightful. Summarize her strategies as she spoke with her families. Do you agree with her apparent priorities? What personal traits do you think contribute to someone choosing and being successful at this nursing specialty?

The choice of hospice care is difficult for most families. What would be your criteria for yourself or a family member?

In Sara’s case, she and her husband did not want to confront her condition. They kept seeking treatments right to the end. How do you walk the fine line between being hopeful and being unrealistic? Acceptance and giving up?

What do we really expect of medicine? Do we really think everyone can be saved?

What were the tradeoffs of Sara’s continued treatments? What did it buy her?

P. 171, Stephen Gould, in 1985, wrote that some of the treatments were the “medical equivalent of selling lottery tickets.” Do you agree? Why do people have exaggerated ideas of the success of medicine?

Cost and a system of insurance payment is a factor. If patients had to pay for end-stage care, do you think they would choose less? What are the pros and cons?

The idea of “rationing” care has been debated at least since 1990, when an insurer was sued because an experimental treatment was denied. The insurance company lost, even though the treatment was later found to be ineffective. Do you agree with Aetna’s “concurrent” care approach?

They also found that “just talking” had a beneficial effect.

In your life, have you found that just talking helped in a difficult situation? Can you just talk without offering a solution? Is that hard to do?

Studies also found that, “You live longer only when you stop trying to live longer.”

Have you found that you have been more successful in something you have tried to do when you stop trying so hard? Why?

Do you have an advanced directive? Do members in your family have one?

How would you answer the questions on P. 179?

Have you had the family meetings described on P. 181? What role can a palliative care specialist play?

How can we find a balance between providing care and honoring the wishes of a loved one?

Gawande says we pay doctors to treat, not to spend time with patients and families. Sometimes they perpetrate myths about treatment and outcomes.

Is death something that should be fought, even denied, to the end?

What are some other hard discussions families should have?

Does your family know what your priorities are? What help have you provided them for when the hard decisions occur?

Chapter 7, Hard Conversations

Gawande describes Sara's treatment to doctors he met from Africa. Their opinion was that her treatment was extravagant and would not have been funded in their countries. Patients there have different expectations. Do you think Sara would have been better off in Africa?

Do you see any evidence that the US is changing its idea of end-of-life care?

Gawande tells the story of his father's cancer, treatment and death. Do you think it was difficult to write his story?

His father rejected the first doctor, who had experience and expertise, in favor of Dr. Benzel, who took time to talk with him.

Was this a risky decision? Would you reject a doctor with excellent credentials in favor of one with good "bedside manners"? What would guide your decision?

Gawande describes three modes of patient interaction by doctors:

1. The doctor knows best approach.
2. The informative approach
3. The interpretive approach

Put your doctors into one of these categories.

Do you really want shared decision making? Should someone control your impulsive decisions – save you from yourself?

P. 203, the doctor took time with Jewel to talk about her life. Would this be comfortable for you? Do you think your own doctor would take that time to get to know you?

Can doctors "soften the blow" of catastrophic illness without seeming disingenuous.

ODTAA Syndrome, or, "one damned thing after another syndrome," can signal the futility of continued treatment. How could this also be a gift? How would you spend what little time you have left? Could this acceptance also be a gift to your family?

Would you prefer hospice care in your home or the "village" approach of places like Athens Village? What are the benefits or shortfalls of each?

P. 229, Gawande gives the commencement address at Ohio University. Whose triumph was this? Who do you think most contributed to making that day possible?

Are there moments in your life where it is important a certain family member be present?

Do we underestimate how much activity someone who is elderly or terminally ill can achieve?

Has someone you know amazed you with their ability to achieve goals even in the face of serious illness?

Chapter 8, Courage

In Plato's dialogue, the question is asked: What is courage?

What is courage to you? Can it be physical, mental, emotional – just foolish?

Plato offers a few definitions:

- Endurance of the soul
- Wise endurance
- Knowledge of what is to be feared and what is to be hoped
- Courage is strength in the face of knowledge of what is to be feared or hoped

With which do you agree?
Have you ever had to be courageous?

Gawande says that for the aged or terminally ill, there are two criteria:
- confronting the reality of mortality
- acting on the truth we find

How do we strike a balance between fear and hope, while still confronting reality?

P. 233, Jewel knows her condition has relapsed, but still greets the doctor with her hair combed and lipstick on. What does that say about her courage? Her priorities?

P. 238, Gawande talks about our tendency to define our experiences in terms of the endings. We remember the end of a game, for example, by the last few plays or the final score, even though the entire game may have been pleasurable.

“Life is meaningful because it is a story,” but even though we have a sense of “whole,” endings matter. Why do we seem to neglect the journey and cling to the endings – of games, movies, books, etc. and our lives? What is your story? Will you define yourself by the ending?

P. 242, Jewel had a “perfect ending.” What can you relate to in her last moments? What would be your own “perfect ending”?

How do you feel about assisted suicide? Is that a way to a perfect ending?
Choose your mistake:
- prolonging suffering
- shortening a valued life

What should the criteria be? Can you add anything to those described on P. 248?

Peg also had a perfect ending. What was her gift to her piano students? If she were in excruciating pain with no chance of improvement, would assisted suicide be a wise choice? What would be the impact on the family and friends?

What is the “dying role”? What should be your role in this situation?
What influence would your faith, ethics, family culture; values have on your role?

Epilogue 4

Just because we could, does that mean we should?
How can we enable wellbeing in the end stages of life?
What should be the responsibilities of the family, doctors, and other staff?
As a person, and then as a doctor, how would you evaluate Dr. Gawande?
Do you think he had a long learning curve?
Do you identify with his initial attitude toward the elderly and dying?

Have you changed your thinking about end-stage illness, old age, and other catastrophic conditions?
What tradeoffs would you agree to in favor of continued treatment?
Will you take any actions based on what you have read and discussed here?
Would you recommend this book to others? Who? Why?

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<http://www.transforminghealth.org/stories/2015/06/summer-read-2015-what-does-a-good-death-mean-to-you.php>