

This summary is from the book “Being Mortal: Medicine and What Matters in the End” by Atul Gawande. ISBN 1250076226. The book is written by a second generation medical doctor and is about Western medicine’s issues with end-of-life care and the struggle between quality of life and length of life. He makes the correct, if uncomfortable, observation that death is not failure – it is a normal part of life. Previous generations and other cultures have been aware of that, but our medical advances have changed society so that it can not deal well with the decisions that will ultimately come. And we often make them badly.

The independent self:

1. In America, and many Western cultures, we strive for a long, healthy, independent life. Most people live for a long time, compared with previous generations. As their age and health catches up with them, they go from living independent lives at home to a spiral of events that leads them to assisted living, nursing homes, etc. This not pleasant and not what anyone really wants.
2. In other countries and cultures, families keep their revered elderly in their lives if not in their homes. Problems that would kill a Western counterpart or push them into a facility are dealt with (not always easily) within the extended family. It often falls to a relative (usually a woman) who gives up a broader life and is tasked with the primary care.
3. There are some cultures that take the extreme of ‘helping’ the elderly move along. Sorry grandma or grandpa – it’s time to take you out in the forest so you can feed the wildlife! (Or go for a float on an ice flow, or whatever.)
4. With advances, more people live longer (and better lives). Fewer and fewer continue to live with their children. Which has made infirm old age a growing problem

Things fall apart:

1. Previous generations experience of aging and disease was either unexpected death (shot, disease, fall, ...) or good life and then some event that caused a slow or less-slow decline to death.
2. With our advances, we now often have a bumpy decline with often times improvements. My father died of a hardening of the arteries – he had a heart attack at age 57 and with issues on his right side. He died the following year at 58.
3. Things now seem to be an ongoing series of issues with longer steady fade. For me, I was diagnosed with Chronic Lymphatic Leukemia in 2005 (not good, but indolent and I’ve been stable). I got pneumonia in 2017 – due to my compromised immune system (and no vaccination). In 2019 I fell in Iceland and broke my right side and got a hip replacement and a repaired shoulder. In 2020 I slipped in the foothills and my right leg clotted from toe to hip. When discovered it wasn’t a sprain, I received a 6 hour surgery replacing the artery with a vein (and it took 6 months to recover). Then in 2021 in a follow up procedure, scans showed my heart was severely block on the left side – pulmonary artery disease – hardening of the arteries. I was supposed to get bypass surgery but talked to the doctors and got 4 stents instead – and came out of it great. This this year my left knee stent crumpled and I needed the same surgery on my left leg. This was much ‘easier’ than the right leg and I recovered more quickly. Any of these issues (and others) would have killed me in the past. But my life is good and am mostly okay (but I’m working at it). The point is I’m following our culture’s decline. But I do worry (not terrified, but worried) about the what comes next.
4. Aging, it turns out, is not really overly genetic. There is no single, common cellular mechanism to the aging process. We just fall apart. (Not very appealing.)
5. There are more and more elderly. There are as many 5 year olds as there are 50 year olds – and it will get more elderly in the coming decades. The Japanese have been working very hard on robotic elder care for many years.
6. The medical and health organizations have been slow to deal with this. There are insufficient geriatric doctors and facilities. And in reality, all specialties should get more training and

awareness. During my late wife's illness, it really seemed like no one was looking at the big picture or whole system: if their tool was a hammer – then your problem was a nail.

Dependence:

Elderly often do not fear death, they fear the ongoing series of losses of ability and independence and being able to make their own decisions. By working on our health (exercise, diet, friends, family) coupled with medicine we can keep it at bay, but it will come. At that point additional institutional help is necessary, but rarely wanted or easily accepted. Full up nursing homes are not great. There are some assisted living places that are better. When a couple goes through this with one still capable, often times the staff and the other part of the couple end up with major issues about care and how things should be done.

Assistance:

When the elderly people are forced to get help, sometimes it is still provided by family members. Other times it falls to nursing homes and institutions. Before social security, it was the poor-house or the alms-house (my mother in her last 3 weeks specifically mentioned 'poor-house' as a place she did not want to go). In recent years, there have been great strides in assisted living facilities. The intent is to be a bridge between independent living facilities and nursing homes. In many ways this is great. However, that issue is that these facilities are built and run and marketed towards the children of the elderly. The children are comfortable placing their parent(s) in these places. They are not institutions that the parents want to be in. They tend to still be an institution where the parent really doesn't have control.

A better life:

A large portion of this chapter is about an ER doctor who switched to be the doctor at a nursing home (for the hours). He found it, not unexpectedly, depressing. He thought about how to make things better for the elderly residents. He proposed a series of changes trying to bring life and happiness in the residents' lives. He proposed a grant that would:

1. Have 2 dogs in the facility
2. Have 2 cats in the facility
3. Have live plants – no artificial - in the facility
4. ...and 100 birds in the facility!

The staff rolled their eyes, obviously. But the grant was approved and they got the money and proceeded (and a series of approvals for exceptions). The doctor didn't want to 'feather' in the changes. He did it all at once. Chaos ensued, but they (residents and staff) figured it out. And the changes were amazing. It felt more like home. The residents came alive and became more involved in the world, their world. And many were involved in care for the animals. There were challenges, but it worked.

Medicine's focus is narrow: doctors focus on repair of health, not sustenance of the soul. And the paradox is that doctors are often the people who define how we live in our declining years. The real goal should be to help elderly people who are dependent to sustain their interest in life and the value of existence. A lot of this has to do with not narrowing to your own pain, but connect with the world and be a part of something, anything, bigger.

Letting go:

As a society and culture, we hold on to living longer at any cost independent of the quality or meaning of life. 25% of all Medicare spending is for the 5% 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. The list price of my string of experiences is somewhere around \$2M. The actual amount paid is considerable less...

And information from European countries is similar. The medical system (industry) is great at and designed to hold death at bay. The thing it sucks at is knowing when to stop. And many doctors and patients and families are complicit in the problem.

We are having to deal with decisions that we previously didn't need to concern ourselves. Death was normally pretty immediate (like really bad weather – it came out of nowhere and you made it through or you didn't). During the middle ages there were many books about dying well – in particular there are many different versions of *Ars Moriendi* (Latin for 'the art of dying').

Hospice has really come in to be the sort of help for people in their final stages of life. Sadly, many people decide to connect when it is really very late. (Personally, I don't think it's ever too late. But doing it earlier is better.) Lots of people view Hospice as giving up or 'accepting' defeat. I felt this way myself when my beautiful late wife, Virginia, was dying from a brain tumor. It turned out that Hospice was (although odd to say) the best part of the process. Hospice is not about helping you die or with-holding treatment. It is about living the best you can in your last days. That was my experience.

Hospice is usually free or covered by insurance. But people are not ready to accept that the '2 minute' warning has sounded. You will spend anything on treatment thinking of the additional years. But sadly, if any benefit exists it is in days, weeks, or maybe a month or two. And even worse, it usually includes terrible quality of life results. There was a study of combining Hospice with continued treatments. It worked well... (patients weren't giving anything up). But the Hospice enrollment went from 25% to 70% and people went to the hospital less – and they lived longer.

When people talk to their doctor about end-of-life issues, it really helps. It gets things clearer in your head and most people who do this have a more peaceful end. As the author stated: "It's very Zen, you live longer only when you stop trying to live longer."

To help people deal with these difficult issues, a hospital in Wisconsin instituted a policy where anyone admitted to the hospital, nursing home, or assisted living to answer a questionnaire about end-of-life:

1. Do you want to be resuscitated if your heart stops?
2. Do you want aggressive treatments such as intubation or mechanical ventilation?
3. Do you want antibiotics?
4. Do you want tube or intravenous feeding if you are unable to eat?

This resulted in end-of-life directives going from 15% to 85%. And it wasn't written in stone, but it got people aware and thinking. It wasn't the questions; it was the discussion. And the way you talk about all of this matters:

- Don't say "I'm sorry how this turned out", saying "I wish things were different" is better.
- Don't ask "What do you want when you're dying?", try asking "When time becomes short, what is most important to you?"

It's also important to recheck/verify. Again with my late wife, Virginia, we had talked over our marriage about what I would do if she was gone and end-of-life questions. It was very clear what she wanted – not to be in severely limited condition. So when she collapsed from her tumor hemorrhaging, after I talked to the doctor and he described the poor outcome, I said to 'let her go'. After some medication, she regained consciousness and the doctor and I described what was going on. The doctor said she would have a year or two with diminished abilities. She was adamant: "I want that year or two!" Quite the change – it is important to re-check.

Hard conversations:

The world is changing and more wealth and growth are happening. The author talked about three levels of medical development and its impact on end-of-life.

1. Poor (3rd world) countries. They don't have the health care resources or money and most people die at home.
2. Developing countries. They are getting middle class and wealthier citizens. And they have better health care infrastructure. More and more people take advantage of the medical system and they die in hospitals. (Where America and the Western world have been.)
3. Developed countries. High income levels and good health care. But the people are recognizing the challenges and quality of life concerns. In 2010, 45% of patients died in America under Hospice care.

But these changes require hard conversations and most are not prepared for them. The medical profession isn't always the most helpful. And it also depends on what sort of doctor the patient wants (and needs). The author described three models of patient/doctor interactions:

1. Paternalistic: The doctors are the specialists and tell you what you should do. (This is the classic 1950's doctor as god.)
2. Informative: The doctors give you the information and let you ask questions. But the decision is up to you. (Whether or not you really understand.)
3. Interpretive: The doctor works with the patient to understand what's important and what they want. (Also called shared decision making.) They ask questions like: 1) What's most important to you? 2) What worries you most?

Courage:

In this last chapter, the author talks about courage in the context of aging and sickness.

“At least two kinds of courage are required in aging and sickness. The first is the courage to confront the reality of mortality – the courage to seek out the truth of what is to be feared and what is to be hoped. Such courage is difficult enough. We have many reasons to shrink from it. But even more daunting is the second kind of courage—the courage to act on the truth we find. The problem is that the wise course is so frequently unclear. For a long while, I thought that this was simply because of uncertainty. When it is hard to know what will happen, it is hard to know what to do. But the challenge, I've come to see, is more fundamental than that. One has to decide whether one's fears or one's hopes are what should matter most.”

The challenge is that it is tough to be wise here – because you can have an idea about what might happen, but you don't really know. At this point the patient and the family need to decide what really matters – fears or hopes. For me, it is a choice/priority that needs to be made consciously.