Notes from: Being Mortal by Atul Gawande
(Most of these are quotations)

Introduction

I learned about a lot of things in medical school, but mortality wasn't one of them. Our textbooks had almost nothing on aging or frailty or dying. The way we saw it, and the way our professors saw it, the purpose of medical schooling was to teach how to save lives, not how to tend to their demise.

As students, we worried about our knowledge. While we knew how to sympathize, we weren't at all certain we would know how to properly diagnose and treat. Much later, I encountered patients forced to confront the realities of decline and mortality, and it did not take long to realize how unready I was to help them,

This book is about 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.

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Scientific advances have turned the process of aging and dying into medical experiences, matters to be managed by healthcare professionals. We in the medical profession have proved alarmingly unprepared for this.

Death and dying confront every new doctor and nurse. The first times, some cry. Some shutdown. Some hardly notice. Medicine is a profession that has succeeded because of its ability to fix. If your problem is fixable, we know just what to do. But if it's not? The fact that we have no adequate answers to this question is troubling and has caused callousness, inhumanity, and extraordinary suffering.

You don't have to spend much time with the elderly with those with terminal illness to see how often medicine fails the people it is supposed to help. Our reluctance to honestly examine the experience of aging and dying has increased the harm we inflict on people and denied them the basic comforts they most need.

Chapter 1: The Independent Self

This chapter covers traditional families from antiquity as opposed to modern families. In the traditional family, the elderly persons stay at home cared for by family members.

They retain their dignity and have an important role to play. We know what aging is in our country and other first world countries. Elsewhere, it’s quite a difference of situation.

Chapter 2: Things Fall Apart

Medicine and Public health have transformed the trajectory of our lives. For all but our most recent history, there was a common, ever present possibility.

Why we age is the subject of the grist debate.

For most of our 400,000 a year existence – all but the past couple of hundred years – the average lifespan of human beings has been 30 years or less. Research suggests that subjects of the Roman empire had an average life expectancy of 28 years.

It turns out that inheritance has surprisingly little influence on longevity. Even genetically identical twins vary widely in lifespans: the typical gap is more than 15 years.

Leonard Gavrilo, a researcher at the university of Chicago, argues that human beings fail the way all complex systems fail: randomly and gradually.

Medicine has been slow to confront the changes that it has been responsible for. Although the elderly population is growing rapidly, the number of certified geriatricians the medical profession has put in practice has actually fallen in the United States by 25% between 1996 and 2010.

The geriatric clinic – or as my hospital calls it, the Center for older adult health, even in a clinic geared to people 80 years or older, patients view words like geriatrics or just elderly askance – is only one floor below my surgery clinic. I passed by it almost every day for years and I can't remember ever giving it a moment's thought. One morning, I made a visit.

The single most serious threat for very elderly patients is not cancer or back pain or anything similar, it was falling. The three primary risk factors for falling are poor balance, taking more than four prescription medications, and muscle weakness. Elderly people without these risk factors have a 12% chance of falling in the year, those with all three risk factors have almost 100%.

Most doctors treat disease and figure that the rest will just take care of itself. And if it doesn't – if a patient is becoming infirm and heading towards a nursing home – well that isn't really a medical problem, is it?

How do we reward geriatricians for the good work they do? Chad Boult, a geriatrician who was the lead investigator of a seminal article from the University of Minnesota, can tell you. A few months after he publish the results, demonstrating how much better peoples lives were with specialized geriatric clinic's, the University closed the division of geriatrics. Scores of medical centers across the country have shrunk or closed the geriatric units. This is because geriatric units are not profit centers.

I asked Chad Boult, the geriatrics professor, what could be done to ensure that there are enough geriatricians for the surging elderly population. Nothing, he said. It's too late. 97% of medical students take no course in geriatrics and the strategy requires that the nation pay geriatric specialist to teach rather than to provide patient care.

Chapter 3. Dependence

It is not death at the very old tell me they fear. It is what happens short of death – losing their hearing, their memory, their best friends, their way of life. Old age is a continuous series of losses.

As fewer of us are struck dead out of the blue, most of us will spend significant periods of our lives too reduced and debilitated to live independently.

In 1913, Mabel Nassau, a Columbia University graduate student, conducted a neighborhood study of the living conditions of 100 elderly people in Greenwich Village. Unless families could take the elderly in, they had virtually no options left except the poor house, or the almshouse, as it was called. Nothing provoked greater terror for the aged than the prospect of such institutions. In the horrible places, the battle for control of the residents escalates until you get tied down or locked in your Geri-chair or chemically subdued with psychotropic medications. In the nice one a staff member cracks a joke, wigs and affection finger and takes your brownie stash away. In almost none does anyone sit down with you and try to figure out what living a life really means to you under the circumstances, let alone help you make a home where that life becomes possible.

This is 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 ills – from freeing up hospital beds 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 them: how to make life worth living when you're weak and frail and can't fend for yourself anymore.

Chapter 4

Your chances of avoiding the nursing home or directly related to the number of children you have, and, according to what little research has been done, having at least one daughter seems to be crucial to the amount of help you will receive.

Taking care of a debilitated, elderly person in our medicalized era is an overwhelming combination of the technological and the custodial. The burdens for today's caregivers have actually increased from what they would have been a century ago.

There is a long discussion of the genesis of assisted-living facilities as conceived and executed by Keren Brown Wilson. At the center of Wilson's work was an attempt to solve a deceptively simple puzzle: what makes life worth living when we are old and frail and unable to care for ourselves?
As people grow older, they focus on being rather than doing and on the present more than the future. Understanding this shift is essential to our understanding old age.
Caring for the elderly and dying in essence has to do with simple but profound service. This is described in Tolstoy's is The Death of Ivan Ilych. To grasp a fading man's need for every day companionship, for help achieving his modest aims– is the thing that is still so devastatingly lacking more than a century later.
Wilson is still trying to work out how ordinary people can age without having to choose between neglect and institutionalization. It remains among the most uncomfortable questions we face.
Many of 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.

Chapter 5: A Better Life

A lot of this chapter deals with Dr. William Thomas who started a green hospice movement. He did this in a small town in New York State. Thomas came to think the missing ingredient in the nursing home he worked in was life itself. He believed that a good life was one of maximum independence. But that was precisely what the people in the nursing home were denied. Thomas decided to try to put some life into the nursing home the way that he's done in his own home. If he could introduce plants, animals, and children into the lives of the residence – fill the nursing home with them – what would happen?
To realize his dream, Thomas imported 100 parakeets into the nursing home as well as dogs and cats and plants. The goal was to attack what he termed the three plagues of nursing home existence: boredom, loneliness, and helplessness.
As he saw it, habits and expectations had made institutional routines and safety greater priorities than living a good life and had prevented the nursing home from successfully bringing in even one dog to live with the residents. He wanted to bring in enough animals, plants, and children to make them a regular part of every nursing home residents life.

That fall they moved in a greyhound named Target, a lap dog named Ginger, four cats and the birds. They threw out all their artificial plants and put live plants in every room. Staff members brought their kids to hang out after school; friends and family put in a garden at the back of the home and a playground for kids. It was shock therapy. Gradually, people started to accept that filling the home with life was everyone's task. The effect on residents soon became impossible to ignore: the residents begin to wake up and come to life.

In the book, Thomas wrote about the experience. He quoted from journals the staff kept and they described how irreplaceable the animals had become in the daily lives of residence, even the ones with advanced dementia.

Researchers studied the effects of this program over two years. The number of prescriptions required per resident fell to half that of the control nursing home. Psychotropic drugs for agitation, like Haldol, decreased in particular. Just fell by 15%. The difference in death rates can be traced to the fundamental human need for a person to live. This reminds one of Victor Frankel's great book: Man's Search for Meaning.

http://streetschool.co.za/wp-content/uploads/2014/07/Viktor-Emil-Frankl-Mans-Search-for-Meaning.pdf

Dworkin R. Autonomy and the Demented Self. Millbank Quartely 64 supp 2, (1986) 4 - 16

The most important finding of Thomas's experiment wasn't that having a reason to live could reduce death rates for the disabled elderly. The most important finding was that it is possible to provide them with reasons to live, period.

The important thing was that, in ascribing value to the cause and seeing it as worth making sacrifice for, we give our lives meaning.

We all require devotion to something more than ourselves for our lives to be endurable. Without it, we have only our desires to guide us, and they are fleeting, capricious, and insatiable. Bill Thomas helped usher into his nursing home a program he called the Eden Alternative.

The problem with medicine and the institutions it has spawned for the care of the sick and the old is not that we have had an incorrect view of what makes life significant. The problem is that we have had almost no view at all. Medicine’s focus is narrow. Medical professionals concentrate on repair of health, not sustenance of the soul. For more than half a century now, we have treated the trials of sickness, aging and mortality as medical concerns. It has been an experiment in social engineering, putting our faith in the hands of people valued more for their technical prowess than for their understanding of human needs. Yet – and this is the painful paradox – we have decided that they should be the ones who largely define how we live and are waning days.

The paradox is – we have decided that they should be the ones which largely defined how we live in our waning days. For more than half a century now, we have treated the trials of sickness, aging, and mortality as medical concerns. It's been an experiment in social engineering, putting our fates in the hands of people valued more for their technical prowess than for their understanding of the human needs. Thomas and those who follow his philosophy aim to help people in a state of dependents sustain the value of existence.

Making lives meaningful in old age is a new concept. It therefore requires more imagination and invention than making them merely safe does.
Our lives are inherently dependent on others and subject to forces and circumstances well beyond our control. As Dworkin wrote in his remarkable 1986 essay on the subject:
The value of autonomy lies in the scheme of responsibility it creates: autonomy makes each of us responsible for shaping his own life according to some coherent and distinctive sense of character, conviction, and interest.

All we ask is to be allowed to remain the writers of our own story. The story is ever-changing. Over the course of our lives, we encounter unimaginable difficulties. Our concerns and desires may shift. But whatever happens, we want to retain the freedom to shape our lives in ways consistent with our character and loyalties. The battle of being mortal is the battle to maintain the integrity of one's life – to avoid becoming so diminished or dissipated or subjugated that who you are becomes disconnected from who you were or who you want to be. Sickness and old age make the struggle hard enough. The professionals and institutions we turn to should not make it worse.
William Thomas and his wife Jude started a nonprofit organization - what they called the Eden Alternative. They became cofounders of the Pioneer Network, a kind of club for the growing number of people committed to the reinvention of elder care. It advocates for changes that can transform the medically dominated culture of care for the elderly. Their homes for the elderly are called Green Houses. They launched the national Greenhouse Replication Initiative.
As people become aware of the finitude of their life, they do not ask for much. They do not seek more riches. They do not seek more power. They asked only to be permitted, in so far as possible, to keep shaping the story of their life in the world – to make choices and sustain connections to others according to their own priorities. In modern society, we have come to assume that debility and dependence rule out such autonomy. What I learned from people like Bill Thomas is that autonomy is very much a possibility.

Chapter 6 Letting Go

As people's capacities wane, whether through age or ill health, making their lives better often requires curbing our purely medical imperatives – resisting the urge to fiddle and fix and control.

A difficult question is: when should we try to fix and when should we not?
One question to ponder is: if you were the one who had metastatic cancer – or for that matter, any similarly advanced or incurable condition – what would you want your doctors to do? Our medical system is excellent at trying to stave off death with $12,000 a month chemotherapy, $4000 a day intensive care, $7000 an hour surgery. But ultimately, death comes and few are good at knowing where to stop.
People with serious illness have priorities besides simply prolonging their lives. Surveys find that their top concerns include avoiding suffering, strengthening relationships with family and friends, being mentally aware, not being a burden to others, and achieving a sense that their life is complete. Our system of technological medical care has utterly failed to meet these needs, and the cost of this failure is measured in far more than dollars.
In our past few decades, medical science has rendered obsolete centuries of experience, tradition, and language about our mortality and created a new difficulty for mankind: how to die.

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 sacrifice the quality of your existence now – but 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. Hospice has tried to offer a new idea for how to die. Although not everyone has embraced its rituals, those who have are helping to negotiate an "ars moriendi" for our age. But doing so represents a struggle against the seemingly unstoppable momentum of medical treatment.

Nicholas Christakis in a study found that 63% of doctors overestimated the patients' survival time. Just 17% underestimated it. The average estimate was 530% too high. Christakis NA and Lamont EB.. BMJ 2000)

There is a school of thought that says the problem is the absence of market forces. If terminally ill patients – rather than insurance companies or the government – had to pay the added costs for the treatment they chose instead of hospice, they would take the trade-offs into account more. They would not pay $80,000 for drugs and end-stage heart failure patients, would not pay $50,000 for the defibrillators offering at best a few months of extra survival.

A 2010 study from MGH show that those stage four lung cancer patients who saw a palliative care specialist stopped chemotherapy sooner, entered hospice far earlier, experienced less suffering at the end of their lives – and they lived an average of 25% longer. In other words, our decision-making in medicine has failed so spectacularly that we have reached the point of actively inflicting harm on patients rather than confronting the subject of mortality.

Susan Block, a palliative care specialist, told me "a family meeting is a procedure, and it requires no less skill and performing in operation."

"A large part of the task is helping people negotiate the overwhelming anxiety – anxiety about death, anxiety about suffering, anxiety about loved ones, anxiety about finances. There are many worries and real terrors. Arriving at an acceptance of one's mortality and a clear understanding of the limits of the possibilities of medicine is a process, not in epiphany.

There is no single way to take people with terminal illness through the process, but there are some rules. You sit down. You make time. You're trying to learn what's most important to them under the circumstances – so that you can provide information and advice on the approach that gives them their best chance of achieving it. This process requires as much listening as talking.

The words you use matter. According to palliative specialists, you shouldn't say, "I'm sorry things turned out this way" for example. Rather, you should say "I wish things were different." You don't ask "what do you want to do when you are done?" You asked, "If time becomes short, what is the most important thing to you?"

With palliative care there are breakthrough discussions. These are a series of conversations to sort out when patients need to switch from fighting for time to fighting for the other things that people value – being with family or traveling or enjoying chocolate ice cream. Few people have these conversations and there is good reason for anyone to read them. Our responsibility, in medicine, is to deal with human beings as they are. People die only once. They have no experience to draw on. They need doctors and nurses who are willing to have the hard discussions and say what they have seen, who will help people prepare for what is to come – and escape a warehouse oblivion that few really want.

Chapter 7. Hard Conversations

When his father received the diagnosis of his spinal tumor that was the moment when he stepped through the looking glass. Nothing about my father's life and expectations for it would remain the same. Our family was embarking on his own confrontation with the reality of mortality.
Gawande's father was a surgeon; yet the information was difficult to take him. How many times has my father given patient's bad news like this – that they had prostate cancer, for instance. The news nonetheless came like a body blow. Making choices required some help for filling the gaps, and what my father filled them with was fear.

The neurosurgeon at my hospital didn't much like my father's questions. He was fine answering the first couple. But after that he grew exasperated. He had the air of the renowned professor he was: authoritarian, self-certain, and busy with things to do. The neurosurgeon at the Cleveland Clinic exuded no less confidence; but he recognized that my father's questions came from fear. So he took the time to answer them, even the annoying ones. As patients, we want information and control, but we also want guidance. An important type of doctor patient relationship is called interpretive. Here the doctor's role is to help patients determine what they want. Interpretive doctors asks what is most important to you? What are you worries?
Experts have come to call this shared decision-making. Bob Arnold, a palliative care physician at the University of Pittsburg says that many clinicians make the mistake of considering their task as just supplying cognitive information – hard, cold facts and descriptions. They want to be *Dr. information*. But a better way to convey meaning is to tell patients what the information means to you yourself. He gave me three words to use to do that.

I am worried.

Bob Allen described a strategy palliative care physicians use when they talk about bad news with people – they ask, tell, ask. They ask what you want to hear, then they tell you, and then they ask what you understood. The author describes a patient with the ODTAA syndrome: one damn thing after another.
For my father the sudden knowledge of the fragility of his life narrowed his focus and altered his desires.

Some of the specialists who saw Gawande's father had not been ready to acknowledge how much more uncertain the likelihood of the benefits of treatment was. Nor had they been ready to take the time to understand my father and what the experience of radiation would be like for him.

When his father was dying he notes that we were up against the unfixable but we were desperate to believe that we weren't up against the unmanageable. Yet short of calling 911 one the next time trouble hit, and letting the logic and the momentum of medical solutions take over, what were we to do? Between the three of us we had 120 years of experience in medicine, but it still seemed a mystery. It turned out to be an education.

Part of one insight he came up with was the importance of living for the best possible day today instead of sacrificing time now for time later. This was the title of an op-ed piece in the times written by Gawande. (http://nyti.ms/1s2nqnz)

Chapter 8. Courage

This starts with a discussion of a Plato's dialogue called the Laches. It is available online.

The findings were that we are of two kinds of courage required in aging and sickness. The experiencing self which endures every moment equally and the remembering self which gives almost all of the weight of judgment afterwords to two single point in time. At least two kinds of courage are required and 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. But even more daunting is the second kind of courage – the courage to act on the truth we find.

Over and over, we in medicine inflict deep gouges at the end of peoples' lives and then stand oblivious to the harm we do.

I stepped back and asked the question I asked my father: what were her biggest fears and concerns? What goals were most important to her? What trade-offs was she willing to make, and what ones was she not? (this is covered in his Times article.

There is a long discussion of Daniel Kahneman thesis in the book Thinking, Fast and Slow. It has to do with a study done on patients undergoing various procedures while awake. People seem to have two different shelves – and experiencing self which endures every moment equally and a remembering self which gives almost all the weight of judgment afterwards to two single points in time, the worst moment and the last one. Just a few minutes without pain at the end of the medical procedure dramatically reduced patient’s overall pain ratings even when they had experienced more than half an hour of high-level pain. This article might be worth reviewing*

Epilogue

We have been wrong about what our job is in medicine. We think our job is to ensure health and survival. But really it is larger than that. It is to enable well-being. Courage to act on the truth we find. The problem is that the wise courage is so frequently unclear. When it is hard to know what will happen, it is hard to know what to do. One has to decide whether one’s fears or one’s hopes are what should matter most.

Whenever serious sickness or illness strikes and your body or mind breaks down, the vital questions are the same. What is your understanding of the situation and its potential outcomes? What are your fears and what are your hopes up? What are the trade-offs you're willing to make and not willing to make? And what is the course of action that best serves this understanding?

* Patients' memories of painful medical treatments: real-time and retrospective evaluations of two minimally invasive procedures.
Redelmeier DA1, Kahneman D. Pain. 1996 Jul;66(1):3-8.
Abstract
Patients' memories of painful medical procedures may influence their decisions about future treatments, yet memories are imperfect and susceptible to bias. We recorded in real-time the intensity of pain experienced by patients undergoing colonoscopy (n = 154) and lithotripsy (n = 133). We subsequently examined patients' retrospective evaluations of the total pain of the procedure, and related these evaluations to the real-time recording obtained during the experience. We found that individuals varied substantially in the total amount of pain they remembered. Patients' judgments of total pain were strongly correlated with the peak intensity of pain ($P < 0.005$) and with the intensity of pain recorded during the last 3 min of the procedure ($P < 0.005$). Despite substantial variation in the duration of the experience, lengthy procedures were not remembered as particularly aversive. We suggest that patients' memories of painful medical procedures largely reflect the intensity of pain at the worst part and at the final part of the experience.