Being Mortal, Atul Gawande (2015)

Scientific advances have turned the processes of aging and dying into medical experiences, matters to be managed by healthcare professionals. This reality has been largely hidden as the final phases of life become less familiar to people. As recently as 1945, most deaths occurred in the home, but by the 1982, just 17% did. The experience of advanced aging and death has shifted to hospitals and nursing homes.

The necessity of nature's final victory was expected and accepted in generations before our own. There's no escaping the tragedy of life, which is that we all age from the day we are born. This experiment of making mortality a medical experience is just decades old, as medicine often fails those it is supposed to help. 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. We have allowed our fates to be controlled by the imperatives of medicine, technology, and strangers.

In my grandfather's premodern world of rural India, how he wanted to live was his choice, and the family's role was to make it possible. He got to live the way he wished with his family around him right to the end. For most of human history, for those few people who actually survived to old age, his experience was the norm. Systems shared the advantage of easily resolving the question of care for the elderly. It was understood that parents would just keep living in their home, assisted by one or more of the children they'd raised. In the past, surviving into old age was uncommon, and those who did survive served a special purpose as guardians of tradition, knowledge, and history. They tended to maintain their status and authority as head of the household until death. So much respect accrued to the elderly that people used to pretend to be older than they were when giving their age.

But age is longer rare. In 1790 Amnricans over 65 constituted less than 2% of the population; today they are 14%. In Germany, Italy, and Japan, they exceed 20%. The exclusive hold that elders once had on knowledge and wisdom has also eroded as increased longevity brought a shift in the relationship between the young and the old. For young people, the traditional family system became less a source of security than a struggle for control—over property, finances, and even the most basic decisions about how they could live.

Global economic development has changed opportunities for the young dramatically. The prosperity of whole countries depends on their willingness to escape the shackles of family expectation and follow their own path. The historical pattern is clear: as soon as people got the resources and opportunity to abandon that way of life, they were gone. Given the opportunity, both parents and children saw separation as a form of freedom. Whenever the elderly have had the financial means, they have chosen what social scientists have called "intimacy at a distance." The pattern is worldwide and choices for the elderly have proliferated.

Retirement communities have become a normal presence. For those who had no interest in moving into such places, it became acceptable and feasible to remain in their own home, living as they wanted to live, autonomously. The lines of power between the generations have been renegotiated. Modernization did not demote the elderly. It demoted the family. It gave people the liberty to be less beholden to other generations. It's been replaced by veneration of the independent self. Our reverence for independence takes no account of the reality of what happens in life: sooner or later, independence will become impossible.

In the past, life and health would putter along nicely until illness would hit and the bottom would drop out, with death soon following. By the middle of the 20th century modern medicine and lifespans had advanced to the point that the pattern of decline has changed for many chronic illnesses—emphysema, liver disease, and congestive heart failure, for example. Instead of just delaying the moment of the downward drop, our treatment can stretch the descent out until it ends up looking less like a cliff and more like a hilly road down the mountain. The trajectory that medical progress has made possible for many is that increasingly large numbers of us get to live out a full life span and die of old age. No single disease leads to the end; the culprit is just the accumulated crumbling of one's bodily systems while medicine carries out its maintenance measures and patch jobs. The curve of life becomes a long slow fade. We've undergone a biological transformation of the course of our lives and a cultural transformation of how we think about that course.

Even as our bones and teeth soften, the rest of our body hardens. Even the lungs pick up substantial deposits of calcium and turn stiff. It's as if the calcium seeps out of our skeletons and into our tissues. As the heart muscle thickens, muscle elsewhere thins. By age 80, we have lost ¼ to ½ of our muscle weight. By 85, working memory and judgment are sufficiently impaired that 40% of us have textbook dementia. Human beings fail the way all complex systems fail: randomly and gradually. Our bodies accumulate lipofuscin, oxygen free-radical damage, random DNA mutations and numerous other microcellular problems.

Equally worrying, medicine has been slow to confront the changes for which it has been responsible—to make old age better. The number of certified geriatricians has fallen and incomes in geriatrics and adult primary care are among the lowest in medicine. The dismal finances of geriatrics are a symptom of a deeper reality: people have not insisted on a change in priorities. What geriatricians do is both difficult and unappealingly limited. It requires attention to the body and its alterations. It requires vigilance over nutrition, medications, and living situations. Their job is to support quality of life--meaning as much freedom from the ravages of disease as possible and the retention of enough function for active engagement in the world. Good geriatrics simplify medications and control arthritis; they ensure toenails are trimmed and meals are square. They look for worrisome signs of isolation and that the patient's home is safe. Creating geriatric specialists takes time, and we already have far too few. We should direct geriatricians toward training all primary care doctors and nurses in caring for the very old instead of providing the care themselves.

The average American spends a year or more of old age disabled and living in a nursing home (at more than 5X the cost of independent living). The risk of a fatal car crash with a driver who's 85 or older is 3X higher than with a teenage driver. The very old are the highest-risk drivers on the road. Old age is a continuous series of losses.

What buoyed Felix, despite his limitations was having a purpose, to be of service to those around him. Most important was the responsibility he felt for his children and grandchildren—and most important of all for his wife. With the narrowing of his own life, his ability to look after his wife had become his main source of self-worth. He kept his social contacts and avoided isolation. He monitored his bones and teeth and weight. And he made sure to find a doctor who had the geriatric skills to help him hold on to an independent life.

Life fundamentally changes in ways we do not want but can do little about. The most common complaint about nursing home is "It just isn't home." The things that make them much safer and more manageable than the house are precisely what makes them hard to endure. With loss of home goes loss of control.

In 1956, Congress passed the Hill-Burton Act, which provided massive amounts of government funds for hospital construction Two decades later the program had financed more than 9000 new hospitals across the country. But as medicine became more powerful, the modern hospital brought an expectation of a place where you could go saying, "Cure me."

The reason old people wound up in poorhouses was not just that they didn't have money to pay for a home. They were there because they'd become too frail, sick, feeble, senile, or broken down to care for themselves anymore, and they had nowhere else to turn for help. Pensions hadn't provided a plan for that final, infirm stage of mortal life. As hospitals sprang up, they became a comparatively more attractive place to put the infirm. By the 1952 the poorhouses closed, and responsibility for those who'd been classified as elderly "paupers" was transferred to departments of welfare, and the sick and disable were put in hospitals.

In 1954 lawmakers provided funding to enable them to build separate custodial units for patients needing an extended period of "recovery." That was the beginning of the modern nursing home. They were created to clear our hospital beds. This has been the persistent pattern of how modern society has dealt with old age. The systems we've devised were designed to solve some other problems. When Medicare, America's health insurance system for the aged and disabled, passed in 1965, it invented the concept of "substantial compliance" to medical and safety standards. The core problem persists. This place where half of us may spend more than a year of our lives was never truly made for us.

There is a likeness between prisons and nursing homes. They are, along with military training camps, orphanages, and mental hospital, "total institutions"—places largely cut off from wider society. All aspects of life are conducted in the same place and under the same central authority. Each phase of daily activity is carried on in the immediate company of a large batch of others, all of whom are treated alike and required to do the same thing together. All phases of the day's activities are tightly scheduled.

The idea of care that had evolved didn't bear any meaningful resemblance to what most would call living. It is a near-universal reality. Nursing home priorities are matters like avoiding bedsores and maintaining residents' weight—important medical goals--but they are means, not ends. The main activities are forms of passive entertainment. The things missed most are friendships, privacy, and a purpose to their days. Some resist mainly through noncooperation—the ones we call "feisty."

In almost none does anyone sit down with you and try to figure out what living life really means to you under the circumstances, let alone help you make a home where that life becomes possible. We end up with institutions that address a number of societal goals, but not the one that matters to the people who reside in them: to make life worth living when we're weak and frail and can't fend for ourselves anymore.

In the main, the family has remained the primary alternative. Having at least one daughter seems to be crucial to the amount of help you will receive. But our greater longevity has coincided with increased dependence of families on dual incomes. The first fall is the harbinger of unstoppable trouble. The single most serious threat of aging is falling. The 3 primary risk factors for falling are poor balance, multiple prescriptions, and muscle weakness. Elderly people without these risk factors have a 12% chance of falling in a year. Those with all 3 risk factors have almost 100% chance.

The burdens for today's caregiver have actually increased from what they would have been a century ago. Shelley had become a round-the-clock concierge/chauffeur/schedule manager/medication-and-technology trouble shooter, in addition to cook/maid/ attendant, not to mention income earner. It seemed as if, once aging led to debility, it was impossible for anyone to be happy.

Today, assisted living is regarded as something of an intermediate station between independent living and life in a nursing home. The fact that this design was supposed to be for their health and safety—for their benefit—made them that much more benighted and impervious to change. Home is the one place where you own priorities hold sway.

People readily demonstrate a willingness to sacrifice their safety and survival for the sake of something beyond themselves, such as family, country, or justice--regardless of age. In young adulthood, people seek a life of growth and self-fulfillment. In the latter half of adulthood, however, most reduce the amount of time and effort they spend pursuing achievement and social networks. As we grow older, we interact with fewer people and concentrate more on time with family and established friends. We focus on being rather than doing and on the present more than the future. Far from growing unhappier, people report more positive emotions as they age.

How we seek to spend our time may depend on how much time we perceive ourselves to have. When you are young and healthy, you believe you will live forever. When horizons measure in decades, which might as well be infinity to human beings, you most desire all the stuff at the top of Maslow's pyramid—achievement, creativity, and other attributes of "self-

actualization." But as your horizons contract—when you see the future as finite and uncertain—your focus shifts to the here and now, to everyday pleasures and the people closest to you. Perspective matters.

The younger the subjects of our study were, the less they valued time with people they were emotionally close to and the more they valued time with people who were potential sources of information or new friendship. However, among the ill, the age differences disappeared. When healthy people ages 8-93 were asked how they would like to spend half an hour of time, the age differences were clear. But when asked to imagine they were about to move far away, the age difference disappeared. The young chose as the old did.

As it happened, a year after the team had completeded this study in Hong Kong, the news came out that political control of the country would be handed over to China. Sure enough, they found that people had narrowed their social networks to the point that the difference in the goals of young and old vanished. A year after the handover, when the uncertainty had subsided, the team did the survey again. The age differences reappeared. When, as the researchers put it, "life's fragility is primed," people's goals and motives in their everyday lives shift completely. It is perspective, not age, that matters most.

From 1990 to 2000, assisted living became the fastest-growing form of senior housing in the country. Even so, the language of medicine, with its priorities of safety and survival, took over again. A survey found that only 22% offered both privacy and sufficient services to allow frail people to remain in residence. Wilson said, "I love it when assisted living works." It's just that in most places it doesn't. Staff members' attitudes seemed to result from incomprehension rather than cruelty, but, as Tolstoy would have said, What's the difference in the end?

It's difficult to make caregivers think about what it really entails. Tasks come to matter more than people in the interest of less time and aggravation. We have very precise ratings for health and safety. So, you can guess what gets the attention from those who run places for the elderly. Assisted living isn't really built for the sake of older people so much as for the sake of their children. They create what marketers call "the visuals"—features that speak more to what a middle-aged person desires for a parent than to what the parent desires. Above all, they sell themselves as safe places. Many of the things that we want for those we care about are things that we would adamantly oppose for ourselves because they would infringe upon our sense of self.

One staffer said, "I was confusing care with treatment." The 3 Plagues of nursing home existence: boredom, loneliness, and helplessness. Culture is the sum total of shared habits and expectations, which had made institutional routines and safety greater priorities than living a good life.

At Chase, they moved in a greyhound named Target, a lapdog name Ginger, 4 cats, and 100 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 the kids. It was shock therapy. Gradually people started to accept that filling Chase with life was everyone's task. They did so because the effect on residents soon became impossible to ignore: the residents began to wake up and come to life. The number of prescriptions required per resident fell to half that of the control nursing home and total drug costs fell to just 38%. Deaths fell 15%.

Living things, in place of boredom, offer spontaneity. In place of loneliness, they offer companionship. In place of helplessness, they offer a chance to take care of another being. The most important finding of Thomas's experiment at Chase wasn't that having a reason to live could reduce death rates for the disabled elderly, but that it is possible to provide them with reasons to live. The only way death is not meaningless is to see yourself as part of something greater. If you don't, mortality is only a horror.

Medicine and the institutions it as spawned have had an incorrect view of what makes life significant. The problem is that they have almost no view at all. Medical professions have decided that they should be the ones who largely define how we live in our waning days. Thomas wanted to help people in a state of dependence sustain the value of existence. Research has found that in units with fewer than 20 people there tends to be less anxiety and depression, more socializing and friendship, an increased sense of safety. Human beings have a need for both privacy and community, for flexible daily rhythms and patterns, and for the possibility of forming caring relationship with those around them.

One apartment complex of aging neighbors self-organized attending services to avoid becoming a certified nursing home or even an assisted living facility. Officially, it's still just a low-income apartment complex—though one with a manager who is determined to enable people to live in their own homes, in their own way, right to the end. No matter what happens. Making lives meaningful in old age is new. It requires more imagination and invention than making them merely safe ones. The places I saw believed that you didn't need to sacrifice autonomy just because you needed help in your life. We want to retain the autonomy—the freedom—to be the authors of our lives. This is the very marrow of being human.

Bill Thomas and his wife cofounded the Pioneer Network, a kind of club for the growing number of people committed to the reinvention of elder care. The plan was to be "a sheep in wolf's clothing." All Green Houses are small and communal. None has more than 12 residents. Their managers were generalists. They did the cooking, cleaning, and the helping with whatever need arose, whenever it arose (except for medical tasks). They were closer to a companion than a clinician. As people become aware of the finitude of their lives, they ask only to be permitted, insofar 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.

If you had an advanced, incurable condition, what would you want your doctors to do? The interval between recognizing that you had a life-threatening ailment and dying was commonly a matter of days or weeks in the past. People generally experienced life-threatening illness the way they experienced bad weather—as something that struck with little warning. And you either got through it or you didn't.

In ordinary medicine, the goal is to extend life. Hospice deploys nurses, doctors, chaplain, and social workers to

help those with a fatal illness have the fullest possible lives right now. As a hospice nurse, I say, "I'm the hospice nurse, and here's what I have to offer to make your life better. And I know we don't have a lot of time to waste." In an era in which the relationship between patient and doctor is increasingly miscast in retail terms— "the customer is always right" --doctors are hesitant to trample on a patient's expectations. We've built our medical system and culture around the long tails of terminal illness possibility—the medical equivalent of lottery tickets. Hope is not a plan, but it is our plan. Rarely is there nothing more that doctors can do. We fall back on the default of "Do Something. Fix Something. Is there any way out of this?"

Raising questions about doctors' and patients' treatment decisions in terminal illness is judged political suicide for insurance companies. People with substantive discussions with their doctor about their end-of-life preference were far more likely to die at peace and in control of their situation. Those who had a palliative care specialist stopped chemotherapy sooner, entered hospice far earlier, experienced less suffering at the end of their lives—*and they lived 25% longer*. You live longer only when you stop trying to live longer.

By 1996, 85% of La Crosse residents who died had a written advanced directive, up from 15%. The discussion about end-of-life was what mattered most. It had brought La Cross's end-of-life costs down to half the national average. A large part of the task is helping people negotiate the overwhelming anxiety about death, suffering, finances, and loved ones. Arriving at an acceptance of one's mortality and a clear understanding of the limits and possibilities of medicine is a process.

Ask, "If time becomes short, what is most important to you?" What do they understand their prognosis to be, what are their concerns about what lies ahead, what kinds of tradeoffs are they willing to make, how do they want to spend their time if their health worsens, who do they want to make decisions if they can't?"

There is a still unresolved argument about what the function of medicine really is—what we should and should not pay doctors to do. The damage is greatest if all you do is battle to the bitter end. And we *can* escape a warehoused oblivion that few really want.

Five of the 10 fastest growing economies in the world are in Africa. There are 3 stages of medical development that countries go through, paralleling economic development. 1st, when a country is in extreme poverty, most deaths occur in the home. In the 2nd stage, when a country's economy develops and its people transition to higher incomes, greater resources make medical capabilities more widely available. People often die in the hospital instead of the home. In the 3rd stage, as a country's income climbs to the highest level, deaths at home rise again. By 2010, 45% of Americans died in hospice. More than half of them received hospice care at home. We are going through a societal learning curve, one person at a time.

Doctors play one of several roles at end-of-life. Most are paternalistic. Some are "informative."—the opposite of paternalistic. In truth, we want information and control, but we also want guidance. A 3rd type of doctor-patient relationship may be called "interpretative." His role is to help patients determine what they want. "What are your worries?"

The aging often experiences the ODTAA syndrome: One Damn Thing After Another. Understanding the finitude of one's time could be a gift. My father's sudden knowledge of the fragility of his life narrowed his focus and altered his desires. It made him visit with his grandchildren more often, put in an extra trip to see his family in India, and tamp down new ventures. I asked, "What were his goals if his condition worsened? What tradeoffs was he willing to make and not willing to make to try to stop what was happening to him?"

He wanted to be capable of not only being with people but also of still being in charge of world and life. His advancing quadriplegia threatened to take that away soon. "Let me die instead." Those questions were among the hardest I'd asked in my life. But what we felt afterward was relief and clarity. He was ready for the spinal surgery. He was more afraid now of what the tumor was doing to him than what an operation might do to him. Between the 3 of us family members we had 120 years of experience in medicine, but his end-of-life seemed a mystery. It turned out to be an education.

Courage is strength in the face of the knowledge of what is to be feared or hoped. Wisdom is prudent strength. Courage, first, 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. Then, courage to act on the truth we find. We must decide whether one's fears or one's hopes are what should matter most.

Our "remembering self" attempts to recognize not only the peaks of joy and valleys of misery but also how the story works out as a whole. That is profoundly affected by how things ultimately turn out. The chance to shape one's story is essential to sustaining meaning in life.

We, as a society, are up against the difficulty of maintaining a coherent philosophical distinction between giving people the right to stop external or artificial processes that prolong their lives and giving them the right to stop the natural, internal processes that end it. At root, the debate is about what mistakes we fear most—the mistake of prolonging suffering or the mistake of shortening valued live. Only a minority of people saved from suicide repeat the attempt.

As life approaches its end, people want to share memories, pass on wisdoms and keepsakes, settle relationships, establish their legacies, make peace with God, and ensure that those who are left behind will be okay. Over and over, we in medicine inflict deep gouges at the end of people's lives and then stand oblivious to the harm done.

At the end the vital questions are the same: What is your understanding of the situation and its potential outcomes? What are your fears and hopes? What are the tradeoffs you are willing to make and not willing to make? And what is the course of action that best serves this understanding?

The most meaningful experiences I'd have as a doctor would come from helping others deal with what medicine cannot do--as well as what it can.

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serious threat of aging is falling. Far from growing unhappier, people report more positive emotions as they age. Assisted living isn't really built for the sake of older people so much as for the sake of their children. Many of the things that we want for those we care about are things that we would adamantly oppose for ourselves because they would infringe upon our sense of self. The chance to shape one's story is essential to sustaining meaning in life.]