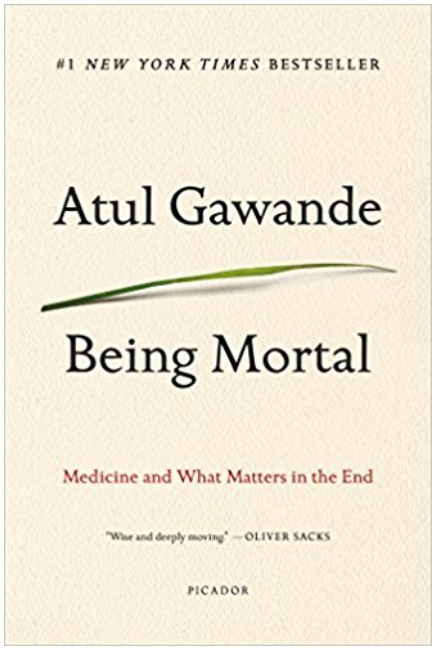
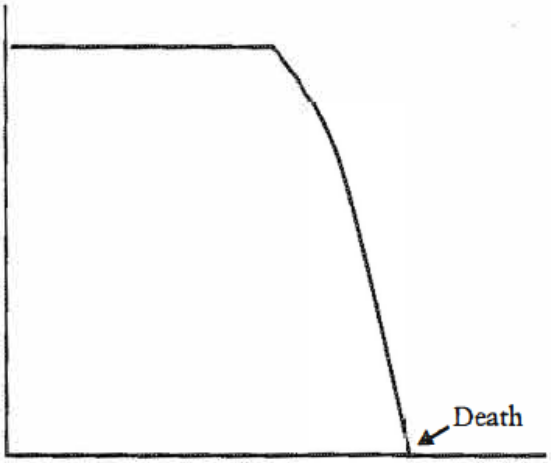


2 – Things Fall Apart

Medicine and public health have transformed the trajectory of our lives. For all but our most recent history, death was a common, ever-present possibility. It didn't matter whether you were five or fifty. Every day was a roll of the dice. If you plotted the typical course of a person's health, it would look like this:

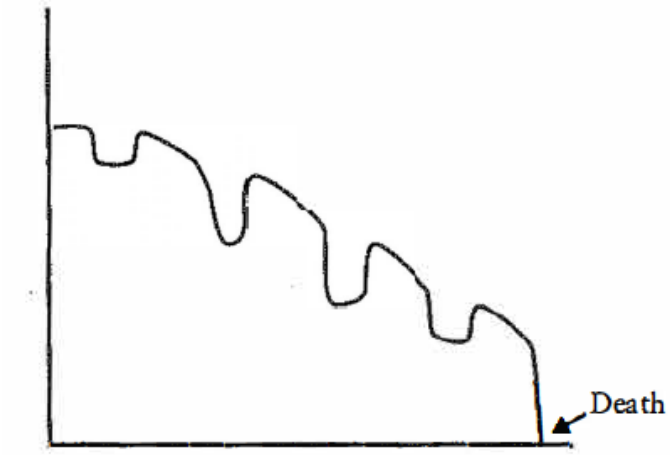


Life and health would putter along nicely, not a problem in the world. Then illness would hit and the bottom would drop out like a trap door—the way it did for my grandmother Gopikabai Gawande, who'd been perfectly well until the day she was struck by a fatal case of malaria, not even thirty years old, or for Rich Hobson, who had a heart attack on a business trip and then was gone.

Over the years, with medical progress, the bottom has tended to drop out later and later. The advent of sanitation and other public health measures sharply reduced the likelihood of death from infectious disease, especially in early childhood, and clinical advances dramatically reduced the mortality of childbirth and traumatic injuries. By the middle of the twentieth century, just four out of every hundred people in industrialized countries died before the age of thirty. And in the decades since, medicine found ways to cut the mortality of heart attacks, respiratory illnesses, stroke, and numerous other conditions that threaten in adult life. Eventually, of course, we all die of something. But even then, medicine has pushed the fatal moment of many diseases further outward. People with incurable cancers, for instance, can do remarkably well for a long time after diagnosis. They undergo treatment. Symptoms come under control. They resume regular life. They don't feel sick. But the disease, while slowed, continues progressing, like a night brigade taking out perimeter defenses. Eventually, it makes itself known, turning up in the lungs, or in the brain, or in the spine, as it did with Joseph Lazaroff. From there, the decline is often relatively rapid, much as in the past. Death occurs later, but the trajectory remains the same. In a matter of months or weeks, the body becomes overwhelmed. That is why, although the diagnosis may have been present for years, death can

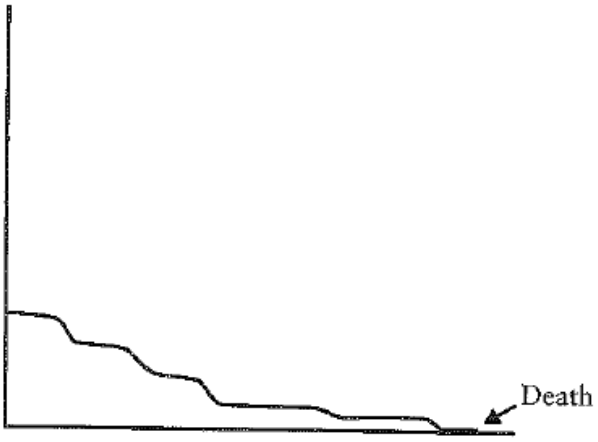
still come as a surprise. The road that seemed so straight and steady can still disappear, putting a person on a fast and steep slide down.

The pattern of decline has changed, however, for many chronic illnesses—emphysema, liver disease, and congestive heart failure, for example. Instead of just delaying the moment of the downward drop, our treatments can stretch the descent out until it ends up looking less like a cliff and more like a hilly road down the mountain:



The road can have vertiginous drops but also long patches of recovered ground: we may not be able to stave off the damage, but we can stave off the death. We have drugs, fluids, surgery, intensive care units to get people through. They enter the hospital looking terrible, and some of what we do can make them look worse. But just when it looks like they've breathed their last, they rally. We make it possible for them to make it home—weaker and more impaired, though. They never return to their previous baseline. As illness progresses and organ damage worsens, a person becomes less able to withstand even minor problems. A simple cold can be fatal. The ultimate course is still downward until there finally comes a time when there is no recovery at all.

The trajectory that medical progress has made possible for many people, though, follows neither of these two patterns. Instead, increasingly large numbers of us get to live out a full life span and die of old age. Old age is not a diagnosis. There is always some final proximate cause that gets written down on the death certificate—respiratory failure, cardiac arrest. But in truth 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. We reduce the blood pressure here, beat back the osteoporosis there, control this disease, track that one, replace a failed joint, valve, piston, watch the central processing unit gradually give out. The curve of life becomes a long, slow fade:



The progress of medicine and public health has been an incredible boon—people get to live longer, healthier, more productive lives than ever before. Yet traveling along these altered paths, we regard living in the downhill stretches with a kind of embarrassment. We need help, often for long periods of time, and regard that as a weakness rather than as the new normal and expected state of affairs. We're always trotting out some story of a ninety-seven-year-old who runs marathons,

as if such cases were not miracles of biological luck but reasonable expectations for all. Then, when our bodies fail to live up to this fantasy, we feel as if we somehow have something to apologize for. Those of us in medicine don't help, for we often regard the patient on the downhill as uninteresting unless he or she has a discrete problem we can fix. In a sense, the advances of modern medicine have given us two revolutions: we've undergone a biological transformation of the course of our lives and also a cultural transformation of how we think about that course.

THE STORY OF aging is the story of our parts. Consider the teeth. The hardest substance in the human body is the white enamel of the teeth. With age, it nonetheless wears away, allowing the softer, darker layers underneath to show through. Meanwhile, the blood supply to the pulp and the roots of the teeth atrophies, and the flow of saliva diminishes; the gums tend to become inflamed and pull away from the teeth, exposing the base, making them unstable and elongating their appearance, especially the lower ones. Experts say they can gauge a person's age to within five years from the examination of a single tooth—if the person has any teeth left to examine.

Scrupulous dental care can help avert tooth loss, but growing old gets in the way. Arthritis, tremors, and small strokes, for example, make it difficult to brush and floss, and because nerves become less sensitive with age, people may not realize that they have cavity and gum problems until it's too late. In the course of a normal lifetime, the muscles of the jaw lose about 40 percent of their mass and the bones of the mandible lose about 20 percent, becoming porous and weak. The ability to chew declines, and people shift to softer foods, which are generally higher in fermentable carbohydrates and more likely to cause cavities. By the age of sixty, people in an industrialized country like the United States have lost, on average, a third of their teeth. After eighty-five, almost 40 percent have no teeth at all.

Even as our bones and teeth soften, the rest of our body hardens. Blood vessels, joints, the muscle and valves of the heart, and even the lungs pick up substantial deposits of calcium and turn stiff. Under a microscope, the vessels and soft tissues display the same form of calcium that you find in bone. When you reach inside an elderly patient during surgery, the aorta and other major vessels can feel crunchy under your fingers. Research has found that loss of bone density may be an even better predictor of death from atherosclerotic disease than cholesterol levels. As we age, it's as if the calcium seeps out of our skeletons and into our tissues.

To maintain the same volume of blood flow through our narrowed and stiffened blood vessels, the heart has to generate increased pressure. As a result, more than half of us develop hypertension by the age of sixty-five. The heart becomes thicker-walled from having to pump against the pressure, and less able to respond to the demands of exertion. The peak output of the heart therefore decreases steadily from the age of thirty. People become gradually less able to run as far or as fast as they used to or to climb a flight of stairs without becoming short of breath.

As the heart muscle thickens, muscle elsewhere thins. Around age forty, one begins to lose muscle mass and power. By age eighty, one has lost between a quarter and a half of one's muscle weight.

You can see all these processes play out just in the hand: 40 percent of the muscle mass of the hand is in the thenar muscles, the muscles of the thumb, and if you look carefully at the palm of an older person, at the base of the thumb, you will notice that the musculature is not bulging but flat. In a plain X-ray, you will see speckles of calcification in the arteries and translucency of the bones, which, from age fifty, lose their density at a rate of nearly 1 percent per year. The

hand has twenty-nine joints, each of which is prone to destruction from osteoarthritis, and this will give the joint surfaces a ragged, worn appearance. The joint space collapses. You can see bone touching bone. What the person feels is swelling around the joints, reduced range of motion of the wrist, diminished grip, and pain. The hand also has forty-eight named nerve branches. Deterioration of the cutaneous mechanoreceptors in the pads of the fingers produces loss of sensitivity to touch. Loss of motor neurons produces loss of dexterity. Handwriting degrades. Hand speed and vibration sense decline. Using a standard mobile phone, with its tiny buttons and touch screen display, becomes increasingly unmanageable.

This is normal. Although the processes can be slowed—diet and physical activity can make a difference—they cannot be stopped. Our functional lung capacity decreases. Our bowels slow down. Our glands stop functioning. Even our brains shrink: at the age of thirty, the brain is a three-pound organ that barely fits inside the skull; by our seventies, gray-matter loss leaves almost an inch of spare room. That's why elderly people like my grandfather are so much more prone to cerebral bleeding after a blow to the head—the brain actually rattles around inside. The earliest portions to shrink are generally the frontal lobes, which govern judgment and planning, and the hippocampus, where memory is organized. As a consequence, memory and the ability to gather and weigh multiple ideas—to multitask—peaks in midlife and then gradually declines. Processing speeds start decreasing well before age forty (which may be why mathematicians and physicists commonly do their best work in their youth). By age eighty-five, working memory and judgment are sufficiently impaired that 40 percent of us have textbook dementia.

WHY WE AGE is the subject of vigorous debate. The classical view is that aging happens because of random wear and tear. The newest view holds that aging is more orderly and genetically programmed. Proponents of this view point out that animals of similar species and exposure to wear and tear have markedly different life spans. The Canada goose has a longevity of 23.5 years; the emperor goose only 6.3 years. Perhaps animals are like plants, with lives that are, to a large extent, internally governed. Certain species of bamboo, for instance, form a dense stand that grows and flourishes for a hundred years, flowers all at once, and then dies.

The idea that living things shut down instead of wearing down has received substantial support in recent years. Researchers working with the now famous worm *C. elegans* (twice in one decade, Nobel Prizes went to scientists doing work on the little nematode) were able, by altering a single gene, to produce worms that live more than twice as long and age more slowly. Scientists have since come up with single-gene alterations that increase the life spans of fruit flies, mice, and yeast.

These findings notwithstanding, the preponderance of the evidence is against the idea that our life spans are programmed into us. Remember that for most of our hundred-thousand-year existence—all but the past couple of hundred years—the average life span of human beings has been thirty years or less. (Research suggests that subjects of the Roman Empire had an average life expectancy of twenty-eight years.) The natural course was to die before old age. Indeed, for most of history, death was a risk at every age of life and had no obvious connection with aging, at all. As Montaigne wrote, observing late-sixteenth-century life, "To die of age is a rare, singular, and extraordinary death, and so much less natural than others: it is the last and extremest kind of dying." So today, with our average life span in much of the world climbing past eighty years, we are already oddities living well beyond our appointed time. When we study aging what we are trying to understand is not so much a natural process as an unnatural one.

It turns out that inheritance has surprisingly little influence on longevity. James Vaupel, of the Max Planck Institute for Demographic Research, in Rostock, Germany, notes that only 3 percent of how long you'll live, compared with the average, is explained by your parents' longevity; by contrast, up to 90 percent of how tall you are is explained by your parents' height. Even genetically identical twins vary widely in life span: the typical gap is more than fifteen years.

If our genes explain less than we imagined, the classical wear-and-tear model may explain more than we knew. Leonid Gavrilov, a researcher at the University of Chicago, argues that human beings fail the way all complex systems fail: randomly and gradually. As engineers have long recognized, simple devices typically do not age. They function reliably until a critical component fails, and the whole thing dies in an instant. A windup toy, for example, works smoothly until a gear rusts or a spring breaks, and then it doesn't work at all. But complex systems—power plants, say—have to survive and function despite having thousands of critical, potentially fragile components. Engineers therefore design these machines with multiple layers of redundancy: with backup systems, and backup systems for the backup systems. The backups may not be as efficient as the first-line components, but they allow the machine to keep going even as damage accumulates. Gavrilov argues that, within the parameters established by our genes, that's exactly how human beings appear to work. We have an extra kidney, an extra lung, an extra gonad, extra teeth. The DNA in our cells is frequently damaged under routine conditions, but our cells have a number of DNA repair systems. If a key gene is permanently damaged, there are usually extra copies of the gene nearby. And, if the entire cell dies, other cells can fill in.

Nonetheless, as the defects in a complex system increase, the time comes when just one more defect is enough to impair the whole, resulting in the condition known as frailty. It happens to power plants, cars, and large organizations. And it happens to us: eventually, one too many joints are damaged, one too many arteries calcify. There are no more backups. We wear down until we can't wear down anymore.

It happens in a bewildering array of ways. Hair grows gray, for instance, simply because we run out of the pigment cells that give hair its color. The natural life cycle of the scalp's pigment cells is just a few years. We rely on stem cells under the surface to migrate in and replace them. Gradually, however, the stem-cell reservoir is used up. By the age of fifty, as a result, half of the average person's hairs have gone gray.

Inside skin cells, the mechanisms that clear out waste products slowly break down and the residue coalesces into a clot of gooey yellow-brown pigment known as lipofuscin. These are the age spots we see in skin. When lipofuscin accumulates in sweat glands, the sweat glands cannot function, which helps explain why we become so susceptible to heat stroke and heat exhaustion in old age.

The eyes go for different reasons. The lens is made of crystallin proteins that are tremendously durable, but they change chemically in ways that diminish their elasticity over time—hence the farsightedness that most people develop beginning in their fourth decade. The process also gradually yellows the lens. Even without cataracts (the whitish clouding of the lens that occurs with age, excessive ultraviolet exposure, high cholesterol, diabetes, and cigarette smoking), the amount of light reaching the retina of a healthy sixty-year-old is one-third that of a twenty-year-old.

I spoke to Felix Silverstone, who for twenty-four years was the senior geriatrician at the Parker Jewish Institute, in New York, and who has published more than a hundred studies on

aging. There is, he told me, "no single, common cellular mechanism to the aging process." Our bodies accumulate lipofuscin and oxygen free-radical damage and random DNA mutations and numerous other microcellular problems. The process is gradual and unrelenting.

I asked Silverstone whether gerontologists have discerned any particular, reproducible pathway to aging. "No," he said. "We just fall apart."

THIS IS NOT, to say the least, an appealing prospect. People naturally prefer to avoid the subject of their decrepitude. There have been dozens of bestselling books on aging, but they tend to have titles such as *Younger Next Year*, *The Fountain of Age*, *Ageless*, or—my favorite—*The Sexy Years*. Still, there are costs to averting our eyes from the realities. We put off dealing with the adaptations that we need to make as a society. And we blind ourselves to the opportunities that exist to change the individual experience of aging for the better.

As medical progress has extended our lives, the result has been what's called the "rectangularization" of survival. Throughout most of human history, a society's population formed a sort of pyramid: young children represented the largest portion—the base—and each successively older cohort represented a smaller and smaller group. In 1950, children under the age of five were 11 percent of the US population, adults aged forty-five to forty- nine were 6 percent, and those over eighty were 1 percent. Today, we have as many fifty-year-olds as five-year-olds. In thirty years, there will be as many people over eighty as there are under five. The same pattern is emerging throughout the industrialized world.

Few societies have come to grips with the new demography. We cling to the notion of retirement at sixty-five—a reasonable notion when those over sixty-five were a tiny percentage of the population but increasingly untenable as they approach 20 percent. People are putting aside less in savings for old age now than they have at any time since the Great Depression. More than half of the very old now live without a spouse and we have fewer children than ever before, yet we give virtually no thought to how we will live out our later years alone.

Equally worrying, and far less recognized, medicine has been slow to confront the very changes that it has been responsible for—or to apply the knowledge we have about how to make old age better. 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 per- cent between 1996 and 2010. Applications to training programs in adult primary care medicine have plummeted, while fields like plastic surgery and radiology receive applications in record numbers. Partly, this has to do with money—incomes in geriatrics and adult primary care are among the lowest in medicine. And partly, whether we admit it or not, a lot of doctors don't like taking care of the elderly.

"Mainstream doctors are turned off by geriatrics, and that's because they do not have the faculties to cope with the Old Crock," Felix Silverstone, the geriatrician, explained to me. "The Old Crock is deaf. The Old Crock has poor vision. The Old Crock's memory might be somewhat impaired. With the Old Crock, you have to slow down, because he asks you to repeat what you are saying or asking. And the Old Crock doesn't just have a chief complaint—the Old Crock has fifteen chief complaints. How in the world are you going to cope with all of them? You're overwhelmed. Besides, he's had a number of these things for fifty years or so. You're not going to cure something he's had for fifty years. He has high blood pressure. He has diabetes. He has arthritis. There's nothing glamorous about taking care of any of those things."

There is, however, a skill to it, a developed body of professional expertise. One may not be able to fix such problems, but one can manage them. And until I visited my hospital's geriatrics clinic and saw the work that the clinicians there do, I did not fully grasp the nature of the expertise involved, or how important it could be for all of us.

THE GERIATRICS CLINIC—OR, as my hospital calls it, the Center for Older Adult Health (even in a clinic geared to people eighty 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, however, I wandered downstairs and, with the permission of the patients, sat in on a few visits with Juergen Bludau, the chief geriatrician.

"What brings you here today?" the doctor asked Jean Gavrilles, his first patient of the morning. She was eighty-five years old, with short, frizzy white hair, oval glasses, a lavender knit shirt, and a sweet, ready smile. Small but sturdy in appearance, she had come in walking steadily, her purse and coat clutched under one arm, her daughter trailing behind her, no support required beyond her mauve orthopedic shoes. She said that her internist had recommended that she come.

About anything in particular? the doctor asked.

The answer, it seemed, was yes and no. The first thing she mentioned was a lower-back pain that she'd had for months, which shot down her leg and sometimes made it difficult to get out of bed or up from a chair. She also had bad arthritis, and she showed us her fingers, which were swollen at the knuckles and bent out to the sides with what's called a swan-neck deformity. She'd had both knees replaced a decade earlier. She had high blood pressure, "from stress," she said, before handing Bludau her list of medications. She had glaucoma and needed to have eye exams every four months. She never used to have "bathroom problems," but lately, she admitted, she'd started wearing a pad. She'd also had surgery for colon cancer and, by the way, she now had a lung nodule that the radiology report said could be a metastasis—a biopsy was recommended.

Bludau asked her to tell him about her life, and it reminded me of the life Alice lived when I first met her at my in-laws'. Gavrilles said that she lived alone, except for her Yorkshire terrier, in a single-family house in the West Roxbury section of Boston. Her husband died of lung cancer twenty-three years ago. She did not drive. She had a son living in the area who did her shopping once a week and checked on her each day—"just to see if I'm still alive," she joked. Another son and two daughters lived farther away, but they helped as well. Otherwise, she took care of herself quite capably. She did her own cooking and cleaning. She managed her medicines and her bills.

"I have a system," she said.

She had a high school education, and during World War II she'd worked as a riveter at the Charlestown Navy Yard. She also worked for a time at the Jordan Marsh department store in downtown Boston. But that was a long time ago. She stuck to home now, with her yard and her terrier and her family when they visited.

The doctor asked her about her day in great detail. She usually woke around five or six o'clock, she said—she didn't seem to need much sleep anymore. She would get out of bed as the back pain allowed, take a shower, and get dressed. Downstairs, she'd take her medicines, feed the dog, and eat breakfast. Bludau asked what she had for breakfast that day. Cereal and a

banana, she said. She hated bananas, but she'd heard they were good for her potassium, so she was afraid to stop. After breakfast, she'd take her dog for a little walk in the yard. She did chores—laundry, cleaning, and the like. In the late morning, she took a break to watch *The Price Is Right*. At lunchtime, she had a sandwich and orange juice. If the weather was nice, she'd sit out in the yard afterward. She'd loved working in her garden, but she could no longer do that. The afternoons were slow. She might do some more chores. She might nap or talk on the phone. Eventually, she would make dinner—a salad and maybe a baked potato or a scrambled egg. At night, she watched the Red Sox or the Patriots or college basketball—she loved sports. She usually went to bed at about midnight.

Bludau asked her to sit on the examining table. As she struggled to climb up, her balance teetering on the step, the doctor held her arm. He checked her blood pressure, which was normal. He examined her eyes and ears and had her open her mouth. He listened to her heart and lungs briskly, with his stethoscope. He began to slow down only when he looked at her hands. The nails were neatly trimmed.

"Who cuts your nails?" he asked.

"I do," Gavrilles replied.

I tried to think what could be accomplished in this visit. She was in good condition for her age, but she faced everything from advancing arthritis and incontinence to what might be metastatic colon cancer. It seemed to me that, with just a forty-minute visit, Bludau needed to triage by zeroing in on either the most potentially life-threatening problem (the possible metastasis) or the problem that bothered her the most (the back pain). But this was evidently not what he thought. He asked almost nothing about either issue. Instead, he spent much of the exam looking at her feet.

"Is that really necessary?" she asked, when he instructed her to take off her shoes and socks. "Yes," he said. After she'd left, he told me, "You must always examine the feet." He described a bow-tied gentleman who seemed dapper and fit, until his feet revealed the truth: he couldn't bend down to reach them, and they turned out not to have been cleaned in weeks, suggesting neglect and real danger.

Gavrilles had difficulty taking her shoes off, and, after watching her struggle a bit, Bludau leaned in to help. When he got her socks off, he took her feet in his hands, one at a time. He inspected them inch by inch—the soles, the toes, the web spaces. Then he helped her get her socks and shoes back on and gave her and her daughter his assessment.

She was doing impressively well, he said. She was mentally sharp and physically strong. The danger for her was losing what she had. The single most serious threat she faced was not the lung nodule or the back pain. It was falling. Each year, about 350,000 Americans fall and break a hip. Of those, 40 percent end up in a nursing home, and 20 percent are never able to walk again. 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 percent chance of falling in a year. Those with all three risk factors have almost a 100 percent chance. Jean Gavrilles had at least two. Her balance was poor. Though she didn't need a walker, he had noticed her splay-footed gait as she came in. Her feet were swollen. The toenails were unclipped. There were sores between the toes. And the balls of her feet had thick, rounded calluses.

She was also on five medications. Each was undoubtedly useful, but together the usual side effects would include dizziness. In addition, one of the blood pressure medications was a

diuretic, and she seemed to drink few liquids, risking dehydration and a worsening of the dizziness. Her tongue was bone-dry when Bludau examined it.

She did not have significant muscle weakness, and that was good. When she got out of her chair, he said, he noted that she had not used her arms to push herself up. She simply stood up—a sign of well-preserved muscle strength. From the details of the day she described, however, she did not seem to be eating nearly enough calories to maintain that strength. Bludau asked her whether her weight had changed recently. She admitted that she had lost about seven pounds in the previous six months.

The job of any doctor, Bludau later told me, is to support quality of life, by which he meant two things: as much freedom from the ravages of disease as possible and the retention of enough function for active engagement in the world. Most doctors treat disease and figure that the rest will take care of itself. And if it doesn't—if a patient is becoming infirm and heading toward a nursing home—well, that isn't really a medical problem, is it?

To a geriatrician, though, it is a medical problem. People can't stop the aging of their bodies and minds, but there are ways to make it more manageable and to avert at least some of the worst effects. So Bludau referred Gavrilles to a podiatrist, whom he wanted her to visit once every four weeks, for better care of her feet. He didn't see medications that he could eliminate, but he switched her diuretic to a blood pressure medicine that wouldn't cause dehydration. He recommended that she eat a snack during the day, get all the low-calorie and low-cholesterol food out of the house, and see whether family or friends could join her for more meals. "Eating alone is not very stimulating," he said. And he asked her to see him again in three months, so that he could make sure the plan was working.

Almost a year later, I checked in with Gavrilles and her daughter. She'd turned eighty-six. She was eating better and had even gained a pound or two. She still lived comfortably and independently in her own home. And she had not had a single fall.

ALICE BEGAN FALLING long before I met Juergen Bludau or Jean Gavrilles and grasped the possibilities that might have been. Neither I nor anyone else in the family understood that her falls were a loud alarm bell or that a few simple changes might have preserved, for at least some time longer, her independence and the life she wanted. Her doctors never understood this either. Matters just kept getting worse.

Next came not a fall but a car accident. Backing her Chevy Impala out of her driveway, she shot across the street, over the curb, and through a yard, and could not stop the car until it ended up in some bushes against her neighbor's house. The family speculated that she'd stomped on the accelerator instead of the brake. Alice insisted the accelerator had got stuck. She thought of herself as a good driver and hated the idea that anyone would think that the problem was her age.

The body's decline creeps like a vine. Day to day, the changes can be imperceptible. You adapt. Then something happens that finally makes it clear that things are no longer the same. The falls didn't do it. The car accident didn't do it. Instead, it was a scam that did.

Not long after the car accident, Alice hired two men to perform tree and yard work. They set a reasonable price with her but clearly saw her as a mark. When they finished the job, they told her that she owed nearly a thousand dollars. She balked. She was very careful and organized about money. But they got angry and threatening, and, cornered, she wrote the check. She was shaken but also embarrassed and told no one about it, hoping she could put it behind her. A day later, the men returned late in the evening and demanded she pay more. She argued with them,

but in the end she wrote that check, too. The ultimate total was more than seven thousand dollars. Again, she wasn't going to say anything. Neighbors, however, heard the raised voices at Alice's doorstep and called the police.

The men were gone by the time the police arrived. A policeman took a statement from Alice and promised to investigate further. She still didn't want to tell the family about what had happened. But she knew this was trouble and after a while finally told my father-in-law, Jim.

He spoke to the neighbors who'd reported the crime. They mentioned that they had become worried for her. She no longer seemed safe living on her own. There was this incident and the Impala in the bushes. There was also what they observed of how difficult managing matters as ordinary as getting her trash to the curb had become.

The police caught the scam artists and arrested them for grand larceny. The men were convicted and sentenced to prison, which should have been satisfying for Alice. But instead the whole process kept the events, and the reminders of her growing vulnerability, alive and lingering when she would have dearly loved to have set them behind her.

Soon after the scammers were caught, Jim suggested that he and Alice go together to look at retirement homes. It was just to see what they were like, he said. But they both knew where this was going.

DECLINE REMAINS OUR fate; death will someday come. But until that last backup system inside each of us fails, medical care can influence whether the path is steep and precipitate or more gradual, allowing longer preservation of the abilities that matter most in your life. Most of us in medicine don't think about this. We're good at addressing specific, individual problems: colon cancer, high blood pressure, arthritic knees. Give us a disease, and we can do something about it. But give us an elderly woman with high blood pressure, arthritic knees, and various other ailments besides—an elderly woman at risk of losing the life she enjoys—and we hardly know what to do and often only make matters worse.

Several years ago, researchers at the University of Minnesota identified 568 men and women over the age of seventy who were living independently but were at high risk of becoming disabled because of chronic health problems, recent illness, or cognitive changes. With their permission, the researchers randomly assigned half of them to see a team of geriatric nurses and doctors—a team dedicated to the art and science of managing old age. The others were asked .to see their usual physician, who was notified of their high-risk status. Within eighteen months, 10 percent of the patients in both groups had died. But the patients who had seen a geriatrics team were a quarter less likely to become disabled and half as likely to develop depression. They were 40 percent less likely to require home health services.

These were stunning results. If scientists came up with a device—call it an automatic defrailer—that wouldn't extend your life but would slash the likelihood you'd end up in a nursing home or miserable with depression, we'd be clamoring for it. We wouldn't care if doctors had to open up your chest and plug the thing into your heart. We'd have pink-ribbon campaigns to get one for every person over seventy-five. Congress would be holding hearings demanding to know why forty-year-olds couldn't get them installed. Medical students would be jockeying to become defrailulation specialists, and Wall Street would be bidding up company stock prices.

Instead, it was just geriatrics. The geriatric teams weren't doing lung biopsies or back surgery or insertion of automatic defrailers. What they did was to simplify medications. They

saw that arthritis was controlled. They made sure toenails were trimmed and meals were square. They looked for worrisome signs of isolation and had a social worker check that the patient's home was safe.

How do we reward this kind of work? Chad Boult, the geriatrician who was the lead investigator of the University of Minnesota study, can tell you. A few months after he published the results, demonstrating how much better people's lives were with specialized geriatric care, the university closed the division of geriatrics.

"The university said that it simply could not sustain the financial losses," Boult said from Baltimore, where he had moved to join the Johns Hopkins Bloomberg School of Public Health. On average, in Boult's study, the geriatric services cost the hospital $1,350 more per person than the savings they produced, and Medicare, the insurer for the elderly, does not cover that cost. It's a strange double standard. No one insists that a $25,000 pacemaker or a coronary-artery stent save money for insurers. It just has to *maybe* do people some good. Meanwhile, the twenty-plus members of the proven geriatrics team at the University of Minnesota had to find new jobs. Scores of medical centers across the country have shrunk or closed their geriatrics units. Many of Boult's colleagues no longer advertise their geriatric training for fear that they'll get too many elderly patients. "Economically, it has become too difficult," Boult said.

But the dismal finances of geriatrics are only a symptom of a deeper reality: people have not insisted on a change in priorities. We all like new medical gizmos and demand that policy makers ensure they are paid for. We want doctors who promise to fix things. But geriatricians? Who clamors for geriatricians? What geriatricians do—bolster our resilience in old age, our capacity to weather what comes—is both difficult and unappealingly limited. It requires attention to the body and its alterations. It requires vigilance over nutrition, medications, and living situations. And it requires each of us to contemplate the unfixables in our life, the decline we will unavoidably face, in order to make the small changes necessary to reshape it. When the prevailing fantasy is that we can be ageless, the geriatrician's uncomfortable demand is that we accept we are not.

FOR FELIX SILVERSTONE, managing aging and its distressing realities was the work of a lifetime. He was a national leader in geriatrics for five decades. But when I met him he was himself eighty-seven years old. He could feel his own mind and body wearing down, and much of what he spent his career studying was no longer at a remove from him.

Felix had been fortunate. He didn't have to stop working, even after he suffered a heart attack in his sixties that cost him half his heart function; nor was he stopped by a near cardiac arrest at the age of seventy-nine.

"One evening, sitting at home, I suddenly became aware of palpitations," he told me. "I was just reading, and a few minutes later I became short of breath. A little bit after that, I began to feel heavy in the chest. I took my pulse, and it was over two hundred."

He is the sort of person who, in the midst of chest pain, would take the opportunity to examine his own pulse.

"My wife and I had a little discussion about whether or not to call an ambulance. We decided to call."

When Felix got to the hospital, the doctors had to shock him to bring his heart back. He'd had ventricular tachycardia, and an automatic defibrillator was implanted in his chest. Within a few weeks, he felt well again, and his doctor cleared him to return to work full time. He stayed

in medical practice after the attack, multiple hernia repairs, gallbladder surgery, arthritis that all but ended his avid piano playing, compression fractures of his aging spine that stole three full inches of his five-foot- seven-inch height, and hearing loss.

"I switched to an electronic stethoscope," he said. "They're a nuisance, but they're very good."

Finally, at eighty-two, he had to retire. The problem wasn't his health; it was that of his wife, Bella. They'd been married for more than sixty years. Felix had met Bella when he was an intern and she was a dietitian at Kings County Hospital, in Brooklyn. They brought up two sons in Flatbush. When the boys left home, Bella got her teaching certificate and began working with children who had learning disabilities. In her seventies, however, retinal disease diminished her vision, and she had to stop working. A decade later, she'd become almost completely blind. Felix no longer felt safe leaving her at home alone, and in 2001 he gave up his practice. They moved to Orchard Cove, a retirement community in Canton, Massachusetts, outside Boston, where they could be closer to their sons.

"I didn't think I would survive the change," Felix said. He'd observed in his patients how difficult the transitions of age were. Examining his last patient, packing up his home, he felt that he was about to die. "l was taking apart my life as well as the house," he recalled. "It was terrible."

We were sitting in a library off Orchard Cove's main lobby. There was light streaming through a picture window, tasteful art on the walls, white upholstered Federal-style armchairs. It was like a nice hotel, only with no one under seventy-five walking around. Felix and Bella had a two-bedroom apartment with forest views and plenty of space. In the living room, Felix had a grand piano and, at his desk, piles of medical journals that he still subscribed to—"for my soul," he said. Theirs was an independent-living unit. It came with housekeeping, linen changes, and dinner each evening. When they needed to, they could upgrade to assisted living, which provides three prepared meals and up to an hour with a personal-care assistant each day.

This was not the average retirement community, but even in an average one rent runs $32,000 a year. Entry fees are typically $60,000 to $120,000 on top of that. Meanwhile, the median income of people eighty and older is only about $15,000. More than half of the elderly living in long-term-care facilities run through their entire savings and have to go on government assistance—welfare—in order to afford it. Ultimately, the average American spends a year or more of old age disabled and living in a nursing home (at more than five times the yearly cost of independent living), which is a destination Felix was desperately hoping to avoid.

He was trying to note the changes he experienced objectively, like the geriatrician he is. He noticed that his skin had dried out. His sense of smell was diminished. His night vision had become poor, and he tired easily. He had begun to lose teeth. But he took what measures he could. He used lotion to avoid skin cracks; he protected himself from the heat; he got on an exercise bike three times a week; he saw a dentist twice a year.

He was most concerned about the changes in his brain. "I can't think as clearly as I used to," he said. "I used to be able to read the *New York Times* in half an hour. Now it takes me an hour and a half." Even then, he wasn't sure that he understood as much as he did before, and his memory gave him trouble. "If I go back and look at what I've read, I recognize that I went through it, but sometimes I don't really remember it," he said. "It's a matter of short-term registration. It's hard to get the signal in and have it stay put."

He made use of methods that he once taught his patients. "I try to deliberately focus on what I'm doing, rather than do it automatically," he told me. "I haven't lost the automaticity of action,

but I can't rely on it the way I used to. For example, I can't think about something else and get dressed and be sure I've gotten all the way dressed." He recognized that the strategy of trying to be more deliberate didn't always work, and he sometimes told me the same story twice in a conversation. The lines of thought in his mind would fall into well-worn grooves and, however hard he tried to put them onto a new path, sometimes they resisted. Felix's knowledge as a geriatrician forced him to recognize his decline, but it didn't make it easier to accept.

"I get blue occasionally," he said. "I think I have recurring episodes of depression. They are not enough to disable me, but they are ... " He paused to find the right word. "They are uncomfortable."

What buoyed him, despite his limitations, was having a purpose. It was the same purpose, he said, that sustained him in medicine: to be of service, in some way, to those around him. He had been in Orchard Cove for only a few months before he was helping to steer a committee to improve the health care services there. He formed a journal-reading club for retired physicians. He even guided a young geriatrician through her first independent research study—a survey of the residents' attitudes toward Do Not Resuscitate orders.

More important was the responsibility that he felt for his children and grandchildren—and most of all for Bella. Her blindness and memory troubles had made her deeply dependent. Without him, she would have been in a nursing home. He helped her dress and administered her medicines. He made her breakfast and lunch. He took her on walks and to doctor's appointments. "She is my purpose now," he said.

Bella didn't always like his way of doing things.

"We argue constantly—we're at each other about a lot of things," Felix said. "But we're also very forgiving."

He did not feel this responsibility to be a burden. With the narrowing of his own life, his ability to look after Bella had become his main source of self-worth.

"I am exclusively her caregiver," he said. "I am glad to be." And this role had heightened his sense that he must be attentive to the changes in his own capabilities; he would be no good to her if he wasn't honest with himself about his own limitations.

One evening, Felix invited me to dinner. The formal dining hall was restaurant-like, with reserved seating, table service, and jackets required. I was wearing my white hospital coat and had to borrow a navy blazer from the maitre d' in order to be seated. Felix, in a brown suit and a stone-colored oxford shirt, gave his arm to Bella, who wore a blue-flowered knee-length dress that he'd picked out for her, and guided her to the table. She was amiable and chatty and had youthful-seeming eyes. But once she'd been seated, she couldn't find the plate in front of her, let alone the menu. Felix ordered for her: wild-rice soup, an omelette, mashed potatoes, and mashed cauliflower. "No salt," he instructed the waiter; she had high blood pressure. He ordered salmon and mashed potatoes for himself. I had the soup and a London broil.

When the food arrived, Felix told Bella where she could find the different items on her plate by the hands of a clock. He put a fork in her hand. Then he turned to his own meal.

Both made a point of chewing slowly. She was the first to choke. It was the omelette. Her eyes watered. She began to cough. Felix guided her water glass to her mouth. She took a drink and managed to get the omelette down.

"As you get older, the lordosis of your spine tips your head forward," he said to me. "So when you look straight ahead it's like looking up at the ceiling for anyone else. Try to swallow while looking up: you'll choke once in a while. The problem is common in the elderly. Listen." I realized that I could hear someone in the dining room choking on his food every minute or so.

Felix turned to Bella. "You have to eat looking down, sweetie," he said.

A couple of bites later, though, he himself was choking. It was the salmon. He began coughing. He turned red. Finally, he was able to cough up the bite. It took a minute for him to catch his breath.

"Didn't follow my own advice," he said.

Felix Silverstone was, without question, up against the debilities of his years. Once, it would have been remarkable simply to have lived to see eighty-seven. Now the remarkable thing was the control he'd maintained over his life. When he started in geriatric practice, it was almost inconceivable that an eighty-seven-year-old with his history of health problems could live independently, care for his disabled wife, and continue to contribute to research.

Partly, he had been lucky. His memory, for example, had not deteriorated badly. But he had also managed his old age well. His goal has been modest: to have as decent a life as medical knowledge and the limits of his body would allow. So he saved and did not retire early and was therefore not in financial straits. 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.

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." Creating geriatric specialists takes time, and we already have far too few. In a year, fewer than three hundred doctors will complete geriatrics training in the United States, not nearly enough to replace the geriatricians going into retirement, let alone meet the needs of the next decade. Geriatric psychiatrists, nurses, and social workers are equally needed, and in no better supply. The situation in countries outside the United States appears to be little different. In many, it is worse.

Yet Boult believes that we still have time for another strategy: he would direct geriatricians toward training all primary care doctors and nurses in caring for the very old, instead of providing the care themselves. Even this is a tall order—97 percent of medical students take no course in geriatrics, and the strategy requires that the nation pay geriatric specialists to teach rather than to provide patient care. But if the will is there, Boult estimates that it would be possible to establish courses in every medical school, nursing school, school of social work, and internal-medicine training program within a decade.

"We've got to do something," he said. "Life for older people can be better than it is today."

"I CAN STILL drive, you know," Felix Silverstone said to me after our dinner together. "I'm a very good driver."

He had to run an errand to refill Bella's prescriptions in Stoughton, a few miles away, and I asked if I could come along. He had a ten-year-old gold Toyota Camry with automatic transmission and 39,000 miles on the odometer. It was pristine, inside and out. He backed out of a narrow parking space and zipped out of the garage. His hands did not shake. Taking the streets of Canton at dusk on a new-moon night, he brought the car to an even stop at the red lights, signaled when he was supposed to, took turns without a hitch.

I was, I admit, braced for disaster. The risk of a fatal car crash with a driver who's eighty-five or older is more than three times higher than it is with a teenage driver. The very old are the

highest-risk drivers on the road. I thought of Alice's wreck and considered how lucky she was that no child had been in her neighbor's yard. A few months earlier, in Los Angeles, George Weller was convicted of manslaughter after he confused the accelerator with the brake pedal and plowed his Buick into a crowd of shoppers at the Santa Monica Farmers Market. Ten people were killed, and more than sixty were injured. He was eighty-six.

But Felix showed no difficulties. At one point during our drive, poorly marked road construction at an intersection channeled our line of cars almost directly into oncoming traffic. Felix corrected course swiftly, pulling over into the proper lane. There was no saying how much longer he would be able to count on his driving ability. Someday, the hour would come when he would have to give up his keys.

At that moment, though, he wasn't concerned; he was glad simply to be on the road. The evening traffic was thin as he turned onto Route I38. He brought the Camry to a tick over the 45-mile-per-hour speed limit. He had his window rolled down and his elbow on the sash. The air was clear and cool, and we listened to the sound of the wheels on the pavement.

"The night is lovely, isn't it?" he said.

6 – Letting Go

Before I began to think about what awaits my older patients—people very much like Lou Sanders and the others—I'd never ventured beyond my surgical office to follow them into their lives. But once I'd seen the transformation of elder care under way, I was struck by the simple insight on which it rested, and by its profound implications for medicine, including what happens in my own office. And the insight was that 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. It was not hard to see how important this idea could be for the patients I encountered in my daily practice—people facing mortal circumstances at every phase of life. But it posed a difficult question: When should we try to fix and when should we not?

Sara Thomas Monopoli was just thirty-four and pregnant with her first child when the doctors at my hospital learned that she was going to die. It started with a cough and a pain in her back. Then a chest X-ray showed that her left lung had collapsed and her chest was filled with fluid. A sample of the fluid was drawn off with a long needle and sent for testing. Instead of an infection, as everyone had expected, it was lung cancer, and it had already spread to the lining of her chest. Her pregnancy was thirty-nine weeks along, and the obstetrician who had ordered the test broke the news to her as she sat with her husband and her parents. The obstetrician didn't get into the prognosis—she would bring in an oncologist for that—but Sara was stunned. Her mother, who had lost her best friend to lung cancer, began crying.

The doctors wanted to start treatment right away, and that meant inducing labor to get the baby out. For the moment, though, Sara and her husband, Rich, sat by themselves on a quiet terrace off the labor floor. It was a warm Monday in June. She took Rich's hands, and they tried to absorb what they had heard. She had never smoked or lived with anyone who had. She

exercised. She ate well. The diagnosis was bewildering. "This is going to be okay," Rich told her. "We're going to work through this. It's going to be hard, yes. But we'll figure it out. We can find the right treatment. "For the moment, however, they had a baby to think about.

"So Sara and I looked at each other," Rich recalled, "and we said, 'We don't have cancer on Tuesday. It's a cancer-free day. We're having a baby. It's exciting. And we're going to enjoy our baby.'" On Tuesday, at 8:55 p.m., Vivian Monopoli, seven pounds nine ounces, was born. She had wavy brown hair, like her mom, and she was in perfect health.

The next day, Sara underwent blood tests and body scans. Paul Marcoux, an oncologist, met with her and her family to discuss the findings. He explained that she had a non-small cell lung cancer that had started in her left lung. Nothing she had done had brought the disease on. More than 15 percent of lung cancers—more than people realize—occur in nonsmokers. Hers was advanced, having metastasized to multiple lymph nodes in her chest and its lining. The cancer was inoperable. But there were chemotherapy options, notably a drug called erlotinib, which targets a gene mutation commonly found in lung cancers of female nonsmokers; 85 percent of them respond to the drug, and, as Marcoux said, "some of these responses can be long-term."

Words like "respond" and "long-term" provide a reassuring gloss on a dire reality. There is no cure for lung cancer at this stage. Even with chemotherapy, the median survival is about a year. But it seemed harsh and pointless for him to confront Sara and Rich with that fact now. Vivian was in a bassinet by the bed. They were working hard to be optimistic. As Sara and Rich later told the social worker who was sent to see them, they did not want to focus on survival statistics. They wanted to focus on "aggressively managing" this diagnosis.

So Sara started on the erlotinib, which produced an itchy, acne-like facial rash and numbing tiredness. She also underwent a needle drainage of the fluid around her lung, but the fluid kept coming back and the painful procedure had to be repeated again and again. So a thoracic surgeon was called in to place a small permanent tube in her chest, which she could drain by turning a stopcock whenever fluid accumulated and interfered with her breathing. Three weeks after her childbirth, she was readmitted to the hospital with severe shortness of breath from a pulmonary embolism—a blood clot in an artery to the lungs, which is dangerous but not uncommon in cancer patients. She was started on a blood thinner. Then test results showed that her tumor cells did not have the mutation that erlotinib targets. When Marcoux told Sara that the drug wasn't going to work, she had an almost violent physical reaction to the news, bolting to the bathroom in mid-discussion with a sudden bout of diarrhea.

Marcoux recommended a different, more standard chemotherapy, with two drugs called carboplatin and paclitaxel. But the paclitaxel triggered an extreme, nearly overwhelming allergic response, so he switched her to a regimen of carboplatin plus gemcitabine. Response rates, he said, were still very good for patients on this therapy.

She spent the remainder of the summer at home, with Vivian and her husband and her parents, who had moved in to help. She loved being a mother. Between chemotherapy cycles, she began trying to get her life back.

Then, in October, a CT scan showed that the tumor deposits in her left chest and in her lymph nodes had grown substantially. The chemotherapy had failed. She was switched to a drug called pemetrexed. Studies had shown that it could produce markedly longer survival in some patients. In reality, only a small percentage of patients gained very much. On average, the drug extended survival by only two months—from eleven to thirteen months—and that was in patients who, unlike Sara, had responded to first-line chemotherapy.

She worked hard to take the setbacks and side effects in stride. She was upbeat by nature, and she managed to maintain her optimism. Little by little, however, she grew sicker—increasingly exhausted and short of breath. In a matter of months, it was as if she'd aged decades. By November, she didn't have the wind to walk the length of the hallway from the parking garage to Marcoux's office; Rich had to push her in a wheelchair.

A few days before Thanksgiving, she had another CT scan, which showed that the pemetrexed—her third drug regimen—wasn't working, either. The lung cancer had spread: from the left chest to the right, to the liver, to the lining of her abdomen, and to her spine. Time was running out.

THIS IS THE moment in Sara's story that poses our difficult question, one for everyone living in our era of modern medicine: What do we want Sara and her doctors to do now? Or, to put it another way, if you were the one who had metastatic cancer—or, for that matter, any similarly advanced and incurable condition—what would you want your doctors to do?

The issue has gotten attention, in recent years, for reasons of expense. The soaring cost of health care has become the greatest threat to the long-term solvency of most advanced nations, and the incurable account for a lot of it. In the United States, 25 percent of all Medicare spending is for the 5 percent 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 United States is often thought to be unusual in this regard, but it doesn't appear to be. Data from elsewhere are more limited, but where they are available—for instance, from countries like the Netherlands and Switzerland—the results are similar.

Spending on a disease like cancer tends to follow a particular pattern. There are high initial costs as the cancer is treated, and then, if all goes well, these costs taper off. A 2011 study, for instance, found that medical spending for a breast cancer patient in the first year of diagnosis averaged an estimated $28,000, the vast majority of it for the initial diagnostic testing, surgery, and, where necessary, radiation and chemotherapy. Costs fell after that to about $2,000 a year. For a patient whose cancer proves fatal, though, the cost curve is CT-shaped, rising toward the end—to an average of $94,000 during the last year of life with a metastatic breast cancer. Our medical system is excellent at trying to stave off death with $12,000-a-month chemotherapy, $4,000-a-day intensive care, $7,000-an-hour surgery. But, ultimately, death comes, and few are good at knowing when to stop.

While seeing a patient in an intensive care unit at my hospital, I stopped to talk with the critical care physician on duty, someone I'd known since college. "I'm running a warehouse for the dying," she said bleakly. Of the ten patients in her unit, she said, only two were likely to leave the hospital for any length of time. More typical was an almost eighty-year-old woman at the end of her life, with irreversible congestive heart failure, who was in the ICU for the second time in three weeks, drugged to oblivion and tubed in most natural orifices as well as a few artificial ones. Or the seventy-year-old with a cancer that had metastasized to her lungs and bone and a fungal pneumonia that arises only in the final phase of the illness. She had chosen to forgo treatment, but her oncologist pushed her to change her mind, and she was put on a ventilator and antibiotics. Another woman, in her eighties, with end-stage respiratory and kidney failure, had been in the unit for two weeks. Her husband had died after a long illness, with a feeding tube and a tracheostomy, and she had mentioned that she didn't want to die that way. But her children couldn't let her go and asked to proceed with the placement of various devices: a

permanent tracheostomy, a feeding tube, and a dialysis catheter. So now she just lay there tethered to her pumps, drifting in and out of consciousness.

Almost all these patients had known, for some time, that they had a terminal condition. Yet they—along with their families and doctors—were unprepared for the final stage.

"We are having more conversation now about what patients want for the end of their life, by far, than they have had in all their lives to this point," my friend said. "The problem is that's way too late."

In 2008, the national Coping with Cancer project published a study showing that terminally ill cancer patients who were put on a mechanical ventilator, given electrical defibrillation or chest compressions, or admitted, near death, to intensive care had a substantially worse quality of life in their last week than those who received no such interventions. And, six months after their death, their caregivers were three times as likely to suffer major depression. Spending one's final days in an ICU because of terminal illness is for most people a kind of failure. You lie attached to a ventilator, your every organ shutting down, your mind teetering on delirium and permanently beyond realizing that you will never leave this borrowed, fluorescent place. The end comes with no chance for you to have said good-bye or "It's okay" or "I'm sorry" or "I love you."

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 on 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. The question therefore is not how we can afford this system's expense. It is how we can build a health care system that will actually help people achieve what's most important to them at the end of their lives.

IN THE PAST, when dying was typically a more precipitous process, we did not have to think about a question like this. Though some diseases and conditions had a drawn-out natural history—tuberculosis is the classic example—without the intervention of modern medicine, with its scans to diagnose problems early and its treatments to extend life, the interval between recognizing that you had a life-threatening ailment and dying was commonly a matter of days or weeks. Consider how our presidents died before the modern era. George Washington developed a throat infection at home on December 13, 1799, that killed him by the next evening. John Quincy Adams, Millard Fillmore, and Andrew Johnson all succumbed to strokes and died within two days. Rutherford Hayes had a heart attack and died three days later. Others did have a longer course: James Monroe and Andrew Jackson died from progressive and far longer-lasting (and highly dreaded) tubercular consumption. Ulysses Grant's oral cancer took a year to kill him. But, as end-of-life researcher Joanne Lynn has observed, 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.

Dying used to be accompanied by a prescribed set of customs. Guides to *ars moriendi*, the art of dying, were extraordinarily popular; a medieval version published in Latin in 1415 was reprinted in more than a hundred editions across Europe. People believed death should be accepted stoically, without fear or self-pity or hope for anything more than the forgiveness of God. Reaffirming one's faith, repenting one's sins, and letting go of one's worldly possessions and desires were crucial, and the guides provided families with prayers and questions for the

dying in order to put them in the right frame of mind during their final hours. Last words came to hold a particular place of reverence.

These days, swift catastrophic illness is the exception. For most people, death comes only after long medical struggle with an ultimately unstoppable condition—advanced cancer, dementia, Parkinson's disease, progressive organ failure (most commonly the heart, followed in frequency by lungs, kidneys, liver), or else just the accumulating debilities of very old age. In all such cases, death is certain, but the timing isn't. So everyone struggles with this uncertainty—with how, and when, to accept that the battle is lost. As for last words, they hardly seem to exist anymore. Technology can sustain our organs until we are well past the point of awareness and coherence. Besides, how do you attend to the thoughts and concerns of the dying when medicine has made it almost impossible to be sure who the dying even are? Is someone with terminal cancer, dementia, or incurable heart failure dying, exactly?

I was once the surgeon for a woman in her sixties who had severe chest and abdominal pain from a bowel obstruction that had ruptured her colon, caused her to have a heart attack, and put her into septic shock and kidney failure. I performed an emergency operation to remove the damaged length of colon and give her a colostomy. A cardiologist stented open her coronary arteries. We put her on dialysis, a ventilator, and intravenous feeding, and she stabilized. After a couple of weeks, though, it was clear that she was not going to get much better. The septic shock had left her with heart and respiratory failure as well as dry gangrene of her foot, which would have to be amputated. She had a large, open abdominal wound with leaking bowel contents, which would require weeks of twice-a-day dressing changes and cleansing in order to heal. She would not be able to eat. She would need a tracheostomy. Her kidneys were gone, and she would have to spend three days a week on a dialysis machine for the rest of her life.

She was unmarried and without children. So I sat with her sisters in the ICU's family room to talk about whether we should proceed with the amputation and the tracheostomy.

"Is she dying?" one of the sisters asked me.

I didn't know how to answer the question. I wasn't even sure what the word "dying" meant anymore. In the 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.

ONE SPRING FRIDAY morning, I went on patient rounds with Sarah Creed, a nurse with the hospice service that my hospital system operated. I didn't know much about hospice. I knew that it specialized in providing "comfort care" for the terminally ill, sometimes in special facilities, though nowadays usually at home. I knew that, in order for a patient of mine to be eligible, I had to write a note certifying that he or she had a life expectancy of less than six months. I also knew few patients who had chosen it, except in their very last few days, because they had to sign a form indicating that they understood their disease was terminal and that they were giving up on medical care that aimed to stop it. The picture I had of hospice was of a morphine drip. It was not of this brown-haired and blue-eyed former ICU nurse with a stethoscope, knocking on Lee Cox's door on a quiet morning in Boston's Mattapan neighborhood.

"Hi, Lee," Creed said when she entered the house.

"Hi, Sarah," Cox said. She was seventy-two years old. She'd had several years of declining health due to congestive heart failure from a heart attack and pulmonary fibrosis, a progressive

and irreversible lung disease. Doctors tried slowing the disease with steroids, but they didn't work. She had cycled in and out of the hospital, each time in worse shape. Ultimately, she accepted hospice care and moved in with her niece for support. She was dependent on oxygen and unable to do the most ordinary tasks. Just answering the door, with her thirty-foot length of oxygen tubing trailing after her, had left her winded. She stood resting for a moment, her lips pursed and her chest heaving.

Creed took Cox's arm gently as we walked to the kitchen to sit down, asking her how she had been doing. Then she asked a series of questions, targeting issues that tend to arise in patients with terminal illness. Did Cox have pain? How was her appetite, thirst, sleeping? Any trouble with confusion, anxiety, or restlessness? Had her shortness of breath grown worse? Was there chest pain or heart palpitations? Abdominal discomfort? Trouble with constipation or urination or walking?

She did have some new troubles. When she walked from the bedroom to the bathroom, she said, it now took at least five minutes to catch her breath, and that frightened her. She was also getting chest pain. Creed pulled a blood pressure cuff from her medical bag. Cox's blood pressure was acceptable, but her heart rate was high. Creed listened to her heart, which had a normal rhythm, and to her lungs, hearing the fine crackles of her pulmonary fibrosis but also a new wheeze. Her ankles were swollen with fluid, and when Creed asked for her pillbox she saw that Cox was out of her heart medication. She asked to see Cox's oxygen equipment. The liquid-oxygen cylinder at the foot of her neatly made bed was filled and working properly. The nebulizer equipment for her inhaler treatments, however, was broken.

Given the lack of heart medication and inhaler treatments, it was no wonder that she had worsened. Creed called Cox's pharmacy. They said that her refills had been waiting all along. So Creed contacted Cox's niece to pick up the medicine when she came home from work. She also called the nebulizer supplier for same-day emergency service.

She then chatted with Cox in the kitchen for a few minutes. Cox's spirits were low. Creed took her hand. Everything was going to be all right, she said. She reminded her about the good days she'd had—the previous weekend, for example, when she'd been able to go out with her portable oxygen cylinder to shop with her niece and get her hair colored.

I asked Cox about her earlier life. She had made radios in a Boston factory. She and her husband had had two children and several grandchildren.

When I asked her why she had chosen hospice care, she looked downcast. "The lung doctor and heart doctor said they couldn't help me anymore," she said. Creed glared at me. My questions had made Cox sad again.

She told a story of the trials of aging overlain with the trials of having an illness that she knew would someday claim her. "It's good to have my niece and her husband helping to watch me every day," she said. "But it's not my home. I feel like I'm in the way." Multigenerational living fell short of its nostalgic image, again.

Creed gave her a hug and one last reminder before we left. "What do you do if you have chest pain that doesn't go away?" she asked.

"Take a nitro," Cox said, referring to the nitroglycerin pill that she can slip under her tongue.

"And?"

"Call you."

"Where's the number?"

She pointed to the twenty-four-hour hospice call number that was taped beside her phone.

Outside, I confessed that I was confused by what Creed was doing. A lot of it seemed to be about extending Cox's life. Wasn't the goal of hospice to let nature take its course?

"That's not the goal," Creed said. The difference between standard medical care and hospice is not the difference between treating and doing nothing, she explained. The difference was in the priorities. In ordinary medicine, the goal is to extend life. We'll sacrifice the quality of your existence now—by 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. In terminal illness that means focusing on objectives like freedom from pain and discomfort, or maintaining mental awareness for as long as feasible, or getting out with family once in a while—not on whether Cox's life would be longer or shorter. Nonetheless, when she was transferred to hospice care, her doctors thought that she wouldn't live much longer than a few weeks. With the supportive hospice therapy she received, she had already lived for a year.

Hospice is not an easy choice for a person to make. A hospice nurse enters people's lives at a strange moment—when they have understood that they have a fatal illness but not necessarily acknowledged that they are dying. "I'd say only about a quarter have accepted their fate when they come into hospice," Creed said. When she first encounters her patients, many feel that their doctors have simply abandoned them. "Ninety-nine percent understand they're dying, but one hundred percent hope they're not," she told me. "They still want to beat their disease." The initial visit is always tricky, but she has found ways to smooth things over. "A nurse has five seconds to make a patient like you and trust you. It's in the whole way you present yourself. I do not come in saying, 'I'm so sorry.' Instead, it's: 'I'm the hospice nurse, and here's what I have to offer you to make your life better. And I know we don't have a lot of time to waste.' "

That was how she started with Dave Galloway, whom we visited after leaving Lee Cox's home. He was forty-two years old. He and his wife, Sharon, were both Boston firefighters. They had a three-year-old daughter. He had pancreatic cancer, which had spread; his upper abdomen was now solid with tumor. During the past few months, the pain had often become unbearable, and he was admitted to the hospital several times for pain crises. At his most recent admission, about a week earlier, it was found that the tumor had perforated his intestine. There wasn't even a temporary fix for this problem. The medical team started him on intravenous nutrition and offered him a choice between going to the intensive care unit and going home with hospice. He chose to go home.

"I wish we'd gotten involved sooner," Creed told me. When she and the hospice's supervising doctor, JoAnne Nowak, evaluated Galloway upon his arrival at home, he appeared to have only a few days left. His eyes were hollow. His breathing was labored. Fluid swelled his entire lower body to the point that his skin blistered and wept. He was almost delirious with abdominal pain.

They got to work. They set up a pain pump with a button that let him dispense higher doses of narcotic than he had been allowed. They arranged for an electric hospital bed, so that he could sleep with his back raised. They also taught Sharon how to keep Dave clean, protect his skin from breakdown, and handle the crises to come. Creed told me that part of her job is to take the measure of a patient's family, and Sharon struck her as unusually capable. She was determined to take care of her husband to the end, and perhaps because she was a firefighter, she had the resilience and the competence to do so. She did not want to hire a private-duty nurse. She

handled everything, from the IV lines and the bed linens to orchestrating family members to lend a hand when she needed help.

Creed arranged for a specialized "comfort pack" to be delivered by FedEx and stored in a minirefrigerator by Dave's bed. It contained a dose of morphine for breakthrough pain or shortness of breath, Ativan for anxiety attacks, Compazine for nausea, Haldol for delirium, Tylenol for fever, and atropine for drying up the wet upper-airway rattle that people can get in their final hours. If any such problem developed, Sharon was instructed to call the twenty-four-hour hospice nurse on duty, who would provide instructions about which rescue medications to use and, if necessary, come out to help.

Dave and Sharon were finally able to sleep through the night at home. Creed or another nurse came to see him every day, sometimes twice a day. Three times that week, Sharon used the emergency hospice line to help her deal with Dave's pain crises or hallucinations. After a few days, they were even able to go out to a favorite restaurant; he wasn't hungry, but they enjoyed just being there and the memories it stirred.

The hardest part so far, Sharon said, was deciding to forgo the two-liter intravenous feedings that Dave had been receiving each day. Although they were his only source of calories, the hospice staff encouraged discontinuing them because his body did not seem to be absorbing the nutrition. The infusion of sugars, proteins, and fats made the painful swelling of his skin and his shortness of breath worse—and for what? The mantra was: live for now. Sharon had balked, for fear that she'd be starving him. The night before our visit, however, she and Dave decided to try going without the infusion. By morning, the swelling was markedly reduced. He could move more, and with less discomfort. He also began to eat a few morsels of food, just for the taste of it, and that made Sharon feel better about the decision.

When we arrived, Dave was making his way back to bed after a shower, his arm around his wife's shoulders and his slippered feet taking one shuffling step at a time.

"There's nothing he likes better than a long, hot shower," Sharon said. "He'd live in the shower if he could."

Dave sat on the edge of his bed in fresh pajamas, catching his breath, and Creed spoke to him as his daughter, Ashlee, ran in and out of the room in her beaded pigtails, depositing stuffed animals in her dad's lap.

"How's your pain on a scale of one to ten?" Creed asked.

"A six," he said.

"Did you hit the pump?"

He didn't answer for a moment. "I'm reluctant," he admitted. "Why?" Creed asked.

"It feels like defeat," he said.

"Defeat?"

"I don't want to become a drug addict," he explained. "I don't want to need this."

Creed got down on her knees in front of him. "Dave, I don't know anyone who can manage this kind of pain without the medication," she said. "It's not defeat. You've got a beautiful wife and daughter, and you're not going to be able to enjoy them with the pain."

"You're right about that," he said, looking at Ashlee as she gave him a little horse. And he pressed the button.

Dave Galloway died one week later—at home, at peace, and surrounded by family. A week after that, Lee Cox died, too. But as if to show just how resistant to formula human lives are, Cox had never reconciled herself to the incurability of her illnesses. So when her family found her in cardiac arrest one morning, they followed her wishes and called 911 instead of the hospice

service. The emergency medical technicians and firefighters and police rushed in. They pulled off her clothes and pumped her chest, put a tube in her airway and forced oxygen into her lungs, and tried to see if they could shock her heart back. But such efforts rarely succeed with terminal patients, and they did not succeed with her.

Hospice has tried to offer a new ideal for how we 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—not only against suffering but also against the seemingly unstoppable momentum of medical treatment.

JUST BEFORE THANKSGIVING, Sara Monopoli, her husband, Rich, and her mother, Dawn Thomas, met with Dr. Marcoux to discuss the options she had left. By this point, Sara had undergone three rounds of chemotherapy with limited, if any, effect. Perhaps Marcoux could have discussed what she most wanted as death neared and how best to achieve those wishes. But the signal he got from Sara and her family was that they wished to talk only about the next treatment options. They did not want to talk about dying.

Later, after her death, I spoke to Sara's husband and her parents. Sara knew that her disease was incurable, they pointed out. The week after she was given the diagnosis and delivered her baby, she spelled out her wishes for Vivian's upbringing after she was gone. On several occasions, she told her family that she did not want to die in the hospital. She wanted to spend her final moments peacefully at home. But the prospect that those moments might be coming soon, that there might be no way to slow the disease, "was not something she or I wanted to discuss," her mother said.

Her father, Gary, and her twin sister, Emily, still held out hope for a cure. The doctors simply weren't looking hard enough, they felt. "I just couldn't believe there wasn't something," Gary said. For Rich, the experience of Sara's illness had been disorienting: "We had a baby. We were young. And this was so shocking and so odd. We never discussed stopping treatment."

Marcoux took the measure of the room. With almost two decades of experience treating lung cancer, he had been through many of these conversations. He has a calm, reassuring air and a native Minnesotan's tendency to avoid confrontation or overintimacy. He tries to be scientific about decisions.

"I know that the vast majority of my patients are going to die of their disease," he told me. The data show that, after failure of second-line chemotherapy, lung cancer patients rarely get any added survival time from further treatments and often suffer significant side effects. But he, too, has his hopes.

He told them that, at some point, "supportive care" was an option for them to think about. But, he went on, there were also experimental therapies. He told them about several that were under trial. The most promising was a Pfizer drug that targeted one of the mutations found in her cancer's cells. Sara and her family instantly pinned their hopes on it. The drug was so new that it didn't even have a name, just a number—PF0231006—and this made it all the more enticing.

There were a few hovering issues, including the fact that the scientists didn't yet know the safe dose. The drug was only in a Phase I trial—that is, a trial designed to determine the toxicity of a range of doses, not whether the drug worked. Furthermore, a test of the drug against her cancer cells in a petri dish showed no effect. But Marcoux thought that these were not decisive obstacles, just negatives. The critical problem was that the rules of the trial excluded Sara because of the pulmonary embolism she had developed that summer. To enroll, she would need

to wait two months in order to get far enough past the episode. In the meantime, he suggested trying another conventional chemotherapy, called vinorelbine. Sara began the treatment the Monday after Thanksgiving.

It's worth pausing to consider what had just happened. Step by step, Sara ended up on a fourth round of chemotherapy, one with a minuscule likelihood of altering the course of her disease and a great likelihood of causing debilitating side effects. An opportunity to prepare for the inevitable was forgone. And it all happened because of an assuredly normal circumstance: a patient and family unready to confront the reality of her disease.

I asked Marcoux what he hopes to accomplish for terminal lung cancer patients when they first come to see him. "I'm thinking, can I get them a pretty good year or two out of this?" he said. "Those are my expectations. For me, the long tail for a patient like her is three to four years." But this is not what people want to hear. "They're thinking ten to twenty years. You hear that time and time again. And I'd be the same way if I were in their shoes."

You'd think doctors would be well equipped to navigate the shoals here, but at least two things get in the way. First, our own views may be unrealistic. A study led by the sociologist Nicholas Christakis asked the doctors of almost five hundred terminally ill patients to estimate how long they thought their patient would survive and then followed the patients. Sixty-three percent of doctors overestimated their patient's survival time. Just 17 percent underestimated it. The average estimate was 530 percent too high. And the better the doctors knew their patients, the more likely they were to err.

Second, we often avoid voicing even these sentiments. Studies find that although doctors usually tell patients when a cancer is not curable, most are reluctant to give a specific prognosis, even when pressed. More than 40 percent of oncologists admit to offering treatments that they believe are unlikely to work. In an era in which the relationship between patient and doctor is increasingly miscast in retail terms—"the customer is always right"—doctors are especially hesitant to trample on a patient's expectations. You worry far more about being overly pessimistic than you do about being overly optimistic. And talking about dying is enormously fraught. When you have a patient like Sara Monopoli, the last thing you want to do is grapple with the truth. I know, because Marcoux wasn't the only one avoiding that conversation with her. I was, too.

Earlier that summer, a PET scan had revealed that, in addition to her lung cancer, she had thyroid cancer, which had spread to the lymph nodes of her neck, and I was called in to decide whether to operate. This second, unrelated cancer was in fact operable. But thyroid cancers take years to become lethal. Her lung cancer would almost certainly end her life long before her thyroid cancer caused any trouble. Given the extent of the surgery that would have been required and the potential complications, the best course was to do nothing. But explaining my reasoning to Sara meant confronting the mortality of her lung cancer, something that I felt ill prepared to do.

Sitting in my clinic, Sara did not seem discouraged by the discovery of this second cancer. She seemed determined. She'd read about the good outcomes from thyroid cancer treatment. So she was geared up, eager to discuss when to operate. And I found myself swept along by her optimism. Suppose I was wrong, I wondered, and she proved to be that miracle patient who survived metastatic lung cancer? How could I let her thyroid cancer go untreated?

My solution was to avoid the subject altogether. I told Sara that there was relatively good news about her thyroid cancer—it was slow growing and treatable. But the priority was her lung

cancer, I said. Let's not hold up the treatment for that. We could monitor the thyroid cancer for now and plan surgery in a few months.

I saw her every six weeks and noted her physical decline from one visit to the next. Yet, even in a wheelchair, Sara would always arrive smiling, makeup on and bangs bobby-pinned out of her eyes. She'd find small things to laugh about, like the strange protuberances the tubes made under her dress. She was ready to try anything, and I found myself focusing on the news about experimental therapies for her lung cancer. After one of her chemotherapies seemed to shrink the thyroid cancer slightly, I even raised with her the possibility that an experimental therapy could work against both her cancers, which was sheer fantasy. Discussing a fantasy was easier—less emotional, less explosive, less prone to misunderstanding—than discussing what was happening before my eyes.

Between the lung cancer and the chemo, Sara became steadily sicker. She slept most of the time and could do little out of the house. Clinic notes from December describe shortness of breath, dry heaves, coughing up blood, severe fatigue. In addition to the drainage tubes in her chest, she required needle-drainage procedures in her abdomen every week or two to relieve the severe pressure from the liters of fluid that the cancer was producing there.

A CT scan in December showed that the lung cancer was spreading through her spine, liver, and lungs. When we met in January, she could move only slowly and uncomfortably. Her lower body had become so swollen that her skin was taut. She couldn't speak more than a sentence without pausing for breath. By the first week of February, she needed oxygen at home to breathe. Enough time had elapsed since her pulmonary embolism, however, that she could start on Pfizer's experimental drug. She just needed one more set of scans for clearance. These revealed that the cancer had spread to her brain, with at least nine metastatic growths up to half an inch in size scattered across both hemispheres. The experimental drug was not designed to cross the blood-brain barrier. PF0231006 was not going to work.

And still Sara, her family, and her medical team remained in battle mode. Within twenty-four hours, Sara was brought in to see a radiation oncologist for whole-brain radiation to try to reduce the metastases. On February 12, she completed five days of radiation treatment, which left her immeasurably fatigued, barely able to get out of bed. She ate almost nothing. She weighed twenty-five pounds less than she had in the fall. She confessed to Rich that, for the past two months, she had experienced double vision and was unable to feel her hands.

"Why didn't you tell anyone?" he asked her.

"I just didn't want to stop treatment," she said. "They would make me stop.'

She was given two weeks to recover her strength after the radiation. Then we had a different experimental drug she could try, one from a small biotech company. She was scheduled to start on February 25. Her chances were rapidly dwindling. But who was to say they were zero?

In 1985, the paleontologist and writer Stephen Jay Gould published an extraordinary essay entitled "The Median Isn't the Message" after he had been given a diagnosis, three years earlier, of abdominal mesothelioma, a rare and lethal cancer usually associated with asbestos exposure. He went to a medical library when he got the diagnosis and pulled out the latest scientific articles on the disease. "The literature couldn't have been more brutally clear: mesothelioma is incurable, with a median survival of only eight months after discovery," he wrote. The news was devastating. But then he began looking at the graphs of the patient-survival curves.

Gould was a naturalist and more inclined to notice the variation around the curve's middle point than the middle point itself. What the naturalist saw was remarkable variation. The patients were not clustered around the median survival but, instead, fanned out in both directions.

Moreover, the curve was skewed to the right, with a long tail, however slender, of patients who lived many years longer than the eight-month median. This is where he found solace. He could imagine himself surviving far out along that long tail. And survive he did. Following surgery and experimental chemotherapy, he lived twenty more years before dying, in 2002, at the age of sixty, from a lung cancer unrelated to his original disease.

"It has become, in my view, a bit too trendy to regard the acceptance of death as something tantamount to intrinsic dignity," he wrote in his 1985 essay. "Of course I agree with the preacher of Ecclesiastes that there is a time to love and a time to die—and when my skein runs out I hope to face the end calmly and in my own way. For most situations, however, I prefer the more martial view that death is the ultimate enemy—and I find nothing reproachable in those who rage mightily against the dying of the light."

I think of Gould and his essay every time I have a patient with a terminal illness. There is almost always a long tail of possibility, however thin. What's wrong with looking for it? Nothing, it seems to me, unless it means we have failed to prepare for the outcome that's vastly more probable. The trouble is that we've built our medical system and culture around the long tail. We've created a multitrillion-dollar edifice for dispensing the medical equivalent of lottery tickets—and have only the rudiments of a system to prepare patients for the near certainty that those tickets will not win. Hope is not a plan, but hope is our plan.

FOR SARA, THERE would be no miraculous recovery, and when the end approached, neither she nor her family was prepared. "I always wanted to respect her request to die peacefully at home," Rich later told me. "But I didn't believe we could make it happen. I didn't know how."

On the morning of Friday, February 22, three days before she was to start her new round of chemo, Rich awoke to find his wife sitting upright beside him, pitched forward on her arms, eyes wide, struggling for air. She was gray, breathing fast, her body heaving with each open-mouthed gasp. She looked as if she were drowning. He tried turning up the oxygen in her nasal tubing, but she got no better.

"I can't do this," she said, pausing between each word. "I'm scared."

He had no emergency kit in the refrigerator. No hospice nurse to call. And how was he to know whether this new development was fixable?

We'll go to the hospital, he told her. When he asked if they should drive, she shook her head, so he called 911 and told her mother, Dawn, who was in the next room, what was going on. A few minutes later, firemen swarmed up the stairs to her bedroom, sirens wailing outside. As they lifted Sara into the ambulance on a stretcher, Dawn came out in tears.

"We're going to get ahold of this," Rich told her. This was just another trip to the hospital, he said to himself. The doctors would figure out how to fix her.

At the hospital, Sara was diagnosed with pneumonia. That troubled the family because they thought they'd done everything to keep infection at bay. They'd washed hands scrupulously, limited visits by people with young children, even limited Sara's time with baby Vivian if she showed the slightest sign of a runny nose. But Sara's immune system and her ability to clear her lung secretions had been steadily weakened by the rounds of radiation and chemotherapy as well as by the cancer.

In another way, the diagnosis of pneumonia was reassuring, because it was just an infection. It could be treated. The medical team started Sara on intravenous antibiotics and high-flow oxygen through a mask. The family gathered at her bedside, hoping for the antibiotics to work.

The problem could be reversible, they told one another. But that night and the next morning her breathing only grew more labored.

"I can't think of a single funny thing to say," Emily told Sara as their parents looked on.

"Neither can I," Sara murmured. Only later did the family realize that those were the last words they would ever hear from her. After that, she began to drift in and out of consciousness. The medical team had only one option left: to put her on a ventilator. Sara was a fighter, right? And the next step for fighters is to escalate to intensive care.

THIS IS A modern tragedy, replayed millions of times over. When there is no way of knowing exactly how long our skeins will run—and when we imagine ourselves to have much more time than we do—our every impulse is to fight, to die with chemo in our veins or a tube in our throats or fresh sutures in our flesh. The fact that we may be shortening or worsening the time we have left hardly seems to register. We imagine that we can wait until the doctors tell us that there is nothing more they can do. But rarely is there nothing more that doctors can do. They can give toxic drugs of unknown efficacy, operate to try to remove part of the tumor, put in a feeding tube if a person can't eat: there's always something. We want these choices. But that doesn't mean we are eager to make the choices ourselves. Instead, most often, we make no choice at all. We fall back on the default, and the default is: Do Something. Fix Something. Is there any way out of this?

There's a school of thought that says the problem is the absence of market forces. If terminal patients—rather than insurance companies or the government—had to pay the added costs for the treatments they chose instead of hospice, they would take the trade-offs into account more. Terminal cancer patients wouldn't pay $80,000 for drugs, and end-stage heart failure patients wouldn't pay $50,000 dollars for defibrillators offering at best a few months extra survival. But this argument ignores an important factor: the people who opt for these treatments aren't thinking a few added months. They're thinking years. They're thinking they're getting at least that lottery ticket's chance that their disease might not even be a problem anymore. Moreover, if there's anything we want to buy in the free market or obtain from our government taxes, it is assurance that, when we find ourselves in need of these options, we won't have to worry about the costs.

This is why the R word—"rationing"—remains such a potent charge. There is broad unease with the circumstances we've found ourselves in but fear of discussing the specifics. For the only seeming alternative to a market solution is outright rationing—death panels, as some have charged. In the 1990s, insurance companies attempted to challenge the treatment decisions of doctors and patients in cases of terminal illness, but the attempts backfired and one case in particular pretty much put an end to strategy—the case of Nelene Fox.

Fox was from Temecula, California, and was diagnosed with metastatic breast cancer in 1991, when she was thirty-eight years old. Surgery and conventional chemotherapy failed, and the cancer spread to her bone marrow. The disease was terminal. Doctors at the University of Southern California offered her a radical but seemingly promising new treatment—high-dose chemotherapy with bone marrow transplantation. To Fox, it was her one chance of cure.

Her insurer, Health Net, denied her request for coverage of the costs, arguing that it was an experimental treatment whose benefits were unproven and that it was therefore excluded under the terms of her policy. The insurer pressed her to get a second opinion from an independent medical center. Fox refused—who were they to tell her to get another opinion? Her life was at

stake. Raising $212,000 through charitable donations, she paid the costs of therapy herself, but it was delayed. She died eight months after the treatment. Her husband sued Health Net for bad faith, breach of contract, intentional infliction of emotional damage, and punitive damages and won. The jury awarded her estate $89 million. The HMO executives were branded killers. Ten states enacted laws requiring insurers to pay for bone marrow transplantation for breast cancer.

Never mind that Health Net was right. Research ultimately showed the treatment to have no benefit for breast cancer patients and to actually worsen their lives. But the jury verdict shook the American insurance industry. Raising questions about doctors' and patients' treatment decisions in terminal illness was judged political suicide.

In 2004, executives at another insurance company, Aetna, decided to try a different approach. Instead of reducing aggressive treatment options for their terminally ill policyholders, they decided to try increasing hospice options. Aetna had noted that only a minority of patients ever halted efforts at curative treatment and enrolled in hospice. Even when they did, it was usually not until the very end. So the company decided to experiment: policyholders with a life expectancy of less than a year were allowed to receive hospice services without having to forgo other treatments. A patient like Sara Monopoli could continue to try chemotherapy and radiation and go to the hospital when she wished, but she could also have a hospice team at home focusing on what she needed for the best possible life now and for that morning when she might wake up unable to breathe.

A two-year study of this "concurrent care" program found that enrolled patients were much more likely to use hospice: the, figure leaped from 26 percent to 70 percent. That was no surprise, since they weren't forced to give up anything. The surprising result was that they did give up things. They visited the emergency room half as often as the control patients did. Their use of hospitals and ICUs dropped by more than two-thirds. Overall costs fell by almost a quarter.

The result was stunning, and puzzling: it wasn't obvious what made the approach work. Aetna ran a more modest concurrent care program for a broader group of terminally ill patients. For these patients, the traditional hospice rules applied—in order to qualify for home hospice, they had to give up attempts at curative treatment. But either way, they received phone calls from palliative care nurses who offered to check in regularly and help them find services for anything from pain control to making out a living will. For these patients too, hospice enrollment jumped to 70 percent, and their use of hospital services dropped sharply. Among elderly patients, use of intensive care units fell by more than 85 percent. Satisfaction scores went way up. What was going on here? The program's leaders had the impression that they had simply given seriously ill patients someone experienced and knowledgeable to talk to about their daily concerns. Somehow that was enough—just talking.

The explanation would seem to strain credibility, but evidence for it has grown in recent years. Two-thirds of the terminal cancer patients in the Coping with Cancer study reported having had no discussion with their doctors about their goals for end-of-life care, despite being, on average, just four months from death. But the third who did have discussions were far less likely to undergo cardiopulmonary resuscitation or be put on a ventilator or end up in an intensive care unit. Most of them enrolled in hospice. They suffered less, were physically more capable, and were better able, for a longer period, to interact with others. In addition, six months after these patients died, their family members were markedly less likely to experience persistent major depression. In other words, people who had substantive discussions with their doctor

about their end-of-life preferences were far more likely to die at peace and in control of their situation and to spare their family anguish.

A landmark 2010 study from the Massachusetts General Hospital had even more startling findings. The researchers randomly assigned 151 patients with stage IV lung cancer, like Sara's, to one of two possible approaches to treatment. Half received usual oncology care. The other half received usual oncology care plus parallel visits with a palliative care specialist. These are specialists in preventing and relieving—the suffering of patients, and to see one, no determination of whether they are dying or not is required. If a person has serious, complex illness, palliative specialists are happy to help. The ones in the study discussed with the patients their goals and priorities for if and when their condition worsened. The result: those 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 25 percent 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. If end-of-life discussions were an experimental drug, the FDA would approve it.

Patients entering hospice have had no less surprising results. Like many other people, I had believed that hospice care hastens death, because patients forgo hospital treatments and are allowed high-dose narcotics to combat pain. But multiple studies find otherwise. In one, researchers followed 4,493 Medicare patients with either terminal cancer or end-stage congestive heart failure. For the patients with breast cancer, prostate cancer, or colon cancer, the researchers found no difference in survival time between those who went into hospice and those who didn't. And curiously, for some conditions, hospice care seemed to extend survival. Those with pancreatic cancer gained an average of three weeks, those with lung cancer gained six weeks, and those with congestive heart failure gained three months. The lesson seems almost Zen: you live longer only when you stop trying to live longer.

CAN MERE DISCUSSIONS achieve such effects? Consider the case of La Crosse, Wisconsin. Its elderly residents have unusually low end-of-life hospital costs. During their last six months, according to Medicare data, they spend half as many days in the hospital as the national average, and there's no sign that doctors or patients are halting care prematurely. Despite average rates of obesity and smoking, their life expectancy outpaces the national mean by a year.

I spoke to Gregory Thompson, a critical care specialist at Gundersen Lutheran Hospital, while he was on ICU duty one evening, and he ran through his list of patients with me. In most respects, the patients were like those found in any ICU—terribly sick and living through the most perilous days of their lives. There was a young woman with multiple organ failure from a devastating case of pneumonia, a man in his midsixties with a ruptured colon that had caused a rampaging infection and a heart attack. Yet these patients were completely different from those in the ICUs I'd worked in: none had a terminal disease; none battled the final stages of metastatic cancer or untreatable heart failure or dementia.

To understand La Crosse, Thompson said, you had to go back to 1991, when local medical leaders headed a systematic campaign to get medical people and patients to discuss end-of- life wishes. Within a few years, it became routine for all patients admitted to a hospital, nursing home, or assisted living facility to sit down with someone experienced in these conversations and complete a multiple-choice form that boiled down to four crucial questions. At this moment in your life, the form asked:

1. Do you want to be resuscitated if your heart stops?
2. Do you want aggressive treatments such as intubation and mechanical ventilation?
3. Do you want antibiotics?
4. Do you want tube or intravenous feeding if you can't eat on your own?

By 1996, 85 percent of La Crosse residents who died had a written advanced directive like this, up from 15 percent, and doctors virtually always knew of the instructions and followed them. Having this system in place, Thompson said, has made his job vastly easier. But it's not because the specifics are spelled out for him every time a sick patient arrives in his unit.

"These things are not laid out in stone," he told me. What, ever the yes/no answers people may put on a piece of paper, one will find nuances and complexities in what they mean. "But instead of having the discussion when they get to the ICU, we find many times it has already taken place."

Answers to the list of questions change as patients go from entering the hospital for the delivery of a child to entering for complications of Alzheimer's disease. But in La Crosse, the system means that people are far more likely to have talked about what they want and what they don't want before they and their relatives find themselves in the throes of crisis and fear. When wishes aren't clear, Thompson said, "families have also become much more receptive to having the discussion." The discussion, not the list, was what mattered most. Discussion had brought La Crosse's end-of-life costs down to half the national average. It was that simple—and that complicated.

ONE WINTER SATURDAY morning, I met with a woman I had operated on the night before. She had been undergoing a procedure for the removal of an ovarian cyst when the gynecologist who was operating on her discovered that she had metastatic colon cancer. I was summoned, as a general surgeon, to see what could be done. I removed a section of her colon that had a large cancerous mass, but the cancer had already spread widely. I had not been able to get it all. Now I introduced myself. She said a resident had told her that a tumor was found and part of her colon had been excised.

Yes, I said. I'd been able to take out "the main area of involvement." I explained how much bowel was removed, what the recovery would be like—everything except how much cancer there was. But then I remembered how timid I'd been with Sara Monopoli, and all those studies about how much doctors beat around the bush. So when she asked me to tell her more about the cancer, I explained that it had spread not only to her ovaries but also to her lymph nodes. I said that it had not been possible to remove all the disease. But I found myself almost immediately minimizing what I'd said. "We'll bring in an oncologist," I hastened to add. "Chemotherapy can be very effective in these situations."

She absorbed the news in silence, looking down at the blankets drawn over her mutinous body. Then she looked up at me. "Am I going to die?"

I flinched. "No, no," I said. "Of course not."

A few days later, I tried again. "We don't have a cure," I explained. "But treatment can hold the disease down for a long time." The goal, I said, was to "prolong your life" as much as possible.

I have followed her in the months and years since, as she embarked on chemotherapy. She has done well. So far, the cancer is in check. Once, I asked her and her husband about our initial conversations. They didn't remember them very fondly. "That one phrase that you used—'prolong your life'—it just ..." She didn't want to sound critical.

"It was kind of blunt," her husband said.

"It sounded harsh," she echoed. She felt as if I'd dropped her off a cliff.

I spoke to Susan Block, a palliative care specialist at my hospital who has had thousands of these difficult conversations and is a nationally recognized pioneer in training doctors and others in managing end-of-life issues with patients and their families. "You have to understand," Block told me. "A family meeting is a procedure, and it requires no less skill than performing an operation."

One basic mistake is conceptual. To most doctors, the primary purpose of a discussion about terminal illness is to determine what people want—whether they want chemo or not, whether they want to be resuscitated or not, whether they want hospice or not. We focus on laying out the facts and the options. But that's a mistake, Block said.

"A large part of the task is helping people negotiate the over-whelming anxiety—anxiety about death, anxiety about suffering, anxiety about loved ones, anxiety about finances," she explained. "There are many worries and real terrors." No one conversation can address them all. Arriving at an acceptance of one's mortality and a clear understanding of the limits and the possibilities of medicine is a process, not an epiphany.

There is no single way to take people with terminal illness through the process, but there are some rules, according to Block. You sit down. You make time. You're not determining whether they want treatment X versus Y. 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. If you are talking more than half of the time, Block says, you're talking too much.

The words you use matter. According to palliative specialists, you shouldn't say, "I'm sorry things turned out this way," for example. It can sound like you're distancing yourself. You should say, "I wish things were different." You don't ask, "What do you want when you are dying?" You ask, "If time becomes short, what is most important to you?"

Block has a list of questions that she aims to cover with sick patients in the time before decisions have to be made: What do they understand their prognosis to be, what are their concerns about what lies ahead, what kinds of trade-offs 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?

A decade earlier, her seventy-four-year-old father, Jack Block, a professor emeritus of psychology at the University of California at Berkeley, was admitted to a San Francisco hospital with symptoms from what proved to be a mass growing in the spinal cord of his neck. She flew out to see him. The neurosurgeon said that the procedure to remove the mass carried a 20 percent chance of leaving him quadriplegic, paralyzed from the neck down. But without it he had a 100 percent chance of becoming quadriplegic.

The evening before surgery, father and daughter chatted about friends and family, trying to keep their minds off what was to come, and then she left for the night. Halfway across the Bay Bridge, she recalled, "I realized, 'Oh, my God, I don't know what he really wants.' " He'd made her his health care proxy, but they had talked about such situations only superficially. So she turned the car around.

Going back in "was really uncomfortable," she said. It made no difference that she was an expert in end-of-life discussions. "I just felt awful having the conversation with my dad." But she went through her list. She told him, " 'I need to understand how much you're willing to go through to have a shot at being alive and what level of being alive is tolerable to you.' We had this quite agonizing conversation where he said—and this totally shocked me—'Well, if I'm able to eat chocolate ice cream and watch football on TV, then I'm willing to stay alive. I'm willing to go through a lot of pain if I have a shot at that.' "

"I would never have expected him to say that," Block said. "I mean, he's a professor emeritus. He's never watched a football game in my conscious memory. The whole picture—it wasn't the guy I thought I knew." But the conversation proved critical, because after surgery he developed bleeding in the spinal cord. The surgeons told her that in order to save his life they would need to go back in. But the bleeding had already made him nearly quadriplegic, and he would remain severely disabled for many months and likely forever. What did she want to do?

"I had three minutes to make this decision, and I realized, he had already made the decision." She asked the surgeons whether, if her father survived, he would still be able to eat chocolate ice cream and watch football on TV. Yes, they said. She gave the okay to take him back to the operating room.

"If I had not had that conversation with him," she told me, "my instinct would have been to let him go at that moment because it just seemed so awful. And I would have beaten myself up. Did I let him go too soon?" Or she might have gone ahead and sent him to surgery, only to find —as occurred—that he was faced with a year of "very horrible rehab" and disability. "I would have felt so guilty that I condemned him to that," she said. "But there was no decision for me to make." He had decided.

During the next two years, he regained the ability to walk short distances. He required caregivers to bathe and dress him. He had difficulty swallowing and eating. But his mind was intact and he had partial use of his hands—enough to write two books and more than a dozen scientific articles. He lived for ten years after the operation. Eventually, however, his difficulties with swallowing advanced to the point where he could not eat without aspirating food particles, and he cycled between hospital and rehabilitation facilities with the pneumonias that resulted. He didn't want a feeding tube. And it became evident that the battle for the dwindling chance of a miraculous recovery was going to leave him unable ever to go home again. So, just a few months before I'd spoken with Block, her father decided to stop the battle and go home.

"We started him on hospice care," Block said. "We treated his choking and kept him comfortable. Eventually, he stopped eating and drinking. He died about five days later."

SUSAN BLOCK AND her father had the conversation that we all need to have when the chemotherapy stops working, when we start needing oxygen at home, when we face high-risk surgery, when the liver failure keeps progressing, when we become unable to dress ourselves. I've heard Swedish doctors call it a "breakpoint discussion," a series of conversations to sort out when they 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 dread them. They can unleash difficult emotions. People can become angry or overwhelmed. Handled poorly, the conversations can cost a person's trust. Handled well, they can take real time.

I spoke to an oncologist who told me about a twenty-nine-year-old patient she had recently cared for who had an inoperable brain tumor that continued to grow through second-line chemotherapy. The patient elected not to attempt any further chemotherapy, but getting to that decision required hours of discussion, for this was not the decision he had expected to make. First, the oncologist said, she had a discussion with him alone. They reviewed the story of how far he'd come, the options that remained. She was frank. She told him that in her entire career she had never seen third-line chemotherapy produce a significant response in his type of brain tumor. She had looked for experimental therapies, and none were truly promising. And, although she was willing to proceed with chemotherapy, she told him how much strength and time the treatment would take away from him and his family.

He did not shut down or rebel. His questions went on for an hour. He asked about this therapy and that therapy. Gradually, he began to ask about what would happen as the tumor got bigger, what symptoms he'd have, what ways they could try to control them, how the end might come.

The oncologist next met with the young man together with his family. That discussion didn't go so well. He had a wife and small children, and at first his wife wasn't ready to contemplate stopping chemo. But when the oncologist asked the patient to explain in his own words what they'd discussed, she understood. It was the same with his mother, who was a nurse. Meanwhile, his father sat quietly and said nothing the entire time.

A few days later, the patient returned to talk to the oncologist. "There should be something. There must be something," he said. His father had shown him reports of cures on the Internet. He confided how badly his father was taking the news. No patient wants to cause his family pain. According to Block, about two-thirds of patients are willing to undergo therapies they don't want if that is what their loved ones want.

The oncologist went to the father's home to meet with him. He had a sheaf of possible trials and treatments printed from the Internet. She went through them all. She was willing to change her opinion, she told him. But either the treatments were for brain tumors that were very different from his son's or else he didn't qualify. None were going to be miraculous. She told the father that he needed to understand: time with his son was limited, and the young man was going to need his father's help getting through it.

The oncologist noted wryly how much easier it would have been for her just to prescribe the chemotherapy. "But that meeting with the father was the turning point," she said. The patient and the family opted for hospice. They had more than a month together before he died. Later, the father thanked the doctor. That last month, he said, the family simply focused on being together, and it proved to be the most meaningful time they'd ever spent.

Given how prolonged some of these conversations have to be, many people argue that the key problem has been the financial incentives: we pay doctors to give chemotherapy and to do surgery but not to take the time required to sort out when to do so is unwise. This certainly is a factor. But the issue isn't merely a matter of financing. It arises from a still unresolved argument about what the function of medicine really is—what, in other words, we should and should not be paying for doctors to do.

The simple view is that medicine exists to fight death and disease, and that is, of course, its most basic task. Death is the enemy. But the enemy has superior forces. Eventually, it wins. And in a war that you cannot win, you don't want a general who fights to the point of total annihilation. You don't want Custer. You want Robert E. Lee, someone who knows how to

fight for territory that can be won and how to surrender it when it can't, someone who understands that the damage is greatest if all you do is battle to the bitter end.

More often, these days, medicine seems to supply neither Custers nor Lees. We are increasingly the generals who march the soldiers onward, saying all the while, "You let me know when you want to stop." All-out treatment, we tell the incurably ill, is a train you can get off at any time—just say when. But for most patients and their families we are asking too much. They remain riven by doubt and fear and desperation; some are deluded by a fantasy of what medical science can achieve. 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 warehoused oblivion that few really want.

SARA MONOPOLI HAD had enough discussions to let her family and her oncologist know that she did not want hospitals or ICUs at the end—but not enough to have learned how to achieve her goal. From the moment she arrived in the emergency room that Friday morning in February, the train of events ran against a peaceful ending. There was one person who was disturbed by this, though, and who finally decided to intercede—Chuck Morris, her primary care physician. As her illness had progressed through the previous year, he had left the decision making largely to Sara, her family, and the oncology team. Still, he had seen her and her husband regularly and listened to their concerns. That desperate morning, Morris was the one person Rich called before getting into the ambulance. He headed to the emergency room and met Sara and Rich when they arrived.

Morris said that the pneumonia might be treatable. But he told Rich, "I'm worried this is it. I'm really worried about her." And he told him to let the family know that he said so.

Upstairs in her hospital room, Morris talked with Sara and Rich about the ways in which the cancer had been weakening her, making it hard for her body to fight off infection. Even if the antibiotics halted the infection, he said, he wanted them to remember that there was nothing that would stop the cancer.

Sara looked ghastly, Morris told me. "She was so short of breath. It was uncomfortable to watch. I still remember the attending"—the covering oncologist who admitted her for the pneumonia treatment. "He was actually kind of rattled about the whole case, and for him to be rattled is saying something."

After her parents arrived, Morris talked with them too, and when they were finished Sara and her family agreed on a plan. The medical team would continue the antibiotics. But if things got worse, they would not put her on a breathing machine. They also let him call the palliative care team to visit. The team prescribed a small dose of morphine, which immediately eased her breathing. Her family saw how much her suffering diminished, and suddenly they didn't want any more suffering. The next morning, they were the ones to hold back the medical team.

"They wanted to put a catheter in her, do this other stuff to her," her mother, Dawn, told me. "I said, 'No. You aren't going to do anything to her.' I didn't care if she wet her bed. They wanted to do lab tests, blood pressure measurements, finger sticks. I was very uninterested in their bookkeeping. I went over to see the head nurse and told them to stop."

In the previous three months, almost nothing we'd done to Sara—none of the scans or tests or radiation or extra rounds of chemotherapy—had likely achieved anything except to make her

worse. She may well have lived longer without any of it. At least she was spared at the very end.

That day, Sara fell into unconsciousness as her body continued to fail. Through the next night, Rich recalled, "there was this awful groaning." There is no prettifying death. "Whether it was with inhaling or exhaling, I don't remember, but it was horrible, horrible, horrible to listen to."

Her father and her sister still thought that she might rally. But when the others had stepped out of the room, Rich knelt down weeping beside Sara and whispered in her ear. "It's okay to let go," he said. "You don't have to fight anymore. I will see you soon."

Later that morning, her breathing changed, slowing. Rich said, "Sara just kind of startled. She let a long breath out. Then she just stopped."