

THE NEW YORKER

ANNALS OF MEDICINE

LETTING GO

What should medicine do when it can't save your life?

by Atul Gawande

AUGUST 2, 2010



Modern medicine is good at staving off death with aggressive interventions—and bad at knowing when to focus, instead, on improving the days that terminal patients have left.

Sara Thomas Monopoli was pregnant with her first child when her doctors 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, 2007. She took Rich's hands, and they tried to absorb what they had heard. Monopoli was thirty-four. She had never smoked, or lived with anyone who had. She exercised. She ate well. The diagnosis was

bewildering. “This is going to be O.K.,” 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, though, 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 perfectly healthy.

The next day, Sara underwent blood tests and body scans. Dr. 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 this on. More than fifteen per cent of lung cancers—more than people realize—occur in non-smokers. 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 relatively new drug called Tarceva, which targets a gene mutation commonly found in lung cancers of female non-smokers. Eighty-five per cent respond to this drug, and, 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 to confront Sara and Rich with this 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.

Sara was started on the Tarceva, which produced an itchy, acne-like facial rash and numbing tiredness. She also underwent a surgical procedure to drain the fluid around her lung; when the fluid kept coming back, a thoracic surgeon eventually placed a small, permanent tube in her chest, which she could drain whenever fluid accumulated and interfered with her breathing. Three weeks after the delivery, she was admitted 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 Tarceva 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.

Dr. 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 lung and chest and lymph nodes had grown substantially. The chemotherapy had failed. She was switched to a drug called pemetrexed. Studies found that it could produce markedly longer survival in some patients. In reality, however, only a small percentage of patients gained very much. On average, the drug extended survival by only two months—from eleven months 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. 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 a fundamental question for everyone living in the 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, a similarly advanced case of emphysema or congestive heart failure—what would you want your doctors to do?

The issue has become pressing, in recent years, for reasons of expense. The soaring cost of health care is the greatest threat to the country's long-term solvency, and the terminally ill account for a lot of it. Twenty-five per cent of all Medicare spending is for the five per cent of patients who are in their final year of life, and most of that money goes for care in their last couple of months which is of little apparent benefit.

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. Medical spending for a breast-cancer survivor, for instance, averaged an estimated fifty-four thousand dollars in 2003, the vast majority of it for the initial diagnostic testing, surgery, and, where necessary, radiation and chemotherapy. For a patient with a fatal version of the disease, though, the cost curve is U-shaped, rising again toward the end—to an average of sixty-three thousand dollars during the last six months of life with an incurable breast cancer. Our medical system is excellent at trying to stave off death with eight-thousand-dollar-a-month chemotherapy, three-thousand-dollar-a-day intensive care, five-thousand-dollar-an-hour surgery. But, ultimately, death comes, and no one is good at knowing when to stop.

The subject seems to reach national awareness mainly as a question of who should “win” when the expensive decisions are made: the insurers and the taxpayers footing the bill or the patient battling for his or her life. Budget hawks urge us to face the fact that we can't afford everything. Demagogues shout about rationing and death panels. Market purists blame the existence of insurance: if patients and families paid the bills themselves, those expensive therapies would all come down in price. But they're debating the wrong question. The failure of our system of medical care for people facing the end of their life runs much deeper. To see this, you have to get close enough to grapple with the way decisions about care are actually made.

Recently, 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. Out 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 I.C.U. for the second time in three weeks, drugged to oblivion and tubed in most natural orifices and 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 tracheotomy, 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 tracheotomy, 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 I.C.U. because of terminal illness is for most people a kind of failure. You lie on 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 goodbye or “It's O.K.” or “I'm sorry” or “I love you.”

People have concerns besides simply prolonging their lives. Surveys of patients with terminal illness find that their top priorities include, in addition to avoiding suffering, being with family, having the touch of others, being mentally aware, and not becoming a burden to others. 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 hard question we face, then, is not how we can afford this system's expense. It is how we can build a health-care system that will actually help dying patients achieve what's most important to them at the end of their lives.

For all but our most recent history, dying was typically a brief process. Whether the cause was childhood infection, difficult childbirth, heart attack, or pneumonia, the interval between recognizing that you had a life-threatening ailment and death was often just 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. Some deadly illnesses took a longer course: James Monroe and Andrew Jackson died from the months-long consumptive process of what appears to have been tuberculosis; Ulysses Grant's oral cancer took a year to kill him; and James Madison was bedridden for two years before dying of "old age." But, as the end-of-life researcher Joanne Lynn has observed, people usually 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 1415 medieval Latin text was reprinted in more than a hundred editions across Europe. 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 incurable condition—advanced cancer, progressive organ failure (usually the heart, kidney, or liver), or the multiple 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 sustains 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, incurable congestive heart failure dying, exactly?

I once cared 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 renal failure. I performed an emergency operation to remove the damaged length of colon and give her a colostomy. A cardiologist stented her coronary arteries. We put her on dialysis, a ventilator, and intravenous feeding, and stabilized her. 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 twice-a-day cleaning and dressing for weeks in order to heal. She would not be able to eat. She would need a tracheotomy. 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 I.C.U. family room to talk about whether we should proceed with the amputation and the tracheotomy. "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 Friday morning this spring, I went on patient rounds with Sarah Creed, a nurse with the hospice service that my hospital system operates. 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. And I knew few patients who had chosen it, except maybe in their very last few days, because they had to sign a form indicating that they understood their disease was incurable and that they were giving up on medical care 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 I.C.U. nurse with a stethoscope, knocking on Lee Cox's door on a quiet street 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 bowel movements 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 stethoscope and 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 the 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 to confirm that her refills had been waiting, and had her arrange for her niece to pick up the medicine when she came home from work. Creed also called the nebulizer supplier for same-day emergency service.

She then chatted with Cox in the kitchen for a few minutes. Her 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 previous life. She had made radios in a Boston factory. She and her husband 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.

“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.”

Creed gave her a hug before we left, and one last reminder. “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 your 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, and social workers to help people with a fatal illness have the fullest possible lives right now. That means focussing on objectives like freedom from pain and discomfort, or maintaining mental awareness for as long as possible, or getting out with family once in a while. Hospice and palliative-care specialists aren’t much concerned about whether that makes people’s lives longer or shorter.

Like many people, I had believed that hospice care hastens death, because patients forgo hospital treatments and are allowed high-dose narcotics to combat pain. But studies suggest otherwise. In one, researchers followed 4,493 Medicare patients with either terminal cancer or congestive heart failure. They found no difference in survival time between hospice and non-hospice patients with breast cancer, prostate cancer, and colon cancer. Curiously, hospice care seemed to extend survival for some patients; 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. When Cox 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.

Creed enters people's lives at a strange moment—when they have understood that they have a fatal illness but have not necessarily acknowledged that they are dying. “I'd say only about a quarter have accepted their fate when they come into hospice,” she said. When she first encounters her patients, many feel that they have simply been abandoned by their doctors. “Ninety-nine per cent understand they're dying, but one hundred per cent hope they're not,” she says. “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 become unbearable at times, 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, Dr. 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 I.V. 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 mini-refrigerator 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 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-litre 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 slippers 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 then 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 of 2007, 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.

Recently, 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. She had told her family on several occasions 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 didn’t think that these were 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 Navelbine. 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 Harvard researcher 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 per cent of doctors overestimated survival time. Just seventeen per cent underestimated it. The average estimate was five hundred and thirty per cent 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 forty per cent of oncologists report 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 also 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?

My solution was to avoid the subject altogether. I told Sara that the thyroid cancer was slow-growing and treatable. The priority was her lung cancer, I said. Let’s not hold up the treatment for that. We could monitor the thyroid cancer and plan surgery in a few months.

