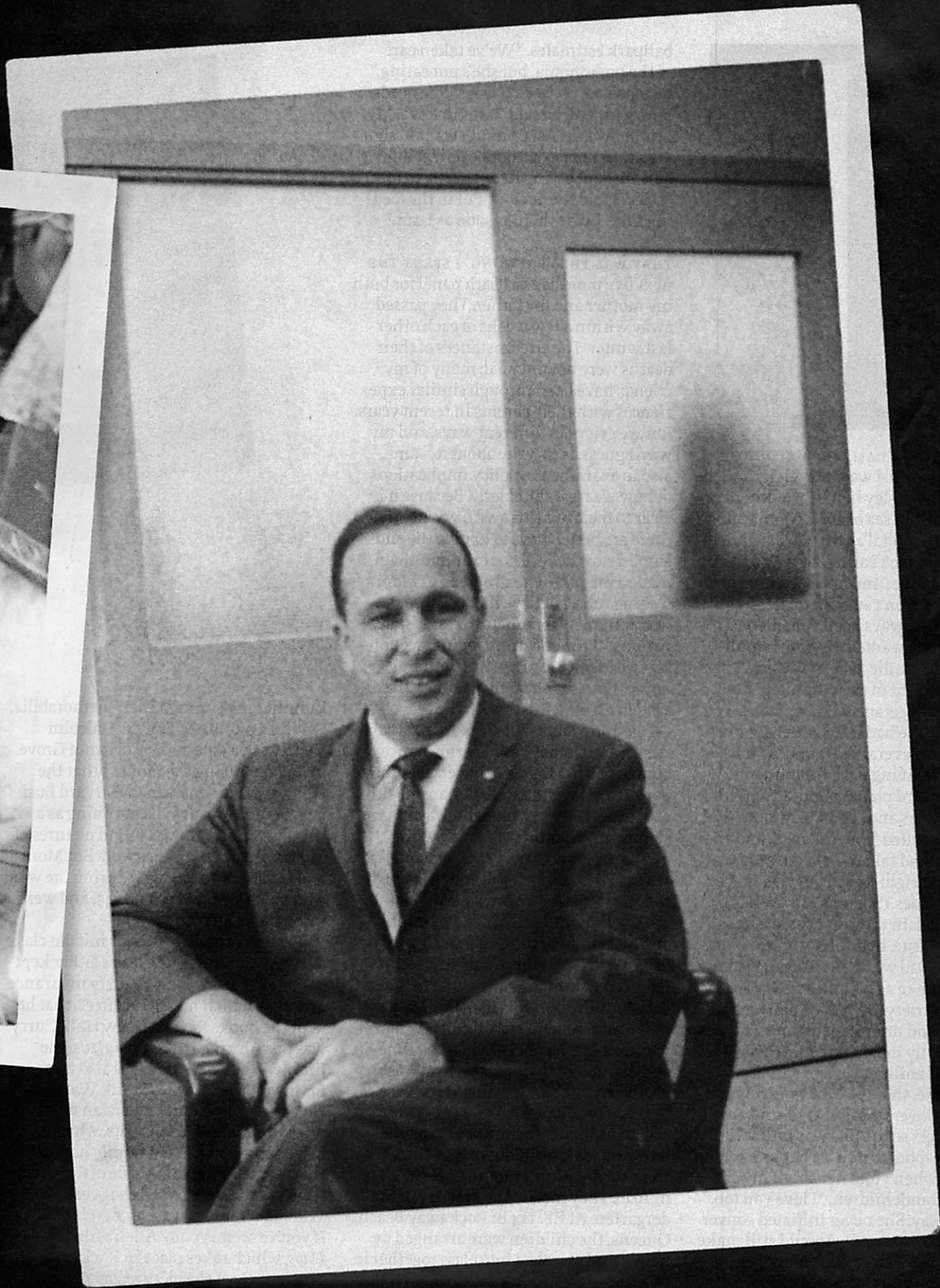


The Long Goodbye

For five months, I was my parents' death panel. And where the costly chaos of Medicare failed, a team of salaried doctors and nurses offered a better way

By Joe Klein





Kindergarten classmates, high school sweethearts **Malcolm and Miriam Klein** shared 86 years

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THE PHONE CALL CAME ON A CLOUDY morning in Iowa. I was interviewing Senator Chuck Grassley in his farm kitchen, surrounded by a sea of corn. Mom was back in the hospital again. She had pneumonia. She wasn't eating. "If we don't put in a feeding tube," my mother's internist told me, "she won't survive on her own."

Mom had always been vehement about how she wanted to go. "Just pull the plug. Let me die," she would say, with more than a hint of melodrama. "I don't want to be a vegetable." But was she a vegetable now? She had been suffering from dementia for several years and at times seemed to be living on a different, prohibitively weird planet populated by angels, murderers and secret paramours. At one point, I called from the road, and she told me she had taken a lover. He was in bed with her right now. They had made love three times. (She was 91.) "Where's Dad?" I asked. In the other room, she said. Which was true, both literally and metaphorically: Dad was also suffering from dementia but of a less florid and more truculent variety. He rattled between wild rages and utter forgetfulness; he was intermittently incoherent, having lost much of his ability to locate words.

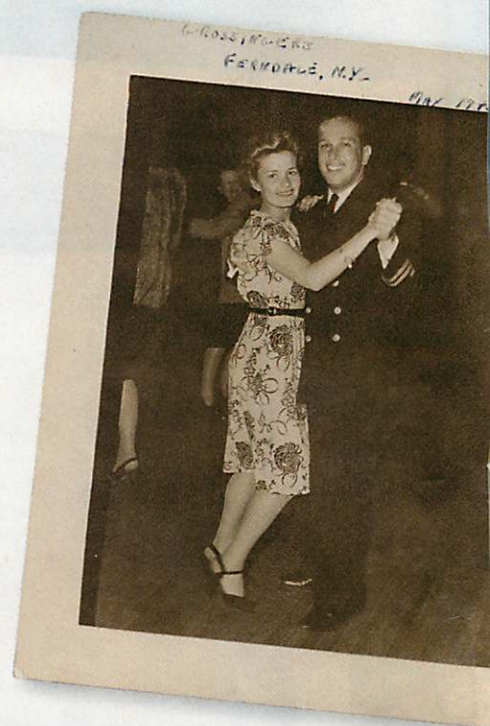
Over time, though, Mom's angels and imaginary lovers disappeared, and an eerie dullness set in. She was rather limited in her responses now. "That's nice," she would say when I told her about my children and grandchildren. "I love you too," she would say. She never initiated conversation, but occasionally I could still make her laugh. Vegetables don't laugh.

"If we don't put in the tube, how long does she have?" I asked the doctor. He wasn't sure. He was the sort of doctor who was allergic to certainty or even to

ballpark estimates. "We've taken care of the pneumonia, but she's not eating," he repeated. So weeks? Days? She needs nourishment, he said. I was in Iowa. My brother was in Asia. I didn't want to sign a death sentence without even seeing her, without giving her a chance to rally. "O.K.," I told the doctor. "Put in the feeding tube. I'll be there as soon as I can."

THAT WAS THE BEGINNING. I SPENT THE next five months as a death panel for both my mother and my father. They passed away within a few weeks of each other last winter. The circumstances of their deaths were not unusual; many of my friends have been through similar experiences with their parents in recent years. But we grieve in different ways, and my way, I guess, is to write about it—and also to examine the policy implications of how we treat the elderly. Because it is clear to me, after this awful winter, that there are better ways to handle the endgame. I now believe, for example, that I made a mistake when I agreed to Mom's feeding tube. I believe that because I was extremely fortunate to transfer my parents, at the end, from regular fee-for-service Medicare to a private nursing home that used the Geisinger health care system, in which—as with the Mayo Clinic and others—doctors are paid salaries and outcomes-based performance bonuses rather than by the services they perform. It is a system that many health care experts see as a model, a way to save significant amounts of money while providing better care. I can't personally attest to the savings—although, as we'll see, the statistics are impressive—but I can say that the level of candor, sanity and humanity of the Geisinger doctors I dealt with was stunningly high. They helped me through some of the toughest decisions I've ever had to make. My parents died serenely, with dignity. When you are a death panel—when the time and manner of their passing is at least partly in your hands—that is the very best you can hope for.

But humanity before policy: let me tell you a little bit about my parents. They were born within a month of each other in 1920. They met on the first day of kindergarten. At P.S. 114 in Rockaway Beach, Queens, the children were arranged by height and marched into class together in two lines. My father was the shortest boy, my mother the shortest girl. They walked into class that first day holding hands. It wasn't exactly a straight line ever after.



Rummaging through their memorabilia, I found a picture of Ensign Malcolm Klein with a date at the Cocoanut Grove in Boston during the months that the U.S. Navy had sent him to Harvard Business School for advanced training as a supply officer in 1942. I found pictures of Mom with other guys as well. But Mom and Dad became engaged during the war, were married on May 13, 1945, and were inseparable after that.

Dad grew up in an upper-middle-class family; Mom was poor. Dad's father kept the books for the John F. Curry insurance agency—which meant, in effect, that he kept the books for Tammany Hall. Curry was boss during the Roaring '20s, the Jimmy Walker era. The '20s also roared for my mother's father Frank Warshauer. He was a professional musician who wrote a couple of Top 40 hits, which enabled him to buy a two-family house on the less fashionable bay side of Rockaway. (Dad's home overlooked the ocean.) The Warshauer house was my first home. If you've seen Woody Allen's film *Radio Days*, which takes place in Rockaway Beach, you get the picture: my parents and I lived upstairs; my grandparents and two maiden aunts, Rose and Madeline, lived downstairs. The aunts eventually



Scenes from a life
Honeymoon, 1945;
a last photograph; at my
bar mitzvah, 1959



become part of the family retinue when my grandparents passed away.

Dad's ability to provide for everyone began with an incredible piece of luck in 1942: he won the largest daily double in the history of the Suffolk Downs race track: \$1,877.40. "Ensign Klien [sic] says he will use his winnings to purchase war bonds," the *Boston Record* reported. After the war, he used the money to buy a small printing company. By the time I joined the payroll at the age of 14, the company had grown to nearly 100 employees and was doing some of the finest lithography in New York.

I was extremely proud of my dad. I could see how his employees respected him. But they feared him too, and so did I. He had made an implicit deal with my mom: she was allowed to have her sisters live with us, and he was allowed to go about screaming like a banshee. He and Mom had a loving marriage, and they had fun. I have in my possession a certificate from the Irv Siegel School of Social Dancing honoring Mal and Miriam Klein for proficiency in "mambo, cha-cha-cha and merengue." But Dad was a terrifying presence in our lives. Even his fatherly duties—helping with a Cub Scout project or coaching Little League—were occa-

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sions for embarrassing rages. I mention this because his anger intensified as he began to lose his wits; it was the terrain on which I had to maneuver as I sought to make decisions regarding my parents' health and safety after they retired to State College, Pa.

DAD BOUGHT A LOVELY HOUSE IN Brookline Village, one of those progressive-care communities that enable you to slide toward senescence from the complete independence of a single-family home to assisted living to nursing care, although Dad refused to slide. He remained flagrantly, stubbornly independent, running his household, which included my two inevitable aunts, even as his health began to decline and then plummet. All four were cared for during the day by two lovely Kazakh women whom Dad hired independently of Brookline Village, but as the years passed, it became apparent they weren't enough. Mom had gone blind—the victim of a rare form of glaucoma that wasn't detected until it was too late—and she suffered from neuropathy, which weakened her legs. Both she and Rose would fall on the way to the bathroom at night; the home health aides would find them on the floor in the morning. My brother and I suggested that he expand the home health care to a 24/7 operation—the Kazakhs had friends who would take the night shift—but Dad refused. "If he ran a nursing home with these conditions," my brother said, "he'd be arrested." (Dad relented only after a hospice worker, who would come to care for Aunt Rose as she neared death from congestive heart failure, threatened to call the authorities and have Mom and Rose removed.)

Things became impossible. Dad was going blind too, but he refused to give up his driver's license. I had to call the police to have it taken away, but he continued to drive anyway. At one point, his urologist called to tell me that Dad had driven into his parking lot and knocked down a sign: "Do you really think he should be driving?" After that, I had the Kazakhs hide the car keys. Dad followed Mom's precise path downward: his macular degeneration grew worse, he developed neuropathy, and dementia set in. He gave orders to his bookkeeper—who was now trying to keep track of the money owed six Kazakh caregivers—and his investment adviser, forgot them and then screamed. He fired the bookkeeper; the investment adviser quit. He caused a public ruckus by claiming that the manager of Brookline

Village was cheating the homeowners, which made it impossible, initially, to move Rose and Madeline into either the assisted-living or nursing-home facilities there. He became credulously obsessed with his junk mail, sending thousands of dollars in donations to “charitable” lotteries run by phony patriotic and veterans groups. I’d tell him he was wasting his money, and he’d say, “But look at the printing. It’s a beautiful four-color job.” He screamed at the Kazakhs, who were patient beyond imagining. He screamed at Mom when the angels and murderers hovered about; he was a bit daunted by her phantom lover though.

Rose passed away in December 2010, and Mom began to decline thereafter. The emergency runs to the hospital became more frequent. She broke her elbow, her hip. And then, finally, came the pneumonia, and the feeding tube in October 2011. By this time, I’d had private conversations with several of my parents’ doctors, who agreed—informally—to allow me to exercise my medical power of attorney. (My son, a lawyer, held the financial power of attorney.) We couldn’t do this formally because Dad would have taken me to court. He was infuriated with me for stopping him from driving and forcing him to have full-time home health care. The hazy legality of the situation was exacerbated by the nature of the Medicare system. There was no coordination among the flotilla of physicians taking care of my parents. There was no real



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supervision of their daily drug taking: Dad was in charge, and sometimes he’d screw up; it was hard for me to communicate on the phone with the Kazakhs, whose English was spotty. On several occasions, Mom was rushed to the hospital because the drugs prescribed by her various doctors had interacted poorly or Dad had given her the wrong dosage. Their internist was a sweet man, but he refused to confront my father. My brother, who was living in Asia by then, figured that only a disaster would change the situation. Instead of a disaster, though, we lucked into Geisinger.

HAPPILY, THE MANAGER AT BROOKLINE Village was willing to forgive Dad their very public battle and let me move them into the on-site nursing home, called the Fairways. I told Dad it was necessary for Mom to go there because of the intricacies of the feeding tube, which wasn’t entirely true. And then I reminded him, “You always said you wanted to be with her. Maybe you should go in too. It’ll help Mom recover.” He agreed, then forgot we’d had the conversation. It took three more such talks—one with their internist—to get him into the facility, and even then, Dad would try to break out. He occupied the elevator in protest one day; I had the nurses give him a tranquilizer. And I must admit, I could see his point. The nursing home was first-rate, with a wonderful staff, but it was a death factory. People went in and didn’t come out. The fellow in the room next to Dad’s, a stroke victim, roared and cried incomprehensibly throughout the day, a terrible sound. “Why can’t we just die at home?” Dad asked. It was a fair point, but I couldn’t give the real answer: because it was safer for them in the nursing home and, as I soon learned, the quality of medical care—which was provided by the Geisinger system—was much better than what they’d been receiving.

My first conversation with a Geisinger doctor, Victoria Devan, was refreshingly different in a no-bull sort of way. I told her I had mixed feelings about Mom’s feeding tube, that Mom had left clear instructions against prolonging her life—but I’d been out of town, I’d wanted to see if she would recover her appetite, and I wasn’t sure how many days she’d have if we didn’t put in the tube. Devan said she understood, “but we should keep a close eye on it. When they lose their appetites, they’re usually telling us something.” Devan also told me that Mom would have had weeks,



The mission: care and candor
Dr. Victoria Devan and Dr. Charles Maxin
in one of the Fairways’ consultation rooms

perhaps a month, more of life if we hadn’t inserted the tube. What a relief: clear, simple sentences. When I asked Devan about it later, she said she’d been relieved as well. “You got it,” she said. “Sometimes the family members don’t. Sometimes they want us to do all sorts of things that just aren’t realistic, and we have to be very patient about walking them through the reality of the situation. You understood where it was heading.”

A week later, I checked in again with Devan. Mom was eating less than 10% of her meals. “Maybe we could reduce the amount of food she’s getting through the tube and see if her appetite revives?” I asked. Devan agreed but told me once again, gently, that the odds were that Mom wasn’t coming back. And she was right. After another week had passed, my brother came home from Asia, and my wife and children joined me in State College for a meeting with Dr. Charles Maxin, who was Devan’s senior colleague. He seemed like a figment of Norman Rockwell’s



imagination—calm and reassuring and flagrantly decent. Like Devan, he didn't mince words. Mom wasn't responding; we were only prolonging the inevitable. He told us her death would not be painful. I looked around at my family and asked if anyone had any objections to pulling the plug on Mom. No one did.

"There's one other thing," Maxin said. "I noticed that your mom has a do-not-resuscitate order in her file, but your dad doesn't. Should we add it on?" I told Maxin that Dad acted as if old age were a reversible condition. He probably would *want* to be resuscitated. "Are you sure about that?" he asked. "You know that he broke two ribs when he fell in the bathroom last week. He's very frail. If we tried to resuscitate him, we'd probably break the rest of his ribs." This was startling but undeniable. I approved a do-not-resuscitate order for Dad. It was becoming clear to me that in the gentlest possible way, these Geisinger doctors did not mess around.

THE GEISINGER MEDICAL CENTER SEEMS almost like a mirage. It is a giant, state-of-the-art medical facility plopped down amid farmland in the town of Danville, Pa. The hospital is the mother ship of an extensive network of medical practitioners tending to 2.6 million patients in 44 mostly rural Pennsylvania counties, including the doctors who took care of my parents at the Fairways. It was founded in 1915 by a widow named Abigail Geisinger and first directed by Harold Foss, a surgeon who had been an assistant to the famed Mayo brothers. Like the Mayo Clinic, it employed a team approach, with doctors, paid as employees rather than as independent operators, cooperating on patient care. "It's like hiring a general contractor to supervise the renovation of your house," says Henry J. Aaron, a health expert at the Brookings Institution. "He brings his team of subcontractors and coordinates their work. It's a lot more efficient than finding and organizing the carpenters, the

Cost of Care. The 2012 average health care costs for the elderly across the U.S.

- Nursing homes, which can provide extensive, skilled medical care, are also the most expensive facilities. The median U.S. rate for a private room is \$222 per day. The highest costs are in Alaska, where the median daily rate for long-term care is \$783. The lowest median rate is in Missouri, at \$137.
- Home health aides allow elderly patients to stay in their homes while receiving daily care. The national median hourly rate for a non-Medicare-certified aide is \$19. Minnesota has the highest median hourly rate, \$28; Texas has the lowest, \$13.
- Assisted-living facilities, which often offer a homelike atmosphere, are the second most expensive option. The national median monthly rate for a one-bedroom private residence is

Source: Genworth 2012 Cost of Care Survey

electricians and the painters by yourself."

There are good contractors and bad ones. The accountable-care-organization model—which is the emerging term of art for places like Mayo and Geisinger—was emulated in all its worst aspects when health-maintenance organizations (HMOs) emerged as a cost-cutting tool in the 1970s and then became unpopular when they became synonymous with hellish bureaucratic medical rationing. But during the years that HMOs were going in and out of fashion, a quiet revolution was beginning—the computerization of medical records. And Geisinger became a pioneer in analyzing those records to find out which sorts of treatment worked and which didn't. Over time, as the data accumulated, it has become clear that quality health care can be provided in a way that makes patients happy, with a minimum of draconian bureaucracy and for less money. "Our core belief is that about 40% of what doctors and hospitals do is wasteful," says Dr. Glenn Steele,

Geisinger's president. "If you can extract that percentage of crap, you can redistribute it into savings and profits but also into procedures that actually help patients."

Geisinger has found, for example, that by adding case managers—nurses who work by phone and in person from doctors' offices—to chronic elderly-care cases (like my parents before they entered the nursing home), they can give more individual attention and produce better results. The case managers call or visit the patients regularly to make sure they've taken their medication, weighed themselves (on Bluetooth scales that send the results to the Geisinger computers), are eating the right things and are aware of upcoming appointments. They are also there to listen to complaints, which, as those of us who've been through parent care know, are not infrequent. A study published in the *American Journal of Medical Quality* found that this system produced 18% fewer hospital visits, a staggering 36% fewer return visits and cost savings of 7%. "Geisinger has made steady progress in reducing per capita Medicare costs over the past 20 years," says Dr. Elliott Fisher of the famed Dartmouth Institute for Health Policy and Clinical Practice. "It has gone from the middle of the pack to very near the top."

Over those years, Geisinger has quantified almost every aspect of health care. A bundle of nine routine procedures has been identified to treat diabetics, for example. The bonuses that Geisinger doctors receive depend on how closely they adhere to proven procedures, as monitored by the Geisinger computers. Bonuses also depend, in part, on how the patients rate their care, and doctors—who are not always the most sociable human beings—are asked to go through a bedside-manner orientation program called Patients 101, which schools them in basic procedures like shaking hands with members of the patient's family, looking them in the eye and introducing themselves. This sort of training is especially important in a system in which doctors sometimes must try to deny care requested by patients or their families that is deemed unnecessary. "It takes more time and effort to sit down and have a discussion with the patient rather than just ordering the duplicative X-ray," says Dr. John Bulger, Geisinger's assistant chief quality officer. But the time spent on the discreet application of candor saves money and develops a deeper level of patient trust and satisfaction.

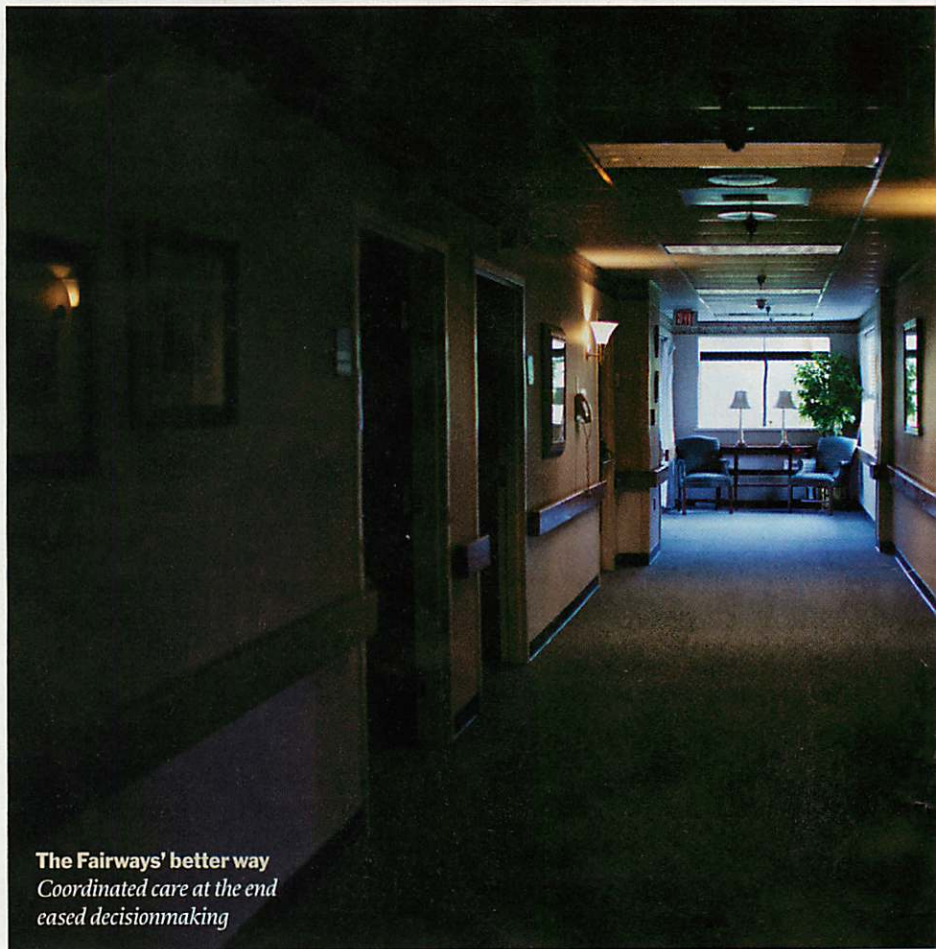
In my parents' case, Geisinger had

worked with the nursing staff at the Fairways. I was consulted about every adjustment in medication and told about every time Dad tried to do a walkabout and inevitably fell down. By the third week, the staff and I were co-conspirators, laughing about Dad's stubbornness and trying out new strategies to make him more content. The situation was, of course, horrific—Mom and Dad were both fading away—but I no longer felt so guilty and frustrated. I was part of a team making their passage as comfortable as possible. After the struggles I'd been through with Dad, it's hard for me to describe what a relief this was.

"This is such a terrific model," says Henry Aaron. "It costs less and gives better results. In a Darwinian business system, you have to wonder why it doesn't spread." Only about 33% of Americans get their health care through organizations like Geisinger. But the model is becoming more popular, encouraged by the Centers for Medicare and Medicaid Services (CMS), which has run hundreds of pilot

projects over the past six years. "If you're a group practice that joins one of the CMS pilots and prove you can improve service while cutting Medicare costs, you get to keep a portion of the savings," says Fisher. Much of the savings projected for the Affordable Care Act—Obamacare—would come from a broader application of his model.

But that's going to be a big fight and difficult to win: most doctors don't like the Mayo-Geisinger way of doing business. The culture of fee-for-service medicine, which features each doctor as the captain of his or her own ship, is incredibly powerful. "What you hear from doctors who don't like our system," says Steele, "is 'We don't want to be robots run by your computers.' But we encourage innovation if it really works." Devan says that while Geisinger doctors don't have to worry about the business hassles of running a fee-for-service practice, it isn't exactly natural for doctors to have their work under constant scrutiny by their peers.



The Fairways' better way
*Coordinated care at the end
eased decisionmaking*



"We have monthly meetings where each patient is reviewed," she tells me. "That's a major cultural shift for most doctors."

The shortcomings of fee-for-service medicine are well known, especially when it comes to Medicare. At the age of 80, my mother insisted on having a heart-valve operation to fix a murmur she'd had since birth. "It's getting worse," she said. "I'm feeling more tired than I used to." The going rate for such operations was more than \$100,000, and Medicare paid for hers. The current system is rife with such unnecessary expenditures—"We're having a national epidemic of wrong patient operations," Fisher says—and it seems clear that a model like Geisinger's, in which doctors aren't rewarded for performing extraneous tests and operations, would be the best way to reduce the costs of Medicare. It also seems clear that asking people like my parents to make market decisions about their health care—the sort of system that Congressman Paul Ryan and other Republicans support—would be an act of cruelty and an unnecessary one at that. In the end, changing the way health care is provided rather than the way it is sold may be the most efficient way to generate savings.

DOCTORS ARE TRAINED TO DO WHATEVER they can to save a patient, even an elderly one, and that is an excellent thing. But that Hippocratic impulse has been subtly undermined by the rewards of fee-for-service medicine and by the threat of malpractice suits, which militate in favor of ordering the extra MRI or blood test or dialysis even for a patient who probably has only weeks to live. And so it was that when my father was rushed to the Mount Nittany Medical Center suffering from acute kidney failure in late January, the immediate impulse of the doctors in the emergency room was to try to revive him by rehydrating him. "That's how they're trained," my father's urologist, Dr. Charles Dalton, told me. Dalton is a terrific fee-for-service doctor who had impressed me with his Geisinger-like candor in the past. "But [rehydrating him] was probably the wrong thing to do," Dalton went on. "Renal failure is a good way to go. You just go to sleep. Your dad's kidneys are pretty much shot. You may revive him, but he'll be back here in a month, six weeks."

My next decision seemed obvious, but it was much tougher than removing Mom's feeding tube. This was Dad. He had always haunted my dreams, and now I had visions of the Mighty Malcolm rising from his hos-

pital bed, screaming at me for trying to kill him. But that Malcolm had disappeared after Mom passed away in November, a few weeks after the meeting with Maxin. At the end, I had fed her several teaspoons of chocolate ice cream and said, "I love you, Mom." Her last words were "I love you too." An hour later she was gone.

The next morning, I told Dad that for the first time in 86 years, there was no Miriam. "Is it definite?" he asked, crushed. His will to live vanished. He pretty much stopped eating. I tried to revive his interest in food by having the nursing home serve him more of the things he loved to eat—salads, pancakes, a glass of sweet white wine with dinner. "You did that? That's amazing," he said of the wine. "I really appreciate what you're doing. You're a good son," he said for the first time in my life. I told him he had been a great dad. "I could have been better," he replied.

But he forgot to ask for the wine with dinner. And he often forgot to eat dinner. He slept through most days. And about eight weeks after Mom died, his kidneys failed and I faced a final decision. Anil Aleti was the Geisinger doctor on call at Mount Nittany, and he was every bit as forthright as Maxin and Devan. We could keep Dad going with intravenous hydration, and he might last a month—there was no question of inserting a feeding tube—or we could stop. I called my brother and told him that I'd decided to let Dad go. He agreed, as he had every step of the way.

I sat by Dad's bedside for that final week in the nursing home. He opened his eyes a few times and tried to speak, but he couldn't. I held his hand; he squeezed mine once or twice. The morning he died, two angels from hospice care sat with my wife and me by his bedside; the nursing staff and Dr. Devan hovered about as well. Betsy Brett—the hospice supervisor who had been on the case since Rose died and had seen Dad rage against his twilight—explained how it would be. His breathing would become shallower, then more intermittent, then stop. And so it went: Dad seemed to sigh at the end. He inhaled and sighed and was gone. He was not a religious man, but there was a gorgeous serenity in this moment—and there was a certain satisfaction for me too, surrounded by the caregivers who had helped me through this passage toward my own maturity, caregivers who really knew how to give care. ■



Only about 33% of Americans get their health care through systems like Geisinger

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