

bet you knew nothing at all about Milly. Once you read her story, you'll never forget her.

At its core, this is a love story, poignantly told. Mort writes of his devotion to Milly with eloquence and surprising candor—from the more intimate details of their virginity-to-Viagra romance to the strengthening of his commitment as together they face the cataclysm of Parkinson's disease. Thank you, Mort, for *Saving Milly*, and thank you, Milly, for the love and passion you've inspired in others. I believe, as do you and Mort, that a cure for Parkinson's disease is very close, and in a very real way you've brought it that much closer. So who's saving whom?

Michael J. Fox  
New York City, February 2001

## Introduction

❧ Parkinson's disease has kidnapped my wife. It is in the process of killing her. I hug and kiss what is left of her, hang photographs of the old, strong Milly throughout the house, and talk to her. We hold hands. We make love. But she is not who she was. She cannot walk, and now she can barely speak. She is being carried into an abyss, and I am helpless to rescue her.

I hate Parkinson's disease for what it has done to my beloved and is doing to one million other Americans. It is a horrible story I have to tell you, but it is also an inspiring one. For what I had and what I still have, I feel profound gratitude. Millicent Martinez was a poor, inner-city Chicago kid who grew up to be a dynamo. I wanted to marry an heiress from the Ivy League, but she was irresistible. Besides, I became convinced that God wanted this marriage to happen. So we married. Then we fought and loved each other in one way for twenty years and in quite another for the past fourteen.

Until she was forty-seven, Milly was always the master of her

surroundings, the kind of woman whose will no bureaucrat, lazy tradesman, or alcoholic husband could resist. She saved Andréa, our younger daughter who's dyslexic, from being discarded by the school system. Andréa is now graduating from medical school at Johns Hopkins. Milly emptied my liquor bottles down the drain and railed until I went into AA, which changed my life and may have saved it.

Milly's Parkinson's diagnosis in 1988 shattered her confidence, but it did not stop her from fighting. A gifted psychotherapist who helped people remake their lives, she worked as long as she could. She underwent two daylong deep-brain operations, awake throughout. She impertuned a president, testified before Congress, and cried in senators' offices to secure increased funding for Parkinson's research.

Her plight transformed me. From her resentful assistant, I became her dedicated partner. I came out of self-absorption and became an activist in the cause of medical research funding—not just for Parkinson's but for all diseases. I call that cause "God's work." It has heroes and heroines, and it is succeeding. If Congress and the president continue on the path of the past three years, they will double the budget of the National Institutes of Health. Then they should do it again.

Milly's disease nearly destroyed her trust in God. Until recently she felt that He was punishing her, but she did not know why. Parkinson's has had a different effect on my faith. I feel that I need to talk to God every day and ask for His help. Every time I have asked God what my job on earth is, the answer I've always received is, "Take care of Milly." But I cannot save her. If God can, He has not shown it.

Without God's intervention, a cure for Parkinson's will arrive too late to save Milly. Brain scientists say that enough is known

that this disease could be cured in five to ten years—if adequate resources are devoted to the task. Despite the general increase in medical research funding, those resources are not yet going to Parkinson's. There is reason to hope this will change as my friend Michael J. Fox leads the struggle to secure research funding.

Virtually unable to swallow, Milly is now being sustained through a feeding tube. She can stay alive, but she is unable to communicate. She says, "I do not want to live this way, but I am afraid to die." I am terrified of losing her. I do not know how this story ends.

This didn't end our arguing, of course. There was always money, visitors, and politics. Of all Milly's many projects, though, her anti-alcohol campaign is one of those about which I am most grateful. It may have saved my life and my marriage. This last exercise of Milly's old power also made it possible for me to cope with, not try to escape from, the challenges ahead. A year and a month from the day I quit drinking, the first signs of Milly's Parkinson's disease appeared.

For nearly two decades we spent every Christmas vacation in Vermont with Milly's sister Alex, her husband, Paul Wheeler, their daughter and son, and their houseful of guests. Paul, a British film writer, thought that the Bing Crosby movie *Holiday Inn* represented the perfect Christmas. So he and Alex traveled to the United States each year beginning in 1973. The next year, he rented a big house that Jill Schuker found near Windsor, Vermont, filling it with his American friends and some of ours. Later he and Alex bought their own place near Chester, and Christmastime there became a tradition filled with merriment—and conflict.

We skied by day at Bromley, Okemo, or Magic Mountain and gathered for loud, crowded dinners each night. As at our Thanksgivings at home, Milly established the rule that children ate with the adults and took part in conversations. It was also a tradition that on Christmas mornings gifts were opened one at a time so that everyone could appreciate what everyone else had given and received. This rule, combined with the sheer quantity

of presents, meant that we started opening at seven, broke for breakfast around nine, and didn't finish until well after lunchtime. I ritually grumbled that the extravagance was obscene, but I was ritually ignored.

Conflict in Vermont mainly had to do with disciplining children. The kids' dorm periodically became a cauldron of rivalry and bullying and, when they got older, a place for experimenting with drugs, alcohol, and sex. When my kids were little and got into fights my impulse was to spank them or sometimes slap them on the head. Milly's practice was to settle quarrels and teach accommodation. Kids who felt hurt or ill-used went running to her for comfort, and she got into disputes with other parents, especially Paul, over how to mete out justice. Milly never hid her opinions. Paul invariably said, "Let 'em handle it themselves." Milly favored supervised negotiation. Also, even though the Wheelers have been lovingly married for nearly forty years, Alex frequently had complaints about Paul that she unburdened upon Milly. And Milly and her sister had their own leftover sibling troubles to resolve. While I made myself useful by cooking meals, washing dishes, and organizing visits from Santa, I used alcohol to make myself as oblivious as possible to the interpersonal goings-on. During our nine-hour drive back to Washington every year, the girls and Milly minutely reviewed the wrongs done over the vacation by various children and adults. Milly also berated me for being inattentive to problems she was trying to solve.

In 1987, the second year I stayed sober and could be of assistance, we decided to alter the tradition by renting a separate house in order to help Andréa with her college applications in peace and quiet. It was there that the first shadow of Parkinson's disease cast itself upon our lives. Milly was writing a check to accompany one of the applications and remarked that she could not

form the letter K correctly. She got a piece of paper and wrote her signature four or five more times, then more times, and said her handwriting just wasn't right. I saw no difference. Anyway, I thought Milly was both vain and perfectionist about her clear penmanship. Whatever was wrong—if anything was wrong—was in her imagination or was being exaggerated, I figured.

Over the next five months Milly persisted in saying that her handwriting was changing. Her script was getting smaller, she said, and the flow was losing its smoothness. I finally noted a change, too, but I assumed it had something to do with the periodic numbness she'd experienced in her hands since early in our marriage, when she'd gotten frostbite in Aspen. I had been determined that Milly learn fashionable skills like skiing and had goaded her into staying out to finish her afternoon lesson even though it was getting cold. Milly also noticed that when she pressed down on the little finger of her right hand it developed a tremor. And she said she felt tingling in her hands.

In May, Milly made an appointment to see her old boss at the Neurology Center in Bethesda, Maryland, Dr. Marvin Koenigsberg. For a few years after earning her master's degree she had worked there counseling patients with chronic illnesses and their families. It was hard work. The diseases the patients suffered from—multiple sclerosis, Alzheimer's, amyotrophic lateral sclerosis (ALS, or Lou Gehrig's disease), epilepsy—were often devastating and incurable, and Milly occasionally brought home harrowing stories of families torn apart by the burden. She was particularly shaken over the case of a woman stricken with guilt because she'd left her father, a Parkinson's victim, at home to die himself. He fell and lay on the floor unable to rise for half a day with no one there to help him. This story triggered something deep in Milly, perhaps guilt at being unable to help her own

father after he suffered his stroke, perhaps empathy with the father's dependency. Physical illness was one of the few things in life that scared Milly. It was always a byword with her that "as long as you've got your health, you can handle everything else." Whenever she prayed, it was for health for herself and our family.

Dr. Korengold examined Milly and diagnosed ulnar neuropathy, a nerve inflamed from pressure at the elbow. He told her to try to keep her arms straight and avoid leaning on the elbow. Milly reported these findings to me with relief that the problem was not serious. But even though she followed instructions, her symptoms did not go away. On a follow-up visit in June, Korengold's records show, he had her swing her arms and noticed that the right did not move as smoothly as the left. He prescribed Symmetrel, which Milly took believing it was meant to help her nerve problem. He did not tell her what it was actually for, evidently not wanting to scare her. She went back to see Korengold a few times during the summer because her right little finger remained weak and she began to notice a slight tremor in her right foot when she pressed the accelerator or brake while driving.

One day in September she called me at work in tears, with a panic in her voice that I'd never heard before. "Something terrible has happened," she said. "You've got to come home." I had a fleeting terror that one of the girls had been injured or killed. She said, "I looked up the medicine Korengold gave me in my pill book. Symmetrel is for Parkinson's disease!" I was relieved that this was not the worst possible news, but for Milly it was. "I know what Parkinson's is. I've seen people with it," she cried. "It's a horrible disease. People shake. They can't walk. They choke on their food. It can't be that!" She said she had torn up Korengold's prescription, thrown away the medicine she had, and would never speak to him again.

I drove home as soon as I could and found Milly utterly distraught. She paced around our bedroom, showed me the medicine and prescription in the wastebasket, repeated what she'd told me on the phone, and said she hated Korengold. She also recalled the story of the man who'd fallen and was unable to rise. She said she would end up just like him. This was the first time in our lives together that I had ever seen Milly out of control. She said that if she did have Parkinson's it meant that she would have to give up her practice because clients would not want to be treated by someone "so pathetic." She predicted, "You won't keep loving me. You'll leave me."

I hugged her and told her that this would never happen. In the moment, I said it mainly to ease her distress and the confusion it caused me. Seeing Milly so upset scared me. But I also meant what I said completely. I could not imagine anything that could ever cause me to leave Milly or stop loving her.

She read my mind. "You don't know what Parkinson's does to people. You'll have to take me to the bathroom. You'll have to feed me. You won't want to do that," she said.

I said rather automatically that I didn't care what happened, I'd never leave her. I meant this, too, although she was correct. I knew nothing about Parkinson's or the extreme disabilities it could cause. And, of course, her problems then were so mild that her grim predictions seemed speculative and extreme.

I tried another tack that did ease her anxiety. "Look, we don't even know that you really have Parkinson's. A couple of months ago it was ulnar neuropathy. We've got to check this out. You're assuming the worst before you know what's going on."

In spite of her vow never to see Dr. Korengold again, she went back a few days later, and I went with her. Milly had been a popular employee at the Neurology Center, and because she was

clearly distraught about his tentative diagnosis, Korengold asked some of his colleagues to help examine her. This was the first neurological exam I witnessed, Milly has now undergone hundreds of them in various doctors' offices. Korengold had her stretch out her arms and try to hold her hands steady. Then he asked her to quickly tap the thumb and index finger of each hand. After that, to touch one index finger to her nose, then the other. Next, to flop her hands, palms up and down. He told her to look at his finger and follow it with her eyes. He asked her to blink, then wink one eye and then the other. He had her tap the toes of one foot and then the other. He hit her knees with a rubber hammer. He asked her to walk down a hallway, swinging her arms. Finally he had her sit down and write some sentences on a piece of paper.

Milly acted as though she were being interrogated by the Inquisition. With each task, she looked nervously at the doctors for signs of whether she was passing or failing, with failure meaning that she might be doomed. The doctors tried to calm her fears, but by the end it seemed to me she was quaking as much in fright as from any neurological problem. Before passing judgment, Korengold huddled with his colleagues, leaving Milly and me alone in an examining room. Milly was weeping, sure that Korengold was going to condemn her with his diagnosis. I tried to tell her that I hadn't seen anything to be alarmed about. I did not tell her that I had noticed that the movements of her left hand were slightly quicker and more facile than those on the right. I also said that, whatever the verdict was here, we would get a second opinion elsewhere.

Korengold returned and apologetically said that he and his colleagues were pretty sure that the tiny impairments on her right side were evidence of Parkinson's. Milly again started to cry, clearly disconcerting Korengold. He tried to reassure us by say-

ing that trajectories for people with Parkinson's vary widely and that some people's symptoms remain mild for years. He cited the case of a dentist who was still practicing and playing golf twenty years after being diagnosed. And, he said, so much promising research work was being done on Parkinson's that a cure might be found within a decade. He gave us some literature on Parkinson's and suggested that we join a support group for patients and their families.

Milly cried and her body shook as we left the building to go to our car. I held her close around the shoulders and tried to be consoling, assuring her that this diagnosis was not necessarily final. When she stopped crying, she said that she would never see Korengold again. She vowed anew that she would not take the medicine he had prescribed. And she said she would never attend a support group. Seeing people with advanced Parkinson's would make her more depressed than she already was, she said.

We began a lengthy process of diagnosis-shopping. Milly was desperate to find someone who would tell her that she did not have Parkinson's. I, too, fervently hoped that something like Korengold's first diagnosis would prove correct, though mainly because I wanted to restore Milly's peace of mind and the serenity of our household. Since I knew so little about Parkinson's, I had only the vaguest sense that Milly's life and both of our futures hung in the balance. I simply knew that we had to find out what the truth was because the possibility of Parkinson's was so unsettling to Milly. So we immediately set about looking for places to go for a second opinion.

In the meantime I also started researching Parkinson's. The disease is named for the British physician James Parkinson, who wrote the first scholarly paper on the "shaking palsy" in 1812. As always, I was inclined to accept expert opinion, and I allowed

Korengold's optimism to dominate my thinking and my words to Milly. Each time she told me how she feared being incapacitated, I reminded her of Korengold's golf-playing dentist. In the literature I read on Parkinson's, however, I could not escape the menacing words "degenerative . . . incurable . . . progressively disabling . . . sometimes fatal." I saw these words, but I could not absorb them emotionally and simply refused to accept them as a prediction for Milly. I comforted myself with the assurances in the literature that "medication can alleviate symptoms and improve quality of life for many years" and with the long list of experimental therapies promising to bring the disease under control. The literature said, encouragingly, that Parkinson's was primarily a disease of the aged—Milly was just forty-eight at the time—but it also reported that the average age of onset was descending, for reasons no one could explain. Whenever Milly saw me looking at a Parkinson's article and asked me what it said, I would read aloud the material that gave reasons for hope and skip what I feared would heighten her distress.

Even though Milly rejected Korengold's diagnosis, she was haunted by it. She took it as a curse. She could talk about little else. She told me she was convinced that she would be abandoned—as she was by her mother, and as her father was by many of his labor union friends when he was disabled and being pursued by the government. Milly's foster mother told me later that, as a little child, Milly cried whenever her dress got soiled and tried to cover up the stains with her hands. Evidently she feared she would be rejected if she were dirty. Now she seemed terrified that her hands would shake and she would not be able to hide them.

With some of her friends and co-therapists—even more than with me, at least then—she wept uncontrollably and said she was sure that I would find her "disgusting" and leave her. She said

she had known several patients at the Neurology Center whose husbands promised to stand by them when they got sick but ultimately didn't. Judy Siegel, our neighbor, says that Milly sometimes seemed interested in reports about people who were successfully coping with Parkinson's. At other times, though, she could talk only about the "horrible" condition she expected to be in and predicted that I would find another woman, leaving her to deteriorate alone.

Similarly, Jill Schuker remembers Milly being totally consumed by the diagnosis and determined to prove it wrong. After years of long, lighthearted shopping trips with Milly and endless discussions about our kids and her career and love life, Jill suddenly found Milly able to talk about one thing only. Milly irrationally demanded that Jill save her from Parkinson's. "Figure out a cure," she cried. "You can do it!" Even though Milly was normally protective of Andréa, she was so upset that she burdened Andréa with her fears of being left by me. Andréa had seen the fathers of two of her close friends leave when their wives got sick and thought it was a possibility that this might happen to us. She worried that she might end up as Milly's caretaker.

I can understand why Milly and Andréa might have worried. There had been mercifully little illness in our family, but when there was I did not deal with it well. I was a bystander as Milly did most of the work to cope with Andréa's dyslexia. Later I was at first dismissive and then struck an "Oh God, what now?" attitude when Milly became concerned that Andréa was gaining weight and becoming uncharacteristically lethargic in high school. It was Milly who took her from specialist to specialist until someone diagnosed hypothyroidism and prescribed corrective medicine. When Milly went to the hospital for surgical removal of hemorrhoids, I was attentive until she had been back home for a few

days. When she complained constantly about pain, didn't want to get out of bed, and had to be helped to the bathroom, I did what needed doing, but I made my impatience clear and even accused her of whining. I acted as though shaming would hasten her recovery. I showed no tolerance for her dependency. In the traumatic aftermath of Korengold's diagnosis, I was comforting and attentive. But on the basis of her experience with me after her surgery, there was good reason for Milly to fear that I would be unsupportive, or even nasty, under the pressure of a long, debilitating illness.

In the meantime, some of Milly's friends thought that she was overreacting to her symptoms and the tentative diagnosis. In fact, a few of them have told me they doubted that she really had a physical problem and wondered whether she was suffering from hypochondria or some psychosomatic hysteria. They thought her symptoms might be related to menopause, or to our daughter Alex's departure for college and Andréa's preparations to go. Milly's distress was great enough, though, that a psychiatrist friend prescribed Valium for anxiety and Desyrel for depression. These helped only modestly.

In November 1988, we went to Johns Hopkins University in Baltimore to see Dr. Mahlon DeLong, who later became Milly's regular neurologist. DeLong is a gentle, scholarly man with a high-domed bald head and thick glasses. Milly broke down and sobbed as she told him about Korengold's diagnosis, what she had seen of Parkinson's, and what she feared for herself. He calmed her and then conducted the same basic exam as Korengold's. To our huge relief, DeLong said that her symptoms were too indistinct for him to make any definite diagnosis. He said he thought that depression and anxiety were her dominant problems and suggested that she see a psychotherapist.

She did that and in January 1989 also consulted an orthopedist, who said he was certain that she had serious ulnar neuropathy. He added that she might also be suffering from thoracic outlet syndrome, a pinching of a nerve as it passes through the shoulder area. He sent her to a physical therapist, who gave her an exercise regimen. Someone also gave her the name of a surgeon in Boston to consult if her symptoms persisted. The revised diagnosis of neuropathy was like a stay of execution for Milly. It created great hope that both of us clung to and pretended to believe in. But we both knew that *this* diagnosis might be wrong. Milly dutifully did her hand-strength exercises, but they seemed to have no effect on her symptoms.

I decided that we should get definitive answers to Milly's problems by having her undergo a complete physical at the Mayo Clinic in Rochester, Minnesota. We went in early April, in both hope and trepidation, holding hands constantly. We spent three days there. During the first two, Milly underwent blood tests, nerve conduction studies, and x-rays of her spine, shoulder, and elbows. I trailed her, trying to keep her spirits up between tests, but mostly reading magazines in waiting rooms. The crucial neurological exam was scheduled for the third day.

On the way to the clinic that chilly, cloudy morning we stopped at a church. Always a believer in God, I had become more religious through AA and had begun attending an Episcopal church in Washington. The Rochester church was Lutheran, an imposing brick building with a dim interior. We knelt, and I fervently asked God please to let Milly not be diagnosed with Parkinson's disease. We left a contribution and picked up small silver lapel crosses that we have to this day.

An hour later our prayers seemed to be answered. Mayo's neurologist was a kindly older man with a Hispanic name, which



Milly took as a good omen. She told him that she had been diagnosed with both ulnar neuropathy and Parkinson's and tearfully said she was terrified at the prospect of Parkinson's. She made it plain that she was desperate that he not discover Parkinson's. I had a flash of worry that she might bias his judgment. But then I figured that this was the Mayo Clinic, one of the best medical facilities in the world, and that sympathy wouldn't overcome science.

The doctor gave her the usual exam. There was a tremor in Milly's little finger when she held out her arm, but it went away when she rested her hand on his exam table. He said, "Do you see that? That means you don't have Parkinson's. You have what's called essential tremor. Lots of people have it. It's benign. It won't get any worse. The nice thing is, you can help control it with a glass of wine at dinner. And the x-rays show you don't have ulnar neuropathy or thoracic outlet syndrome either."

We returned home filled with relief and joy. But it was short-lived. Milly soon noticed that she was losing strength in her right hand—especially, she said, when she was washing her hair. She said she could not hold a pencil correctly or use tweezers. And there *was* a tremor in her little finger when her hand was at rest. Milly became agitated and depressed again. She got her internist and a psychiatrist to give her prescriptions for Valium, Prozac for depression, and also Xanax, an anti-anxiety drug. And still determined to escape the conclusion that she had Parkinson's, Milly went to Boston with Jill and consulted the orthopedic surgeon who'd been recommended to her. He said he thought she had thoracic outlet syndrome and tentatively scheduled shoulder surgery for July.

Before she underwent an operation, I said, we needed to be sure about what was wrong. I scheduled a return trip to Mayo for

late June. This time, in addition to other tests, she had an MRI of the head and spine and a spinal fluid test. The Hispanic doctor had retired—a sign of incompetence, I feared—and she saw a new neurologist. After the customary exam he said that he detected "parkinsonism," but added that the only way to know for certain was for Milly to take Sinemet, or levodopa, the standard drug for Parkinson's. If her symptoms improved—especially if the tremor went away—it would mean she had the disease. This time we left Mayo deeply depressed, but still clinging to hope that L-dopa might not work.

Alas, L-dopa did work. Developed in the 1960s, the drug replaces the dopamine normally produced by a cluster of black cells deep in the brain known collectively as the substantia nigra. Parkinson's symptoms begin to appear when about 70 percent of these cells have died. The cause of their death—or self-destruction, as scientists now describe it—is unknown. Sinemet does not affect cell death, but for several years it adequately provides the dopamine the body needs for fluid motion. Over time, however, it ceases to be as effective, and patients again experience tremor and rigidity, which gradually worsen. Some neurologists believe that prolonged use of L-dopa causes damage to brain circuits, inducing dementia in some patients. It definitely causes hallucinations in others, and sometimes wild gyrations of the neck and arms called dyskinesia. In the true story dramatized in the movie *Awakenings*, L-dopa brought patients out of a mysterious coma, but their dyskinesias were so violent that they chose to return to sleep.

Milly's tremor subsided, and strength returned to her hand. Her handwriting improved. Through this wracking, months-long ordeal, Milly continued her work schedule, seeing clients individually and in group therapy. She kept her office in Bethesda, a

few blocks from our home, and also drove to Georgetown two nights a week to lead groups. She remained a strong, involved mother, calling the girls at college almost daily. When she could not reach one of them for a day or two, she would call—or tell me to call—campus security at Dartmouth or Boston College and have the police knock on her dorm door with a message to call home. The girls protested that this was invasive and embarrassing, but they also understood that it was typical of their mom. In her sophomore year at Dartmouth, when Alex became stressed out from overwork, Milly was constantly on the phone with her and ordered her to quit a part-time job she'd taken. Andréa, in her first year at BC, also was homesick and depressed. Once Milly insisted that we fly to Boston to make sure she was okay.

Milly functioned, but the life we had known before her diagnosis was over. Friends still came to call, but they weren't invited to stay over. Parkinson's disease had moved in, invading our home. It was a malevolent presence that became the preoccupation of our lives, crowding everything except our love for each other and for our kids. The definite diagnosis shattered Milly psychologically. She often clung to me and sobbed piteously, sometimes several times a day, saying that her life would be terrible. "Why is God punishing me?" she cried. "I've always tried to be good. What did I do that was bad?"

On occasion she said she had thought that her adulthood would be safe because she had suffered so many losses in childhood. Now, she realized, this was not true. Other times she said she believed she was the latest victim of some family curse. Her mother was mentally unstable. Her father had died young. Her half-brother had suffered from schizophrenia and committed suicide. She told me she was afraid that her clients would find out that she had Parkinson's and leave her practice. Alternatively, she

said she was not serving them well because she was so preoccupied with her condition. She also insisted, again and again, that eventually I would stop loving her. "Someday I'm going to kill myself," she said.

I did my best to be reassuring. I told her that she was a great therapist, that she'd helped so many people and was still doing so, that they would not abandon her. I told her she had great friends who loved her. She'd given them so much, I said, that they'd always be there for her. "Your kids love you, and I love you," I said. "No matter what happens, I'm here."

I meant this, utterly. I felt as bonded to Milly as ever. I still adored her smell, taste, and touch. Despite her despair about the future, she remained the Old Milly, decisive about people, politics, and projects. I still yelled when she bounced a check or committed us to see friends of hers when I wanted to vegetate. But we stopped fighting incessantly because our disagreements had lost the power stakes I once had assigned to them. With a twinge of self-importance, I felt as though Milly now needed me more than I needed her for the first time in our marriage. When I agreed to some project of hers—for instance, lending money to our cleaning lady and co-signing a mortgage so that she could buy a townhouse—it seemed like I was participating in a good idea, not caving in to pressure. I felt as though I was no longer her assistant, but her partner.

Despite my attempts at reassurance, Milly often was insoluble. But Xanax helped. I admit, I was so unsettled by her despair that almost every time she wept I encouraged her to take a pill, which seemed to calm her. She became dependent and took too much of it. She also was taking a dangerous cocktail of other medicines: Sinemet, prescribed in too-large doses by a neurologist we visited in Philadelphia; a Sinemet-booster called Eldepryl;

Prozac, Halcion, a sleeping pill she got through a psychiatrist friend, and an occasional Valium.

Milly lost weight. She had trouble sleeping. And most frighteningly, she often felt faint. The combination of medicines evidently was causing dehydration and depressing her blood pressure. I bought a drugstore blood pressure device and was alarmed by the wild fluctuations it registered. We had to find a doctor close to home, but Milly repeated that she would never see Dr. Korengold again, holding him somehow responsible for her illness. In January 1990, we went back to see Dr. DeLong at Johns Hopkins. He was appalled at the list of drugs she was taking—the combination of Eldepryl and Prozac can be fatal—and set out a regimen for weaning her down. His nurse intervened to suggest that he admit Milly to the hospital, and he agreed that would be the best way to rehydrate her body, begin easing her off Xanax, and lower her dosage of Sinemet.

Her blood pressure returned to normal, and the danger of fainting abated. But then other symptoms developed. For a time, the worst was severe nightly leg cramps. For years Milly and I have closed out our day watching the eleven o'clock local news and then ABC's *Nightline* in bed. But during this period, when Milly tried to get to sleep afterward the muscles in her calves would freeze into tight knots and sometimes jolt with excruciating spasms. I regularly stayed up until two or two-thirty with my head under the covers, rubbing first one leg and then the other. Eventually I had to go to sleep in order to function at work the next day. Then Milly would get up, wandering the house until nearly dawn to make the cramps go away. She was exhausted most of the time and looked emaciated.

She also developed severe upward curling of the toes on her right foot, called dystonia, and the beginnings of slurred speech.

When she swung her arms in an arc, there were hitches in her movement, known as "cogwheeling." These are common symptoms of Parkinson's, especially as Sinemet begins losing its power to fully replace the missing dopamine. In addition, Milly suffered severe back pain that we assumed was related to Parkinson's. Acupuncture and physical therapy did no good, so we went to see a neurosurgeon, who diagnosed a herniated disc. Milly underwent back surgery.

One day in late 1990, Dr. DeLong informed us that he was leaving Hopkins to become chairman of the Neurology Department at Emory University in Atlanta. This was a blow to both of us because up to that point DeLong was the ablest and most empathetic doctor we'd found. But, he said, Emory would give him significant support for the experiments he was doing on monkeys, inducing Parkinson's symptoms chemically and then surgically ablating deep-brain organs to correct the symptoms. At the time I paid little attention to what he said about his research, though it was gaining national attention in scientific journals, because the benefits seemed too distant to have any meaning for Milly. Five years later, though, Milly had one such operation under DeLong's supervision. And three years after that, another.

Besides looking for another neurologist, we searched for other remedies. Milly's foster mother, Annie, believed profoundly in Chinese herbal medicine, as did other members of the Villarreal family. Milly's foster brother, Larry, said he had been cured of severe back pain, and Milly's foster sister, Lori, had been cured of chronic stomach pain. So, on a visit to Chicago, we went to Chinatown, where an herbal doctor held Milly's hand for a moment, said he understood what her problem was, and began reaching into various boxes to assemble what looked like a collection of twigs and tree barks. He also supplied detailed instructions on

how to prepare an herbal brew. For months I meticulously followed the directions—boiling, cooling, and reboiling the mixture until it produced an evil-smelling black tea that Milly could barely swallow. Nevertheless, she bravely made herself do so, but without any effect on her symptoms.

Another course was recommended by Milly's friend Gloria Doyle, a former researcher at the *Los Angeles Times* who has a tumor growing on her spinal cord. Surgeons trying to remove the tumor damaged the cord, causing partial paralysis of her legs, and the tumor's continued growth is progressively robbing her of other motor functions. A fighter like Milly, Gloria applied her research skills to the world of alternative medicine and found, among other things, "prano therapy," whose practitioners are licensed in Europe and elsewhere. Gloria and her husband Denis visited one therapist in Milan, Gabriella Passoni, and reported some improvement in feeling in her limbs. She told us that Gabriella was eminent enough that she had spent time at a paralysis center in Florida where her skills were taken seriously. Milly was desperate to try this, and though I doubted it would work for Parkinson's, I couldn't refuse her anything.

So we flew to Italy and visited Gabriella in her basement office for four mornings. A deeply religious woman, Gabriella was convinced that her healing gifts were akin to those of Jesus, but obviously far less powerful. Without question, an unusual heat emanated from her hands. She showed us a sheet of x-ray film with handprints on them that her energy had produced. She also said that part of prano-therapy training in Italy consisted of holding and gently manipulating an orange until it dried out inside. She showed us her petrified orange.

Her therapy consisted partly of massage and partly of flicking her hands over Milly's head, back, and legs "wicking away" "unde-

sirable" energy. Her hands did crackle, and Milly said she felt better after the sessions. We had a delightful mini-vacation in Italy, driving to Lake Como and Venice. But it was clear, as I had feared, that Gabriella's therapy made no lasting impact on Milly's condition. Milly and Gloria read books about alternative therapy, and I heard enough from them that I'm convinced prano therapy merits scientific attention, but Milly's visits to other prano practitioners in the United States did no more good than the ones in Italy.

Following a fad made respectable in upscale circles by the journalist Bill Moyers, we also experimented with various mind-body health nostrums. We got audiotapes from some of the country's noted healers and meditation experts and listened to them in bed. Following someone's advice, I tried visualization therapy, calling on Milly to imagine a warm, golden light descending from God, penetrating her brain and restoring life to her dying dopamine cells. None of this had any effect, though Milly did get some mental relief from yoga classes.

We never considered alternative cures a substitute for conventional medicine. And after Dr. DeLong departed for Atlanta, we had to find Milly a new neurologist. She saw several but couldn't find one with whom she shared the chemistry she'd had with DeLong. In late 1991, a friend of Milly's, Sharon Jayne, suggested that we visit her boss, Dr. David Kessler, head of the U.S. Food and Drug Administration, who liked to interview patients as a way of staying in touch with practical medicine. Later famous for his war on tobacco, Kessler asked Milly whether she was willing to become a subject in experimental studies. She said she would do anything that might work, so Kessler said he would call the National Institutes of Health to see whether doctors there would see her.

Milly has been a patient at NIH ever since. The doctors and nurses of the experimental therapeutics branch of the National Institute of Neurological Disorders and Stroke (NIINDS) have been Milly's support system for nearly a decade. The chief of that branch, Dr. Tom Chase, now sixty-eight, is a slender, white-haired, career NIH scientist and administrator who has worked with at least two Nobel Prize winners and helped design clinical drug trials that perfected Sinemet and its timed-release variation, Sinemet CR. Over the years Milly has volunteered for a few drug trials, which usually did not produce any beneficial results and sometimes made her feel sick. In terms of medical attention and kindness, however, she and I have received far more than we have given. The nurses, especially Marge Gillespie, compassionately listened to Milly as, visit after visit, she unburdened her despair, many times saying that she intended to commit suicide someday. Medically all that NIH could do for several years was modulate the basic Parkinson's drugs Milly took, especially Sinemet. In May 1995, one Sinemet experiment led to one of the most harrowing experiences that Milly—and I—have endured during her Parkinson's affliction.

Milly's principal doctor at NIH, Leo Verhagen, began to suspect that she did not have a classic case of Parkinson's because her symptoms did not respond well to Sinemet. He suggested that she enter the hospital, be gradually taken completely off Sinemet, and then receive precisely measured intravenous doses to gauge her response. Perhaps, he said, this would enable him to calculate her ideal dosage.

This procedure proved to be a descent into hell. After a few days without medicine, Milly was totally unable to move, speak, or swallow. She had to be fed intravenously. I watched my wife turn almost into a living corpse, able only to move her eyes,

which had a look of terror in them. She could understand what I said when I talked to her, but she could not respond or even squeeze my hand as I held hers.

I appealed to Verhagen to begin giving her Sinemet again, and he agreed that it was time. Over the course of a week she gradually ascended out of hell, but she never regained as much body control as she had before the experiment. Verhagen said the test—lasting twelve days in all—confirmed that her "parkinsonism" consisted of more than simple loss of dopamine. This is not unheard of. About one-third of Parkinson's victims have something vaguely known as "Parkinson's-plus." Milly evidently has it, but no one knows exactly what it is, what causes it, or how to treat it. Various complications of Parkinson's have been identified—multi-system atrophy, Lewy body disease, corticobasal degeneration—but none exactly fits her symptoms. Dr. DeLong later told me that he thought her case *sui generis*—"Milly Syndrome," he called it.

One definite Parkinson's-plus symptom—and the most dangerous to Milly—is loss of balance. Milly had never been an athlete. No matter how many skiing lessons she took, she stayed on beginner slopes. When we went bike riding she often fell. My reaction, when she was in danger of injury, was to get angry and accuse her of not being careful. And this is how I began to react to her falls. The first serious one was on Saint Martin, the Caribbean island, which we visited on a Christmas-New Year's ocean cruise in 1993 with Milly's foster sister Lori and our families.

I was in a store when one of our daughters ran up to say, "Mom has fallen. Come quick!" Milly had stumbled over a curb and fallen headlong into a street. She had smashed her upper lip and was bleeding badly inside her mouth. My instant reaction

was, "Oh, goddammit, Milly. Why can't you be more careful!" But I swallowed the fright and anger, apologized profusely, and got her back to the ship, where the doctor put several stitches in her lip.

It was a pattern that would be repeated over and over. Once we spent a weekend at a friend's home on Nantucket. Milly stumbled at the airport and bruised her lip. Later, at our friend's home, she was sitting on the edge of our bed. Suddenly she keeled over and hit her forehead on the nightstand. We rushed to the hospital for stitches. Another time we were visiting Lori and Jerry Long at their vacation house in Wisconsin. Milly tripped on a rug and fell forward, again hitting her lip and requiring stitches.

The falls were utterly unpredictable and frightening. Milly could go for days without an incident, then fall twice in one day. When she fell, she seemed to have no reflexive ability to put out her arms to break the impact. We became regular visitors to the emergency room at Suburban Hospital near our home. At various times Milly got stitches there in her lips, forehead, chin, and eyebrows. On an early visit I was asked to leave the examining room while the nurse talked to Milly. Clearly she was inquiring about spousal abuse. Later the doctors and nurses regarded our visits as grimly routine. Sometimes I would arrive home when Milly should have been there and chase around looking for signs that she had gone to the hospital. Several times I found a smudge of blood on a bathroom floor or on a rug and drove to the emergency room to find her. NIH assigned Milly to see a physical therapist to teach her how to break her falls, but that did not seem to work. I bought her a kayaking helmet, but she refused to wear it.

Ultimately she needed a walker. For a while we were con-

stantly trying new models—with wheels, without wheels, with and without handbrakes. Some worked for a time, but eventually she fell despite the walker—or on top of it, causing another injury. She was determined to stay out of a wheelchair. Milly insisted on walking and also driving her car. Her office garage had terribly narrow parking spaces, and her car gradually began to look like the loser in a demolition derby. Milly's face eventually was a mass of scars and bruises. She often said, "Look how ugly I am." I'd reply, "You look like you have been through a prize fight, but you are still beautiful."

Milly stopped driving in 1994 after she bumped into the rear of another car at a stop sign. Evidently her foot slipped from the brake as she was slowing down. She didn't hit the other car hard or do any damage. But the driver, a huge man, jumped out and demanded to see her license and registration. He identified himself as a lawyer—he turned out to be a mere paralegal—and accused Milly, whose medicine was not working, of being drunk. He called the police on a cell phone. They arrived, interviewed everyone, and, of course, declined to press charges. But Milly was so shaken by the experience that she started taking cabs or getting rides to work and eventually decided to move her office back to our basement. But that magnified the risk—all too imminent—of her falling down stairs.

One day in October 1995, I pulled onto our block and found fire trucks and an ambulance on the street. A neighbor said, "They're at your house." I ran up to find Milly inside the ambulance, being comforted by her sister Alex, who had been visiting from England. Milly was on a stretcher, her neck in a brace. Alex said she thought Milly was not badly injured, though she was going to the hospital for x-rays. Alex said she had been cooking and

heard Milly scream and fall—backward, as it turned out—down a full flight of stairs. Alex said she'd rushed to help and left the pan on the stove, which burned and scorched the kitchen ceiling.

It was a miracle that Milly was unhurt, but this accident terrified us both. It conjured up the worst case of Parkinson's we knew about—that of the onetime Democratic presidential candidate and congressman Morris Udall, who had fallen down stairs a few years earlier and thereafter was confined to a hospital room, unable to move, eat, or talk and had to be fed through a feeding tube. We had lived in our beloved Chevy Chase home for nearly twenty years when this fall occurred, but I knew that we would soon have to leave.

Loss of balance was Milly's most menacing symptom, but it was not the only one. Like many other Parkinson's victims, she gradually became unable to voluntarily turn in bed. On the other hand, she was also in danger of sliding out of bed at night, and we had to install a partial railing both to keep her in and give her something to hold on to when she was sitting on the edge. She complained more than anything else about a persistent pulsing, or dystonia, of her lips that she said made her feel sick. Periodically, when her Sinemet unaccountably "turned off," she also became frozen in a chair, unable to move her arms or legs. On one occasion, we were at a dinner party and when it was time to move from the living room to the table Milly could not lift herself. She had a stunned, frightened expression on her face. After several minutes the paralysis passed, and she made it to the table. Milly also reported that several times she had been frozen while doing therapy.

As Milly's condition got worse, we began looking at drastic surgical therapies to relieve the symptoms. Basically, two were available—a fetal cell transplant and a pallidotomy. I read a lot

about both. In 1994 Milly and I had met up with Joan Samuelson, president of the Parkinson's Action Network, who got us involved in advocacy and lobbying for increased federal funding of Parkinson's research. Joan put us in touch with some of the top neurologists in the country, whom I called for advice about what we should do next for Milly.

They told me that, theoretically, a fetal transplant would be the most advisable thing to do for a direct hit at Milly's Parkinson's. The procedure, made controversial by opposition from the right-to-life movement, involves injecting dopamine-producing cells from aborted fetuses into the brain of a Parkinson's victim to replace those that have died. At the time we were considering the operation, federally sponsored research trials were just beginning because a ban imposed by the Reagan and Bush administrations had only recently been lifted.

A few doctors were performing the operation without federal sponsorship, notably a surgeon in California who was reporting dramatic results and had been featured on a national TV magazine show. But the researchers I talked to warned me away from him, saying that he was not publishing any scholarly findings and stories were circulating about botched operations and brain damage. When he was unable to obtain enough aborted fetuses in the United States, the critics said, this doctor would take a patient to Japan. He'd open a hole in the patient's head there, then fly the patient to China, where aborted fetal tissue is easily obtainable—it takes material from about seven fetuses for each implant—and complete the procedure. I'd heard that Chinese hospitals were filthy. I was not about to trust this guy with Milly.

The experts I consulted also said that their review of results from Europe and elsewhere indicated that while fetal transplantation was a promising area of research, there were significant

problems keeping cells alive after they were transferred. They advised looking seriously into pallidotomy instead.

This was the operation Dr. DeLong had been studying. Because of him, Milly decided that she wanted it. And she wanted him to do it. We hadn't seen DeLong in more than four years, but he was happy to hear from us again and gave us an appointment in September 1995 for a consultation. We flew to Atlanta in trepidation, fearful that DeLong might not think Milly was a good candidate for a pallidotomy. It was reassuring that he hadn't changed much. He was still gentle and soft-spoken. He was just getting balder. He gave Milly the usual exam, noting that her condition had become a lot worse since he'd last seen her. Then, to our relief and delight, he said he thought that pallidotomy might work for her.

He explained the procedure. It was a daylong operation in which Milly would be awake throughout, helping to guide doctors to the targets they would be trying to hit deep in her brain. First they would insert a long, fine probe to electronically "map" the globus pallidus, a centimeter-long neurological "circuit box," to find the exact places affecting movement of her arms, fingers, legs, and face. Once the mapping was completed, another probe would be inserted to singe the organ at the correct spots.

Mahlon DeLong was fifty-seven at this time. A Californian whose father had been a gold prospector and town clerk, DeLong had gone to Stanford, where he fell in love with scientific research. He did not decide to be a physician until his senior year, but he still got into Harvard Medical School, where he became interested in neuroscience, then a new field. Before moving to Johns Hopkins, he spent five years at the National Institute of Mental Health, part of the National Institutes of Health in

Bethesda, doing research on techniques for recording the activity of brain cells.

He'd been interested from the outset in Parkinson's and the organs involved in it, located in a deep-brain region called the basal ganglia. In 1990, the year he treated Milly, he published the findings that established his eminence. His research on monkeys showed that Parkinson's symptoms—especially tremor and stiffness—don't result from diminished activity in the circuits of the basal ganglia, but from hyperactivity in the subthalamic nucleus (STN), a kind of internal regulator for brain signals. This excess STN activity translates into excessive braking of mobility by a nearby structure, the globus pallidus. He showed that the symptoms could be reduced by doing microscopic damage to the STN. At first he was worried, though, that inflicting lesions in the STN in humans might cause unwelcome complications, so he began experimenting on the globus pallidus. He'd begun doing pallidotomies on people in 1992.

DeLong said—and I had read in various articles—that some patients experienced dramatic improvement from the operation. He cautioned that others showed little improvement, though. And both he and the literature warned that there was potential danger. Some patients suffered brain hemorrhages. Others, because the globus pallidus sits immediately atop the optic nerve, were rendered permanently blind by a surgical accident. None of this had happened at Emory, he said, but we had to take the risk into account.

Milly dismissed the danger and begged him to perform the surgery. "I can't stand to live this way anymore," she said. "I'd rather die."

He agreed to do it.



## *Her nine*

✎ A hospital attendant stuck her head into the waiting room and chirped, "Would you like to wish good luck to the patient?" We leapt out of our seats and into the hallway. Our daughter Alex, first out of the door, took one look at Milly and burst into tears.

Milly was being rolled out of a prep room in a wheelchair toward an elevator. Her head was surrounded by a square, gold-colored metal frame that looked like an instrument of medieval torture. It's called a "halo" and serves the godly purpose of healing. But it looks obscene. It was screwed to Milly's skull in four places. We could not see the two pins at the back of her head, but the two in front were obviously penetrating the skin and flesh of her forehead, which was pinched and rust-colored from disinfectant.

It was quickly clear that Milly was not suffering any pain from the penetration. Characteristically, she immediately asked us how she looked. I told her she appeared ready for transport into some

other dimension. She'd been given a local anesthetic where the halo was attached and was mildly sedated to keep her calm for a CAT scan and the early phases of surgery. However, Andréa did not know this when she ran up to join us at the elevator door—I don't know where she'd been—and when she saw Milly, she burst into tears, too.

We rode on the elevator with her—me, Alex, Andréa, Milly's foster sister Lori, Joan Samuelson of the Parkinson's Action Network, and our goddaughter, Jenny Cabrera. The girls and I kissed Milly through the contraption as we came to a sliding door marked "Authorized Personnel Only." It opened, and she was wheeled into an antiseptic-looking hallway with another set of sliding doors beyond. "Good luck, we love you," we shouted as the doors slid shut.

We spent twelve hours, all told, in and around Waiting Room 3G at Emory University Hospital that day, November 1, 1995. Periodically we'd get an update from the Neurology Department's patient coordinator, Jim Stanton, who relayed information from the operating room that all was going fine. To ease our tension, Stanton assured us that Milly was patient 96 in Emory's pallidotomy program and that there had been no serious complications connected with the previous ninety-five. He also recounted pallidotomy lore: a Baptist minister, while undergoing the surgery, had "begun using the kind of language you're not supposed to hear from a Baptist minister." Another patient, a local Georgia resident, emerged from the surgery able to do a perfect, no-tremor Atlanta Braves tomahawk chop for the first time in years. I conveyed all of Stanton's upbeat reports on Milly's progress to friends and relatives by recording new messages on our home telephone answering machine.

I didn't necessarily believe what Stanton was saying about

Milly, however. I told Alex—a graduate student at NYU's film school, she was videotaping for a possible documentary—that if there were a "serious complication" in surgery, the doctors probably would not tell family members while it was under way for fear of causing panic in the waiting room. "I'm not pessimistic," I said. "It's just that I'll believe everything is okay when DeLong comes up here and tells us everything's okay." I remembered that I neglected to tell the doctors that Milly bruises easily. I worried that she might be prone to hemorrhaging. I also worried because she had not been able to sleep for two nights despite taking sleeping pills. Perhaps, I thought, lack of sleep would reduce her ability to cooperate during the surgery.

Fortunately, friends came to interrupt the worrying. Fred Barnes, my friend and colleague on *The McLaughlin Group*, joined us in the waiting room for a few hours on his way to Washington from visiting his parents in Florida. Jerry Leachman, an evangelist and leader of a men's religious fellowship that Fred had invited me to join a few years earlier, flew down from Washington for a few hours, too. We prayed together in the hospital chapel for Milly's safety and health. Alex fenced with Jerry about religion. "Christianity is not cool," she said. "You have an image problem with my generation—and I'm a moderate on this stuff." I told her that for someone to travel in a middle seat on Valuejet down to Atlanta to be with us was Christianity in action and that she should reconsider her values. I felt renewed chagrin that I had failed to provide my daughters with a religious education.

During the wait Alex and I had a conversation that was nearly as life-changing for me as anything else that has occurred during Milly's illness. Interviewing me for her film in a conference room, Alex asked me what would happen if Milly died in surgery. I said that I'd be bereft, but that I didn't know whether I'd fall apart,

resume drinking, have a heart attack and die—or find some way to endure. I asked her what would happen to her. We turned the camera around, and she said that she and Andréa had had a long discussion about this the night before—their first ever, they realized.

"Andréa said that our family would fall apart and she would never see me or you again," Alex said. "She said that she'd never come home for Thanksgiving because you probably wouldn't bring her home."

I was shaken by this. "That's ridiculous," I said. "I'd want to feel closer to you kids than ever, though I don't know that you'd want to be close to me."

"Why?" Alex asked.

"Because Mom is the glue that holds our family together," I said.

Alex responded, "That's what Andréa said. And I said the same thing. 'Mom is the glue.' And if she was gone, everything would fall apart. I think I would maybe have to get married." She laughed nervously.

I said I thought I had drawn closer to the girls since I'd stopped drinking and since Milly had been sick, though I granted that most of the talk I had with them was "career talk," not "girl talk" like Milly could have. But I said, "Our family is not going to break up under any circumstances. I won't let it happen. If the worst happened in this operation, I would try to be as much of a Mom as I possibly could be. But the worst is not going to happen. So let's not talk about this anymore."

Indeed, the worst did not happen, but I resolved on the spot to be as good a father in the future as I was trying to be a husband to Milly. I have been as good a father as I know how to be—calling the girls almost every day whether Milly instructs me to or not, seeing to it that they *are* home for holidays, hugging

them often, praying for them every day, helping with money, and talking about their hopes and fears and souls as much—well, almost as much—as about their careers. The girls have had very different reactions to Milly's affliction. Alex will sit on a bed beside Milly and me and sob openly about how bad she feels. Andréa pulls away, talks clinically and practically about Milly's disease and confides her emotions only to her therapist. I notice her crying occasionally when she sees new evidence of Milly's decline, but she brushes away her tears if she knows someone is watching her.

I had asked Dr. DeLong whether I could be in the operating room for Milly's surgery. He told me firmly, "No." But I do have an idea of what happened in the operating room. I later witnessed an operation like Milly's, and I've seen videotapes of others. Milly was wheeled into Operating Room 15, a place surprisingly cluttered with books, papers, boxes, and spare surgical equipment as well as monitors and the operating table. The table was not flat; Milly's head was raised to a half-sitting position, and her legs were also elevated.

A four-foot frame was clamped to the table at head level and blue surgical sheets were attached to create a sterile environment from her forehead back. Her face, with the front of the halo bent outward over her nose and mouth, protruded from the front side of the sterile screen. The room was effectively divided in half. The front side was DeLong's side, dominated by electronic screens.

On the other side of the screen, the surgeon's side, a six-inch by three-inch swath of Milly's hair was shaved away as part of the preparation for surgery. A neurosurgery resident swabbed the area liberally with red disinfectant, then covered it over with layers of plastic prior to the arrival of the surgeon, Roy Bakay. Overweight,

bearded, gruff, and prematurely gray—but commanding—Bakay was forty-six when he operated on Milly the first time. He'd been at Emory since 1982 after training in neurosurgery at the University of Washington and doing research at NIH. He met DeLong and his neurology associate, Jerrold Vitek, when they came to Emory from Hopkins in 1990. They'd done their first pallidotomy in 1992. Vitek and DeLong were both present for Milly's pallidotomy. Only Vitek was there for the operation I witnessed.

On Bakay's side, the patient's swathed head protruded through the sterile screen. Above her head, a complicated superstructure of frames was attached to the halo. Most prominent was a metal arc marked in centimeters and millimeters that could be moved forward and back and locked into the exact right place above her head. Attached to that was a black fitting for the microdrive, the \$65,000 engine that would drive thinner-than-hair needles into her brain one millimeter at a time. The halo was bolted to the back of the operating table. The saying in brain surgery is that "a millimeter is a mile." There is no room for "play" or mistaken motion in any machine. Bakay attached the microdrive to its housing, then moved the arc out of the way temporarily as the surgery began. Bakay is celebrated, even notorious, at Emory for ensuring that everything is working correctly.

In the operation I witnessed, when Bakay cut the plastic coverings over the patient's head with scissors, exposing the scalp, he said, "This is the worst prep I've ever seen." He grabbed a razor blade and widened the area of exposure. He applied more disinfectant. Then he told the patient, "This will sting a little. It's a pain killer," and jabbed a surprisingly large needle into her scalp about three inches above the hairline. He touched the scalp to see whether numbing had begun, then jabbed again and again, deadening the entire area.

With a scalpel, he cut at a pre-marked place on her scalp and began using scissors to aggressively cut and pull the tissue away from the skull. An assistant clamped it back quickly. There was surprisingly little blood for such a large wound, about three inches in diameter.

Bakay abruptly left the sterile area, went around to the neurologist's side of the room, and studied the patient's MRI pictures, posted on a light-screen. He stripped off his outer surgical gown and gloves and dumped them into hampers.

When he returned to the sterile area, a nurse was waiting with fresh gloves—he wore three pairs much of the time—and a new surgical gown. He barked, "I don't know who set this up. The incision is about a mile behind where it's supposed to be." He went back to the patient and cut some more, now exposing about a four-inch-wide area on her skull. When I saw this operation I was thankful I'd been denied permission to watch Milly's. I would have been terrified, outraged at seeming errors, afraid to complain and afraid not to. The tension might have affected the outcome. For the surgery I watched, I was detached—and impressed with Bakay's refusal to accept less than perfect work. Out of earshot, a nurse called him "Mr. Grumpy." For the patient's sake, I was glad he had that attitude.

Once Bakay had made the incision he wanted, he moved the metal arc and the microdrive into place above the patient's scalp and fit a long, thin shaft with a protruding needle into the microdrive housing. He moved the needle above the exact spot where he wanted to open the skull and marked the spot with a pen, then moved the needle away again.

He swabbed on more disinfectant. Then he took a blue hand drill and began grinding at the skull. He stopped, chipped at the bone with a small chisel, and resumed drilling. At last he opened a

hole twelve millimeters in diameter, about the size of a dime. Somehow it looked bigger to me, almost as big as a half-dollar. (In Milly's case, the hole and the operation were on the left side of her brain, so that the right side of her body would be affected.) When he had penetrated the skull, Bakay said, "We're now at the dura"—the tough, thin tissue that covers the brain. He used another small drill to penetrate it, then he moved the microdrive and needle into place above the hole, where fluid seemed to pulsate at the rate of heartbeats. "Are you ready down there?" he asked across the sterile screen. "Yeah," said Vitek.

The action moved to the neurologist's side. Vitek—or, in Milly's case, Vitek and DeLong taking turns—used a small hand-wheel to operate the microdrive, lowering the needle through the frontal lobe of the brain, where intelligence is centered, through the midbrain, and finally into the basal ganglia, which controls motion. The patient can feel none of this because the brain itself contains no nerve endings. The basal ganglia is located about three and a half inches deep in the brain. It contains the structures—striatum, globus pallidus, subthalamic nucleus, and substantia nigra—whose misfiring causes Parkinson's symptoms. The pallidotomy, by wounding the globus pallidus, is designed to restore fluidity of motion. In some cases a pallidotomy—or an operation on the subthalamic nuclei, as in Milly's later surgery—has also helped to restore a patient's balance.

Before the globus pallidus can be "burned," however, it must be precisely located and mapped. As Bakay and Vitek explained, an MRI does not provide a perfect, distortion-free picture of brain structures, so probes must be used to get a more accurate picture. It struck me that the pallidotomy "mapping and zapping" process resembles sonar-based submarine warfare as depicted in Tom

Clancy's *The Hunt for Red October*. In each case the doctor (captain) has a rough map of the terrain but must rely on sound readings to be sure of where he is and where his target is.

In the medical case, the tip of the needle penetrating the patient's brain contains a tiny electrode that picks up the distinct electrical signals transmitted by various kinds of cells. The signals are converted into sounds and electronic graph readings in the operating room. The sounds crackle like radio static. Just as a good sonar operator can distinguish one class of enemy submarine from another, Vitek and DeLong can distinguish one part of the brain from another. Vitek compares the process to riding in a train through Europe wearing a blindfold: "You can tell where you are by the languages you hear." The neurologist's side of the operating room is dark during the mapping, and Vitek, wearing ear-phones, reads out reports to technicians who use flashlights to record his findings on a graph sheet.

The globus pallidus is the size of a small plum, with an internal and external structure, the GPI and the GPE. It's the GPI that must be damaged at precise points. These are located by having the patient move limbs, fingers, eyes, eyelids, and tongue, each setting off a distinctive electronic signal. Vitek and DeLong can move the electrode up and down into the brain structures one micron (one-tenth of a millimeter) at a time, a distance no deeper than a cell. But to move to different planes or lines of attack, they have to extract the needle and reinsert it. In a pallidotomy, special care has to be taken to avoid damaging the optic nerve or the brain's internal capsule, which can render the patient blind or paralyzed.

In the operation I saw, as Vitek mapped, Bakay periodically came around to study the MRI picture and calculate new courses

for penetration. Then he would regown and reglove, return to his post, adjust the magnifying lenses attached to his eyeglasses, and change the position of the microdrive for the next insertion.

In Milly's case, the three doctors made nine separate penetrations of the brain on different parallel planes. The average is four to five, according to DeLong. On the first mapping pass they found the GPI but wanted to explore further. On the second and third, moving the needle's angle, they hit the GPE and the striatum, not the GPI. On the fourth they hit no significant cells at all. On the fifth they found the optic track—doing it no damage, fortunately—but not the globus pallidus. On the sixth they got good readings from the internal globus pallidus. Having found the target again, they went in three more times with another sort of electrode—this time not to listen and map but to inflict lesions with a tiny heat probe.

When the damage was done, with hoped-for beneficial results, the main action in the operating room reverted to Bakay, who installed a hard plastic plug in the hole in the patient's skull and then, with a resident assisting, unclamped and meticulously stitched up the patient's wound. Then he installed dozens of staples into the scalp and covered the whole with a large white bandage. From start to finish, Milly's first ordeal lasted from 8:00 A.M., when the halo pins were drilled into her head, until 6:00 P.M., when she left for the recovery room. The surgery itself had lasted seven hours.

DeLong came to see us in the waiting room and said he thought he had noticed improvement in her fluidity of motion. And he told us that she had been "a star" in the operating room. "She kept worrying that she wouldn't do things right," he said, "but I told her she won the prize." There was no problem with hemorrhaging or any other complication. The doctors had

put her to sleep while closing her wound and removing her headgear, he said. We could see her in an hour or two. Milly's NIH doctor, Leo Verhagen, had been in the operating room, and he, too, came in to report to us that everything had gone well. DeLong said that he could not predict how long any good effects from the surgery would last. At this point we were all ecstatic merely that Milly had come through the surgery and that there had been "improvement." We were not surprised that she had behaved like a heroine.

Milly's first words were, "Alex, turn off that camera. I look terrible." We all laughed at her vanity and told her that, to us, she looked beautiful. And in spite of bandages and dark circles under her eyes, she did. Her forehead seemed less wrinkled, and her face looked more relaxed. I had her grab my fingers with her right hand. Her grip seemed significantly stronger than it had been before the operation. As we left the room to let Milly rest for the night, Alex asked, "Well, what do you think?" I said, "I think, terrific."

Milly and I were deeply invested in the success of this operation. The week before going to Atlanta, Milly had said she hoped that she wouldn't freeze anymore, that she would be able to walk, that her posture would improve and she wouldn't fall. "I want to be perfect," she'd said, "but the doctors say I won't be. But I'll take 80 or 90 percent." I said, "I'd be deeply grateful to have 80 percent of the Old Milly back." I hoped, on the basis of something DeLong had told me, that some of Milly's indomitable personality and fast wit might return because, with her body functioning better, she'd be less depressed. "Depression saps mental energy," he had contended. We were all talking guardedly, but somewhere inside we harbored a vision of Milly whole again—able to walk and drive, work and argue, boss and laugh and give good advice.

The first indications were good. The next morning DeLong and Vitek got Milly out of bed, and she and I danced briefly around the room. Her balance wasn't perfect, but it seemed improved, and I thought she moved less haltingly than before the surgery. She was back on Sinemet, and she performed better on all the tests in the classic neurological exam. Later Alex and Andréa arrived with the rest of Milly's army of visitors, now joined by Jill Schuker. Milly's first solid food was brought in, and she ate and drank without any sign of tremor or stiffness. We all agreed that her appetite was much better. Jill said, making a toasting motion, "A success. A new beginning. A new sense of normal." Milly responded, "I don't know. I'm still afraid." I took the group out shopping, buying each person a gift to commemorate the occasion. For Milly, we bought a half-dozen smart hats and caps that could cover her bandages for the trip back home and for as long as it took for her hair to grow back. I tried to get Milly to keep her hair short and let it go all white, like her sister Alex's. But when we got back to Washington, she immediately bought an expensive dark brown wig. And when her hair grew in she dyed the white away—determined, she said, not to look older than I did. Even though we hoped she would be liberated from many Parkinson's symptoms, Milly anticipated that tremor might make it hard for her to put on makeup, so she painfully had eyeliner tattooed above and below her lashes.

The pallidotomy produced some immediate improvement, and we judged it a net success. But it did not bring back the Old Milly. To the good, her lips stopped involuntarily pursing, which had made her feel sick. She no longer froze in a chair. She could "scoot" and turn in bed. Her grip remained strong. But Milly's voice kept losing power. She did not become less depressed. And she did not stop falling.

The old pattern resumed: some days, she could walk around the house safely by herself or using a walker. In 1996, when a PBS crew filmed her being examined at NIH for a documentary I did on the politics of medical research, she walked around the hallway on my arm with only a brief stumble. But other times, at home and away, she collapsed forward or to the side and was unable to break her fall. The emergency room visits recurred, and the stitches. One day when Andréa was home from medical school, Milly had almost reached the bottom of the stairs when she suddenly fell forward, hitting her head on a wall. She was stunned and couldn't remember our dog's name. We put our three-story house on the market and signed a contract on a one-story rambler. But Milly, typically, refused to set a realistic price on the house that she loved, and in a down-market, we got no offers for more than a year. I lived in renewed fear that she would fall down the stairs again and injure herself severely.

My anxiety—both immediate and long-term—deepened when I visited Mo Udall's hospital room in 1996. *The Washingtonian* magazine asked me to write an article on Parkinson's after Attorney General Janet Reno announced she had been diagnosed the previous year. She refused to be interviewed, though. I was also turned down by the Reverend Billy Graham, then misdiagnosed as having Parkinson's. (It later turned out he had hydrocephalus, which could be relieved by a fluid-draining shunt.) So I made Mo Udall—and Milly—the central characters of my article. I got help from Udall's wife, Norma.

Long considered the funniest man in Congress and one of the strongest liberals and environmentalists, Udall was diagnosed in 1976, at the age of fifty-three, while he was running for president. He kept it secret at the time and was helped in doing so by NIH's Dr. Tom Chase, later Milly's doctor. Chase has helped other

celebrities hide their Parkinson's as well. L-dopa kept Udall largely symptom-free until the early 1980s, when his six-foot-five frame began to stoop, his head began to shake, and his facial muscles began to freeze into "the mask," a common Parkinson's symptom that Milly does not share. Udall's speech, like Milly's did later, became progressively slurred. His personality also changed, though not the way hers did. He became forgetful, retelling jokes everyone had heard before, even the same evening. By the late 1980s he was experiencing mild hallucinations, as some Parkinson's patients do in response to L-dopa. Norma said he thought he saw a little white dog ducking around their house, though they didn't have one.

As time went on, Udall could barely get into and out of a car. He had difficulty getting words out. Either the medicine or the disease turned his internal clock around, so that he'd stay up all night pacing the house and be dead tired the next day, when he was supposed to be alert in chairing the House Interior Committee. He couldn't cut his food and eventually had to be fed. He did not suffer from depression, according to his wife. "He'd kid," she said. "When he couldn't get out of the car, he'd say, 'Look at me, the star athlete.' It was black humor."

Udall announced after his reelection in 1990 that he wouldn't run again, but he did not make it to the end of his term. In January 1991, tired of watching an NFL playoff game, he decided to go upstairs to bed. "See ya later," he told Norma. The Udalls' townhouse had an elevator, but he hated to use it because if he leaned against the door, it would stop between floors and he couldn't make it start. Besides, of all the afflictions of Parkinson's, the one he didn't seem to have was trouble climbing stairs.

Norma said she heard him mount four or five stairs. Then she heard him yell—and crash. She ran to find his head covered with

blood. He had suffered a concussion and broken four ribs, a collarbone, and a shoulder blade. He spent weeks in intensive care, then went to the Veterans Administration hospital about three miles north of the Capitol. He was unable to swallow and was fed through a tube into his stomach. He never returned to Congress and formally resigned in May 1991 after thirty years of service. "See ya later" were the last clear words anyone ever heard Udall utter.

When I walked into Udall's hospital room with Norma, he was asleep. He looked younger than his seventy-three years. The room was plastered with photos from his pro basketball days, presidential campaign posters, and other political mementos. A guest book indicated he'd been visited by First Ladies Barbara Bush and Hillary Rodham Clinton and by many House and Senate colleagues—most frequently by Senator John McCain, whom Udall had befriended, even though he was a Republican, when McCain was a freshman Arizona congressman and the most junior member of the Interior Committee.

When Norma woke him up, telling him that he had a visitor, Udall looked at me with what seemed to be recognition and a small smile, the way an experienced pol does with a constituent whose name he doesn't remember. I started regaling him with the latest political news: President Clinton's election-year State of the Union address, Newt Gingrich's diving poll ratings. For five minutes or so he seemed to brighten and his eyes suggested comprehension. Then he fell back to sleep.

I could not tell whether he understood anything. Norma said that she couldn't tell either whether he comprehended what she said and read to him. *If he does, I thought, it's a terrifying situation: he is trapped in his body, unable to connect with other people.* I hoped that his mind had closed down, but I knew that Milly's had not. While



gets upset. On one such occasion, as we tried to negotiate a too-small stall in a women's bathroom at Midway Airport in Chicago, she whispered to me, "I hate my life."

The pallidotomy did nothing to ease Milly's depression. Neither did Prozac or Zoloft, which marginally worsened it because they were not only ineffective but caused Milly to gain weight. When I interviewed her for the PBS show she said, "I can't do anything for myself because I can't stand. So I have to have somebody here all the time. They have to clean house because I can't do it. I'll fall. I can't wash dishes. I can't dress myself. I can't pick up my pants myself. Someone has to go into the bathroom with me. I've lost my dignity. People have to help me do everything. Even eat—I can't cut my meat."

She sobbed. "It makes me feel terrible because I have to depend on you for everything," she told me. "I'm completely lost. I haven't got any independence. I used to drive my own car. Now you have to help me in and out of the car. You have to go with me every place, and if you sit me down I have to stay seated there because I'll fall if I get up.

"Every day something new happens to me, something else I can't do. Something else. Something else. Make another adjustment. The worst is that I have to ask permission for things. I'm going to be a baby. A baby—that's what I am. I can't do anything. I have to ask permission to go to the refrigerator, permission to get a book, permission to go to the bathroom."

About the pallidotomy she said, with a little laugh, "Well, they put an umbrella or a lampshade on your head. And then they drill a hole in your head, and they go into your brain and hit something. You're awake the whole time and doing different things for them." She got serious. "The operation didn't work. Some things

are worse because of it. My handwriting got worse. My balance didn't improve. And I'm constipated all the time."

I asked her whether there was anything on the medical horizon that gave her hope. "I don't see anything. I see a dead future. They aren't going to find anything. Maybe someday, but not for me. I have no hope."

I asked her whether she was depressed. "This depression really owns me," she said. "I want to die before I become a vegetable. I think I have about three years because it seems to be going rapidly, the deterioration. I think I'm going to be Mo Udall in three years." She started to cry again. "I'm probably going to die. I want to live. I don't want to be like Mo Udall. I don't want to be kept alive."

She wanted to live, but not like this. So in 1998 we began looking again for medical options. Joan Samuelson consulted all the leading neurologists she knew and made a list of who was doing what kind of procedure. I started calling them to ask what we might do. At the University of Colorado, Dr. Curt Freed said that fetal transplantation still wasn't ready. In any event, he said, Milly would not fit into his study protocol because she had already had a pallidotomy. Dr. Ole Isaacson at Harvard raised the same issue about a study he was involved in, using fetal cells from pigs. Two other promising theoretical areas, neural growth factors and genetic engineering, were nowhere near ready for trial on humans.

The newest practical thing being done was deep-brain stimulation (DBS) of one of the structures of the basal ganglia—the globus pallidus or the subthalamic nucleus (STN). This involved implantation of a pacemaker-like device in the brain—and a battery under the flesh of the chest—to modulate the hyperactive circuits. The operation had been performed most often in Europe

but was also being done in Canada, at the University of Kansas—and by DeLong and Vitek at Emory. Milly and I went to Kansas City for an exam, and doctors there said they thought she might benefit from the surgery. We briefly considered going to Liège in Belgium after a Washington friend said she could arrange for us to stay with the royal family there. Instead, because of DeLong, we went back to Emory.

We saw him in September, and Milly begged him to schedule the surgery—and to install an electrode not just on one side of her brain but on both sides at the same time. She wanted a decisive outcome. DeLong said that he thought she might benefit from stimulation of the STN, but he said that the Emory team had never done a bilateral procedure before and that he'd have to check with Bakay and Vitek to see whether it made sense. After we went back home, Milly told me over and over that only a double stimulation would do. I relayed her wishes to DeLong, and he finally said that he'd do it—on October 26, a Monday.

Milly and I arrived in Atlanta on the Thursday before, and she underwent preliminary checks on Friday. All weekend I drove back and forth to the airport to collect a small army of family and well-wishers who assembled to be with her, including Alex and Andréa, Lori, Joan Samuelson, Dr. Verhagen, and Milly's foster mother Annie. Of course, we took everyone shopping, too. Lori, who is as close to Milly as a real sister, told me later that while I was off doing something, Milly confided in Annie how frightened and desperate she was. The first operation had done little lasting good. She hoped for a miracle with this one, but feared it would not happen. She was furious at the endless doctor visits, tests, medicines, and trips to the hospital that she had to endure. "Why me?" she cried, and tried to figure out what terrible wrong she had committed to be condemned to this.

"Here she was," Lori told me, "blaming herself, when she had been nothing except a tower of strength to everyone in crisis all her life. Milly's love is boundless. It has no end. I think it feeds her own need to be loved and cherished by others, but it comes out as pure generosity." Annie tried to comfort Milly by telling her stories of crises in her own life that her daughter, Lori, had never heard before. "True to form, Milly was so touched by someone else's pain that she put aside her own," Lori told me.

On the day of the operation we gathered in the same room where we had waited out the first operation, 3C. But this time DeLong said I could accompany Milly for the installation of the halo and the MRI to follow, though not for the operation.

The prep room looked familiar, like a hospital emergency room with screened-off areas in which many patients were being readied for surgery of various kinds. Milly complained not at all as an attendant cut off most of the hair on the front half of her head and shaved a wide swath. The aide also cut and shaved spots at the rear of her head. Then a nurse, warning Milly that it would hurt, stuck needles in her forehead and in the back of her head. When the skin was numb, she fitted the halo over Milly's head and began turning the four sharp screws on its mount toward Milly's head and then into her skin. She turned each with a small wrench tight into Milly's scalp. It was painful for me to watch, but Milly took it like a heroine. She was a veteran, after all.

Then, with the halo around her head, she was wheeled to an elevator and downstairs for an MRI. Milly has been inside this massive machine dozens of times over the years, and she still detests MRIs because they are so confining and noisy. She usually wants me with her, and I was glad that I could be there this time, holding her leg, massaging her feet, and telling her amid the clanking how much I loved her.

Afterward she disappeared again into the operating room—this time for more than twelve hours. Stanton reappeared to give us periodic updates on Milly's progress—again, all positive. This time I was more inclined to believe him, although I did not share Milly's hopes that the implants would be the miracle that she yearned for. My wildest dreams would be fulfilled, I thought, if there were just some improvement in her balance, if she could perhaps use a walker again. Jerry Leachman once more flew down to Atlanta to be with us and to pray for Milly's well-being. As during the pallidotomy, I left messages on our home answering machine reporting that Milly was doing fine.

Again, I know something about what was happening in the operating room. The surgery I witnessed later was a DBS implant in a woman's subthalamic nucleus. Much of the operation was similar to a pallidotomy except that the target was different and the purpose was not to damage the organ. After three mapping tracks, Bakay installed a millimeter-thick tube into the microdrive. Inside was a thinner wire with four electrical contact points on the end, all crowded into a space of three millimeters.

About the time the actual implant was to occur, everyone in the operating room had to don lead vests as technicians wheeled a huge fluoroscope into the room to give Bakay and Vitek a real-time picture of the insertion. The machine was positioned on Bakay's side of the sterile barrier and aimed at the woman's head from two sides. A monitor showed the long tube extending into the patient's brain. Bakay told me that the purpose of having this picture was to make sure that when the guide tube was removed the electrical lead did not move with it and leave the target point.

I asked Vitek whether it wouldn't make sense to have a machine—an MRI or a super-fluoroscope—that could guide the surgeon and the neurologists during the entire operation. He said

that some hospitals did have such a device—including the University of Minnesota, where he'd received his M.D. and Ph.D.—but not yet Emory. I said that, as things were, "what you do here definitely is rocket science, but it is also art." He agreed with that. And to prove the point, the fluoroscope picture showed an unwanted bend at the end of the electrode wire in the patient's brain. Bakay delicately manipulated the microdrive to straighten it and put the lead exactly where it was supposed to be—the STN, a structure that's even smaller than the globus pallidus, about the size of a large pea or small grape. When it was in place, Vitek sent impulses of various voltages down the wire and tested the patient for responses. He asked her to move her fingers, hands, feet, and legs at each voltage—one to five—and tried out various combinations of contacts. The patient reported feeling dizzy at three volts, but that subsided.

When Vitek believed he had the optimal setting, Bakay and a resident closed the wound, as in the pallidotomy. But in this case a wire extended through the plug in the top of the head. The patient, awake throughout the STN implant, was given a general anesthesia. Then Bakay made a two-inch opening in her chest just below the collarbone. He installed a two-inch-square battery and, using another guide tube, ran the wire under the scalp, behind the patient's ear and down into the chest, connecting it to the battery. Then he sewed her up for removal to the recovery room.

The surgery I watched lasted from 9:45 A.M., when Bakay made his first incision, to 4:30 P.M., when the patient received her last stitches. This was just a one-side STN implant, however. Milly received two implants. And before they installed them, DeLong, Vitek, and Bakay did twelve mapping tracks, seven on her left side and five on the right. Milly's surgery lasted until 10:00 P.M., more than twelve hours. It was an ordeal for her and also for

Bakay. DeLong and Vitek, when they came to the waiting room to report, made it clear that Bakay had not appreciated the task. When he arrived I thanked him profusely.

The doctors warned that Milly's brain had undergone a lot of penetration. So, they said, if the operation achieved results, they might be longer taking hold than for the pallidotomy. This warning didn't prepare us, however, for the scare that followed: Milly did not wake up on schedule from the anesthesia. "This happens," DeLong said, trying to be reassuring. "The brain takes time to recover." DeLong did not use the word *coma*, but that is what we feared he meant. All of us in the waiting room found ourselves begging God to let Milly be okay.

Sometime after midnight, we were allowed to see her briefly in the intensive care unit. Andréa lovingly caressed her mother's forehead and softly called on her over and over to wake up. Andréa asked her to move a finger. She put her finger in Milly's hand and encouraged her to squeeze it. Milly did not respond. We were ushered out and went back to the waiting room. We stayed there nearly until dawn, hoping for some positive word, but we were merely told that Milly was "sleeping." We went back to our hotel for a few hours, reassuring each other that Milly would be awake when we returned. None of us slept that night, however.

Milly was better the next morning. She was alert. She could be understood, though her voice was soft. But she was having difficulty swallowing and had to continue receiving nutrients intravenously. She got out of bed and tried to walk, but there did not seem to be any improvement in her balance. This operation seemed less successful than the pallidotomy. On Wednesday she was able to eat soft foods, which was a huge relief. But DeLong surprised and disturbed me by saying that she would have to stay in the hospital for several days of recovery and after that would

need to be transferred to a rehabilitation hospital for physical and occupational therapy. Her brain had undergone more probing and stress than during the pallidotomy, he said, and she needed extra time and help recovering.

I started scrambling—first to find the appropriate hospital and get insurance clearances, and then to figure out whether I could still do all the work I was committed to. The 1998 congressional elections were less than a week away, and I had lined up a horrendous schedule that I'd thought I could handle based on Milly's quick rebound after the pallidotomy. It was easy enough to phone in from the hospital the two columns I had to write Tuesday and Thursday for *Roll Call*—one on the Monica Lewinsky scandal and one on the forthcoming elections. But then I was supposed to be in New York Friday to tape the Fox News show *The Beltway Boys*, which I had started with Fred Barnes that summer, departing from *The McLaughlin Group* after sixteen years. And I was supposed to stay in New York for an election rehearsal Saturday morning and Fox News Sunday. I was also scheduled to make a speech in New Orleans Sunday night.

Andréa and Alex said they'd stay in Atlanta with Milly while I traveled, and Jill arrived to be with them. I canceled the New Orleans speech but flew to New York on Friday, then flew back to Atlanta Sunday afternoon. I spent Sunday and Monday with Milly and flew back to New York Tuesday morning, did election commentary Tuesday night, and flew back to Atlanta Wednesday morning on next to no sleep. I wrote my column on the plane and phoned it to *Roll Call* from the hospital. I checked Milly out of the hospital that afternoon. As we drove to the airport she was sporting one of a new set of hats we'd bought. Back in Washington we drove to the National Rehabilitation Hospital and checked her in. It remained all too obvious that the surgery had done Milly

little good at all and might have done harm. Again, to the good, the dyskinesia in Milly's face eased, relaxing the muscles in her lips and forehead. But there was no improvement in her balance. Her voice volume and ability to articulate were worse. She could no longer chew food and continued to have difficulty swallowing. While Milly was at NRH for two weeks, I bought various microphones, amplifiers, and portable speakers, which I hoped would allow her voice to be heard. But she still could not be understood because she could not articulate words well. She could not swallow her medicine with water. She'd gulp and the liquid would go down her windpipe. She risked aspirating the pills, so she had to begin taking her medicine with applesauce. The rehab hospital taught her how to move from a bed to her wheelchair and from the wheelchair to a toilet.

We went through one last procedure that we fervently hoped would improve Milly's basic condition. A specialist from Medtronic, the company that makes the DBS system, came to NIH to adjust the voltage and other settings of the electrodes. Watching, I prayed that some new combination would suddenly produce a transformation. He worked for three hours, repeatedly moving a magnetic wand above the control system embedded in Milly's chest. He tried one permutation after another—three volts on the right side, two on the left, top lead on the right and bottom on the left, and so on. But in the end he concluded that DeLong and Vitek had established the optimal settings in the first place. There was no longer much hope that Milly could avoid being rendered a permanent invalid by Parkinson's.

The prospect was made harder to bear by the astounding success at Emory experienced by a woman named Sybil Guthrie, who was the subject of a widely watched *Dateline* NBC segment in 1999. Before her first STN implant, Mrs. Guthrie had many of

Milly's symptoms. She was confined to a wheelchair and had difficulty eating and speaking. She suffered severe tremor and had to be helped getting dressed. Her face was freezing into a "mask." After one implant operation, she was able to walk and talk slowly and the tremor subsided on one side. She had a second STN implant some months later, and the transformation was profound. She laughed. She spoke clearly. And in the last scene of the segment she ran freely, beaming, through her backyard. When Milly and I watched the segment together, we were glad for Mrs. Guthrie, but the question of Milly's that I could not answer was: "Why didn't that happen to me?"

We watched this together. We do as much together as we possibly can. But just before Milly's first surgery she'd said, "If you get sick, you are alone. Nobody can be with you. Nobody knows how you feel. Nobody wants to be with you that long. You are alone. No matter how much people love you, you are alone." I love her profoundly, and I am determined not to let her suffer alone.

## *Losing Milly*

The bride, Nicole Reyes, and the groom, Michael Dadich, and their attendants seemed blissfully unaware that a parallel festivity was taking place at their wedding reception outside of Chicago in September 2000. It was a reunion of the Roulettes and the Latin Dons. The honored guest—bathed in affection, laughingly recalled memories, and blinked-back tears—was Milly. Her old neighborhood girlfriends and guyfriends are all middle-class suburbanites now, filled out and gray. They see each other from time to time at weddings and funerals, but when the word got around that Milly was coming to the wedding of Mona Reyes's daughter, calls poured in from the whole gang asking for invitations.

I have not seen Milly so happy in years. I pushed her in her wheelchair from table to table, with her foster sister Lori videotaping as I asked her old pals for their favorite Milly memories. There was a constant theme: as president of the Roulettes, she was bossy, "the dictator," "the headmistress," but with everyone's

welfare and respectability in mind. She established rules: no smoking in public, no kissing boys in public, no French kissing ever, no drinking, no swearing. Don't ditch classes, get your homework done before you go out, and graduate and go to college. Violators—there were lots of violators, they mirthfully reported—had to pay a fine of twenty-five cents per offense, which was used to build up the Roulette treasury so the girls could buy club jackets. Milly also organized hayrides and dances in church basements to raise money.

Ex-Dons reported that she'd also tried to boss them around but was even less successful. Besides drinking, some of their activities—petty theft, stealing a car, robbing drunks—could have had consequences, and no one dared tell Milly about them then, and they even hesitated to tell her about them now. To put her down in the old days, one of the guys used to pinch her nose, knowing that she thought it was too big and that she hated it when he did that. He ceremonially did it at the party, causing everyone to roar, especially Milly. It developed that Milly once had a crush on one of the guys, green-eyed Rudy Ortega, who'd invited himself to the wedding from California to see her. "She always wanted him to kiss her," Lori said, "but he never would." He finally did that night, and Milly looked like a schoolgirl.

It's fair to say there might have been no wedding that day without Milly. The bride's father, Danny Reyes, said his favorite Milly story was that when he returned to Chicago from serving in the army, his old girlfriend, Mona, didn't want to see him or even talk to him. At a beach party Milly told Mona: "Go kiss him." She did, they got back together, and they've been married for forty years. And this was not the only match made by Milly, her friends said. In recognition of the leadership and judgment she'd shown in

her youth, and the courage she was obviously showing now—unable to speak, only to laugh, receive hugs, and be there—these old friends swathed her in love and made her bloom. To see it made me as happy, too, as I have been in years.

Then, on her first day back in Washington, Milly went to see a dentist about her latest project—orthodontics. Her lower front teeth have always been mildly crooked—West Side Chicago kids didn't get braces—but Parkinson's has caused her chin to recede and her teeth have become more misaligned. She has somehow convinced herself that if her teeth are straightened, the effects of Parkinson's will be less visible. This almost surely won't work, but I can refuse Milly nothing, so she is getting braces at age sixty-one. Vanity is a sign that, in her tormented inner debate about whether to keep fighting or give up, the balance still favors life.

I take joy in such signs because I desperately do not want to lose her. I am happy that Milly pores through the catalogs that come in the mail and each season orders clothing to keep herself smartly dressed. She cannot be heard on the phone, so she shows Grelanda or Felly what she wants and hands them a credit card. She takes excursions to Saks and one day racked up purchases worth \$8,000; that time I did refuse and made her take it all back, or almost all. Afterward she justified the spree to her friend Netty Graulich on the grounds that, "as the wife of Morton Kondracke, I deserve to be well dressed." She is forever showing grit. When the Siegels bought an elegant brownstone in our neighborhood, Milly insisted on fully inspecting it—every room and closet on all four floors and the roof deck, with me helping her mount and descend the stairs. When she's wheeled through a doorway, she insists on reaching around to turn out the light and shut the door, even though she's liable to hurt her arm in the process. She wants

her eyebrows tweezed. She's never satisfied with the way I brush her hair and invariably redoes it herself. When there was a reception for Michael J. Fox at the 2000 Republican convention in Philadelphia, she insisted on being driven up from Washington to attend and had her picture taken, beaming, with Muhammad Ali. Even though drugs and operations have failed to arrest her Parkinson's, she is willing to try anything that might work.

As Milly is regularly brave, I fleetingly indulge in fantasies that she might recover. One day when I was giving her a shower I noticed that her hair is not all white; in the back there are some strands of black. I thought, *Could this be the first hint of a reversal of the Parkinson's?* It was no such thing, of course, and I knew it. But there are other moments. Once in a while she will speak absolutely clearly. The Old Milly will be back for an instant, telling me to phone the girls, saying she wants to make this or that trip or reminding me to send flowers to somebody. She can never walk unaided, but sometimes she moves smoothly, especially on stairs. Ordinarily she needs to have her food chopped up or pureed and she can't manipulate a fork or spoon by herself and has to be fed. But sometimes she'll insist on having mussels or barbecued ribs for dinner and gets them down without choking. Other times, she pushes away help and manipulates her own fork. Whenever any such thing happens, I think, *Could the disease be turning around somehow?*

Alas, it is not. The flashes of hope disappear and the reality dominates: my wife is slipping away from me. She is dying, slowly but inexorably. It's progressively harder for her to eat solid foods, and if she tries to drink from a glass it usually goes down the wrong pipe, making her gag. Often she has trouble even drawing liquids up through a straw. For unexplained reasons, she drools some of the time, but other times not. She is able to make

herself understood only intermittently. Her voice has no volume, and she has difficulty forming intelligible words. She remains willing to try any experimental procedure that might improve her condition, but the doctors are running out of ideas.

It grieves me to look at what is happening to her, but often my heart is filled with awe that she is so beautiful—radiant, almost luminous. Her white hair, cut short, makes her look like an angel. Her skin is smooth. Sometimes her jaw relaxes and she sits with her brow furrowed and her eyes closed tight, making her look like an aged philosopher deep in meditation. Other times, eyes closed peacefully, she looks like a child asleep or a saint in a mystical reverie, almost transfigured. But my favorite expression is Milly wide-eyed, sharing a joke. I get that look when I tease her about being an indiscriminate Democrat, when I remind her of one of the many times over the years when I was wrong and she was right, or if I suggest that perhaps tonight would be a good night for Viagra.

Her taste is impeccable. The dresses she buys tend to be loose-fitting, and her trousers usually have elastic tops to make it easy to take her to the bathroom. But they are stylish. She likes fine jewelry, and I like to promise her that I will buy things for her—a ring for Christmas, a necklace for her birthday, diamond earrings for our wedding anniversary. One of our favorite things to do together is to go buy them. One of my favorite things to do is to buy them without her and surprise her.

One day a local TV channel doing a piece on Michael J. Fox showed an old clip of an interview with Milly when her hair was dyed. She told me she wanted it dark again and had Felly make an appointment. I had to argue and enlist her friends, Grelanda, Alex, and Andréa to convince her she looked much better all-white. Milly also likes to go on trips—to Chicago, to the annual



Parkinson's Unity Walk in New York, to Mexico, on ocean cruises. And I plan them. Purchases, trips, and visits from our daughters are the current version of the Old Milly's projects. In fact, they are more important. Anticipation and fulfillment help keep her alive.

Milly can still make me angry. Sometimes I'm exhausted from work and she decides at 11:00 p.m. that she wants to rearrange her clothes closet. I yell at her that for God's sake why couldn't she do this during the day with one of her ladies? But I end up doing what she wants just to make her happy. I do not know how much longer I will have her, so I treasure tasks I used to find unpleasant. If she needs to go to the bathroom, we "dance" to the toilet, and it's a chance for me to hold her. When I change her disposable underwear, I view it as a chance to do stretching exercises. We make a joke out of the enemas she needs three or four times a week. I tell her, "I know you'd do the same for me," and I get the wide-eyed look that I love. Milly usually wakes up earlier than I do and immediately wants to turn the TV on. If she can't find the remote, I hunt for it, click it, and bury my head under a pillow. I tell her to report to me if something's happened I should know about.

Because of communications difficulties, I do not know completely what she is thinking. We tried microphones and voice amplifiers, but they didn't work because Milly can't articulate well. We tried two rounds of Silverman Method speech therapy, which involves deep-breathing exercises, but they've produced no long-term improvement. Singing sometimes warms up Milly's voice for a few words of speech, but the next ones can't be understood. We have tried various computer-based voice synthesizers, but they are either too complicated or require too much manual dexterity for Milly to operate. Stephen Hawking, the British as-

trophysicist stricken with ALS, uses one of these machines. But when Milly and I tried something like it, we concluded that one had to have Hawking's IQ to program it. Also, the electronic voices built into these machines are hard to understand at best, and given Milly's tendency not to use a space bar between words, what came out was gibberish.

I thought at one stage, what about magnetized letters, the kind parents put up on the refrigerator door to help children learn the alphabet? I got some at a toy store but couldn't find a metal board for Milly to arrange them on. On a visit, her sister Alex suggested a cookie sheet. A good idea, but it proved unwieldy. I bought several Scrabble sets, but it was hard for Milly to move letters very fast. I bought a children's computer, but when Milly touched any letter it raced repetitiously across the screen.

Finally a speech therapist suggested a paper alphabet chart, laminated in plastic, and we've been using it ever since, though it's sometimes hard to follow as Milly drags her finger across the page. Sometimes, too, she spells words backward or scrambles them. She means "WHAT" but spells "HATW." Recently I've rigged up laptops with desktop keyboards in the kitchen and bedroom, and she communicates by punching out words in forty-eight-point type, though she often hits the wrong key and never uses the space bar. And we've recently acquired a nifty small computer, an AlphaSmart, which we take with us outside the house, though it presents the same problems. Milly cannot nod or shake her head well, so she raises one finger if the answer to a question is yes and two if it's no. We play Twenty Questions a lot. I cannot hear her at all if we are driving, so we've invented a system: she holds my index finger, and I run through the alphabet. She squeezes when I get to the right letter. It takes a while to spell out a message, but the system works.

The thoughts she expresses now are perhaps a quarter as complex as those of the Old Milly. She mainly tells me what she wants—to go to the bathroom or kitchen or to the movies or a bookstore. Or to get her candy or give her money. She tells me to call the girls, and when I do she listens in on an extension and taps out messages for me to relay. Mainly, she writes, “WHENAREYOUCOMINGHOME?” She has me call up friends who have been sick. She tells me which political candidates she likes, and we bet each other \$1,000 on election outcomes—it’s the same bank account, after all—but she doesn’t carry on extended political arguments any longer. Nor does she make her old penetrating character evaluations of other people.

Once I feared that Milly, like many Parkinson’s victims, was descending into dementia. One neurologist looked at an MRI and said he believed she had Lewy body disease, a condition in which free radicals attack the cerebral cortex and lower IQ. When she had her second operation at Emory, though, Dr. DeLong looked at his extensive MRI collection and said that he saw evidence only of damage in the cerebellum, which controls balance. Andréa, then a second-year medical student, agreed with him.

To get a later reading on all this and help determine whether any other invasive treatments made sense—a fetal transplant, for instance—we went to New York University’s North Shore Hospital on Long Island for a PET scan in the summer of 2000. This procedure, using radioactive isotopes injected into the blood, yields pictures showing the level of metabolic activity in various parts of the brain. In the picture, active parts turn up red. Damaged, inactive parts come up blue-violet. Milly’s PET scan showed violet areas in the basal ganglia and striatum, where movement signals are transmitted, which is usual in Parkinson’s victims. But it also showed a disconcerting amount of loss in the cerebellum and

the cortex. It was as though acid had eaten away at parts of her brain. The several doctors who looked at the pictures have confirmed once again that Milly has no ordinary case of Parkinson’s.

Exactly what it is and what’s caused it, none of them seems to know. At NIH, Dr. Chase looked at the pictures and said, “If I had to put a name on it, I’d call it cortical basal ganglionic degeneration. I can give you a paper on the subject, but you’ll see, it doesn’t say anything about causes or consequences because we don’t know anything. The truth is, we don’t know what Milly has, and if we did know we wouldn’t know what to do about it.” Another NIH researcher, Dr. David Goldstein, said that he thinks Milly has Shy-Drager syndrome, also known as multi-system atrophy. Like Chase, he said that no one understands this condition either. The PET scan did seem to establish that the currently available Parkinson’s treatments—and those on the immediate horizon—will do her very little good. Fetal and stem cell transplants, new surgical techniques, and most new pharmaceuticals are all designed to deal with classic Parkinson’s, the absence of dopamine. They will control freezing and tremor. Some may correct for loss of balance. But the combination of these symptoms, plus loss of speech and swallowing ability and cortical damage—“Milly Syndrome,” as Mahlon DeLong called it—is beyond current science.

This means that, absent a miracle, Milly will continue to deteriorate. In early 2001, it appeared that a small miracle might be under way. But it could prove to be a great disappointment instead. In late 2000, Dr. Goldstein casually told Dr. Chase that there was anecdotal evidence that yohimbine, a drug derived from an African evergreen tree that’s used to treat male impotence, helped strengthen the speech of people with Shy-Drager syndrome. In February of 2001, the two of them conspired to fit Milly into a study that Goldstein was doing on heart responses to

yohimbine, which increases the body's production of norepinephrine, a substance akin to adrenaline. They gave her a PET scan of the heart to satisfy that protocol and infused a very small dose of yohimbine intravenously. Within seconds, Milly's speech became intelligible—still weak, still slurred, but understandable.

When I got home, I was amazed and overjoyed, as were Alex and Andréa, who both happened to be in town at the time. The level of our discourse wasn't profound, but when Milly told us what had happened that day, we could understand her from a few feet away. The next day, however, the effect began to wear off, and I had to put my ear close to her face to make out what she was saying. Within two days she again could not be understood.

The obvious next step was to increase the dosage and see what would happen, but this did not fit into Dr. Goldstein's protocol. So Dr. Chase designed a new study to see what oral dose of yohimbine might restore her speech and whether there were any side effects. So far, however, oral yohimbine has failed to produce any positive results. The intravenous experiment initially gave us great hope that Milly would be able to take yohimbine pills every day and speak. The experiments are still under way. If they succeed they could transform the way Milly lives. She could gossip, make phone calls, and tell people what she thinks. She would no longer be isolated. And her swallowing might improve. The prospect thrills me. On the other hand, if the experiment fails it would be a cruel letdown—a great hope dashed.

Even at the best, however, yohimbine can not cure Parkinson's disease. Looking further for experimental treatments—miracles—Dr. Chase has found suggestions in some literature that a common antibiotic, minocycline, may arrest apoptosis, the process by which cells kill themselves in Parkinson's and kindred diseases. Conceivably, this drug could slow the progression of her illness,

though it has yet to be tried in humans. There is no downside to trying this, Chase says, so when the yohimbine experiment is finished, he will try minocycline. And Milly, of course, is game for it. She is game for anything.

If that does not work, Chase says, hope may lie with so-called neurotrophic factors, proteins that seem to repair neurological damage when injected into the brains of animals. So far, however, these substances haven't worked in humans. Moreover, the procedure for administering them—through a tube into the brain—is dangerous enough that it's been tried only on patients with dread conditions such as progressive supranuclear palsy (PSP), which kills its victims in five years or less. I have no doubt that if Milly were convinced that this procedure was her only hope for life, she would try it, too.

The existence of mysterious complications like Parkinson's-plus, Shy-Drager syndrome, cortical basal ganglionic degeneration, and PSP is further reason for an all-out research effort centered on the brain. For Milly and me, though, Chase's reminders of the research progress currently being made—or promised—have only heightened the excruciating sense that we are in a race against time—and that we are losing.

After the Reyes-Dadich wedding in Chicago, one of Milly's childhood friends, Helen Metoyer, organized the Roulettes and the Dons into a prayer circle for her and sent out instructions for saying rosaries on her behalf. Milly was touched by the gesture. She had left the Catholic Church decades ago, but we found old rosary beads in a drawer and she began praying, though on much the same premise as she agreed to take yohimbine and will try minocycline: she'll try anything.

Helen's initiative made me wonder why I, supposedly so much more faithful than Milly, have so seldom prayed for a miracle. I pray fervently and often for deliverance from petty problems—

"Please, God, let me not have lost my car keys"—and also for the success of career ventures and for the safety of my children. I have prayed for help for myself in taking care of Milly. I have prayed that Milly could have peace of mind in coping with her condition. But since her diagnosis, I have rarely prayed for her rescue. I believe that prayers are often answered. I believe that I have seen them answered. Yet somehow a cure for Milly seemed to be beyond what I imagined God could or would deliver. Helen's gesture—and the full recognition that I was losing Milly—caused me to resolve that I would pray every day for her cure and for God to forgive me for not asking Him sooner. Yohimbine may be an answer to those prayers. At least, it would give human contact back to Milly. That would be an enormous blessing.

And yet I do not trust that a miracle will be forthcoming that will save her life and restore her fully. I can't. Milly and I both must deal with reality as we perceive it, and with our fears. Before we went up to Long Island for the PET scan of her brain, Milly expressed apprehension that it would show mental deterioration. She wrote on the computer, "I THINK IM LOSING MY INTELLIGENCE. MY WORLD IS GETTING NARROW." Reviewing the PET scan pictures, I asked various doctors out of Milly's earshot whether what they saw implied lost cognitive ability. The answer was, in effect, yes. "But how much or where this is going, we can't tell. What you see is what you have," one of them said.

I definitely see diminution. On the other hand, it's crushingly evident that much of the savvy, wise, and tough Old Milly still lives in her wasting body and inside her head. For example, we had dinner one evening with a very liberal friend who expressed regret that he couldn't watch me on TV because his cable system

doesn't carry Fox News. Milly tapped out the message on her AlphaSmart: "THAT'S GOOD IF YOU SAW WHAT HE SAYS YOU WOULD HATE HIM." After we saw the movie *The Talented Mr. Ripley*, I said to her that I couldn't understand how Gwyneth Paltrow's character, a smart writer, could be in love with a cad, played by Jude Law. She slowly spelled the message out on her letterboard: "E-V-E-R-Y-O-N-E-K-N-O-W-S-T-H-A-T-Y-O-U-U-N-G-W-O-M-E-N-O-F-F-T-E-N-F-A-L-L-F-O-R-S-H-I-T-S." I said, "You did—me." She gave me her wide-eyed smile, but I added quickly, "But you made me not-a-shit. Everyone becomes a better person because of you."

Well, not everyone. Milly once had a huge cadre of Washington friends, people who came to her for free advice about husbands, children, and other relationships. Of these, many have remained close and loyal. Jill Schuker comes to visit Milly every week, calls often, and arranges birthday and anniversary parties. Jill says that she and Milly communicate almost telepathically, their friendship is so deep. Mark and Judy Siegel bring food, invite us to their beach house, and do Thanksgiving, Passover, and July Fourth. Netty Graulich, Milly's old sewing teacher, takes Milly to the theater and for long dinners. Milly pecks out advice for Netty, and Netty always allows Milly to unburden her most desperate fears. Terry Schaefer, who has moved to New York, writes often to tell Milly how much she loves her. Gloria Doyle invites her to lunch and to tea. Another friend, Susan Lee, takes yoga instruction with Milly, and they have lunch and shop together. Milly's former psychotherapy partner, Sue Bailey, is always up for a movie. Some others, including the old Tunlaw Road wives, stay in touch, call to ask how Milly is, and sometimes gather for a dinner. Other old friends e-mail good wishes or call

on the phone, offering to stop by when I am at home. These people, I assume, are afraid to be alone with Milly because they don't know how to communicate or don't know what to say to her.

Some people, however, have abandoned her. I phone these former neighbors and professional colleagues to say Milly misses them. Jill and other close friends call and write to them. They promise to call or visit. But they don't. I can understand why. She cannot be understood on the phone. Carrying on a conversation with her in person takes patience and effort. Needy people can't get their needs met easily by Milly anymore. They have to give. I understand what's going on, but it's hard to forgive them because Milly feels so hurt that they've dropped her. Yohimbine offers the promise that these people will come back. I know that Milly will welcome them. It's the way she is.

Milly reads books, likes movies, and has favorite TV shows, including *Oprah*—whose recommended books she always buys—and *Who Wants to Be a Millionaire*? Each time the show is ending and Regis Philbin refers to the 800 number for prospective contestants, Milly points to the screen and whispers, "Call!" I tell her that if I ever got on I'd miss a \$200 pop culture question and disappoint her horribly. This is another occasion when she gives me her wide-eyed, knowing laugh. She also always remembers where things are in the house, including objects I put away and then forget. She remembers everyone's birthday and other special occasions and insists on sending flowers. She loves it when she can prove her memory is sharper than mine.

Milly has much to complain about, but she rarely complains. She once said to me that "suffering doesn't make you a better person. It makes you worse. You think about yourself all the time." This may apply to her, but it has less effect than it would for others. Unlike some people who suffer, she does not inflict her suffer-

ing on others—especially me. She tells me on her letterboard that she's angry if I leave her alone too long at a party or if I leave her on a Saturday or Sunday in the care of someone who doesn't drive. She lets me know if she thinks a caregiver is ignoring her. These are all legitimate issues to raise, though. She does not abuse anyone.

But she is deeply unhappy. Milly sometimes tells me—and others more than me—that she wants to commit suicide or die soon. One day she wrote to me on her letterboard: "I C-A-N-T T-A-L-K-O-R W-A-L-K-I-D-O-N-T W-A-N-T-T-O L-I-V-E-L-I-K-E T-H-I-S." Another time she wrote: "N-E-V-E-R T-O E-A-T A H-O-T-D-O-G A H-A-M-B-U-R-G-E-R O-R A S-A-L-A-D O-R B-E A-B-L-E T-O T-A-L-K I-S I-N-T-O-L-E-R-A-B-L-E." In a restaurant she painstakingly wrote out on the AlphaSmart, "I have been thinking about dying. You make me very happy, but I wonder how much longer God is going to make me suffer."

Incidents constantly occur that magnify her misery. We were at a noisy book-signing party for a good friend, and when people came up to talk to Milly, they could not make out what she was saying. So they quickly moved on. We'd brought her AlphaSmart, but its battery was low and it conked out. I scribbled out a makeshift alphabet chart on a piece of paper and knelt by her chair to interpret for her, but few people had the patience to stay for long as she slowly traced out letters. As a result, Milly spent the evening essentially isolated and alone. When we got home, she told me, "I couldn't talk to anyone. I don't want to live anymore."

A worse incident occurred at NIH. For a moment, Felly left Milly sitting at a cafeteria table in her wheelchair. Her eyes evidently were closed. An enormous woman at the next table said something to Milly. When Milly didn't respond, because she couldn't, the woman screamed out that Milly was unconscious.

The woman yelled for help, pulled Milly out of her chair, and laid her out on the floor. Milly wanted to protest, but couldn't. An emergency crew rushed in. Felly ran up and said that Milly was fine, but couldn't speak because of Parkinson's disease. The crew paid her no mind. They checked Milly's vital signs, which were normal, but nonetheless hoisted her onto a stretcher and rushed her to an emergency room. She was quickly released, but she was shaken. "I felt like I was locked in a cage," she told me that night. "I couldn't do anything." She started to cry. I hugged her, but she broke into sobs. "I want to die," she said.

For Milly, even contemplating the future is bleak. As we were concluding our annual August week in Wisconsin with Lori and Jerry Long in 2000, I suggested we might go on a Christmas–New Year's ocean cruise with them in 2001. Afterward in our bedroom, Milly began weeping. "I want to die soon," she said on her Alpha-Smart. "I do not intend to be alive in 2002."

I used to be speechless at such moments. Or I would say, "You can't die. It would devastate the girls." Or, "You've got to see Andréa through medical school." The truth is that there are fleeting moments when I wish that Milly would die. I fantasize about a new life, post-Milly, post-Parkinson's, maybe with another woman who I can walk around Paris with, talk to in a normal way, and share retirement with. I confess that I sometimes indulge the fantasy to the extent of wondering about life with this or that particular woman I know. I also fantasize, though, that when Milly dies I'll contract melanoma or have a heart attack and follow her soon after, God having no more missions for me. In yet another idle daydream I marry a woman who shortly comes down with Parkinson's or an even worse chronic disease, like Alzheimer's or aggressive cancer. This is the future I would least want and one that would sorely test my faith. Yet I realize that if I did marry again in my mid- or

late sixties, death is a challenge I would have to face again—hers or mine.

I never get very far with any of these scenarios because, as a stoic, I know that I can't possibly predict what my fate will be. I'm sure that what does happen will be completely different from anything I've fantasized or dreaded. As a faithful stoic, I leave the future in God's hands because I must. "The Author" will write the play. I merely hope that I can handle the part, whatever it is, with His help.

I have never discussed any of these fantasies with Milly. Typically, though, she has tried to engineer my future. "WHEN I DIE," she once tapped out on a laptop, "I WANT YOU TO STAY IN THE APARTMENT. IT WILL GIVE THE GIRLS A HOME." The truth is that Alex and Andréa don't regard our D.C. condominium as home at all. Like Milly, they still miss our house in Chevy Chase. More embarrassingly, twice Milly has said to different unmarried women friends in my presence, "When I die, I want you to marry Morton." In both cases, in unison, we've said, "Milly, shut up!"

Some friends have suggested that I should perhaps "develop a relationship" with another woman. Sometimes they genuinely just mean "talk, have lunch." Other times they are suggesting that I have an affair. One well-intentioned person recounted to me the story of a friend of hers who thought of leaving his wife but decided to stick with her when she was diagnosed with cancer. He fell in love with another woman and carried on a discreet affair with her for years, finally marrying her when his wife died. I quickly told this friend that my situation wasn't remotely analogous because I had never considered leaving Milly before she got sick and I've never been tempted to get involved with anyone else. Nor has anyone shown the slightest interest in me.

I won't deny that I feel lonely for intimate conversation, for someone to discuss my worries with and be nurtured by. My wonderful therapist, Dorree Lynn, has helped me get my narcissism under control, accept advice and praise, overcome the chronic mild depression that had me on Prozac for several years, kick away my preoccupations with status, and realize that my feelings of sadness over Milly's condition are entirely appropriate. Of course, two sessions a week don't substitute for long talks and long walks. I do tell Milly when I get home every night what I have done and what I'm worried about—some days it's the money in our checking account, and other days it's my boredom with politics and my vain wish to do something else professionally, like write novels or biographies. She listens, but I do not get a lot back—certainly not the challenging and penetrating advice Milly gave me when she was well. And until recently we talked hardly at all about what obviously tortured us both: Milly's deterioration and where it was heading.

In 1999 Dorree—who's also Milly's therapist—told me that Milly felt I was refusing to face up to the prospect of her dying. Dorree said that I was being selfish—forcing Milly to face death alone. She was absolutely right. In reality, I thought about the subject constantly but was afraid to talk to Milly for fear she would think I wanted her to die. I also was avoiding the pain that her thoughts about death would cause me. And I was petrified by what I thought were the only two options available. One was (and is) that we would do nothing and Milly would become like Mo Udall, spending years nourished through a feeding tube and, perhaps, eventually be warehoused in a nursing home. The only other option, I thought, was to use one of the techniques described in the book *Final Exit* to effect her suicide.

Milly and I started talking about her death in joint sessions

with Dorree, and the first of these only increased my terror. Using her letterboard, Milly talked only about suicide. "T-H-I-N-K A-B-O-U-T D-Y-I-N-G E-V-E-R-Y D-A-Y," she said. "F-O-R M-Y-S-E-L-F I W-O-U-L-D D-O-I-T S-O-O-N-B-U-T I D-O-N-T W-A-N-T T-O D-I-S-A-P-P-O-I-N-T O-T-H-E-R-S L-I-K-E M-I-C-H-A-E-L J-F-O-X H-E-T-H-I-N-K-S-I-M-A-H-E-R-O-I-N-E."

With Dorree present, Milly poured out her feelings in a way that she rarely did when we were alone. On either the computer or the letterboard, she said in different sessions, "I do nothing every day. I can't talk in Bible study or movie group. I can't walk, and I can't eat. I don't know how you can love a mannequin." One day she said, "I'd like to get a fetal transplant and die on the operating table." Another time she wrote, chillingly, "Your love is not enough. I want to kill myself. I'm afraid, but I'm more afraid that I won't be able to move to do it." I asked her whether she wanted me to collect information and materials. She said, "Yes."

For months I lay awake nights and early mornings playing out strategies for the *Final Exit* option, becoming more panicky each time I did so. I dwelled on the rumor that Jacqueline Kennedy Onassis, stricken with terminal cancer, allegedly ended her own life with her loved ones gathered around her. But she was connected (I figured) with Fifth Avenue doctors who would have quietly prescribed the right medicine and signed her death certificate so that no questions were asked. Where would I find Second or Nembuta? I couldn't imagine any doctor I knew helping me.

When we lived in Chevy Chase, a kid down the street killed himself with a combination of over-the-counter medicines washed down with white wine. How could I find out what he'd used? Ask his parents? Look at his board of health records? Some friends suggested that I look for suicide information on the Internet, but not use my own computer, lest a record remain on the hard drive.

When I actually bought the book *Final Exit* I found it of little help: get a stash of barbiturates, it says, and mix them with pudding. Or take lots of Valium and put a plastic bag over your head.

After telling Milly I would get information and materials, I spent months in a state of near-terror trying to figure out what to do. If it were me, I thought, *I'd do the Valium-plastic bag thing*. But Milly couldn't do that without my help. If she opted for that—and insisted on it—would I really assist her? Could I stay in the apartment and watch her gasp, thrash, turn purple, and die? What would I tell the police afterward? Could I lie and tell them I'd gone out for a jog and found her dead when I got back? Could I pull that off? Would I go to jail? Maybe, I thought, I should just buy a gun somewhere and make it a mercy killing—suicide. I even thought about places in our apartment where I could do this and create the least possible cleanup problem.

At the end of most of these fevered scenario-plottings, I fervently prayed for help. I asked God, "Does this mission of Yours, 'taking care of Milly,' necessitate my killing her and maybe standing trial, ending my own future?" I decided, with a touch of shame but with conviction, that if killing Milly was what the mission demanded, I would not fulfill it. I would not go to jail. And of course, I would not commit a murder-suicide.

I believe that God speaks and acts through others—angels, as it were—and I believe I received a merciful gift through Milly's and my wise friend, Sue Bailey, a doctor who formerly was the assistant secretary of defense for health and head of the National Highway Transportation Safety Board. She said that, if Milly really wanted to end her own life, the way to do it would be to wait until a feeding tube became necessary. Milly could refuse it, enter a hospice, receive morphine to relieve discomfort, and starve to death. Afterward Milly and I talked about what Sue had

said, and Milly said that this seemed the best alternative to her. We contacted our lawyer and had Milly's living will adjusted to permit her (or me as her agent) specifically to refuse a feeding tube as well as other artificial life-sustaining procedures. I also visited a hospice, the Washington Home, and arranged to get help if this is what Milly is determined to do when the time comes.

I was reassured by a doctor, a counselor at the hospice, and literature I read that death by starvation is not painful if the patient doesn't take liquids except to keep the mouth moistened. Food deprivation causes proteins and fat to burn up, inducing a process called ketosis, which produces euphoria and dampens discomfort. Giving the patient liquids causes swelling and pain; dehydration results in a clouding of consciousness. Death occurs in about six weeks through starvation alone, or in about three weeks through a combination of starvation and dehydration.

The hospice option came as a gift, a blessing, greatly easing my mind about how Milly might die. It delivered me from having to contemplate the horrific *Final Exit* suicide options. In fact, I think the growth of the hospice movement in America largely obviates the suicide issue—and the assisted-suicide issue—for the terminally ill, except for those in unbearable pain. If people can starve themselves to death peacefully, why would they (or their doctors) have to administer barbiturates to do it? As hospice literature argues, refusing or withholding food and water allows a natural death to happen.

Even so, what lies ahead is agony. Milly and I got a glimpse of it in Bill Moyers's PBS series on death and dying. In one episode a veterinarian with ALS contemplated using animal medicines in his possession to kill himself but let the opportunity slip because he waited until he could no longer swallow. His wife would not administer poison, and he finally realized that he was going to



choke to death or die by starvation. Milly turned to me and whispered, "Is this what is going to happen to me?" The question, the closest we have yet come to speaking of the reality of her dying, struck me like an electric shock. I said, inadequately, "Yes, I think, something like that, but it will be a longer time coming. ALS is much faster than Parkinson's."

Of course, there is no way of telling how much time we have until we face the feeding tube decision—which I cannot bring myself to think of as the "starvation" decision. I hope that the time is measured in years, not months. I judge that I would have some warning if Milly started to need frequent Heimlich maneuvers to stop her from choking on food caught in her windpipe.

I have had to perform the maneuver three times in the past eighteen months. These are occasions of momentary terror, and I remember each one vividly. Milly had been urging me for years to arrange to be a speaker on an ocean cruise, and finally I was invited to do so during the Christmas–New Year's holidays in 1999–2000. It was a delightful time for us—traveling for three weeks from Florida, through the Panama Canal, and up the Pacific Coast to Los Angeles. Milly and I spent virtually every moment together. Alex and Andréa joined us for part of the cruise and gave me short breaks to work on my speeches or exercise. At lunch on a fantail deck of the ship one day off Mexico, Milly insisted on having a cracker-and-cheese as part of her meal. Since she cannot chew, I try to veto crackers. But she insisted. I told her, "Small bite, Milly." She took a small bite, but within seconds she was gasping. Milly often gets minute pieces of food caught in her windpipe and has to cough them up. There is a danger of aspiration into the lungs and pneumonia, but so far coughing works. On the ship it did not. She could not get the air in that would enable her to expel the food.

We were lunching with a British couple we'd met. They looked panicked. I said, feigning jauntiness, "Sorry, this happens," and jumped up. I ran behind Milly and lifted her around the torso, jerking hard on her abdomen. The cracker came out quickly. After Milly got her breath, she insisted on continuing lunch. I said, "No more crackers, Milly. Ever." She does not obey the rule.

The second Heimlich came three months later. Our friends Bob and Phyllis Greenberger—he of the *Wall Street Journal*, and she the head of the Society for Women's Health Research—always host a black-tie New Year's Eve party packed with Washington journalists and political activists, with a sprinkling of liberal congressmen and State Department officials. But so many people were out of town for the millennium that Bob and Phyllis held a costume party in the early spring instead. Our original plan was that Milly would go as FDR and I as Eleanor. I managed to find a getup for her, but not for myself, so I uncreatively just bought a Richard Nixon mask. We were sitting with the Siegels before dinner. I went off to refill our Cokes, and when I got back Mark was saying, "Milly needs help." She had tried to eat a Chinese dumpling. She was gasping and looking panicked. Simultaneously a menacing gurgling sound emanated from her throat.

I thought, "Please, God, no!" and jumped around to the back of her wheelchair. I tried to lift her to a standing position, but I forgot that she was still buckled in. I undid the seatbelt, pulled her up, and began pumping just below her sternum. Mercifully, after two tries, the food popped out. Milly sucked in air for a second, then quickly recovered. I tried to make a joke of it again: "No more dumplings for you! Hummus is all you get." The incident happened so quickly that no one but a horrified Mark Siegel even noticed. I am sure that he could have performed the maneuver

in my absence or gotten help from someone else. Milly's "ladies," Grelanda and Felly, know how to do the maneuver, too. Indeed, each has had to do it once.

The third occasion was the scariest. We were at the Siegel's for Thanksgiving dinner. I carefully chopped Milly's turkey and mixed it alternately with stuffing and mashed sweet potatoes. She tried to eat some of it herself, but mostly I guided her fork. Milly seemed to be processing everything smoothly. She took in one forkful of food after another and indicated quickly that she was ready for more. Suddenly she emitted that awful sound, the combination of gasping and gurgling. Everyone at the table, fifteen people, stopped talking and sat stunned and scared. I jumped, wheeled Milly a few feet away from the table, lifted her, and pumped. Nothing came out. I did it again, and nothing happened. And again. I prayed. I had a fleeting vision of an ambulance arriving, a rescue squad, an emergency room, and possible brain damage, Milly living on a respirator. On the fifth or sixth try, though, the food began to come up. But Milly continued to choke, so I repeated the procedure. More food came out. And more. As it turned out, much of her meal had gone down her windpipe, not her esophagus. And worst of all, she hadn't known it was happening. This could happen again at any time, with disastrous consequences. Thankfully, it has not.

Even though she is supposed to stick to soft foods, Milly always wants to violate the rule, and it's impossible not to accede to her wishes sometimes. She insists on getting popcorn at the movies, for instance. I order it heavily buttered to make it softer, but often she makes disturbing coughing sounds as she eats it. I whisper in the dark at least once per show to ask if she needs the Heimlich. She has never needed more than a sip of Diet Coke to wash the popcorn down. Since the last Heimlich we have worked

it out that if she does require help she's to wave a fist at me. Fortunately, she hasn't had to.

But I'm always scared that something will stick in her throat that the person with her can't dislodge, or that Milly will try to eat something she shouldn't when the person is out walking the dog or running an errand. In my worst fantasy I come back to find Milly choking, fail at Heimlich, call 911, and wait an eternity for help while trying CPR. If this happened, Milly could die in my arms, or if emergency crews did arrive, her brain could be deprived of oxygen long enough to put her into a coma. Then I would be faced with the decision about whether to leave her in a vegetative state.

That terrible fate is the worst possible future that Milly and I face. But it is probably not the likeliest, which is terrible enough. It is that three months, six months, or a year from now, Milly will be unable to swallow anything. There are moments already when even ice cream or applesauce goes down her windpipe, causing her to choke and gag. At such times I fear that we will have to decide soon whether to have her fed through a tube surgically implanted into her stomach. Presumably she will be alert and able to tell me, one way or the other, what she wants. I can imagine that she will be ambivalent, part of her wanting to die, part afraid to die, part wanting to live. Would she look to me to decide? What would I say? Surely I will say—indeed, I have said—that she should stay alive. We could convert our second bedroom into a hospital room if necessary.

But later, after months on a feeding tube, Milly will surely despair and say that she wants it removed. I can imagine her wanting that one day and becoming doubtful the next. It's also conceivable that someday she will be utterly unable to communicate, as happened to Mo Udall and to Milly herself at NIH when her body was deprived of L-dopa. As with the loved ones of Mo

Udall, who died in 1999, I may not know what Milly wants or whether she retains the mental capacity to want anything. What should I do? Could I order the tube's removal and watch Milly starve to death? Now, I think I could. But in fact, I may lack the courage. Or I may be so guilty about wishing for the end to our ordeal that I find myself prolonging it. I will surely ask God what to do.

This is not the way I want this story to end. I want a medical miracle to save her. But even if there is none, our story will not end. However I lose Milly, if I lose Milly, memory will survive. I remember the restaurant where we met, the raincoat she was wearing the moment I knew I had fallen in love with her, the soft couch where we first made love, the smell and the taste of her, the ski slope breakup. I remember everything about the day and night we were restored to each other for keeps—the beach, the Beatles, the pot, the rainstorm, and the kisses under a street lamp. And thirty-four years of marriage—the fighting, the children, her steel, her generosity. Her courage. I will keep working to end Parkinson's disease on her behalf, and I will hug her in my heart forever.

## 2002 *Afterword*

❧ In the late spring of 2001, just as *Saving Milly* was about to be published, the life-or-death “feeding tube decision” I so dreaded suddenly rushed upon us. Milly was nearly unable to swallow anything—food, liquids, or medicine. A simple meal of soup or oatmeal took hours to complete, and Milly's distress at not being able to eat made swallowing solid foods even more difficult. We shifted to Ensure and other supplements, but she also had difficulty drinking and pulling liquids up through a straw.

She subsisted largely on a blended-and-frozen mixture of Ensure, ice cream, and fruit, which she was able to swallow better than anything else—though not in sufficient volume to give her adequate nutrition. And she was getting less than optimal doses of Sinemet and her other medicines.

These combined deprivations left her weak much of the time. She couldn't help lift herself out of a chair, and her legs could barely support her when I tried to “dance” her from room to room. Also, she suffered some scary near-fainting incidents. In

mid-May, a week or so before the book was scheduled to be unveiled at the Udall dinner, Milly's friend Jill Schuker and her caregiver Grelanda Te called me at work to say that Milly's face had gone deathly pale and that, while conscious, she was unable to respond to them.

I called Milly's neurology nurse, Marge Gillespie, who said they should lie her down and elevate her legs. She also said that the decision about whether Milly would accept a feeding tube could not be put off much longer. I called home. Jill said they'd already done what Marge advised and that Milly seemed okay. But I knew that Marge was right.

For months, I had avoided discussing the issue with Milly. I feared she would follow through on her vow to refuse a feeding tube and starve to death. She had enshrined this wish in her living will. As I hung up with Marge, I had the fleeting dread that instead of enjoying the launch of this book together, Milly and I would spend the coming weeks in a hospice awaiting her death. I planned to argue for the tube—and, if necessary, beg her to take it—but I couldn't be sure what Milly would do.

Thankfully, Milly decided to live. And the resolution of the issue was infinitely easier than I had envisioned. Sometime amid the blur of events in May and June—I cannot remember exactly when—I simply blurted out to Milly, "You have to decide about the feeding tube soon." So many good things were happening at the time—Andréa's medical school graduation, book parties, a cover story about us in *USA Today*—that I hoped Milly would decide to live and enjoy them. When I broached the subject, she said, "I'll do it." "You'll have a tube installed? You'll stick around?" I asked. "Yes," she said. It seemed no big thing to her. But to me, it was the world.

Installation of a PEG tube is surprisingly simple. PEG stands for percutaneous endoscopic gastroscopy, which means it's a "through the skin, installed using a camera, into the stomach" tube. It's done on an out-patient basis with a local anesthetic and mild sedation. Milly had the operation on July 25. It took no more than 20 minutes. The surgeon passed a tube down Milly's throat and into her stomach. It had a tiny camera and very bright light on the end that showed him where to make a small incision on the outside of her abdomen. He inserted the end of a plastic tube and inflated a little balloon inside her stomach to hold the tube in place. Then he bandaged the wound and called Grelanda and me into the recovery room to show us how to use the tube and keep it clean. He prescribed an antibiotic to prevent infection and gave us an ointment to apply until the wound healed. That was it.

Ever since, eight or so times a day, Grelanda, Milly's other caregiver, Felly Relano, or I open the cap at the end of the tube, insert a plastic syringe, and pour in Milly's medicines, crushed and dissolved in water, or a vitamin-rich liquid food formula called Jevity Plus. Diet Sprite, Milly's favorite drink, keeps the tube clean. Obviously, though, she can't taste it. Typically, Milly was concerned whether the tube, 16 inches long, would cause a noticeable bulge in her clothing. Looped and taped to her tummy, it doesn't.

Ensuring her adequate nutrition, hydration, and medication, the tube had an immediate positive effect on Milly's strength and spirits. Episodes of near-fainting and low blood pressure stopped. More gradually, she has become better able to walk and stand with assistance. And, she says that she wanted to live.

I fancied—until recently—that all the excitement connected

with publication of the book had motivated Milly's decision to live. Certainly it was buoying to both of us. First, the *Washington Post* magazine published an excerpt, causing people to walk up to us on the street and tell us how inspiring we were. We started getting letters from around the country when Susan Page wrote her *USA Today* piece, which was accompanied by a huge picture of us on the front page. At one book party, a dozen or so of Milly's former clients showed up and told her again how she'd helped them change their lives. Our daughters made moving speeches about how ours was the most successful marriage they'd ever encountered or could hope to. Alex made a short video from our collection of home movies that was played at the Udall dinner and again when I was invited to appear on NBC's *Today Show*. I also was interviewed on C-SPAN's *Booknotes*, practically every program on the Fox News Channel, and on dozens of other TV and radio shows.

Reviews of the book were sometimes dazzling. Andrew Ferguson, in the *Wall Street Journal*, wrote that "it is one of those uncommon books that manages—quietly, beyond any expectation—to ennoble its author and its readers alike." The *Chicago Tribune's* reviewer said it was "unflinching, honest, powerful, unvarnished, heartrending." Others said it was "a beautiful love letter," "tender, loving, and funny," and "a truly compelling read." The *New York Times* said it was "excruciatingly painful," but also "a powerful argument for more financing for Parkinson's research." There was hardly a negative word.

The book came out just as President Bush was going through his own excruciating process of deciding whether to allow federal funding of medical research using stem cells derived from (and requiring the destruction of) fertilized human embryos. Parkinson's is one of the diseases that may be cured someday through stem

cell research. Milly and I appeared on ABC's *Nightline* amid the controversy. The *Washington Post* columnist Richard Cohen wrote that "if George W. Bush reads just one book this summer, I hope it's *Saving Milly*." He said, "I finished it last night in tears." Such publicity and gracious words helped land the book on some national bestseller lists.

The most gratifying—and daunting—response we got, however, was the mail. Hundreds of people wrote to offer Milly and me encouragement and prayers. Some were victims of Parkinson's or other chronic diseases, some the spouses of victims, recounting their own medical and spiritual journeys or telling us how our story had inspired them to persevere. Others recommended alternative medical treatments for Parkinson's. We received so many letters that I was unable to respond to them. I think about the unanswered mail almost daily, with guilt.

But to my even deeper regret, the book caused pain to Milly's wonderful foster family in Chicago. I could not have avoided writing that one of the houses Milly grew up in was infested with bedbugs. She is convinced that soaking her mattress and bedroom walls with DDT to kill them somehow triggered her Parkinson's. However, my account left out the fact that the Villarreal family swept and scrubbed the house constantly to keep it clean. Members of the family told me that they, their friends, and some business associates felt that I'd portrayed the home as "filthy" and the neighborhood as a "slum." Moreover, they said, I conveyed a sense that Milly's childhood was unrelievedly miserable, leaving out joyful times—hayrides, birthdays, pranks, and graduations. In writing disparagingly about Milly's nephew, who once lived with us, I also neglected to say that Alex and Andréa loved him as they would an older brother, and still do.

I am deeply sorry for the hurt I caused—particularly because

the book came out just as Milly's valiant foster mother, Annie, was dying from respiratory problems. She spent weeks in the hospital, with family members led by Milly's sister, Lori, standing twenty-four-hour watch as she sometimes rallied, neared death, and rallied again until her system finally failed in late July. Annie evidently shared the family's dismay with the book, even though I'd written that she was the person who'd given Milly her values, her self-confidence, and her giant capacity for love. Milly and I scheduled flights to Chicago to see her, but had to cancel each time because Annie was in a medical crisis. We saw her last at her wake, attended by hundreds of people she'd helped in Chicago's Mexican-American community, plus local and national politicians. Thankfully, most members of the family acted as though my book had never been written.

While the feeding tube improved Milly's health and strength, it did not have much effect on her ability to communicate. Various book reviewers wrote that ours had been a "tempestuous" or "volatile" marriage. I think those words imply infidelity and separations, which never occurred. A better way to describe our marriage, pre-Parkinson's, is "loud." We argued a lot and we didn't keep our voices down. But in recent years, as Milly's disease has progressed, our marriage has gone virtually silent. In the morning before I leave for work and when I get home at night, I tell Milly what I've been doing and what I'm thinking. I tell her often that I love her. But we don't have real conversations.

In a cruelty akin to Beethoven's deafness, Parkinson's has robbed this gifted therapist and wise friend of her ability to question, penetrate, and give advice. Milly tries to speak, but most of the time she cannot enunciate words clearly enough to be understood. She also has lost the manual dexterity needed to punch computer keys or point to letters on a chart to spell out words.

This makes communication arduous and its level has become mostly very simple. Grelanda invented the catchphrase we use when Milly is trying to say something: "What's the topic, Milly?" It usually has to do with calling our girls, movies we're going to see, her clothing choices, or the fact she's out of spending money.

One small miracle I'd hoped for didn't occur, but another may be in process. NIH experiments with yohimbine, a drug derived from an old African aphrodisiac, have not succeeded in helping Milly speak. The drug raised Milly's voice volume once, when administered intravenously, then failed to do so again. Doses administered through the feeding tube made her body shake, caused drooling, and gave her the hiccups, but had no effect on her speech.

Believe it or not, though, we've recently achieved successful results with Godiva white chocolate bars, which I now buy in bulk and which Milly can swallow. I have no idea what ingredient in the candy stimulates her voice, but there is no mistaking the effect. Sometimes she can be heard.

And so, we've begun to talk more. She still cannot form words well, so I have to stop her and ask the topic or say, "Slow down. What's the first word, Milly?" When I understand that, we slowly work through her sentence. I ask her to spell words I can't make out. Eventually, her thoughts come through. And some of them are moving. Preparing this afterword, I asked her why she had decided last year to live. Did the book influence her? "No," she said. "I just decided to live." I asked about it another time and she said, "I decided to stay alive because I have you to love."

Just before Christmas—about the time we were transitioning from yohimbine to Godiva—I also asked her about God. She said, "I love God. I talk to Him every day. I pray for you and for

the girls. I ask Him to give me my speech back." Stunned, I asked her when she had stopped believing that God had abandoned her. She said it was last year, when I stopped writing on Sundays and we started going back to church regularly—and when, she said, the priests at St. Columba's began coming to where we sit in church and praying over her at communion time. Every week this gesture brings tears to my eyes because it has had such an impact on Milly. I asked her again recently why she had changed her mind about God. "He is the only one I can talk to whenever I want," she said. I am profoundly grateful that Milly is spiritually at peace. It is the fulfillment of many of my own prayers.

Some elements of what I called in the book "God's work"—medical research—are proceeding. President Bush, prodded by Senators Tom Harkin of Iowa and Arlen Specter of Pennsylvania, is fulfilling his promise to complete the process of doubling the NIH budget over a five-year period. On the other hand, he failed for more than a year to appoint an NIH director, leaving the agency without effective leadership.

And, despite the urging of disease groups—led by the Juvenile Diabetes Research Foundation, the Parkinson's Action Network, and the Christopher Reeve Paralysis Foundation—Bush decided to permit only limited federal funding of embryonic stem cell research. To the good, he did not ban it entirely, but decided to fund only research using cells already derived on the day of his decision, August 9, 2001. He claimed that some sixty "lines"—or batches—of cells were available for research around the world. But many scientists dispute the number and contend that Bush's decision means that private funds and scientists in other countries will have to carry the research forward. The president also wants to make it illegal to clone embryos to acquire stem cells for research and therapeutic purposes.

One group that will vigorously advance stem cell and other promising Parkinson's research is the Michael J. Fox Foundation. Powered by Michael's dedication and endearing nature, the foundation attracted a first-rate board of directors, scientific advisory panel and staff, and raised more than \$11 million in its first full year of operation. The foundation has conducted three research initiatives, attracting hundreds of grant applications from scientists around the world—proving, in case anyone doubted it, that impressive strides can be made in curing Parkinson's if adequate funding is available. In its first two years, the Fox Foundation may have raised as much as \$30 million and lead half a dozen major new research initiatives.

Besides leading the foundation, Michael has written a wonderful book, *Lucky Man*, in which he says that he would not trade the life he has had with Parkinson's for the one he might have had without it. The sentiment only deepens my devotion to Michael, but I cannot share it for Milly and me. I would give anything for her not to have Parkinson's disease, regardless of where that might have led our lives.

At best, the Fox Foundation and other private groups can fund only a fraction of the research possible for the federal government. The NIH says it is now spending \$155.9 million per year on Parkinson's, or about \$156 per U.S. victim. This figure includes both direct and "related" projects, so it does not mean that funding has been quintupled since 1994, when the Parkinson's Action Network began demonstrating how underfunded PD research was in comparison to other diseases.

Prodded by Congress, NIH conducted a study in 1999 to determine what the optimum level of PD funding would be. The study confirmed scientists' testimony that promising strides could be made in gene and stem cell therapies, surgery, neuron repair,

epidemiology, and prevention. And it said that one billion additional dollars could be spent productively on PD research over five years, beginning with \$70 million in the first year. Alas, despite the best efforts of a rejuvenated Parkinson's Action Network, that money has not been asked for by the executive branch nor appropriated by Congress, although it's been pushed for hard by some members, notably Senator Harkin. Joan Samuelson remains the president and guiding spirit of PAN, but now she has a vigorous board, executive director, and advocacy director working with her, increasingly making PAN the Washington voice of a united Parkinson's disease community.

There continues to be every reason to believe that a cure for Parkinson's will be discovered within five or ten years, but it also remains true that—barring a miracle—it will not arrive in time to save Milly, particularly because she suffers from a complicated case. Thanks to her inner will and the grace of God, Milly has decided to remain alive and to fight Parkinson's to the finish. She has revised her living will to give her the option—or me, as her agent, in the event she is totally incapacitated and unable to communicate—of discontinuing feeding and liquids. But her rate of decline has slowed, so that decision is probably years away.

I will do everything in my power to make her life worth living. To the extent what I do is work, it is never hard work and it is always lightened by love. Milly has recovered some of her ability to swallow, for instance, and so I delight in buying expensive ice cream for her and cooking tubs of vichyssoise almost as rich as ice cream. I do not have infinite patience trying to divine what she is saying, one word or one letter at a time, but I always want to know what she wants and thinks, whether it's mundane or pro-

found. I shout at her when she tries to do something unsafe, like trying to get out of bed when no one's in the room to help. But I also admire her courage. I do wish I had someone to have intimate conversations with. I wish I had more time to play tennis and golf and read books, but there is nothing I would rather do than sit or lie next to Milly, hold her hand and kiss her. I tell her she is beautiful. She winces at herself in the mirror and says that Parkinson's has made her ugly. But it hasn't. Each time I look at her, my heart melts. I still do not know how this story ends. Thankfully, it is not ending soon.