

mental ideas back to their own countries. I can provide assistance to Tibetan groups developing self-sustaining industries.

It's not enough, I know. But my right to complain and shout doesn't necessarily do a damn bit of good. In the meantime, I keep asking myself: What do I believe is right? What are my intentions? What are my responsibilities? How can my intentions match the hopes of those real lives I hope to affect?

*· the opposite of fate ·*

At the end of June 2001, after a four-month book tour that had taken me to forty cities across the United States, then to a dozen more in the United Kingdom, the Republic of Ireland, Australia, and New Zealand, I returned home to San Francisco. I lowered the shades, crawled into bed, and began the long rest I felt I deserved. I slept for nearly twenty-four hours that first day, and then another twelve to twenty at a time in the weeks that followed.

Even before the tour, I had been exhausted, always desperate for sleep. Any amount of activity felt overwhelming. Mail piled on my desk, and I had no motivation to sort through the debris. While on the tour, I was plagued with a constant headache, a stiff neck, a heart rate that zoomed to 130 at odd times, as well as middle-of-the-night insomnia and a moldering apathy, all of which I would blame on the constant change of hotels, the frequent-flyer miles, and the emotional upheaval of recently having lost my mother and my editor just two weeks apart.

Back at home, I told my husband, Lou, that I felt as if something in my body had broken. Something was not right. Weeks

went by, and still I did not feel rested. If anything, I was more tired than ever, in part because I could sleep for only two or three hours before being awakened by a sensation I described as "Dolby Digital syndrome," a constant vibration within my body, which felt as though someone had installed in me a souped-up megabass system for stadium-strength rap music. Unfortunately, such symptoms do not match anything in the standard diagnostic criteria.

During the day, I could not concentrate long enough to write anything new and found myself looping around and around the same pages I had written months before. Writer's block too, however, is not a recognized medical malady. Reading had become a similar challenge with my waning attention span. By page three or four of the stories I started, I was unable to recall anything I had read, and had to begin anew. At dinner parties, I often could not keep up with fast repartee. I could not follow segues in conversation. Everyone I met seemed quick-witted to the point of intimidation. I nodded and laughed at the moments when I saw everyone else do so.

For reasons unknown to me, I was easily overcome with dread when I was alone. Small sounds startled me, made me leap and jerk, then imagine descendants of the boogiemer from my childhood. I guessed that I was not acknowledging some deep-seated anxiety, and so off I went to consult a psychiatrist, the first time I had done so in nearly twenty years. The last one I had consulted had been pivotal in my life: he was a taciturn Jungian analyst who fell asleep during three sessions, and that had the effect of leading me to replace the sleepy doctor with a more lively fiction-writing workshop. With that, I began to write stories, a

whole new career opened for me, and voilà, here I am, able to appreciate the absolute necessity of the doctor's falling asleep when he did. Had he been more attentive, I might have continued my other course in life. Naturally, I wondered what profound changes in my life the new psychiatrist would bring.

This psychiatrist remained awake. She listened, and thought I had posttraumatic stress disorder, aside from my long-seated depression. There were obvious elements in my life that might have accounted for that. For one, I had a mother who had often been seized by rages and despair. I had seen her dramatic attempts to end her life on numerous occasions during childhood, and instead of becoming inured to these episodes, I had grown up with an anticipatory angst, what people develop after a big earthquake, unsure as to when the next temblor will come along, yanking the ground from beneath them. As a teen, I had watched my father and brother waste away to skeletons from brain tumors, which my mother feared she, my other brother, and I were destined to have; I would hear this prediction echoed the rest of my life whenever I had a headache. Since we were doomed to die anyway, why not sooner than later? That logic led my mother once to vow to kill me as she pressed a meat cleaver to my throat for twenty long minutes.

In later years, I accumulated, as others might Hummel figurines, a variety of accidents, assaults, and acts of God. While I was in college, I was a passenger in a car without seat belts that crashed into a pole; I was thrown into the windshield, with the result the rearrangement of my face. While I was in graduate school, a robber pressed the muzzle of a gun against my temple and made me and my co-workers at a pizza parlor lie facedown

in the meat locker; he promised to blow out our brains if we made a single sound, whereupon the woman lying beside me began to scream like an actress in a bad horror movie. The next year I entered a bloody room that smelled of nervous sweat, so that I might identify what items had been stolen by whoever had also tortured and killed a former roommate of Lou's and mine. Lou and I had slept in that same room the night before, and only by chance were we elsewhere the night of the crime.

Just before my first book debuted, I nearly managed to be published posthumously, when I came close to drowning in the Sea of Cortez. I had to be dragged back to shore and have salt water pushed out of my lungs. More recently, after forty inches of rain melted twelve feet of snow, mudslides the size of container ships ramrodded their way down the sides of our cabin in Tahoe, leaving Lou and me stranded next to a perilously rising river. To add to my sense of foreboding, there was the dark side of being published: the overly devoted fans and detractors, three of whom had expressed fantasies of killing me, one of whom had followed me onto a plane to tell me how he would do it.

In retrospect, it is no wonder I was jumping out of my skin at every little noise. I seemed to be a magnet for danger. Why was I so unlucky? Was this karmic payment for some carelessness in a past life? Were these signs that my demise was one breathless moment away? Or could it be that the reverse was true, that these calamities were proof, deliberately sent, that I was amazingly lucky, as invulnerable to weapons and villains as a comic-book action figure? I have fluctuated between the two views: incredibly lucky, incredibly unlucky, doomed to die soon, destined to overcome all. And until recently, I had accommodated

an eventful life with high resilience and a low dose of anti-depressants. Why was my body now expressing its outrage at these traumas?

The psychiatrist wisely suggested that I have a complete medical workup, so off I went to consult with my regular doctor. Wouldn't it be wonderful if it turned out I was merely deficient in one of those vitamins or enzymes without which one becomes nervous, weak-minded, and neurotic?

A week later, while I was in New York, my doctor in San Francisco called with the results of my blood tests. I was perfectly normal, she told me, except for one thing: my blood sugar was low. Well, no surprise there. I had told her years before that I was prone to "low blood sugar," especially when I was traveling or under stress. And besides, everyone had occasional hypoglycemia. It was the yuppie disease, and a bag of M&M's was usually the remedy.

"This is really low," my doctor said. "In fact, the number is rather alarming." Doctors tend to be unfazed when your limbs have nearly rotted off, so I wondered what could be viewed as "alarming."

She explained that the glucose reading was 27, a level that in most people would mean unconsciousness or at least inability to sit up and talk, whereas I had walked into her office the day the blood was drawn, and remained both conversant and vertical. My doctor ran through the possibilities that might account for the glucose anomaly, but dismissed most of them, including my having secretly injected myself with purloined insulin or eaten unripe ackee fruit from Jamaica. Finally, I heard her say she wanted to do more tests when I returned to San Francisco, so we

could rule out a tumor in my pancreas and possibly my brain. Those two things, she hastened to add, were highly unlikely.

I remember that I forced myself to sound calm, almost unconcerned, when in truth I was the one who now felt alarmed. Could this be the fulfillment of the curse my mother had feared? At last, it was happening. I could sense it: I had a brain tumor, just as my father, older brother, and mother had had. Mine would make four, and four was the unluckiest number in Chinese, for the *si* for “four” is homophonous with the *si* for “death.” Then again, this might not be a Chinese curse but a genetic one, a fate that lay within my family’s DNA, encoded in a cell that was all too eager to turn ugly, proliferate like roaches, and squeeze its nest into the limited confines of my skull.

Confronted with all this, I did what any person with Chinese curses and bad medical news does these days: I consulted the Internet. While my mother had turned to the supernatural for its infinite wisdom, I found solace within the vastness of the World Wide Web. There I could continue the search for a diagnosis and cure with the help of Dr. Google, who guided me, nonjudgmentally, through a universe of astrocytomas and migraines, chemotherapy and miracle cures of charlatans.

My preoccupation with illness could be only short-lived, for the next day I had to go to the CNN newsroom in midtown Manhattan for a live interview related to the launch of *Sagwa*, an animated series on PBS based on a children’s book I had written. I had struggled against fatigue to awaken before eight that morning. In the newsroom, I was sitting in a tall director’s chair, earpiece inserted, lavalier microphone hooked to my lapel, black monitor before me as visual focus so I could pretend to be talking face to face with my interviewer. On the TV monitors to my

right, I saw images of pregnant models wearing scanty rave-style clothing that exposed their ballooning bellies from bra line to crotch. It was Fashion Week in New York, and in my opinion, someone had scraped the bottom of the barrel for that one.

“One minute to live,” I heard a voice say in my earpiece. It was shortly before nine a.m. Eastern Daylight Time. This was the soft-news hour, when hardworking people in New York had already gone to their jobs, when alarm clocks on the West Coast were starting to sound, and mothers between those geographic points were preparing their children’s breakfasts and were eager, I hoped, to learn of a new cartoon that would occupy the minds of their brilliant young progeny.

I was relaxed, an old hand at interviews, yet something did not feel quite right. People in the newsroom were talking in loud, tense voices. I knew that background sounds gave the impression of fast-breaking news, but this level of verisimilitude was ridiculous. People seemed gruff, even rude. I concluded that these were colleagues who disliked one another and were suffering job burnout. Listen to them yell at each other:

“What do you mean, you can’t get him on the line? Then go and find him. Quick!”

“Where the hell is Aaron?”

“That’s insane! This is absolutely insane!”

“Go down to the Port Authority, right now—I said right *now!*”

“All right, we got live feed! Everybody, here it is.”

And I saw an image flash onto a dozen screens: a burning building.

I pulled off the earpiece, undid the lavalier. From years of doing two-minute television interviews, I knew that just about anything—breaking news on political scandals, updates on O. J.

Simpson's trial, and certainly a local fire with live footage—would be deemed more important than an author plugging her own work. And then I noticed a bizarre element. There was a plane stuck in the heart of the building, and the building itself was not just any building with a city's downtown horizon behind it. It was one of the World Trade Center towers, and the horizon was the clear blue sky.

"It's a commercial jet," someone confirmed. "We have a witness." And I realized that the shouting in the newsroom had not been rude exchanges but tension bordering on chaos.

When another plane hit the other tower, I heard someone murmur, "This is war." I left my chair and walked to the green-room, trying to fathom what this meant. What do you do when World War III has erupted and you're in a newsroom hearing about it? An intern came up to me and said, "I'm sorry, but we'll have to do this some other day." I nodded, although I knew there would be no other day, certainly not for this interview, and possibly not for anything else. Another woman grabbed me and said frantically, "Have you seen Aaron? We need Aaron in Hair and Makeup right away."

"Okay," I said, having no idea who this Erin woman was. Was she a paramedic? People were going about doing their jobs, enacting approximations of what they usually did, but making no sense in this altered context. I needed to go home and turn on the news to find out what was going on. But wait—these were the very people viewers turned to for that. To everyone's credit, no one in the newsroom was racing out the door or hiding under a desk in fetal position. Yet to judge from the stunned faces, the tearful curses, the sky was falling, and we were all going to die.

Of course, I was not close to death, not like those who worked in the towers and had escaped by accident, or God's grace, or whatever timely circumstance intervened and delivered them out of harm's way. It could have been a missed train, a daughter's earache, a decision to go downstairs to buy a new pair of reading glasses. As for me, I would be the answer to a trivia question that would never be asked: Which guest on CNN was preempted by the attack on the World Trade Center?

An hour or so later, I found myself walking along Seventh Avenue, trying to reach home to be with Lou. I was heading downtown against a stream of people moving uptown, their dusty bodies like figures from Pompeii come back to life. We all stopped when the second tower collapsed, descending like a runaway elevator into the earth. In my mind, I rode it the whole way down and felt in my chest the crush of lives.

For the next six days, while barricaded in our home a mile north of the site, I paced about with tightened sphincter muscles and gritted teeth, waiting for the next explosion, the next wail of fire trucks, the roar of F-16s zooming past our windows and then across the television screen. I felt lucky to be alive, but like those around me, I did not know how long that luck would last. I didn't know what would come next. The only thing any of us could do was pass the time as fate took its course.

When I returned to San Francisco, I sensed I had been given a reprieve from terror. The danger was far removed now. Or was it closer than ever? While I was no longer as

focused on the uncertain future of the world, I had to turn to the uncertain state of my own body. Another blood test showed dangerously low blood sugar. And thus began a regime of tests to rule out the usual, and the unusual, suspects. There was a terrorist in my body, and I wanted it caught and removed.

Several times a week, I went to the hospital for tests—giving what felt like liters of blood and urine, as well as undergoing two CAT scans, an MRI, and a forty-eight-hour hospitalized fast. For most of my life, I had rarely gone to a doctor's office, let alone a hospital, save for an annual Pap smear and mammogram. I had not suffered from any prolonged illness. Flu symptoms lasted no more than twenty-four hours. I always managed to avoid colds, while my husband might catch two or three a year. I had been so confident of my health that I had only the barest of insurance policies, one that cost a few hundred dollars a year, and that accordingly covered only the most basic of emergencies, such as decapitation.

Now I was paying the price for arrogance about my good health. I had been thrown into the maze of hospital corridors and insurance forms, with every procedure automatically denied by a grand vizier who lived unseen behind an 800 number. To this magistrate of maladies, my symptoms did not exist unless I died from them. So for now, since I was still very much alive, the tests were unnecessary and not covered.

Some good news came early on. I did not have a brain tumor. There were fifteen "unidentified bright objects" in my frontal and parietal lobes, but that might be nothing more than the residue of age, I was told. So the curse was off, the images of my blank-eyed father and comatose brother receded.

I found myself wishing for a diagnosis, which in essence meant I was wishing for a disease. As the weeks passed, I grew impatient having to keep my life on hold until the next batch of test results arrived. I had to cancel lectures in Maryland and New York, an appearance for *The Washington Post's* book club, a trip to Aix-en-Provence to honor Toni Morrison, a fête in New Delhi with Salman Rushdie and V. S. Naipaul—though who wanted to fly in this time of heightened security? Better to stay home, where I could stand on my toes, watching for the demise of the Golden Gate Bridge, waiting for the latest tests results. I was struck by how my sense of danger matched the new national climate. We were all anxious over the unknown terrorist who was awaiting us, in tall buildings, at monuments, in amusement parks. We all delayed going on vacation, taking airplanes, and crossing bridges. If anything, my disease served me well as a distraction from a larger uncertainty. Nonetheless, I wanted to secure a diagnosis, good or bad, and then move on with my life in some place other than a hospital waiting room with unread *Golf* magazines and elderly patients who looked genuinely unwell.

What if I had to spend the rest of my life being this lethargic and foggy-headed and not know why? What if I would never again have the energy to hike along the trails of Mount Tamalpais, or ski in races that didn't matter, or dance like a fool with The Rock Bottom Remainers? What if I had to struggle with each sentence I wrote, feeling as if I were writing with a terrible head cold and lack of sleep? What the hell was wrong with me? The cause had to be medical, for I wasn't unhappy with my life. I wasn't the sort who needed a psychosomatic ailment to compensate for a psychic wound. Yet no cause for my illness would turn

up. Time after time, the tests came back as disgustingly “normal.” To me, “normal” meant that I had *failed* the tests. I wanted numbers that were tangibly abnormal, anything that would explain the problems, lead to the correct treatment, and enable me to return to a truer normal, to be oblivious of my state of health. Soon the doctors would exhaust the possibilities, and if nothing was found, they would give me a benevolent look, tell me that I was quite healthy, and that I should discuss this further with my psychiatrist.

Somewhere in the parallel universe, where everything is absolutely known, was the elusive namable reason. Could the reason be changed? Could I do as Christians did when they went to China in the 1800s and conquer Chinese fate with religious faith? If I prayed for a less serious ailment, could I really change an already given cause? Was it possible to have symptoms to suit a dozen diseases and have God decide later which one, if any, it was? Hadn't He already decided what I had when He allowed the symptoms to arise? Or was He in charge only of reducing the medical sentence? How did prayer work, anyway? What were you praying to alter or affect?

And then one day, finally, after so many tests, a promising candidate surfaced as the source of my problems: a tumor on one of my adrenal glands, that set of organs above the kidneys that does not exist in most people's minds until something goes wrong. *A tumor!* So my mother was right once again.

The tumor, on my left adrenal, was a tiny little thing, a tad more than a couple of centimeters wide, called an “incidentaloma” because it was the kind of anomaly doctors find incidentally when searching for other problems. As the specialist explained, if you examine anyone's body long enough, you will

find all kinds of bugaboos: cysts and scotomas, lesions and adhesions, calcification and clogs, thinning and thickening of cells, tissue, and arteries, and skin eruptions as varied as snowflakes, most of which are the usual detritus of commuting, fast food, and the vicissitudes of time. It sounded as harmless as finding loose change and popcorn stuck between the seat cushions in an old movie theater. A small portion of incidentalomas might require cleanup and removal, but for the most part, some degree of body weirdness and decrepitude was expected. And indeed, my doctor told me my tumor was probably benign, given its size, meaning it was probably not malignant.

In my posttraumatized state, “probably not” was not a reassuring prognosis. After all, did most people nearly die a dozen times? Did most people have three brain tumors among their immediate family members? The answer to both was “probably not,” but look what had happened to me. The specialist went on to suggest a reasonable plan: I could wait and see, then have a CAT scan done every six months to check whether the tumor was growing. Or I could choose to have the left adrenal gland taken out now. Let's see, I said to myself, which would I rather do—gnaw my fingers down to the bone over the next six months, or convict and sentence the tumor right now, guilty on all counts? Off with its head, I said.

After the laparoscopy, I was given steroids to help me along until my right adrenal gland kicked back into service. As I recovered from surgery, I noticed that the Dolby Digital buzz and fast heart rate were gone. My doctor and I congratulated ourselves on having found the apparent culprit. But then the hallucinations began.

The night they first came, I had retired to bed early. Three hours later, I suddenly woke up, as I often did. I glanced at the clock. It was only twelve-thirty a.m. The light in the dressing area was still on, and I was about to get up to turn it off when I saw my husband standing in the doorway. "Lou?" I called out. He walked silently toward me until he reached my side of the bed. Oh no, bad news. I waited for him to turn on the lamp and tell me who had died. But he said nothing. Was he dumbstruck with grief? "Lou?" I said again, and as I reached for him, my fingers raked thin air, and the figure before me warped and then evaporated.

I jumped out of bed, certain now that Lou was dead and the vision I had just seen had been his ghost. I ran down the stairs and through the house, my dogs at my heels, calling his name until I found him, very much alive, watching television. So what had I seen? Was the hallucination the residual effect of being on morphine and anesthetized during surgery? Since my release from the hospital, besides steroids, I had been taking nothing more powerful than ibuprofen.

My doctors did not think the vision was a drug reaction. Yet they could not say what it was. With their kind but concerned looks, did they think I had the dreaded medical malady known as "loose screw"?

The hallucinations came once a week, then every few days, and eventually, daily. This was especially problematic when I was away from home and staying in a hotel. Since I had had stalkers and death threats, I could not automatically assume that the stranger I thought I saw lying next to me in the middle of the night was a phantom of my mind and not a flesh-and-blood lu-

natic (on one occasion years before, a *real* man, drunk and completely naked, had come into my hotel room from an adjoining door). To deal with the hallucinations, I trained my Yorkshire terriers to search hotel rooms before I entered. "Find bin Laden" became my cue, and their game was to dash behind doors and into dark closets, to zoom under beds and behind curtains in search of vermin in their mind and a villain in mine. When the odd people appeared to me at night, I would whisper, "Who's there?" and the dogs would instantly leap to attention, scan the room, sniff the air. When they settled back to sleep, so would I. That is, I would try to sleep after having seen a corpse lying next to me, or a pudgy poodle dangling from the ceiling, or two girls skipping rope by the side of my bed, or a woman in a white dressing gown standing in a garden, or a carnival barker playing a circus organ.

I began to track when the hallucinations occurred: always when I had just awakened from sleep. The hour did not seem to matter, whether it was midnight or seven in the morning. It did not seem to correspond to the degree of light in the room, or to my blood sugar levels, whether I was home or away, whether I had had wine at dinner or none for weeks. Some switch in my brain that controlled dreams now seemed to fail to turn off once I opened my eyes, and before me would spring forth the embodiment of my nightmares, the incarnation of my imagination. Had I been a science fiction writer, I would have been blessed with abundant material.

My bedtimes became even wilder, and not in the ways most people would find sexy and desirable. Along with having hallucinations, I began to act out my dreams. I ran in bed, I sat up, I

talked. Since I often had dreams of being attacked, I would kick and thrash, push and pummel, and Lou would bear the brunt of those kung fu moves. Other victims of my assaults were a lamp, the sharp corner of my nightstand, and my pillow. I awoke with bruised fists. One night, while dreaming that a woman was about to stab me, I tackled her in my dream and in doing so dived out of my real bed and landed with full bodily force on my crown.

Then there were the bizarre acts I committed of which I have no memory. I purportedly threw laundry around our loft in New York, draping clothes over chairs, sofas, and tables in odd configurations, so that when I saw my rearranged rooms the next morning I thought a deranged interior decorator had broken in. The notion of ghosts also came to mind. Another time I apparently crammed several boxes' worth of tea bags into a small bowl. I thought Lou had assembled this odd presentation of herbal choices for future guests. And one night, while in a hotel in Pasadena, I reportedly called a friend at midnight and left a message in a woeful little-girl's breathy voice, asking whether my friend had seen Lou and my dog Bubba. The next day, after I refused to believe I had called her at such an ungodly hour, she played back the message for me. Listening to my recorded voice, I had the eerie feeling I had developed multiple personalities. Had I been a drinker, I would have sworn off alcohol.

I was worried that I was developing dementia, that I might be following in my mother's footsteps and have Alzheimer's disease; I gave Lou permission to place me in an assisted-care facility, should the time come. We revised our wills and set up a trust. I consulted a few more doctors. I saw a sleep-disorder specialist who found only that I did not have apnea. I saw a neurologist, who said I did not have signs of seizures. I was starting to won-

der whether perhaps nothing was wrong with me but the general malaise of growing older and stranger. Did other people simply accept that their bodies broke down like automobiles the moment their warranties expired?

The psychiatrist believed that there was indeed something more. It relieved me greatly that she did not think I was crazy. She pressed me to have more tests done. The most troublesome problem now was my inability to work because of exhaustion and poor concentration. If anything, going to and from the hospital made it even less possible to write. I decided to stop seeing all doctors for a while and try to follow the British example: with a stiff upper lip, carry on.

As my problems worsened, I made light of them with my friends. "Good thing I'm a fiction writer and not your airline pilot," I would say. To them, I looked normal; they assured me I was suffering only from the forgetfulness common to all baby boomers. We all walk into rooms and wonder why we are there, they said. We can't remember names, and even our own phone numbers. We all have stiff muscles and aching joints. We all suffer from bad dreams, especially since September 11. We are all losing our hair.

Rather than feel comforted, I felt alienated, for that was not how it was for me at all, yet it would have sounded crazy to explain why not. Did most baby boomers lose their hair in clumps, so that their shower drains had to be unclogged almost daily as the equivalent of a small wig was extracted? Did my friends read e-mails, respond at length, then have no memory of doing either? Were they stunned to read unfamiliar pages of stories they had evidently composed? Did they leave the first letters off words when writing by hand? Did their speech become garbled,

such that they substituted like-sounding but nonsensical words? And did they become lost in their own neighborhoods, unable to recognize familiar landmarks, too mortified to ask for help? When flustered by a distraction, were they overwhelmed, then disoriented? I would stand on the sidewalk, paralyzed with indecision, fully aware that I looked like a potential victim for a mugger as I glanced up and down the street, baffled. My salvation was to nudge my dogs to walk ahead of me on their leashes to keep me going in any direction until I could find my bearings. If we were close to home, they went in that direction. In New York once, without the dogs, I wandered aimlessly for an hour in a snowstorm, just two blocks from home, because that blanketing of white rendered the terrain unfamiliar.

Driving a car was no longer something I could do with natural ease. It became a mental chore, a test of my reflexes. I marveled that most people knew automatically not to brake at green lights but to do so at stop signs. Colors and foot movements became tricky, as did directions. People honked in exasperation at my mistakes. I stopped driving. I no longer left the house alone. Bit by bit, I learned to make accommodations to deal with my problems. But consequently, my life was becoming very small.

I have Madonna to thank for my diagnosis. In November 2002, Lou and I were headed to Miami for a reunion with my fellow bandmates in The Rock Bottom Remainers. The boys in the band thought it would be hilarious if I sang "Material Girl," badly—not that there was any other way I was capable of doing

it. I had my doubts about singing this particular song, but I went ahead and purchased a new wig for the act, as well as a nylon bag with the Enron logo, both of which I found on eBay. My Material Girl would be a corporate-scumbag lady. On the plane from San Francisco to Miami, I studied the lyrics and listened to a karaoke version of the song on my CD player.

For the next six hours, I tried to commit the lyrics to memory. They were not profound—this was about a girl who liked to fool around but who was no fool when it came to money. Yet trying to hang on to the words was for me like trying to wrangle oiled fish. After six hours of study and karaoke-style practice, I still could not recall the first line without having the printed words in front of me. I reasoned that I was tired. Once in a hotel in Miami, I continued to practice, from nine p.m. until two a.m., at which point I tried a test neurologists use with Alzheimer's patients—counting backward from one hundred, subtracting seven each time. It was terrifying. I felt as if I were swinging on monkey bars, having to remember simultaneously which hand to release and which bar to grab, only I would hesitate too long in figuring this out and would fall between bars. I was sweating with frustration and fear. I noticed also that my left arm, which had been numb down to my forefinger, now developed an icy-burning sensation. I'd had a similar problem with my right arm two years before. In the morning, I still could not remember the "Material Girl" lyrics, and could barely move my left arm without the shock of exquisite pain.

Lucky for me, our band is known for being ludicrous, so it didn't matter that I had to read the lyrics stiffly to perform them. Yet even reading them was difficult, for in doing so, I had to sing,

listen for musical cues of when to come in, and move my body in more or less rhythmic fashion. There was so much I had once taken for granted that I now struggled to do. My bandmates thought it went over hilariously well. I was mortified.

When I returned home, I made an appointment with another neurologist. This time I was determined to continue with tests until something came up. I had taken a look at an MRI report from more than a year before. What were those fifteen small "unidentified bright objects" on my brain? Were they *always* a normal part of aging? Could they relate to something else? And what about the burning in my arm, which an MRI showed to be synovitis? Why did I have synovitis first in my right arm and now in my left? The doctor agreed to prescribe more tests to rule out multiple sclerosis, lupus, and a squiggly word on a lab slip that I thought said "Lyme."

Until then it had not occurred to me to consider Lyme disease. Wasn't that something that was on the East Coast only? Then again, I was someone who bounced back and forth between coasts. In any given week, I might be in San Francisco, New York, or five cities in five different states. I recalled that I had found engorged ticks on both of my dogs, several times as a matter of fact, and even as recently as a few months previously, shortly after being in Washington, D.C. Upon seeing a wad of matted hair on my dog Lilli, I cut it off, and blood spurted onto my fingertips. Had I injured my dog? I brought the wad closer to my eyes, and the fleshy-looking piece began to move, legs bristling, combing the air in a desperate search for another patch of warm skin. I nearly vomited with disgust. Both of my dogs had received Lyme vaccines as a precaution, but I now took them to their veterinarian to be tested just in case.

Why had I never thought to test myself? The reason was simple: I had never seen the "bull's-eye rash" that everyone said was the defining sign of a tick gone bad. I had read about it in a newspaper or magazine. I thought that "bull's-eye" referred to a visible tick bite surrounded by a thin red ring about the size of a wedding band. But now, unsure as to what it looked like, I did a search for Lyme disease on the Internet. Up came a website with photographed examples of erythema migrans, the rash characteristic of the spirochete *borrelia*. My scalp prickled. *There was my rash*. I recalled it: a huge red splotch wrapping my shin, just below the sock line, about four inches in diameter. What was that? With my impaired memory, I tried to piece together clues. I remembered seeing the growing rash and thinking it might have been caused by a tick, but there was no red circle. So I assumed it was a spider bite. Now, after viewing these examples from the website and reading the descriptions, I knew that rashes did not necessarily develop the bull's-eye immediately or at all, and the bull's-eye itself was not necessarily a thin perfect band; it could be the remnants of the large rash as it cleared outward from the center. It might be better described as a cloudy halo, sometimes well demarcated, sometimes messily, appearing in some cases like the primordial outline of an unevenly submerged volcanic cone, as mine had appeared when it gradually faded over the month. In more than fifty percent of the cases, the website said, the patient never even saw the tick bite or the rash.

The most dangerous ticks, another website reported, were nymphs, so small as to be the size of the period in this sentence. They often went unnoticed. Now I recalled that at the center of my rash there had been a very black dot. I remembered its blackness, and that it was unusual. The dot was rounded and raised, so

I assumed it was a blood blister formed from my scratching at the rash. When it fell off, it left a pit with edges that continued to slough. Soon more rashes appeared on the sides of my lower leg, and then three more bloomed on my upper arm. I remember thinking I must have had an infestation of spiders that dropped down from my ceiling at night. But the website led me to new conclusions: As Lyme disease disseminates, the rash may appear on other parts of the body.

I then recalled that sometime later, the tops of my feet had gone numb, and I had wondered whether the rash had anything to do with it. I had mentioned this to my doctor during my annual checkup, and I remembered the approximate date of that appointment, November 1999, shortly before my mother died. In some quick tests of my ankle reflexes, which proved absent, my doctor had scratched along the top and bottom of my feet, which lacked normal sensation but strangely were also painful. She concluded that I had peripheral neuropathy but no other apparent neurological problems. I would keep a watch for other problems, but for now, we agreed, this symptom seemed only a curiosity, nothing to worry about.

Three years had passed since my feet had gone numb. As I scanned the websites on Lyme disease, I felt the heightened tension of reading the inevitable conclusion of a murder mystery. Here were all the clues, so obvious now: the rash, the exhaustion, the numbness, the stiff neck, even the hypoglycemia. Reading the list made me feel as if I were watching that old show *This Is Your Life*, in which sentimental details from someone's past were dredged up and paraded before the public: an old math teacher, a boy once dated, a first boss. But instead, these were the visitors

from my past: thinning hair, rapid heart rate, hypersensitive hearing, palpitations, the sense of internal vibration (my Dolby Digital Syndrome!), stiff muscles, migrating joint pain, ringing in the ears, sensations of burning and stabbing, a crackling neck, synovitis, insomnia. Then came the cronies of late-stage borreliosis: such cognitive problems as slowed mental processing, geographic disorientation, lack of concentration, and even hallucinations, my visitors in the night.

A new question came to mind: When had I been bitten? Where, exactly? Had it been while I was walking the pastures in New Jersey, attending an outdoor dog show in early autumn? Was it during the spring when I was in upstate New York, visiting my editor, who was ill? Did it happen during the hot summer when I went to a writers' conference in Old Chatham, New York? Was it at the outdoor wedding in Dutchess County? Or had it been when I was hiking the grassy woodlands of Sonoma, Mendocino, or the Yosemite basin? Did it happen in China, Italy, Poland, or Czechoslovakia, places I had visited that had borrelia ticks of a different strain? It was impossible for me to know, because I had led such a peripatetic life recently. A tick that had attached on to me in one location could have been transported home with me to San Francisco.

Yet this was the question that came back to me throughout the day and in the middle of the night. I could not stop imagining the various scenarios, me blithely enjoying myself, walking along a grassy path on a gorgeous day, while the little vampire scurried up my leg. I wanted to envision it so that I could uselessly ask: "Why me?" Why had I, out of hundreds or thousands who might have passed that same spot, become the hapless meal

for a nymph tick? What was I doing while the spirochetes were swimming in my bloodstream, using their corkscrew tails to propel themselves quickly into my tissue, my organs, my brain?

Because that tick bite had changed the course and quality of my life, I wanted to be able to capture the precise moment, see it as live feed on a CNN monitor. I wanted to play it back repeatedly, and the moments right before and after, as we do with all the great and terrible moments of our life, the ones that are both personal and universal, the seconds that changed our world forever, be they the birth of a child or the death of a loved one, the assassination of a great leader or the collapse of the World Trade Center towers.

I knew my doctors would advise against gorging myself on excess information, but I was desperate to know as much as possible about the parasite in my body. I searched the Internet again and found a support group, inhabited by a virtual underworld of longtime sufferers of Lyme disease. The recent posts came from the newly frightened, often the mothers of children whose perfect peach skin had been defiled by a tick and who were now listless and doing poorly in school. I had yet to be diagnosed, but I felt certain I had found my culprit.

In reading the posts, I learned my case was typical. I had spent a few years looking for a cause. I had had surgery and more than \$50,000 of diagnostic tests. Some of the Lymies, as they called themselves, had been long undiagnosed—some for ten, twenty, even thirty years. Like many of them, I had been told Lyme disease was rare. There were only 139 new California cases reported in 1999, the year I was probably infected. *Reported* cases, the Lymies countered. They knew of a Lyme specialist in San Francisco who had treated five hundred patients.

Now what should I do? My virtual friends were more seasoned warriors than I, of both borrelia and ignorance in the medical community. They urged me to avoid the screening test most doctors gave, the enzyme-linked immunoassay, or ELISA. It had a ninety-percent specificity but only a sixty-five-percent sensitivity: this test delivered an unacceptable level of false negatives. In contrast, tests for anthrax were 110 percent sensitive, which meant some false positives. With a deadly disease, wasn't it better to err on the side of being overly inclusive? Yet the opposite was true of the screening test for borrelia. If you take the ELISA and it's negative, the Lymies warned, that is what your doctor will believe, and you will not be given the Western blot, the test given to those who test positive on the ELISA. The Western blot is a more sensitive test, they said, but the disease has to be diagnosed by someone who recognizes the whole panoply of history and clinical symptoms.

Unfortunately, few doctors took the time to be updated on the intricacies of such a clinical diagnosis. Why should they? They had never seen a Lyme patient. For the latest information, they depended on one-sheets that spelled out the basics: "Use the ELISA screening. If it's positive, it may be a false positive, unless you see the bull's-eye rash. For actual infections, ten days of antibiotics will suffice." Even newscast doctors received press releases with similar advice, and without questioning the source, they passed this along to viewers as sound advice. But the ten-day "standard" took as its basis a single study considered grossly flawed by many Lyme doctors who saw hundreds of patients each year. Ten days of antibiotics was a recipe for relapse, the Lymies said. That was like saying one Roach Motel was sufficient for any house, no matter how small or large, whether you

had seen one roach recently or your house had been thick with them for years. If you don't believe undertreatment is dangerous, the Lymies told me, look at us. We are the fallout from this advice. We relapsed and were refused further treatment. We who were once professors, lawyers, carpenters, doctors, social workers, teachers, and busy mothers became bedridden, then lost our jobs, our homes, and sometimes our hope.

I felt I was hearing from people drowning in the River Styx. What sort of disease had I acquired? Was it Lyme that made these people suspicious and cranky? The Lymies demanded to know why the medical community had been so hasty, so determined to say short-term treatment was good enough. They pointed out that no one even knew for certain what the etiology of Lyme disease was until 1982. And in twenty years, there had not been enough research to know how to knock back borrelia's hydra-headed ways of invading the body and remaining entrenched in its favorite eatery, the brain.

Whether I had Lyme or not, I knew I was developing what some might call a "terminal illness," what one acquires sitting in front of a computer terminal, ingesting Internet information in megabyte doses. But I had to know who my terrorist was. I had to visualize what was now in my body. My enemy was a spirochete, a clever bacterium with a tail, four times more complex in its genetic structure than the spirochete that causes syphilis, for which patients are given *months* of antibiotic treatment. Like the frightening creatures of *Alien* moviedom, the borrelia spirochete is a smart bug that has the ability to transform itself into other forms, a cellular version of a wolf in sheep's clothing, able to hide and go unrecognized by antibiotics and the body's immune

defenses. A changing arsenal of weapons was needed to knock it back, with treatment lasting years, if not a lifetime. Yet insurance companies, HMOs, and medical organizations had latched on to the notion that ten days of antibiotics was quite enough to defeat borrelia and restore patients to a pain-free, productive life. Their rationale for this parsimonious approach stemmed from concerns over antibiotic-resistant diseases that had developed worldwide from indiscriminate use of antibiotics. But acne patients continue to receive years' worth of antibiotics without any hassles. Acne was not a life-threatening disease, the Lymies pointed out, while chronic neuroborreliosis was.

The old-timers on this message board were a skeptical bunch. They did not trust most of the medical community, only those doctors they considered "Lyme-literate," the ones who saw hundreds of cases a year, as opposed to those who had seen only one or two, if any, in their entire years of practice. The Lymies exhorted me to find a Lyme-literate doctor, one who would order the tests by IGeneX, the lab that included all sixteen bands of the Western blot and more strains of borrelia, of which there are approximately three hundred worldwide, than any other lab.

But I was not as cynical as these Lymies. Not all doctors refused to consider Lyme. The new neurologist I was seeing had ordered the Lyme test without my bringing up the subject. He must have indeed considered it possible that I had the disease. Soon the test results would arrive, and I would have my answer.

The answer arrived: The tests were negative, all of them. I had been so sure I had Lyme disease. I still was. The Lymies' remarks about the poor sensitivity of the ELISA stuck in my mind. I called the specialist to say I had recalled important information

that I had failed to tell him and my other doctors. I mumbled about the rash, the numbness, the stiff neck that led to my buying new pillows every week.

"I really doubt you have Lyme disease," he said. "It's extremely rare in California."

I hurriedly pointed out that I lived part-time on the East Coast, that I was often in Dutchess, Putnam, and Columbia counties of New York, which were known to have Lyme disease infestations. I had vacationed in Mystic, Connecticut, which is near Old Lyme, the town for which the disease was named. "I know that I tested negative," I said, "but I would like to take further tests, just to make sure."

And then my doctor surprised me. He said that the lab had not run the test for Lyme disease after all. They had tested me for syphilis, that other spirochete. But if it would make me feel more at ease, he could order the best test for Lyme, the ELISA. And if that was positive, we could do a spinal tap to make sure.

That evening I wrote an e-mail to the Lyme specialist in San Francisco who had been mentioned by Lymies on the Internet; considered by them among the top experts on the disease, he saw patients from across the country and one year had been voted as among the best doctors in San Francisco. At my appointment, I told him my symptoms, and instead of looking puzzled, this doctor nodded. "Quite common," he said. He looked at my MRI. "Characteristic," he noted. Nothing seemed too surprising or bizarre. He filled out a lab slip for the Western blot that would be run by IGeneX, the same lab the Lymies had recommended. In short order, I had my answer: the Western blot came back highly positive for Lyme disease, lighting up many bands. A scan of my

brain showed hypoperfusion, also known as "clogged brain," which accounted for slowed processing and other damage, all typical of Lyme. My immune system showed abnormalities indicative of an immune system battling a chronic infection—a lymphocyte count of fifty-five percent, way over the high normal of forty-two percent. I also had abnormally low natural killer cells, a marker that this doctor had seen in almost every patient with late-stage Lyme disease. He wrote the name of my official diagnosis: neuroborreliosis, also known as neurological Lyme disease.

That day, I began taking megadoses of antibiotics. Two days later I was worse than ever. My brain felt as though it were swelling; I had a terrific headache. My joint pain had grown worse, the ringing in my ears was shrill, and my hands and feet were burning. I was exhausted, as though I were coming down with the flu. I told the doctor what was happening.

"That's good to hear," he said. The worsening of symptoms, the Jarisch-Herxheimer reaction, happens with very few diseases in response to antibiotics; one of them is syphilis and another—wouldn't you know it—is Lyme disease. The fact that such a reaction occurs is a confirmation of the diagnosis.

After ten days, the antibiotics had not had much effect on ridding me of my symptoms. Thank God I was not with a doctor who stuck by the ten-day standard. But after eight weeks, some of the fogginess lifted and I had an amazing amount of energy—that is, a normal amount. I was elated. I cleaned my desk, rearranged furniture and changed bedding, drove to the hardware store for supplies, then returned to paint the garage, hang a bar in the closet, and hose down the terrace. Later I shopped for gro-

ceries, cooked a meal for friends, and washed the dishes—all ordinary chores I had not been able to do for lack of organizational skills, energy, and motivation. The next day I began to write again. A couple of weeks later the fog returned and once more I was easily tired and overwhelmed. When I tried to drive, I stopped at a green light and ran a red one.

As word of my diagnosis went around, a dozen people came forward to tell me that they too had been infected with Lyme disease. I had been initiated into a secret club. They included writers, a publisher, a publicist and his partner, a librettist, a veterinary technician, and the wife of a writer. I thought to myself: This is a rare disease? To judge from the numbers reported by the Centers for Disease Control, I should have seldom or never encountered another person who had this. Most of these people lived on the East Coast, where a tick bite is taken more seriously. A good many had been seen by savvy doctors who prescribed antibiotics without taking a screening test. The one who was not given early treatment lives in California and is also a writer. Like me, he had been unable to write. He has been battling the disease for six years. He has gone through various combinations of antibiotics, daily intravenous infusions, and painful shots. He is slowly getting well. "When the good days come," he said to me, "they are golden. Savor them. Write your heart out."

Finding the cause should have been the end of this story, yet I feel it is still close to the beginning. I am in it for the long haul, with treatment that will likely last for years. I won't feel safe until my brain scan and the blood tests on my immune system return to normal, until the Western blot is negative for Lyme disease, and the myriad symptoms are gone. Well, perhaps not

all of them will disappear. I'm told I should expect to keep the joint problems as a souvenir.

Moreover, simply by having Lyme disease, I have been drawn into the medical schism over both diagnosis and treatment. I now know the greatest danger that borrelia has highlighted: ignorance.

I was ignorant and did not think the original symptoms were important enough to recount. The majority of doctors still believe that Lyme disease is extremely rare, yet each day I hear of more and more people who have it. The medical community believes without question that the ELISA is a fine diagnostic tool and that a short course of antibiotics is all that is needed. That, I learned, is the board position of the California Medical Association. Why did it issue such a dangerous precedent-setting recommendation? Executive staff there told me no proof exists yet that Lyme disease can turn into a persistent infection.

Where does that leave me? I have a persistent infection. And I am also, by nature, quite persistent. I persisted in finding the right doctor, finding the bug that got me. I will do what it takes to get well, ignorance and medical politics be damned. I am in charge of my body now. And thus for the first time I am certain I will get well. Even if I do not recover completely, I am grateful to have made a small improvement, for I am able to write again when the golden days quietly arrive. Writing comes with great effort. I have to think harder. But then again, the world is now a more difficult place for all of us. We all have to think harder.

For the time being, I can accept with aplomb and humor that I do indeed get confused and am not as quick as I once was. When I am disoriented, I know this is not panic born out of fear

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of the unknown. The terrorist in my body has been found. Yes, the world to me is still a scary place, but no more so than it is for most people. I am no longer governed by fate and fear. I have hope and, with that, a determination to change what is not right. As a storyteller, I know that if I don't like the ending, I can write a better one.



*My mother and me.*