Introduction

“When you’re going through hell, keep going.”

—Unknown

Sometimes there is a moment in a person’s life that, although seemingly insignificant at the time, heralds a drastic and unalterable change in everything that follows. For me, it was August 15, 1996. The “insignificant event” was, I thought, a virus. I had a fever and chills. The fever was high, 104 degrees, and the chills made my teeth chatter and the bed shake. My body ached so much I felt like a discarded New England Patriot’s tackling dummy.

But I had no other symptoms commonly associated with the flu, no cough or respiratory congestion, and influenza does not occur in the summer. I didn’t have the upset stomach or diarrhea typical of a stomach bug either. I never saw an insect bite, and I didn’t notice a rash. For two days I was so sick that I stopped worrying that I would die, and started fearing that I would live. On the third day, it was all just a memory.

It seemed quite strange, but since I was able to resume full activity, including several three-mile runs, I didn’t think much of it—until one week later, when it hit again. Once more, the fever, chills, and muscle aches lasted two days and then went away. Still pretty strange, I thought, but since I felt well after this relapse I chose to ignore it. Denial works well when you feel okay. But when the symptoms recurred a third time a week later, the denial stopped working and I began to worry. This time I went to see a physician friend of mine. Upon examination, he palpated an enlarged spleen. He ordered some blood tests, and the laboratory reported a positive antibody test to Lyme. The diagnosis came as a relief. The cause of my problems was a simple bacterial infection. Two weeks of antibiotics would clear it, and then I could resume my normal life.

Was I in for a surprise.

I tolerated the antibiotics without difficulty, and the fever and chills did not return. But instead of feeling better, I felt worse. The next symptom that hit me, and hit me hard, was insomnia. One night I woke up at 4:00 a.m., and couldn't fall back to sleep. The next night I woke up at 3:00 a.m., the next at 2:00 a.m., and then 1:00 a.m., unable to go back to sleep. This went on for weeks. I only slept a few hours a night. I was exhausted. But even worse, I became consumed with anxiety.

I would lie awake through the dark hours of the night riddled with fear. Initially the apprehension focused on my sleeplessness, anticipating the difficulty of getting through the day in my worn-out state. Gradually the anxiety generalized into a constant dread that something terrible was about to happen—impending doom. It wasn't rational. It wasn't something I could control with reason. It was just always there. It felt like a black cloud was enveloping me, cutting me off from any future; it was pure existential terror. It was so intense that some nights, as I lay awake with insomnia, I shook so violently that I added disrupting the San Andreas fault to my list of fears—and I was living in Boston!

I stayed on antibiotics, but the symptoms continued to worsen. I had muscle aches throughout my body, but my thighs were especially painful. Walking up a flight of steps made me feel like I had just run a marathon. I was exhausted, both mentally and physically. I would somehow manage to go to work each morning, hoping that helping patients with their own problems would distract me from mine. But once at work, I would count the hours to get through each day, and when I finally left the office I felt even worse without the distraction of work. I would plod home, lie down on the sofa, focus on my breathing, and try to get through the next minute—one moment at a time.

Although I'm a physician, I had little experience with Lyme. So I mustered what energy I could—I phoned a Lyme specialist in Boston who was considered a world expert in Lyme disease and asked for advice. He listened courteously to my story as I described my history of symptoms and lab tests, but what he told me came as a shock.

"You don't have Lyme," he concluded.

I was confused. "Well, then, what do I have?"

"Something else," he replied.

"But what about the lab tests?" I asked. "Using the Western Blot technique, the assay demonstrated the presence of antibodies highly specific for Lyme. I even repeated the tests one month later, and they confirmed the initial results. Isn't this the CDC criteria for the diagnosis of Lyme?"

"The laboratory must have been wrong," he informed me.

"Why do you think I don't have Lyme?" I responded.

"Because if you had Lyme, you'd be better by now."

I thanked him for his time, hung up the phone, and tried to make sense out of what I had just heard. I considered this doctor's logic: if the cure didn't work, I didn't have the disease. I had had an acute illness with fever, chills, and muscle aches. I had blood tests that confirmed a diagnosis of Lyme. I live in an area endemic for Lyme. I had seen deer ticks on our dog. I continued to feel terrible, but I didn't have Lyme because I wasn't better. I was getting my first taste of the controversies surrounding Lyme disease.

Next I consulted with a friend and colleague, a physician in upstate New York who treats a lot of people with Lyme. When I told him what the Lyme expert had said he replied, "Welcome to the Lyme wars." He informed me that there are two different Lyme camps: those who maintain that Lyme is hard to get and easy to treat, and those who believe Lyme is easy to get and hard to treat. The so-called Lyme expert was a strong proponent to the former. Given my personal experience, I now subscribed to the latter.

What is clear now is that while the Lyme expert was categorically wrong when he denied I had Lyme, he was correct that I did indeed have "something else." The something else was a co-infection, specifically *Babesia.* However, this bug was under the radar in 1996. If I were taking my history now, I would immediately suspect this infection.

Under my friend's supervision, I proceeded to take several different antibiotic regimens. Over the next ten months, I took high doses of doxycycline, as well as Biaxin and Ceftin, sometimes alone and sometimes in combination. But the medications didn't seem to make a difference—the antibiotics that were treating my Lyme weren't effective for *Babesia*. I took three different sleep aids every night to get five or six hours of sleep, and then woke up in the morning looking forward to nothing but the next night when I could go back to sleep. During the day, I dragged myself around like a dead weight. I feared I would rub the flesh off my thighs in a vain attempt to get relief from the constant aching.

The anxiety was constant. Catastrophe awaited around every corner, and a dark cloud hovered overhead on the sunniest of days. Even the simplest of tasks seemed impossible. Changing a light bulb or going grocery shopping were major undertakings. One afternoon I walked into my bedroom and found a pile of clean laundry on the floor waiting to be folded and put away. The thought of doing this simple task was so overwhelming that I began to weep. I sobbed for hours unable to stop the tears, unable to stem the misery of utter defeat, the despair of never feeling well again.

I was barely hanging on by my fingernails to get through each day. I was increasingly depressed. I used to love to play tennis, go swimming, and run with my best friend, but it seemed as if I had aged forty years and would never enjoy them again. I had always had a stockpile of jokes that I took great pleasure in telling, but my spirit seemed to be dying along with my stamina.

Although I tolerated the antibiotics for Lyme with minimal side effects, after one year I stopped them, and there was no change in my symptoms. But six months later, for some miraculous reason, I began improving. Life was good again. I was smiling, productive, and enjoying life. Lyme was history.

Or was it? I still had drenching night sweats and my thighs ached on and off. I still needed sleep meds. These issues were easy to ignore considering what I had been through. But my thirty-year marriage was unraveling, and then I unraveled as well. Symptoms returned with a vengeance. The worst, by far, were the anxiety and depression.

In my medical practice, I had encountered patients daily who were chronically ill and became depressed simply because they had felt poorly for so long—but this was different. This depression was virulent, cloaking every waking moment with anguish and despair. The lens through which I perceived the world had gone from gray to black. The anxiety was over the top, with symptoms of agoraphobia, agitation, and panic attacks. I was afraid to be in my house alone and afraid to go out. I thought I was losing my mind. I was right.

I started seeing a therapist, a psychiatrist, and a psychopharmacologist. That winter I began taking Celexa, an antidepressant, and Klonopin, an anti-anxiety agent. They helped a little, but not enough, so I was switched to Zoloft and Remeron for depression and higher doses of Klonopin around the clock to control the panic attacks. Despite these medications, I felt suicidal. My world-view lens continued to be black. There was no escape.

I prayed and meditated regularly. And I continued to seek help from every quarter. A friend took me to a priest in Boston whose touch on the forehead caused people to pass out and drop to the floor. There were reports of miraculous healings, and I had images of people throwing away their canes, or tumors dissolving on X-rays. Since I am Jewish, it was quite a leap.

Standing in the pews while my fellow congregants sang hymns to Jesus felt as if I were in a foreign country, not Boston, Massachusetts. I knew my parents would never understand this one, but I rationalized that there is only one Great Spirit, and it’s the intention that counts. I was surprised when one of my own patients took the podium to describe her incredible recovery at the hands of this priest. Unfortunately, it only served to undermine my confidence, since I knew that she was far from recovered.

My friend walked me into the aisle and I waited with trepidation. In front of me, people were dropping like flies as a distinguished looking priest with white hair and black robes put his hands on their foreheads. Two burly men in brown suits would catch the limp bodies and set them down. Father O’Connell put his hands on my forehead and gave me a push. I took the plunge like the other supplicants—I didn’t want to be the only one standing. When I got up, I felt the same, no miraculous healing that night.

My parents attended synagogue every Sabbath. When the torah scroll was open, the rabbi would ask for names of people who were ailing. My folks always made certain to include my name, asking for *r’fu-ah sh’lemah*, a complete and speedy recovery. I was covering all the bases.

Meanwhile, my symptoms continued. With the slightest provocation, like watching something suspenseful on TV or even just standing up, my heart would race and pound as if it were trying to escape from my chest. Sometimes I would be lying still in bed and my entire body would actually move from side to side with each beat. Since then, several patients have described the same symptom to me.

Much later I realized that I had suffered another tick bite and had become additionally infected with *Bartonella.* But I had reached the end of my rope. My family wanted to hospitalize me, fearing that I would harm myself. My therapist, psychiatrist, and psychopharmacologist all agreed it was time for an in-patient evaluation. But one person felt otherwise—Kay Lyon, a friend and former patient. Kay had had Lyme disease; so did her daughter, son, and husband. She had done a great deal of research and had become quite knowledgeable about this illness. She had to be, since her two children had been in and out of psychiatric hospitals before Kay convinced their doctors to treat them for Lyme instead of psychosis. Kay had suggested that my severe symptoms were all attributable to a Lyme recurrence, but it was just one more thing that I couldn't deal with. I was too overwhelmed.

By the end of May, Kay wasn't taking no for an answer. She literally dragged me out of my house to the laboratory to get me re-tested for Lyme. The results returned positive, but these were antibody tests, and could only confirm that I had had Lyme in the past. The tests could not determine if the infection was still active. I made an appointment to see Dr. Sam Donta, an infectious disease specialist at University Hospital in Boston.

Donta listened to my history, did a careful examination, and reviewed my lab results. I was impressed by his compassion and soft-spoken style. "Dan," he told me, "I think you still have it. I don't think you ever got rid of it the first time, and now you've relapsed." Dr. Donta believes that long-term antibiotics are necessary to treat Lyme disease complex, making him quite unusual among infectious disease experts in this country.

I found out later that my story is not uncommon. Lyme can go into remission, only to relapse when a person is under stress. People have gone years without symptoms, then have surgery, experience the death of a loved one, or get poison ivy and take prednisone, which suppresses the immune system, and the Lyme becomes active again. I wanted to believe Donta, but I was skeptical.

Nevertheless, that night I started on Biaxin and Plaquenil. Biaxin is a macrolide antibiotic, in the erythromycin family. Plaquenil is an antimalarial drug that has anti-inflammatory action and increases the alkalinity inside the cell, thereby enhancing the effectiveness of the Biaxin. I continued on my antidepressants and anti-anxiety medications. And I watched and waited.

I didn't have to wait long. After just one week, I recall telling Kay that I no longer wanted to die. That may not sound like much, but it felt significant at the time. After two weeks, the anxiety had subsided somewhat and I occasionally felt like telling a joke. By the end of four weeks, my kids and friends couldn't believe I was the same person that they had wanted committed to a psychiatric hospital just one month previously.

I felt great that summer. I began running again and completed a ten-mile road race with my best time in several years. Every weekend I would go somewhere different, enjoying concerts by the Boston Symphony Orchestra at Tanglewood in the Berkshires, visiting my family in Pittsburgh, and backpacking in New Hampshire's White Mountains. I felt well enough to start seeing a few patients.

But still, I knew I wasn't quite normal. There was a constant racy feeling internally, my concentration remained impaired, my short-term memory was pathetic, and I continued to need more sleep than normal. I wasn't depressed, but I was irritable and short-tempered. Despite all this, my recovery thus far appeared nothing short of miraculous. Only in retrospect was it clear that I was experiencing a hypomanic episode.

Mania is the flip side of depression experienced by people with bipolar disorder, formerly called manic-depression. Feelings of grandeur and excessive enthusiasm typify a manic episode, and hypomania is a less extreme version. I wasn’t attempting to leap small buildings in a single bound, but I was doing back flips off a rope swing in the Ipswich River! Incredibly, none of my practitioners—my therapist, psychopharmacologist, or psychiatrist best friend—recognized my hypomanic state for what it was. Although it has been well documented that Lyme can cause bipolar disorder, the combination of high dose antidepressants could also have been at fault.

During the summer of 2001, I felt liberated from the black cloud that had enshrouded me and kept me cloaked in despair. But by the end of the summer the skyline again began to darken. It was like the movie *Awakenings,* with Robin Williams and Robert DeNiro. Williams played a physician who had discovered an apparent cure for DeNiro, a patient who had been catatonic since the age of twelve. The joy and celebration of his apparent recovery were enormous, but the remission was short-lived and never repeated—DeNiro returned to his morbid vegetative state. Similarly, I was able to keep my head above the clouds until September 11th. The terrorist attacks on the World Trade Center disaster were traumatic, and the clouds descended. After that, that wonderous summer felt like a dream—an unreal and never again attainable memory.

Depression is a strange thing. It doesn’t seem to matter if the logical brain knows that life is not bleak, it just feels that way. It doesn’t seem to matter that the rational mind knows that recovery is possible, if not probable. It doesn’t seem to matter that your friends tell you that all is not lost and there is plenty to live for. Depression overwhelms the logical and rational mind, completely distorting reality. And I was back in it.

I returned to see Sam Donta. He was not surprised by my crash. I had already done much better than expected, but the majority of patients go through cycles, and I was due. Most people have a die-off reaction when they start antibiotics. This is known as a Jarisch-Herxheimer response, named after the doctors who originally described the phenomenon in patients treated for syphilis. Lyme patients now refer to this as 'Herxing.'

But my scenario appeared to be different, and Donta did not have a good explanation. He kept me on the same antibiotics, but suggested I switch to tetracycline when the days shortened and sun sensitivity, a serious side effect of the tetracycline family of antibiotics, was no longer an issue. I went home and crawled back under the covers.

I couldn't get out of bed in the morning. It felt as if chains were binding me to the mattress. I didn't care about anything. By nighttime I felt better, and after midnight I felt pretty good. I did my best to change my sleep cycle. I would stay up as late as possible, and try to sleep through the morning.

I consulted with another Lyme literate physician and he diagnosed me with Babesiosis. Babesiosis is a protozoal infection that is a cousin to malaria. It is one of the many co-infections associated with Lyme. The deer tick is a virtual cesspool of microbes, and when it buries itself in our skin, it can result in several infections in addition to Lyme. Unfortunately, these co-infections can be even more troublesome than the Lyme bug.

It has been my experience, and that of other physicians treating chronic tick borne infections, that *Babesia* can trigger severe anxiety and depression. This diagnosis explained why my illness hadn't resolved despite getting treatment for Lyme soon after its onset, since the drugs for Lyme will not clear Babesiosis. Later I found out that I was also suffering from infection with *Bartonella*, another microbe that causes severe neuropsychiatric symptoms.

My doctor prescribed a combination of Mepron and Zithromax for three weeks to treat the *Babesia* infection. I felt even worse on the new regimen. The anxiety and depression worsened, and panic attacks returned. I was experiencing a classic *Babesia* herx. It wasn't until after the completion of the three weeks of treatment that I began to feel better. The cloud had lifted a little, though I still felt like hell.

I was beginning to think that I was suffering from an illness that wasn't curable. But by some miracle, I had improved before. So somewhere inside, I knew recovery was possible. I was aware not only of my own suffering, but also that of my youngest daughter Tovah, who was now also afflicted with Lyme disease complex. She had severe fatigue, depression, anxiety, and muscle and joint pains. She would spend all day in her bedroom, then, like a vampire, come out at night and stay up as late as possible so she could sleep through the anguish of the morning hours.

In pursuit of more information and research on my condition, I attended the 2001 meeting of the Lyme Disease Association and became conscious of the thousands upon thousands of others throughout this country, as well as in other parts of the world, who were misdiagnosed, ill-treated, and chronically ill with a disease the medical community was largely ignoring.

I have shared my story here because there are millions of people today suffering as I did: people who are losing their cognitive function, are severely depressed, anxious and irritable, in chronic pain, and tired beyond exhaustion; people who are losing their jobs, are disabled, are going bankrupt, and whose families are breaking up; people who are contemplating suicide—and sometimes following through. The toll in medical costs and lost income is huge. The toll in human suffering is beyond calculation.

The bad news I learned on my journey is that there is no single treatment regimen that will cure any chronic illness—no magic pill, no simple injection. Healing from chronic illness requires a multipronged and multidimensional approach. Each person is different, and treatment protocols need to be individualized. It requires assembling the pieces of a puzzle, with each person presenting their own clues. There is no single recipe for success.

While Lyme has been the worst thing that has ever happened to me, it has also been the best. This experience has been profoundly humbling. There were times I felt so poorly that the only way I could get through the day was to tell myself that tomorrow I could commit suicide. But Lyme has also blessed me with deep compassion and empathy for others who are suffering. Lyme has stirred in me a passionate commitment to help others who are challenged with this illness. Lyme has filled me with hope that each and every patient coming through my office door will get well. I can’t think of anything more rewarding or more gratifying than helping people restore their well-being.

My medical practice is now limited to treating people with tick-borne infections. And despite living in Colorado, where the state Department of Health continues to deny that one can acquire Lyme Disease, I have a long waiting list that keeps growing. There is a huge need out there for more Lyme literate practitioners, and I hope this book will help both physicians and patients better address this tremendous demand.