

Inflicted

Living with Lyme disease

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When he and I first met, I figured Bill had Parkinson's disease.

Every so often, he would remove one of his hands from his front pocket to gesture. The trembling would cease only after at least two of his fingers returned to his hip, and his eyes said, "I wonder if she noticed."

I did not ask questions and stuck to the topic at hand. The woodland surrounding us remained silent as we stood in a cold, ice-scented midst. Bill tried to explain the nuances of the excavation project he had completed in November, but Justin, his congenial adult son, did most of the talking. When the tour in my backyard was over, Bill stayed quiet, reserved, as if he were embarrassed or sad, like a soldier who had done everything right but was still losing the war.

Regardless, small talk prevailed. It was deer season, and the topic of illegal hunting came up. The two remembered a scene during their work: "The gun was over there (Justin pointed east), we were here (he pointed at the ground), and the buck was there (to the west). We tried to shush it away, for its sake and ours."

I scanned the tall cedars and responded, "This park is the reason we bought this place. It's posted 'recreation area,' but every neighbor I met so far has warned me about the shooting that goes on. I'm not against hunting, but they should respect a safety zone."

The men glanced at each other and shook their heads in agreement.

"Although, I have to admit," I continued, "the woods are overrun with deer, and I'm really worried about Lyme."

Suddenly Bill's armor fell off. I had hit the source of the tremors and apprehension: Lyme disease.

"This is much better than it was," Bill said, stretching his fingers flat out in front him, forcing his hand steady. "Before, I couldn't get off the couch."

“It’s true,” Justin said.

For the next forty-five minutes, I endured the dreary cold without hesitation as a story of woe poured from this hearty, weathered, middle-aged man, an outdoor warrior brought down by a tick, a pinhead-sized foe.

He told of misdiagnosis, undiagnosis, and years of growing devastation. No longer was this an infection in his veins, it was a storm throughout his body. He was, by all accounts, disabled. He relied upon Justin to explain to him the procedures he alone had developed while building the family business.

“I just couldn’t think,” Bill said.

After depleting the local doctor referrals, medical universities, and alternative health centers, he finally found a “Lyme-aware doctor.” “He’s helped me a lot,” Bill said. But the relief in his voice faded quickly when, a moment later, he said, “My insurance doesn’t cover it. They don’t recognize chronic Lyme disease. They won’t approve my treatment, which is really just massive doses of antibiotics. I should be getting them intravenously, but I can’t afford it. The oral doses are still costing me tens of thousands of dollars, and my recovery will be slower this way. It’s what I have to do; I’m not going back to that couch.”

He finished, “Were it not for Justin, I’d have lost the business.”

As the two climbed into their truck, I tried to bid a farewell of hope and encouragement, but I frankly didn’t know what to say. This man was living my worst nightmare.

I’ve always considered Lyme disease an assault on a love for nature. It’s as if, during a time when we desperately need to be outdoors, Satan has invented a plausible reason to hide inside. Lying in the tall grass, resting on a fallen log, relaxing by a babbling stream, wandering through a foliage cathedral: these iconic and healthful retreats are now taboo inside an ever-growing geographic boundary.

The disease escaped its namesake town decades ago. In 2013, the Centers for Disease Control and Prevention (CDC) made head-

lines when it released a new national estimate of annual diagnoses: 300,000 people, 10 times worse than previous reports indicated, and 100 times greater than the population of Lyme, Connecticut.

Still, its treatment remains mystifyingly controversial. Patients continue to endure skepticism from doctors who miss the initial diagnosis and fail to make them better. Great expense goes into treating symptoms as if the source were some other cardiac, neurological, gastrointestinal, or psychiatric disorder.

Of the patients who have been diagnosed and treated within Infectious Disease Society of America's guidelines, many still suffer with serious, long-term ailments. They must prove to the healers to which they turn that they are not lying, that they are being crippled, that they need further treatment, and that the source could be Lyme.

The condition is commonly called chronic Lyme disease, but the CDC prefers instead post-treatment Lyme disease syndrome (PTLDS), a name that suggests a secondary, autoimmune disease rather than a failure to knock out the first infection. And while leaders fight over labels, the victims pray for release from torture. Horrifically out-of-touch is the CDC's statement, posted on its website, "patients with PTLDS almost always get better with time." Of all the long-term sufferers I have interviewed, none have gotten better with time. Many have just given up.

But the fundamental problem is not a lack of caring. Trickery is to blame. The bacteria leave the bloodstream and hide in all corners of the body, where they mutate into other problems. Without an ability to detect the *Borrelia burgdorferi* spirochete that causes Lyme, tests scan for the presence (or lack) of reactive antibodies. Various strains of bacteria are known to exist, as are potential co-infections with a list of other concerning, deer-tick-transmitted diseases. As with many autoimmune reactions, symptoms in one person may differ from those in another. And while there is agreement that treating Lyme in its early stage is crucial for returning good health, there is a lack of consensus on how to do that.

The results of persistence however are pretty consistent: nerve

damage, mental damage, reputation damage, hope damage, and one's quality of life destroyed.

My hope rests on ecologists such as Dr. Richard S. Ostfeld at the Cary Institute of Ecosystem Studies in New York, who are laboriously studying the source. For instance, they have determined that the chipmunk, shrew, and white-footed mouse are the real vectors for the disease, not deer. The more they learn, the better armed we become. Also increasing is the number of Lyme-focused advocates, such as the Lyme Disease Association, who teach the facts to the public and the decision-makers.

But, sadly, prevention campaigns read like advertisements for diethyltoluamide (DEET). A 2007 national water survey detected the insect repellent in 75% of streams tested in 30 states. Meanwhile, homeowners treat their yards with tick-killing pesticides, which also eliminate nature's tick-killing predators.

Lyme first came to my world when, 12 years ago, my brother was stricken. Beyond the fact that I loved him, he might as well have been me. He was an avid hiker with a strong immune system and a penchant for good hygiene. My fortune told, I pushed aside the fear and moved to my dream-come-true woodland retreat anyway, even with its failed septic system. In the second spring here I found deer ticks everywhere—walking across the patio table, hanging on the screen door, climbing up my neck, embedded in my back and then my pubic hairline. So small, each nymph could be mistaken for an ingrown hair. I was being attacked by a hungry army of pepper flakes with legs. By summer it happened: I found a bull's eye rash, the telltale sign of the disease.

My discovery of the erythema migrans caused physical ailments that day, all related to stress. Conceptualizing derailed health had a bigger impact on my well-being than the malady itself.

Questions flowed like flood waters: After my current antibiotic treatment regime runs out, won't I just get bitten and infected again? What shall replace my therapeutic walk outside, the one that could

cripple me for life?

Is this the penance we must pay for abusing the earth? And how long for this world are we, now that the most independent humans, the ones with the skills to survive in the wilderness, have become dependent on the medicine of strangers, medicine they are reluctant to give? Who is going to restore our trust in the doctors? What's in store for a society that has yet another excuse to disconnect from the natural world?

The last I heard from Bill he was back to light duty but now had Rocky Mountain spotted fever, one of those other concerning tick-delivered diseases.

I am questioning. I am trembling. And I wonder if anyone's noticed.