

ALSO BY POROCHISTA KHAKPOUR

Sons and Other Flammable Objects
The Last Illusion

SICK

A MEMOIR

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HARPER ● PERENNIAL

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"Those great wars which the body wages with the mind a slave to it, in the solitude of the bedroom against the assault of fever or the oncome of melancholia, are neglected. Nor is the reason far to seek. To look these things squarely in the face would need the courage of a lion tamer; a robust philosophy; a reason rooted in the bowels of the earth."

—VIRGINIA WOOLF, *On Being Ill*

"Do you believe, she went on, that the past dies?
Yes, said Margaret. Yes, if the present cuts its throat."

—LEONORA CARRINGTON, *The Seventh Horse and Other Tales*

AUTHOR'S NOTE

It seems impossible to tell this story without getting the few certainties out of the way, the closest one can come to "facts." The hardest part of living with Lyme disease for me has always been the lack of concrete "knowns" and how much they tend to morph and blur over the years, with the medical community and public perception and even within my own body. To pinpoint this disease, to define it, in and of itself is something of a labor already.

Still: Lyme disease is a clinical diagnosis, a disease that is transmitted by a tick bite. The disease is caused by a spiral-shaped bacteria (spirochete) called *Borrelia burgdorferi*. The Lyme spirochete can cause infection of multiple organs and produce a wide range of symptoms. Less than half of Lyme patients recall seeing a tick bite, and less than half also report seeing any rash. (They say the deer tick—which is usually the carrier of Lyme—can present as smaller than a speck of pepper.) The erythema migrans (EM) or "bull's-eye" rash is considered the main sign of Lyme, but atypical forms of this rash are seen more frequently. Testing is quite flawed; the commonly used

ELISA (enzyme-linked immunosorbent assay) screening test is unreliable, missing 35 percent of culture-proven Lyme disease. There are five subspecies of *B. burgdorferi*, over one hundred strains in the USA, and three hundred strains worldwide. Testing for babesia, anaplasma, ehrlichia, and bartonella (other tick-transmitted organisms) should always be performed as well, as coinfection with these organisms points to probable infection with Lyme and vice versa.

There are multiple stages and progressions of the disease. Stage 1 is called early localized Lyme disease, and it signifies a stage where the bacteria have not yet spread throughout the body; this form of Lyme can be cured with timely antibiotic use. Stage 2 is called early disseminated Lyme disease, and here the bacteria have begun to spread throughout the body. Stages 3 and 4 are often known as chronic and late-stage Lyme disease, and at this point the bacteria have spread throughout the body. Many patients with chronic Lyme disease require prolonged treatment, all while relapses may occur and retreatment may be required. There are no tests to prove that the organism is at any point eradicated or that the patient with chronic Lyme disease is "cured," although one can test for inflammation and other markers. Each year, approximately thirty thousand cases of Lyme disease are reported to the CDC. Over the past sixty years, the number of new cases per decade has almost quadrupled; the number of outbreaks each year has more than tripled since 1980.

I have Lyme, with "bands" (lines on a test that represent antibodies to different components of the bacteria) that afford it CDC-level recognition (bands 23 and 41). My main coinfection has been ehrlichia. Several doctors believe I also have babesia and bartonella due to certain symptoms, although my tests don't always come out positive for them.

Living with this disease has cost me more than \$140,000 so far. Experts put the average cost of late-stage Lyme at somewhere around \$20,000 to \$200,000. The annual cost of Lyme disease in the United States is more than \$1-\$3 billion as of 2017.

It is unclear when I got the disease. Doctors have mostly pinpointed somewhere in the 2006 to 2009 range, but I've had doctors who think I've had it since childhood. Although the disease and its complications—including addictions—have defined my life, it is unlikely I will ever know when I contracted it, just as it is unlikely I will ever be rid of it entirely.

ON THE WRONG BODY

I have never been comfortable in my own body. Rather, I've felt my whole life that I was born in the wrong body. A slight woman, femme in appearance, olive skin that has varied from dark to light, thick black curly hair, large eyes, hands and feet too big, of somewhat more than average height and somewhat less than average weight—I've tried my whole life to understand what it is that seems off to me. It's deeper than gender and sexuality, more complicated than just surface appearances. Sometimes the dysmorphia I experience in my body feels purely psychological and other times it feels like something weirder. As a child, I thought of myself as a ghost, an essence at best who'd entered some incorrect form. As I grew older, I accepted it as "otherness," a feature of Americanness even. But every room I walk into I still quickly assign myself to outsider status, though it seems not everyone can see this. Many have in fact called my looks conventional, normal, even "good." I've accepted it while also feeling like I've deceived them.

I've looked for answers from my first few years on this earth, early PTSD upon PTSD, marked by revolution and then

war and then refugee years, a person without a home. Could that have caused it? Was displacement of the body literally causing a feeling of displacement in the body?

Only decades later did I confront something that may have been there the whole time: illness, or some failure of the physical body due to something outside of me, that I did not create, that my parents did not create. Illness taught me that something was wrong, more wrong than being born or living in the wrong place. My body never felt at ease: it was perhaps battling something before I knew it was. It was trying to get me out of something I could not imagine.

At some point, with chronic illness and disability, I grew to feel at home. My body was wrong, and through data, we could prove that.

Because my illness at this stage has no cure, I can forever own this discomfort of the body. I can always say this was all a mistake. To find a home in my body is to tell a story that doesn't exist. I am a foreigner, but in ways that go much deeper than I thought, under the epidermis and into the blood cells. I have started to consider that I will never be at home, perhaps not even in death.

PROLOGUE

It's New Year's Eve, about to turn 2016, and I've been where I always am: inside. A neighbor visits and drops off some leftover Christmas chocolate I can't eat but gladly accept; a friend a few blocks away comes by with his toddler son and invites me to his home for a small party that we both know I can't attend; friends all over the city send email and text invites to events "just in case." I've never not been a party girl. This was my father's greatest fear for me in the United States, but one that I balanced with what would become his greatest dream for me: being an author. *A cross between Salman Rushdie and Paris Hilton*, he used to joke.

But I know that this New Year's there will be no parties for me. This New Year's will be my first spent alone.

Twenty days before, I was in a car accident. Hit by a semi—an eighteen-wheeler tractor-trailer, to be precise—on the way home from my job, teaching at Bard College. Class was out by 1:10, but I stayed late that Friday, rare for me. It had been a season of hate crimes, a month and a half after the Paris attacks, and tensions were especially sky-high for brown and black

students. I was the only faculty of color in our department that term and the students seemed to look to me for answers. I hid that I was as lost as them. I had packed extra snacks and all sorts of "reinforcements," as I'd call the supplements that I'd been taking for years for Lyme disease relapses—from Celtic sea salt to magnesium to nuts to protein shake mixes to bee pollen and propolis. These reinforcements were meant to shore me up, so that I could stay a few extra hours and meet with all my students who seemed to have some sort of depression that season.

I understood: so did I.

The first sign of a Lyme relapse is always psychiatric for me. First the thick burnt fog of melancholy that crept slowly—mornings when I couldn't quite get out of bed, sticky inability to express my thoughts, hot pangs of fear and cold dread at unpredictable times, a foundation of anxiety, and panic—that fluorescent spiked thing, all energy gone bad, attacking like clockwork around noon daily—all unified toward that endless evil white, insomnia.

Everything was again a danger, everywhere and everyone and every time.

Days after I returned from a blissful but exhausting book festival in Indonesia that November, I began to consider that I might be having a Lyme relapse. At that point, I'd been healthy for years, so to relapse into bad health was a transition I couldn't quite fathom. I tried to blame jet lag at first, the disappointment of leaving a wonderful place like Indonesia, the hectic schedule they had me on (three Indonesian cities, all spread apart, in ten days). I tried to think it might be the news I got upon return: that my editor was leaving publishing, and that maybe this very book would be in jeopardy. I tried to think it was the Paris at-

tacks and the new wave of Islamophobia that had suddenly gone mainstream. I tried to think anything, everything else.

I wasn't going to lose myself again.

After a Thanksgiving spent intentionally alone—I never liked people seeing me in an off-period—where the one event of my holiday was finally caving in to my doctor's suggestions and buying a cane from the local CVS, I broke down and wrote my friends an email on November 28.

dear some of my closest nyc friends who are in town currently or might be soon,

i am getting more and more ill very fast. i'm scared at the moment. in case you don't know, i've had a late stage lyme relapse but this one feels very intense. rapidly things are going downhill.

i'm trying not to be extra alarming online—some important work stuff i want to be well enough for—while also letting people know some things are off.

i have various lyme communities and that's the way to reach them.

but also i don't want to drop out as last time i became completely disabled that way—i need to stay engaged

but i'm scared.

at points in the day i don't know where i am exactly. at night it somewhat clears.

i've been falling again a lot. etc. very faint, very dizzy. getting a cane.

having trouble with reading and writing.

it's very reassuring to be around people when I'm confused.
alone it is very hard.

i'm not totally sure what i'm asking.

it's hard to ask for help here because what can you do even?
i don't have the imagination to know what is help right now
completely

but some things maybe

would you mind occasionally checking in on me? i might not
be able to text back very effusively as i'd wish but perhaps
briefly—it doesn't mean i am mad, it just means i can't think.
i'm also worried something will happen to me and cosmo will
just be alone

also if anyone had the time and was interested in being a
passenger in my car with me? i have 2.5 more weeks of
classes.

for now i think i can drive. or was able last week. but i go to
bard twice a week (weds and thurs) and sarah lawrence mon
and tues.

i have nice offices at both if you wanted to work there too and
even hang out with cosmo?

or if you were ever in harlem? just walking with me to the
dogpark? i'm not that deep in harlem, just 120th.

or perhaps riding the subway with me? (i tend to avoid
subways alone when relapsing)

i might even drive cross country if i find i can't take cosmo
with me on a plane to the west during break. just will do the
southern route slowly. if anyone wanted a free ride there too!

i'm also happy to pay anyone for their time. not meant to be
insulting! just meant to say i value your time.

basically just the presence of others around me right now is
helpful i think.

(tho i also have a lot of work to do so i can't take breaks.
perhaps study dates?)

all my friends are busy people who do work i love so i'm
hesitant to ask. also you all have your own shit right now.

i will not be mad at all if you can't deal with this right now!
i'm embarrassed to ask frankly. i thought to write people
individually but i didn't want you to feel the burden like you
were the only one!!

basically i am very bad at this.

and sorry for chaotic nature of this email. hard to express
myself.

love p

Most of my friends had never received an email like that
from me. When I had my first definitive Lyme Crisis—what
I now call 2011–2013—I removed myself from many people's
lives, while some removed themselves from mine. Here and
there friends stuck by me, sometimes a partner, but the only
consistent presence was a few doctors. Then, my dog, Cosmo. I
was by no means alone—I had distant but steady support, but all
in all, when it came down to it, it was me alone going into it and
me alone coming out of it: driving cross-country in the dead of
winter just past remission to pick up life somewhere, anywhere.

And here I was again.

My doctor did what he did the past two times I had had

Lyme relapses and prescribed me supplements and medications: words like *glutathione*, *acetylcholine*, *methylfolate*, *fluconazole*, and more all back in my life. I was back to having dozens and dozens of pill bottles. It was done in an email and a phone call. And it all felt more or less under control for some weeks.

Still, I was cautious and did not drive the two hours back and forth to Bard College, where just the year before I'd been appointed "writer in residence," and to Sarah Lawrence, where I'd been adjuncting to make the Bard job financially feasible.

In that penultimate week of the semester, I had a bad experience with my usual cab ride from Bard to the Poughkeepsie station, where I'd catch the Metro North to my apartment in Harlem. My forty-minute cab ride to the station was usually uneventful, but this time my driver Alan confessed to me that he was back on drugs. We had spoken about drugs before, on another ride I had taken with him, so he felt comfortable getting into it with me.

"You know how it is, Porshka," he said. He could never say my name. "Come on, you know how it is."

"I do know," I said cautiously, as I noticed him speeding faster and faster. "And that's why I think you should be . . . careful."

I was tempted to ask him if he was on drugs right then and there, but I had my answer. I thought. I tried to make out his speedometer.

"You know, I gotta make some money on the side," he said absently. He had recently begun dating a woman who worked in real estate. He had mentioned they "have a lot of fun. She likes it when I share my coke."

I had tried to switch the subject to the weather, to my students, to all the generic things we used to complain about together. (I tried to avoid talking about the Middle East—too many

times I could tell Alan and I were not politically aligned and I didn't want to push the subject.) I even got to Lyme. The ride was nearly an hour, always so much space to fill, but this time felt particularly taxing. I tried to concentrate on the trees blurring by: maple, oak, hemlock, cedar, pine, all still lush in that season of little snow, starkly stabbing into the immaculate blue of twilight. I wanted him to slow down, but I also wanted the ride to end.

"You take anything for it?" he was asking.

I realized I was barely listening to his end of things.

"The Lyme—you take any pills? You need pills for it? Pain pills?" he was asking.

I remembered he had once told me his mother was addicted to some "pain pill."

"I don't take those kind of meds," I said. "I take mostly supplements. Nutrients. I don't do that other stuff."

"Anymore," Alan said with a smile, as he pulled in to the station.

"Anymore," I decided to agree with him—he was not wrong, after all—but I also decided for myself that there would be no more Alan in my near future, that the bulk of the semester away from him had actually been good for me.

The Poughkeepsie train station was less bleak than usual that night, the holidays in the air. As I went up to the ticket counter, I realized it was the same attendant I always used to see, a guy I nicknamed Lou because he looked like a Lou, while really his name was something like Lawrence. He would always ask me out at the end of our transaction, often a *I hope you don't mind me asking but you got a boyfriend?* I always said I did even though I never did during my time commuting. He'd always tag on, *Well, keep me in mind.* I'd always throw him something between a nod and a shrug and walk off with a weak wave.

This time he looked shocked to see me.

"Yeah, it's been a while!" I said quickly, hoping this time I could avoid his propositions.

"No, no, look at you, what happened?" he cried. He pointed to my cane. "Why do you have . . . *that*?"

I waved off his question as I often did. "Lyme. I get dizzy. that's all."

He kept staring at the cane, and then I realized his eyes were welling up with tears.

I nearly laughed it was so absurd. "Hey, are you okay? It's nothing, I'm fine. I've dealt with this for years!"

He shook his head. "No, no, it's just that . . . Lyme." I should have remembered that, unlike in the city, upstate everyone knew about the severity of Lyme disease. But I wasn't ready for what he said next: "My father passed away a couple months ago from complications of Lyme."

I suddenly felt a burst of heat in my face. It was rare that I'd meet anyone who'd understand Lyme, much less someone who had experienced the loss of life that could come with it, the outcome that people seemed to be only slowly realizing was possible. And of all people, this guy. I avoided his eyes so I wouldn't cry and quickly handed him my credit card. "I'm really sorry to hear that," I kept saying quietly as he ran my card, but he seemed speechless. "Well, have a good night, okay?" He didn't seem to hear me, his eyes still glassy and dazed, staring at his monitor.

When I got to the track, the train was packed. Just before I took my seat, there was a loud boom, an explosion of sorts, and throughout my car the sounds of human panic rippled from audible gasp to scream. Everyone's minds were momentarily in sync: bombs. We were all thinking of the Paris attacks, I assumed, and how NYC could be next. Manhattan at that time

reminded me of the days after 9/11—worse, even. The first few mornings after the attacks, when I'd go out to walk my dog I'd see more police than civilians on my usually sleepy brownstone-lined street in Harlem.

Another explosion, and then another. More sounds of horror from the train, louder this time. My heart went into a familiar racing, as I scanned the frenzied passengers in my car, all of their eyes looking a bit animal. But before we could be overcome by our fear, someone figured out the source of the booming. "It's just fireworks!" a gruff male voice in the aisle muttered. "The parade, people!"

A few of us looked confused, and another voice explained, "They have this Christmas parade in Poughkeepsie."

I heard another few voices, "Oh yeah."

And one more, "It's a really nice parade, you know."

That was my last public transit ride before the car accident. Two days later, I decided to take my car out, a 1988 Subaru station wagon that I'd bought at the end of the last semester, which had taken me to work several times a week for months—not to mention two cross-country trips in the summer. I was happy to be back in the car after so much time away, but the truth was I didn't want to deal with Alan and his relapse, or Lou and his grief and the reminder of the direness of my condition, or even the tension on the train of a sound, any sound. So much already felt unbearable that season.

I had no idea I was about to hit new limits of unbearable.

After spending the extra hours with my students that Friday, I drove home that evening with a particular cautiousness I had acquired since this latest relapse had begun. For the first time in two decades of driving, I was suddenly someone who strictly

observed the speed limit. It was past seven and it had been many hours since the sky had turned dark, and only as my last student left did I realize that I had never driven home this late. It only gave me the slightest pause, though, as I was someone who drove cross-country and had done several legs solo. I reminded myself.

Besides, I had promised my students I would be there. *Extra office hours*, I had said all week, *I want to hear you all out. It's been a miserable semester for all of us and I am here for you. You don't have to come, but if you want I am here.* Two-thirds of the class came to see me that day.

I remember the drive, like one often remembers the moments before something monumental, in crystal-clear vision that feels indisputable. The cold brisk night air coming through a small opening of the window, meant to counter the thick blast of heat from the car's heating vent. The barely black of early evening sky, the many stars that were out that night. The unease of a snowless December, like slack tide, the taut serenity when you know something is coming. The mild murmur of my car's radio playing familiar oldies on an a.m. radio station I'd taken a recent liking to. The emptiness of the highway, a surprise for me, until I realized this is what Friday night looked like in the Catskills.

After an hour or so on the road, I was feeling a bit bored, so I left a phone message for Mason, my old graduate assistant at another university I had adjuncted at, who'd also been my recent cross-country road trip partner. He'd often check in with me, worried about my health. I remember rambling on his voice mail, *Oh hi, it's me, Porochista, how are you, hey I'm back to driving, long day at Bard but good one. I think I'm feeling better, things are getting good, want to catch up on your week, call me back.*

okay, bye, kiddo! It was one of the rare times he did not pick up on first ring.

Mason had gone through one of my "incidents" with me already. He had been the first person I'd called when the Lyme relapse first hit me in November, when I'd pulled over on the side of the highway one rainy evening, suddenly feeling like I couldn't tell where I was after a long day of teaching. He was the only person I could think to call since he was always checking to make sure I was okay. He had met up with me at the hospital where they'd checked for a stroke with a CT scan but found nothing—*Probably like you say, it's Lyme*, the neurologist said lukewarmly. I didn't think twice about it. Hospital visits were to be expected for the Lyme-struck, after all. And that was when I'd simply called my doctor and he'd ramped up my supplements and suggested the cane.

I left another message that night for my friend Bobby, who lived only blocks from me, who was the gay Iranian American brother I never had but always wanted, and who had been so concerned about my health that season: *Hey Bobs, I made it through a really long day up at Bard and I'm driving home again! Yes, driving with Cosmo, all good! You know what that means—I think I'm feeling better! Anyway call me back!* It was also one of the rare times when Bobby did not call me back just seconds after screening his landline calls.

I put the phone down and glanced in the rearview mirror at my standard poodle, Cosmo, deep in sleep in the backseat. Just moments later, a giant truck burst from the darkness and completely overtook my lane, like a monster that absorbs you, full speed and confident, no hesitation in sight.

I felt two impacts and it took both of them to realize what was happening. I'd been in two car accidents before, so I knew

well the sensation of watching one's self melt into a slow motion movie montage: here I am honking my horn, here I am praying out loud, here I am screaming, here I am accelerating and braking and nothing feels right, here I am spinning, and here I am stopped. And here I even am alive, it seems.

On the side of the road, the car smelled like it was burning and I turned to Cosmo, who seemed shook, but okay. We were okay, we had to be okay, which I thought would be how I'd say it all, but by the time 911 answered I was screaming and I'm not even sure it was words that were coming out.

It took two 911 calls. And a lot of waiting on the New York State Thruway. We were on the side of the road but on something that wasn't quite a shoulder. There were no lights. After some time I turned on my hazards and looked into the rearview mirror and watched more cars speed by, each seeming faster than the one before. Everything seemed black and gold, confusing, elaborate, deadly, and strangely a little bit beautiful. It was then that I realized this could be it—the odds of being struck again by a speeding vehicle seemed higher than us just being comfortably lodged there until help came. I calmly thought that this was the end. And it took me a second to fight the thought and dial 911 again: *Please. There are no lights, no shoulder, cars are speeding, we are going to die. Please.* I remember my voice was too calm for those words.

The ambulance finally arrived. It seemed like I had no visible injuries and perhaps only a concussion, but I refused to go to the hospital because I was informed I could not take my dog.

"What am I supposed to do then?" I asked, pointing to a blinking and panting Cosmo, who looked only moderately flustered.

"You have to abandon the dog, ma'am," the paramedic kept saying.

"Of course I can't," I kept replying even as they told me stories of many accidents where the pets were just let loose in the woods on the other side of the highway, as if to console me.

There was no way. I finally made them a deal—that I'd get checked out when I got home. "I promise."

The police officer looked at me like I was making a bad choice, and his gaze paused at the cane by my front seat, as if I already had a prop of injury perfectly on hand. "It's for my Lyme disease," I said, and he nodded blankly.

They called me a tow truck that took me all the way home—me with a shaking Cosmo in my arms, my head suddenly pulsing, the tow truck driver taking an interest in two things: my not being married and my name. Eventually we got into it: Iran and Muslims and 9/11 and the Paris attacks, and after I realized this man wasn't going to hit on me, I was so focused on not letting him hurl anything racist at me that I barely remembered the accident.

At one point he said, "I'm gonna be honest with you, you Arabs have not been my favorites, you know?"

I didn't correct him and just focused on Cosmo's fast breaths, which seemed synced with mine.

"You are all right, you know," he said at another point, which I tried to imagine was meant about my health but he of course meant me as a Middle Eastern person. "You're a good rep of your people, we need more of that. Especially after what just happened in France, you know."

I knew. But I took this as him taking a liking to me, which felt at least safer than where my mind originally went, and so I was grateful when he dropped me off in front of my building as a reward. They weren't supposed to do that, he told me. Then he rambled on a bit about how he had once towed an Iranian restaurant owner—"Iran or Iraq, one of those"—who'd then fed

him for free. "Sometimes you guys are good" was his moral, apparently.

I nodded numbly, thanked him. By the time I got into my apartment, I had many worried calls on my cell phone.

How did everyone know this happened? I texted back my friend Alex.

He reminded me that I had made a Facebook post about it, when I was waiting for the ambulance—just as I'd apparently called back Mason, who said I sounded incomprehensible. I remembered neither.

Alex kept asking if I felt okay, and I did. I told him I survived, and I instead lingered on the tow truck driver and the season of xenophobia and all its perils, what was most on my mind.

Please check in with me, Alex kept writing.

K, I kept typing back. K.

I began to get sleepy.

That night I fell into the deepest, thickest sleep of maybe my entire life, but definitely since my Lyme had begun to relapse that fall. In Lyme relapse, I never get proper sleep; it always feels like that light buzzy rest of past drunken nights. But this night was different. I slept twelve hours. When I finally woke up I was on my couch, and everyone was calling and texting at once, wondering why I wasn't at the hospital.

Why would I do that? I'm fine. I slept well.

But people were reminding me that I wasn't supposed to have fallen asleep. That people are supposed to wake you up every few hours after a potential head injury, in case of a concussion.

But so what, I'm fine now. Who says I have a concussion?

But no one thought I was fine.

Okay I'm not fine—I've been having a Lyme relapse.

Soon my old editor was ringing my doorbell and at my side, taking me to the hospital.

Upon seeing that dear friend, a deep panic took over me. I had a feeling I didn't want to get into what came next; it was something I knew well and had fought to get away from. "I don't want to do this again," I cried into his shoulder in the cab. "Not another hospital. You know how many hospitals I've had in my past. Not this again, please."

My editor knew my story and reminded me this was different, that I had to go, that it wouldn't be like those other times.

At the hospital on the Upper East Side, I fell back to my old element, almost finding the waiting comforting, all the systems ones I knew well. I was explaining to my editor how it would all go, when he interrupted me. "But we're not here for the Lyme, we're here for your accident. Remember?"

It was sometimes hard for me to comprehend there could be room for anything more.

I had been to the hospital so many times for my Lyme disease, not just explaining but overexplaining, as if I had something to hide. Lyme is a disease that many in the medical profession, unless they specialize in it, find too controversial, too full of unknowns, to fully buy it as legitimate. It's thought of as the disease of hypochondriacs and alarmists and rich people who have the money and time to go chasing obscure diagnoses. For years I'd become used to dealing with all sorts of skeptics whether in person or online, but it never stopped being frustrating. I'd always catch myself getting preemptively ready to argue, feeling a defensive heatedness from years of impossible experiences with so-called medical professionals. It was always a risk, me getting into it, and yet I had no choice. I had the script down as if it was a script and not my reality. *My case is a CDC-level Lyme case*, I'd learned to say, which was true,

hoping doctors would understand I was one of the small percent of Lyme sufferers who actually had the luxury of CDC recognition, what the rest hope for. *I'm not like those other ones* . . . I'd try to knowingly add, to speak their suspicious dismissive language, to let them know I was real.

After hours of waiting, my editor had to leave to catch the last train upstate. When the young internist finally admitted me, he was surprised by my cane, but I didn't want to get into a conversation about Lyme right away, especially without an advocate at my side. The internist examined me and wanted to give me x-rays or a CT scan, but I insisted on an MRI.

"I've had too much radiation in my life," I said. My Lyme doctor always reminded me to say this; he did not like me going through airport full-body scanning machines, either, to this day only getting pat-downs. I had just had a CT scan in November and I remembered even then feeling like I shouldn't be going through with it.

The internist asked, "Why?"

Here it went: the great downhill. "Lyme."

And there it came: his half smile.

And here it followed: my rage.

He ended up prescribing me some Tylenol and said it might be a concussion but that they could not do an MRI and that I was likely fine, and to follow up with my Lyme doctor.

I watched him walk away, and as I put on my shoes and coat, I saw him and a nurse laughing.

As I walked out of the ICU, I felt that old state of mind consuming me, taking me back to my time in so many other hospitals, and the anger at being misunderstood boiled up in me again, that feeling of not being taken seriously by those who had your life in their hands. All the many times, the people who shook their heads at Lyme, who looked at me with pity for

my circumstances, who could barely stifle their rolled eyes. I'd tried to avoid this hostile world of hospital rooms and doctors' offices for years, but it haunted me. Here I was again, with something unrelated to Lyme and only two choices—to come clean or to hide, but I knew every decision would have something to do with my diagnosis. It amazed me that even after all these years, with all the time that had passed, as I managed to stay out of the medical system for the most part, and my fluency in their language still being proficient, that I could still be in this position—helpless, crazy-seeming, confusing, inconvenient, out of their norm, a problem. And not one worth the time to be solved.

The internist and nurse were still smirking as I walked by. I couldn't keep quiet. Long ago I had promised myself to keep my self-esteem intact in a medical system that had too often threatened to destroy it. "I hope you know I can see you laughing there," I called into the room.

"No, come on" was the call I got back.

"How can you prove that anyway" was another call I got back.

"I can file a complaint," I shouted, and just like that I was escorted by a nurse to a desk where supposedly people filed complaints.

For hours I waited, though I could hear the voices of family and friends telling me I needed to rest. Instead I watched every interaction with the people in the ER waiting area, which was remarkably vacant. Eventually they told me whoever I was supposed to talk to was not there till the next day, and so I left.

Like I was never there. The old feeling: like a ghost I walked out into a still Manhattan, taking a cab home with little idea of what had happened those hours.

That Monday my friend Bobby came with me to my last day of Sarah Lawrence classes—me showing up to class was already

against the wishes of my department chair, but I felt with a friend's assistance I could get through that final bit of semester. I was in denial about what indeed turned out to be a fairly severe concussion: all I wanted was to hold on to some sort of normalcy.

I'm fine, I kept saying. I have Lyme. I've had Lyme.

But what I meant was I did not have room for this new thing that happened to me, this thing that was making the old thing worse.

I had been hit by a truck; I had hit my head; I was far from okay. But in too many ways, I could not afford this reality.

In the next few weeks of my life, I saw everything turn upside down and my life became more bizarre than ever. I could not tell where I was at times—at a stoplight down the street from my house, a neighbor said I asked him if I was in New York City and he walked me back home. I began hearing things—on the phone with my friend Laura, I heard a brisk swirling sound that I knew as the ocean in high tide: *Do you hear that, Laura? Why are we hearing the ocean now? What is this?* Another time, walking with my editor down the street, I suddenly was overwhelmed with a metallic flapping in my ear. *What the hell is that?* I screamed. All I could describe it as was the feeling that the illustration on the paperback cover of my second novel, a winged man, had lodged himself in my inner ear cavity and this was the sound of his giant metalwork wings that were scraping against my eardrum.

With a friend at my first NYU neurology appointment, I fell into violent convulsive crying when shown a chart like the ones you get during eye exams—not only could I not make out the letters, but they were flying at me in all sorts of directions, the entire room wobbling along with it. And my one solace, the com-

puter that was for writing and communicating with friends and learning about the world, suddenly made me nauseated at best and put me in panic attacks at worst, as if its thinly vibrating frequency was suddenly amplified so that I could see its inner workings, its multitudinous networks busily announcing their duties, as if I could suddenly see the blood vessels underneath my skin. I was only allowed brief spurts of computer use—five minutes at a time for severe concussions like mine, followed by hours of rest, eyes closed, in the darkness. If I tried to do more, my body would punish me. All my senses had gone hostile.

What I didn't know for sure—though my doctor certainly did—was that I was having a major Lyme relapse now, with the accident and concussion nearly finishing me off.

By the time New Year's Eve came I was still in a haze and could not really register that this could be seen as a fresh start, that the holidays were over at least, and life in 2016 could now take hold. I wasn't mentally together enough to invite a new beginning.

Instead, I was focused on the logistics of my limitations.

I knew, for instance, that I could not go outside for Cosmo's last walk at midnight, when I usually did it, as there would be too much going on. I had never been in my neighborhood for New Year's—always leaving town in previous years—so I didn't know for sure, but I could imagine it.

But as usual, as the hours went by, I grew more and more lazy about that final little stroll. Cosmo's walks had been cut down by many times at this point, and he himself—I was still a week or so away from realizing he had suffered pulmonary contusions from the accident—had adjusted to his limited time outside. It was a miracle to me that I was even maintaining a basic walking schedule with him.

I finally got up, got him leashed, and got us out. I paused at our doorway.

I didn't know what time it was, but it was possible it was that wrong time.

Just as we walked out the lobby I heard my answer in the form of a husky laugh: *Five minutes to midnight!* went a tenant, a short shiny dress of a woman slung over a suited man.

How had I picked that time to go out, of all times?

But it was too late.

There we were in my Mount Morris neighborhood of Harlem, at the gates of Marcus Garvey Park, taking a longer walk than I had tried of late. It felt good outside to me somehow, far quieter than I'd imagined, the perfect temperature, the outdoor air somehow emitting *special occasion*.

I had lost my watch at the ER, so I couldn't tell on my own when it was coming, but moment by moment, out of sync, I began to hear countdowns. In the grand windows of my neighborhood's countless brownstones, I could see all the signs of celebration: disco lights flashing, groups of friends gathered around a table, champagne flutes raised.

3-2-1

Happy New Year!

Then all the sounds of joy. And pops. Gunshots maybe.

And there we were, woman and dog, alone, survivors I hoped.

The full weight of my aloneness hit me in that moment.

If I was going to survive it at all, this time, it was all by myself. And here, in this place that I had to reconcile with as home. If you face yourself properly, you also have to at some point face where you take up space.

I hadn't thought that way before. Far from it.