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Healthy Aging

The Mystery Illness That Plagued This Writer For Years

When Julie Rehmeyer's body started shutting down, doctors were stumped. Her search for relief led to an unlikely plan: two weeks alone in a tent in Death Valley.

By Julie Rehmeyer



Illustration: Brian Stauffer

On Saturday, November 4, 2006, I woke up semiparalyzed. My legs felt lead-plated; the signals instructing them to move seemed to get scrambled on the way down. It was as if someone had sloppily replaced my limbs with those of an elephant and connected only 10 percent of the nerves. My brain felt like an overripe peach, its juices threatening to seep from my eyeballs. Pain glowed out of my bones.

For seven long years, something hadn't been right. On countless mornings, I'd wake up exhausted even after a full night's sleep. When I exercised, my body reacted like an old nag, one that flattened its ears and bit when spurred. Early on, my doctor had gently asked about my stress levels. I burst into sobs: On top of my teaching job, I was building a straw-bale house outside Santa Fe with my own hands; in the meantime, I was living in a pair of ramshackle travel trailers with my husband, who was in the midst of a bipolar breakdown. "Sounds like you have good reason to be stressed!" my doctor declared. Days after the appointment, though, I found myself dragging my hand along a wall to steady myself, afraid I might pass out, and wondered, *Could stress alone really do this?*

I buckled down to reorganize my life, figuring my body would follow. I finished building the house. I accepted that no amount of love would stop my husband's manic spending sprees or pull him from his suicidal gloom, and got divorced. I forced myself to have dinner with friends when all I wanted was to lie prostrate under my comforter. I rejoined a wilderness search-and-rescue team, remembering how, before I started building my house, I'd relished hiking through blizzards at 3 a.m. in search of some lost soul. I started a new relationship and volunteered for Big Brothers Big Sisters to channel my ardent maternal energy. I even went to graduate school, pursuing my dream of becoming a science writer.

But while all of that productivity lifted my mood, my physical endurance was shot. Life was a constant uphill slog. I had figured that time would take care of whatever was up with my body. But instead, time led me here: paralysis.

I had moved temporarily to Washington, D.C., for a science writing internship and knew almost no one, so I flew to San Francisco, where my new boyfriend lived and where I hoped I'd find top-notch medical care. I staggered into a neurologist's office, panic-inducing possibilities reeling through my mind: Multiple sclerosis? Parkinson's? Lou Gehrig's disease? The doctor came back to the examining room, clipboard in hand, his expression indecipherable.

"There's nothing neurologically wrong with you," he pronounced flatly. "You have chronic fatigue syndrome."

Fatigue? I thought. Did you fail to notice I'm fucking paralyzed?

I seemed to have molasses clogging my brain's synapses, but I managed to mumble some questions about tests, treatments, other doctors. He was silent. Finally, I asked, "What if your wife were sick like this?" I studied his face for sympathy, or sheepishness, but it was blank.

Bizarrely, Google turned up only one chronic fatigue specialist in the entire Bay Area. I was wary when I arrived at his office and saw a flier touting the healing powers of acai juice, which he sold in wine bottles for \$35 a pop. But I went ahead with the exam, after which he theorized that I had suffered a "cytokine storm," an immune system freak-out that had inflamed my nervous system and triggered my paralysis. He recommended supplements—Siberian ginseng, acetyl-L-carnitine, R-lipoic acid, curcumin—and ordered tests to determine whether Lyme disease, thyroid issues, or liver problems had contributed to my chronic fatigue syndrome. I swallowed mountains of candy-colored pills, but they could have been actual candy for all the good they did. The tests showed minor abnormalities and low iron and B vitamin levels; interesting, but hardly an explanation. So I dug into the research literature myself.

Since childhood, science and math had been my source of safety, reliability, sanity. My mother was prone to unpredictable moods and stretches of self-imposed isolation. It never occurred to me that she might have a mental illness, even though she spent hours every day in bed playing solitaire. She could fly into a rage at the smallest infraction, furiously hitting me with a belt if I ate my Twinkies before I'd finished lunch. But we loved each other ferociously. I believed I'd been brought into the world to save her.

Science and math had provided a practical respite from that exhausting effort; among the most pleasurable hours of my life were those I spent one wonderful weekend powering through an entire year's worth of Algebra 2 for a correspondence course, scrawling ellipses and parabolas on worksheets that piled up next to me. I started college at 14. After my mother died when I was 18, I earned a master's in mathematics from MIT.

Now I pored over jargon-filled research, my brain sputtering as I gradually pieced together

what was happening to me. Chronic fatigue syndrome (CFS) is also known as myalgic encephalomyelitis (ME/CFS), meaning "muscle pain and inflammation of the brain and spinal cord." Apparently some trigger or combination of triggers—staggering levels of stress? an exposure to toxins?—had tilted my body into an altered state, causing ME/CFS.

Unfortunately, the research on ME/CFS sucked. The studies were small, and scientists hadn't followed up on them, so I couldn't be certain the findings were even true. Researchers were starved for funding: The National Institutes of Health spent only \$5 million per year on ME/CFS research, though the condition affected at least a million Americans. The scientists' grant proposals were routinely rejected, sometimes on the grounds that patients' suffering was all in their heads.

Meanwhile, my body told a profoundly different story. One day not long after my visit to the neurologist, I felt myself grinding to a halt as I navigated the aisles of the grocery store. I'd started the day feeling unaccountably better than usual, but by the time I got to the parking lot, I could hardly lift my bags into the car. Later, in the middle of dinner, I could no longer hold up a spoon. That night it was as if my feet were lodged deep in mud; each step meant wrenching them from sludge. Mentally, I was lumbering, like I'd taken too much cold medication—I saw the world in slow-mo through a dense sheet of plate glass. On the way to the bathroom I froze, and my boyfriend had to carry me back to bed. Hypothesis: Overdoing it made things worse. Intensive rest made things better. I learned to stop everything the instant I thought, *I'm a little tired*.

I tried diet after diet: near vegan, then ultrameaty paleo, then only turkey and potatoes for two weeks to check for food allergies, then no carbs at all. Along with a flotilla of regular doctors, I saw a renowned acupuncturist, a chiropractor who "trained" my brain by having me listen to a series of random electronic tones, an alternative endocrinologist who asked whether my poop stank and reprimanded me when I laughed. I tried Iyengar yoga, daily meditation, swimming. But I never got closer to a long-term solution.

For four years, I managed. Living with the illness felt like running a marathon while wearing my search-and-rescue pack—but hey, I was strong, I could handle it. Occasionally, my legs buckled as I walked down the street and I had to ask a stranger for help, but on very good days, I could stroll along Stinson Beach, holding hands with my boyfriend as my hound-mix puppy, Frances, crashed through the waves. Sometimes I could

even hike, albeit ploddingly slowly, until the day that changed everything.

On a visit to Santa Fe, Frances and I were a mile deep in the wilderness when I thought, *I'm a little tired*. I sat down immediately. After 15 minutes or so, I turned around, knowing I'd pay for every additional step. This trail was my secret, rarely traveled by other hikers, and my throat closed as I thought, *What if I get paralyzed out here?* With progressively longer rests, I eventually made it home and wept with relief.

The next day my whole body felt fiery— even speaking was difficult. *Stay calm*, I thought. *You'll be okay soon*. But after I returned home to Berkeley, I could do little more than crawl to the bathroom. I wrote apologetic emails to my editors as my deadlines sailed past, my brain too sodden and soft to produce publishable work. I saw virtually no one except my boyfriend. I spent hours studying the irregularities in the drywall on my ceiling.

The days turned to weeks, the weeks to months. I went to one of the top ME/CFS specialists in the world; she gave me treatments including a mysterious drug called naltrexone to help regulate my immune system. I left her office high on hope—but as time went on, the treatments were a bust. She had nothing more to offer.

My boyfriend grew resentful of my constant hardships; I tried to reduce the burden on him, which left me feeling pinched and sullen. Eventually I left him, moving back home to Santa Fe, staying in the travel trailers I'd lived in while building my house, since I'd rented it out. I got sicker, the paralysis so extreme I often couldn't turn over in bed. I kept a pee bucket nearby, hoping I could roll over in time to use it. I tried to distract myself from my terror by focusing on immediate pleasures: the whipped-cream softness of Frances's ears, the sound of the stream outside my door. But I was too sick to care for myself. I was 39, alone, and running out of money, with no viable treatments to try. I imagined myself destitute, on Medicaid, living out my life in a dilapidated nursing home.

And then I met the moldies. I'd taken an assignment for an online magazine to write about CFS, worked on it for five days, then remained motionless in bed for a week with the curtains drawn. I told my editor I had the disease myself; he insisted I divulge that, which I'd never done publicly. When the story was published, fellow sufferers began sending me friend requests on Facebook. They were an invitation to an online world teeming with housebound patients who were knitting and selling hats to earn money, pressuring the National Institutes of Health to increase funding, even founding research start-ups.

On one new friend's wall was a stream of posts theorizing that toxic mold had caused her illness. By scrupulously avoiding the mold, she claimed, she'd gone from being bedbound to mostly recovered. I rolled my eyes. *Pseudoscientific hokum*, I thought; *mold might cause asthma or allergies, but it can't cripple you*. Then something caught my eye: a post from a 20-something guy who'd been living mold-free in the desert for two months and was back to hiking and lifting weights. As I imagined running through the mountains again, I felt as though longing would burst my heart.

But the theories espoused by the moldies, as they called themselves, didn't seem relevant. They described having lived in homes where mold oozed from cracks—“I never had. They told stories of fainting upon walking into some buildings—“not me. Still, the 20-something's story haunted me, so I reached out and was invited into the moldies' email group.

More than one of them zeroed in on the travel trailers I was living in, almost certainly mold magnets. I felt a shiver of recognition: I'd first started feeling sick when my ex-husband and I had lived in the trailers while building the house. If I'd lived in just one contaminated space, said the moldies, my belongings could have picked up enough spores to keep me sick. Think, they said, of the havoc infinitesimal fragments of peanut dust could wreak on someone with a serious allergy.

It was as coherent a theory as anything else I'd heard. And the moldies were hardly dim-witted kooks, among them a Harvard-trained lawyer, an MIT computer scientist, an art history professor. They suggested an experiment: spend two weeks in the "GFD"—“the godforsaken desert, in their lingo—“with none of my own contaminated belongings and let my body "get clear." When I returned home and was reexposed, they claimed, I'd become really, really sick. After that, I could learn to "perceptify"—“detect mold, based on my own bodily responses—“and avoid it so I could recover. It sounded nuts, but the idea of having an adventure, even when I was so damn sick, at least made me feel like *me*. What did I have to lose?

With less than \$5,000 left in my bank account, I couldn't afford to buy a new tent, sleeping bag, clothes, cell phone, computer, and hairbrush. But the moldies argued strenuously that a single contaminated object could ruin the whole experiment. So I swapped cars with a friend, borrowed camping gear, and bought cheap new clothes from Target. The moldies

agreed that I could take my credit cards and cell phone, but only if I kept them in ziplock bags.

As for my destination, I considered California's Anza-Borrego, but one of the moldies reported that the winds blew in contaminants from San Diego, so the air wasn't sufficiently clean. They preferred the lunar sterility of Death Valley, which suited my mindset: I felt like I was going to the desert to die. I didn't expect to be carried out in a coffin, but life as I'd known it was over. Chatting with a friend one evening, I heard my laughter turn hysterical. *Hahaha, I can barely hold up my phone and I'm going camping in the desert alone for two weeks, hehehe!*



And that's how, in February 2012, I found myself bouncing up a rutted dirt track in Death Valley in my friend's tiny Subaru Impreza, pulling over at a sandy area three miles from the main road to pitch my tent. As I opened the car door, the wind clobbered me, and I hustled to set up camp before I lost light. When I'd practiced with the borrowed tent in my windless yard, I barely managed, my muscles withered to dental floss by endless hours in bed. Now, as I wrestled with the nylon, a silent but deafening alarm blared inside my head. I was overdoing it, and I knew the cost.

When the last pole finally slid into its grommet, tears stung my eyes. I sank onto a rock,

allowing myself a second to rest, then trudged back to the car for supplies. I called Frances into the tent, "I'd washed her in vinegar before we left, to eliminate any mold particles" and crawled into my sleeping bag, wrapping my arms around her. My limbs throbbed. *Tomorrow will come tomorrow, I thought. Now sleep.*

The next morning, I cracked open an eyelid and carefully stretched my fingers, rolled my shoulders, moved my legs. I was creaky and hurting, but functional. I scooped to the tent's entrance and gawked: Light beams fanned above my head, shooting honey-colored rays across the sky. A moonscape surrounded me, with only scraggly weeds punctuating the rubble. A single car inching through the valley, miles away, was the sole sign of human life. My breathing slowed, the grand emptiness and quiet expanding my chest.

Before the trip, I'd frozen vats of vegetable chili and Moroccan lamb stew in containers; now I propped a two-burner stove on a folding table. Setting up camp took most of the day, and at dusk, I watched shadows stretch across the rocks as I sat in my chair, a bowl of stew in my lap.

Over the next week, I took short walks. Each day I retreated to my sleeping bag for hours, lying inert as my body vibrated with the wind's drumbeat on the tent, listening to the zipper pulls jingle an accompaniment.

Time felt suspended, and I was powerless inside that lull. Contemplating my life from a camp chair in Death Valley, I smirked. I could do nothing to force my career back on track, find a new boyfriend, have children. Unrelenting ambition had always goaded me, but where had it gotten me? "Success" seemed hilariously impossible. Just following one breath with another, heating my dinner and washing the pot, scratching Frances's belly—that felt like an accomplishment. My mere existence was an act of grace. Though I often felt lousy as I went about the humble business of surviving in the GFD, an unfamiliar contentment came to fill me. *Enough, I thought. This is enough.*

But what next? If I went home, walked into my trailers, and my body didn't react, I had nothing left to try. And if I collapsed in a wretched heap, proving the mold hypothesis was true, what then? I'd have to move out, throw away every object I owned, and find a new home. I fantasized about staying in the desert, never returning to the civilization I could no longer tolerate.

Of course, I had to return to my life, such as it was. I went back to Santa Fe. I planned to set up a tent on my land and sleep there through the first night; the next day I would do my first test. Problem was, the spot where I planned to camp was on the wrong side of a wire fence; I'd have to cut the fence with wire clippers, and the clippers were inside the trailers.

A few seconds shouldn't be a problem, I reasoned. Holding my breath, I dashed in.

That night I woke up to pee and couldn't move my legs. I felt indescribably horrid, as if every cell in my body wanted to puke. Threaded through the aching nausea was glee: *Maybe I'm learning to perceptify!* But this was just one data point, hardly conclusive proof. So that day, and in the days to come, I started testing myself every way I could. I spent 15 minutes in my trailers, and a couple of hours later, I couldn't walk. I sat in my own car and when I stood, my legs dragged. Just handling some paperwork from the trailers was enough to cripple me. But would removing mold from my life be enough for my body to heal?

A week after I returned, I was sore and muddleheaded, so I sat outside in the sun for a couple of hours until I felt better—well enough to take Frances for a walk. I ambled cautiously uphill and was dumbfounded to reach the saddle at the top of the arroyo, a good half mile of climbing. *Better stop*, I thought. But my body—seemingly of its own volition—turned left up the hill, driven by strength I scarcely remembered. My legs carried me to the top, 350 feet above my house. My breath suddenly came hard; I hadn't been able to climb that hill for a year and a half. I emailed friends a picture of the Rio Grande Valley, with the subject line: "Oh. My. God."

Over the next several months, I became an expert at sensing contaminants: After I entered a moldy building, my skin would prickle or my teeth would chatter, and immediately I'd leave, wash my face, and change my shirt. It all felt bizarre and improbable, but with months of constant vigilance, my life came roaring back. I moved back into the house I'd built, which turned out to be blessedly mold-free. I started publishing stories again. I fell in love with the man I'd soon marry.

The renewal has been overwhelming. At times, I still worry that it will all vanish: that my beloved will turn into a monster, that my body will collapse, that I'll again be impoverished, inhabiting my trailers as if they're coffins. In those moments, I send my thoughts back to Death Valley and remember the inner spaciousness I discovered there, at my worst. There,

where I set down my imagined obligations—along with my dreams, some of which were miraculously restored to me. Maybe I'll never have the children I've so longed for. Maybe I'll never achieve the kind of success I imagined. But I try to remind myself that I died out there in the desert. This is all extra, an unearned gift. The only thing I have to do is breathe.

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