

Excerpt from *Lightening the Shadow*:

## Diagnosing and Living with an Invisible Chronic Illness

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### *Introduction: I'm Not Just Tired*

I don't feel *tired*; I feel stunned on the ground from body slamming a brick wall. I feel fifty years older. I feel unplugged in the dark.

That's how I felt while combing my hair in the YMCA locker room after one of my hour-long swims. What I actually thought was *Maybe this is more than a cold. I'm whipped, and my legs are sore, even though I didn't swim as hard today.* Usually, swimming made me feel calm and strong, without causing sweating, even after the two-hour practices I'd done on my high school swim team.

"How are you doing, Darla?" asked another lap swimmer, who had been my journalism teacher.

"All right. Just trying to shake off a cold," I answered.

"Are you home for the summer, then?"

"Yeah. I plan to take a couple online classes through Lansing Community College, though."

I also planned to work at McDonald's, a job I'd had for two years. But I'd had this cold, which was mild except for utter exhaustion that made me not want to do anything

involving physical or cognitive effort, for a week now. I'd come down with it the Friday before Mother's Day of 2009, the day after I came home from my first year at Central Michigan University (CMU). I'd had a successful semester, declaring my major in English, completing eighteen credits with the hope of graduating a semester early, and being elected secretary of a writing club and an honor society.

I tucked my comb into my swim bag and said good-bye to my former teacher, whom I haven't seen since. *If I'm not better by Monday, I'll go see the doctor.*

I didn't know I would see many doctors: four internists, two neurologists, two endocrinologists, two rheumatologists, one alternative medicine doctor, one osteopathic doctor/certified naturopath, one psychiatrist, one cardiologist, one gynecologist, and one sleep medicine specialist. I didn't know I'd travel to various cities in my state, Michigan, to see them. I didn't know I'd try treatment after treatment, including extra vitamins and minerals, vitamin B12 injections, antidepressants, a stimulant, herbal remedies, extra water, bed rest, pretending I was fine, taking fewer credit hours, quitting that McDonald's job, yoga, a therapeutic white noise machine, diet changes, environment changes, counseling, light therapy, oxygen therapy, you name it.

I didn't learn my diagnosis until two years and five months had passed and my condition had worsened. Two years represented a tenth of my life. Falling ill at age nineteen was like having my wings chopped off just as I was taking flight. Maybe the timing would've been worse if they had been chopped when I was hundreds of feet in the air, a year into a career in a city far from my parents. But I would've liked to soar through the air. My heart goes out to pediatric patients who will never fly on their own.

Plenty has been written about adopting a healthy lifestyle but not as much about adopting a chronically ill lifestyle. I've lightened the weight of my incurable illness enough to live a life that's of value to society and me. By sharing my experiences and seven major

lessons I've learned, I mean to shine a light for my fellow patients and people without diagnoses and to enlighten healthy people, especially doctors, about my invisible chronic illness. I don't pretend to have suffered more than other patients, but the ones who have suffered the most are too sick to speak out about this confounding illness and about how little health care professionals know about it.

## *Chapter One: The Shadow Descends*

As I sat in the waiting room of my family's doctor, I was deciding how to describe my fatigue but couldn't concentrate. I'll call my internist Dr. One. (I'll change the names of doctors I say negative things about, along with some details about what we said in our interactions and about their appearances. I do not intend to harm them, and I recognize my bias.)

Dr. One had been my doctor since before I was born. He was about my parents' age. We liked his sense of humor, and he knew us more as people than as specimens.

I ended up telling him that I felt much like when I'd had mono a few years earlier, the only serious illness I'd had in my life. Based on my physical exam, nothing was wrong. Height 5'6", weight 122 pounds, no tenderness, no fever, no swollen glands, paler than many redheads but not in an unhealthy way, and so on. I looked much like the other woman sitting in the room, Mom. Same short, baby-fine blonde hair that requires an act of God to curl—Mom, unlike me, cares enough to wield perms and curling irons religiously to impose a bend on her hair. Same attractive legs, and same blue eyes, although I wear glasses.

Dr. One suspected that I had mono, which can strike more than once, he informed me, or some mystery condition that would resolve itself within a few weeks. He ordered some blood tests. In the meantime, he said to take a rest period, about fifteen minutes every morning and every afternoon, and to reduce the hours I worked. The blood tests came back normal.

I've never been able to sleep during the day, so I spent most of the rest periods listening to gentle music or praying. I was surprised I had enough to say to talk to God for fifteen minutes straight. The rests benefitted me spiritually but not physically. I tried going further by staying in bed for a few hours a day for a couple of weeks. This just reminded me that I was ill, then frustrated me when I felt no better after rising—and rising was suddenly challenging. When I told myself to get up when sitting or lying down, my body wouldn't obey. I sometimes leaned forward and shifted my weight to my feet. But then, I felt unable to move and unable to concentrate on the next step in the process. Next, I leaned back into the couch because that was more comfortable than sitting up. Or my thoughts wandered off. Then, I repeated my command to get up, usually with some progress but not enough to put me on my feet. The whole routine could take ten minutes, and the routine for forcing myself to get out of bed could take half an hour. On days when I had to wake by a certain time, I put my alarm clock as far from my bed as possible. Unless I was in public and there was urgency associated with the movement, such as getting off a bus when it reached my stop, I had to fight to exert myself.

I started writing down my activities and feelings in my personal journal, trying to find some explanation for my sudden illness. Journaling had been my way of recording memories and expressing feelings since third grade, when I missed the activity from first and second grade. I remember things best when I write them down, and I didn't want to forget to tell Dr. One about any patterns I noticed. Some days were harder than others, so I reread my entries from those days, trying to find out what made them worse. I noted that if I drank more than one cup of coffee or drank an espresso drink to give myself a boost the way I had while at school, I felt shaky, not energized. When the caffeine wore off, I often felt worse than I had before the drink. About once every other week, I had a day on which I

was more energetic than usual. The problem with that was I tended to do so much on a good day that the next day was what I called a bad day, a day on which I felt much worse.

While journaling, I realized that the soreness in my back and neck I sometimes felt after work probably wasn't a result of that because I'd never had pain after work before. I wasn't sure whether I was having abnormal pain or my exhaustion was amplifying what would otherwise have been mild tenderness, like when being hungry while having a headache intensifies discomfort. I also noted multiple occurrences of a cruelly ironic phenomenon: trouble sleeping. I was exhausted, but it took an hour or two to fall asleep. It was like after a whole day of fighting fatigue, my body didn't know when to retreat and regroup. Or, I'd wake up before five o'clock, unable to go back to sleep.

The same week I noticed my frequent achiness, I had the first of countless occasional stomachaches right after eating. It wasn't a severe pain, closer to an annoyance, like the other sore areas I'd experienced. The exhaustion still concerned me much more. A shadow has no weight, but I felt like an invisible shadow was crushing me. If I knew what it was, its darkness would become less frightening. Maybe I'd even find a way to make the shadow fade.

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*End of excerpt*