

soulful simplicity



how living with less
can lead to so much more

courtney carver

Chapter One

An Ironic Diagnosis

I could feel the gadolinium contrast pushing through my vein. A wave of warmth rushed up my arm, and then through my entire body. I knew my face was flushed. Then, as they slid me back into the MRI machine, nausea hit, and then the panic. "There is no room to sit up. I am going to throw up and choke on my own vomit." My head was in a plastic cage snapped tightly shut, my arms were down by my side, and the machine started to shake and sounded like ten thousand jackhammers. I hadn't let myself get really scared until now. For months, I'd been fighting vertigo, fatigue, and other symptoms, chalking it all up to stress and an ear infection. I was training for the Harmon's MS 150, a cycling event in Salt Lake City, in the spring of 2006. I was going to our local recreation center for indoor training sessions because it was still too cold to ride outdoors.

I didn't know much about multiple sclerosis, but my boss had it. I worked for a publishing company and the owner was in a wheelchair. When I first started working for him, I didn't know what was wrong with him and I was too intimidated to ask. Even though he was in a wheelchair, he was a powerhouse. He was committed to his company and enjoyed the stressful nature of the business, and made it more stressful whenever he could. Eventually, I found John's softer side. I had great respect for him and his wife even though we couldn't be more different. That stress they thrived on twisted me up. Once I got to know them better and had been with the company for almost two years, I decided to raise money for MS research by participating in the 150-kilometer ride. I wasn't sure if I'd ride the whole thing but I was looking forward to trying. I wanted to raise money for MS research, but I was really riding for John, for his softer side.

It was a stressful spring, and there were several events that likely triggered the exacerbation that led to my diagnosis. I was working long hours and had volunteered to chair the annual auction at my daughter's school. I took a little detour from my cycling training and went to visit my sister, who lived in Germany. I was so excited to see her, my brother-in-law, and my niece and nephew. We didn't see each other very often because we were an ocean apart, but we talked almost every day or exchanged messages. We weren't always the best of friends when we were kids, but we get closer and closer year after year. Bailey, Mark, and I went together and we had a blast. Between afternoon prosecco toasts celebrating our reunion and late nights, though, I completely stressed out my already stressed-out body. Add work deadlines and jet lag, and it's no wonder that I didn't feel well when I got back. My grandfather died that spring too. Research shows stress can cause MS relapses or episodes. I was just getting by in the craziness of my life, just making ends meet, just barely handling it. On the outside, it looked like balance. On the inside, it felt like hell. Losing my grandfather tipped the scales.

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When my grandfather died, he was living in an Alzheimer's facility. It was always hard to visit him because he always remembered me, but couldn't really remember why he was there, why he didn't have his driver's license, and why his life was gone, but he was still here. On the day he died, I spent most of the day with him. His eyes were closed and he was lying down, but he wasn't peaceful. He was agitated, frustrated, restless. Pissed, really. Not completely lucid, but feisty and verbal. Some things never change. He kept raising his arms up and saying "Lift me up, pull me up," over and over again. I'd lift him up and fluff his pillow and he'd start all over again. I could not make him comfortable. I've lost people before. Friends, my grandmother, other more distant relatives, but I've never been with them when they left. It wasn't the peaceful passing I had heard about. It was volatile and awful.

For months I had nightmares about my grandfather yelling at me, "Lift me up, pull me up!" Those words and moments haunted me. About six months after he died, I asked a minister at my church to meet me for coffee so I could tell her how mad I was that God let my grandfather die like that and I couldn't help him. I couldn't ease his pain. I repeated the words. I said, "He kept yelling at me and raising his arms: 'Lift me up. Pull me up.'" After a moment of quiet contemplation, she looked at me and said very matter-of-factly, "Maybe he wasn't talking to you."

I thought about each of those stressful moments as I lay in the MRI tube, choking down the bile rising in my throat, and pushing back tears and panic, I started to pray, or plead, or some messy combination of the two, trapped in the tiny tube. "Please don't let me die in this machine. Please don't let me have a brain tumor or some crazy disease. Get me out of here. Get me out of here." By "here," I meant the machine, the hospital, the day, and the nightmare. Get me out of here.

I was living in the perfect storm of stress in my life: lack of sleep, overworking, jet lag, regular life stress, and the loss of someone I had loved my whole life. The vertigo was joined by overwhelming fatigue, tingly hands, and a numbness in part of my face. I was sad, tired, and completely depleted and sick. I thought the vertigo was an ear infection and my doctor thought so too, at least that's what he told me. Two weeks later, I still couldn't walk a straight line, let alone ride a bike, and I went back to the doctor. We started with MRIs of the head. Lesions suggested something, but nothing definitive. More tests: ear testing, eye testing, spinal cord MRIs, heart ultrasounds. Was I having mini strokes? Did I have ALS? The last test, a spinal tap, sealed the deal.

That's when I got the phone call from my doctor at the neurology office. At first, she told me I didn't have MS, and we should take a "wait and see approach" to determine the next step. She said she was surprised no one had called me since they got the results the week before. I told her I had only had the test a few days ago. She said she had to call me back. Three minutes later, she called back and said, "Oops. I was looking at the wrong chart. Yep, you have MS."

This wasn't the defining moment, although it felt like it for a while. It was the scariest moment and the messiest. My fate was delivered over the phone, while I was at work, as casually as "Do you want fries with that?" I didn't know what to do with the information. I had no next step, no plan, only fear.

I had missed the MS ride, was diagnosed with MS while raising money for it, and still couldn't get on my bike. I hung up the phone, cried all the way home, and took a Valium left over from treating the ear infection I never had.

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