

Chapter 10

LEARNING I HAVE MS, THE “MY, YOU LOOK SO WELL” DISEASE

My life wasn't perfect, but it was getting better all the time. I loved my work. I was busier than ever. Not only was 2005 the year of Katrina, but we had Hurricanes Dennis, Emily, Rita, and Wilma. We had so many storms, for the first time in its history, the National Hurricane Center had to go to the Greek alphabet to name them. I was working long hours and found myself feeling overwhelmingly tired. I chalked it up to lack of sleep for weeks on end and depression from all the devastation we were seeing on television. Little did I know that as I was warning people of the next hurricane, my body was dealing with its own neurological storm, one that had been forming for years.

I took time off and decided to go back home to Canada with Sean

for a week. The first day of my vacation I woke up to numbness in my feet and parts of my legs. I felt like I couldn't get out of bed from exhaustion. I had no idea what was wrong.

I went to a doctor in my hometown to see if she could figure it out. She was blunt and honest. "This could be anything from a slipped disc to multiple sclerosis. You should get back to the US to see a neurologist."

I thought she was crazy. *MS? Isn't that the wheelchair disease?* I took her advice, though. When I got back to New York, I made an appointment to meet with a rather unemotional and very detached neurologist.

He took one look at my MRIs and decided to give me a most unpleasant spinal tap in his office right away. I was by myself in one of those hospital gowns open from the back as this robo-doctor was putting a gigantic needle into my spine. Tears rolled down my face.

Dr. Distant came in and asked if I wanted to call a family member to come and pick me up, and he would go over the results with me. I called Sean, and asked if he would come. I remember my teeth were chattering, but I couldn't tell if it was because I was cold from wearing an open hospital gown or scared to death.

We sat holding hands as he told us the news.

"It would appear you have multiple sclerosis."

In every single technical term possible, Dr. Feelbad told us the MRIs had shown lesions (abnormal damage on an organ or tissue) on both my brain and spine. He pointed these out on my scan. Then he showed us the paperwork that showed I had the protein or oligoclonal banding they look for in MS patients. He had extracted this finding from that god-awful spinal tap. The presence of these bands suggested inflammation of the central nervous system.

In simpler terms, my explanation of MS is this:

Multiple sclerosis is a disease in which the immune system eats

away at the protective covering of the nerves. We don’t know why. The fatty substance that protects our nerves is called myelin. This is similar to the plastic coating that covers electrical wires to keep everything together. Wires that lose their insulation can “short out”—so when our immune system eats away at that protective coating, messages can get fuzzy as they are transmitted from our nerves to our brain. When I wake up at night from a random shooting pain, I chalk it up to my body having an electrical storm.

Sean asked questions, and I tried to listen, but truthfully I completely zoned out. How did these little injuries get there? Why did my body hate itself enough to hurt itself? Had I done something wrong? I started imagining myself in a wheelchair.

The doctor gave me steroids to help with the numbness and tingling and told me I more than likely had multiple sclerosis, but we’d have to wait and see over the next few months, since I had to have another “episode” to diagnose it officially. We’d have to book another appointment for more MRIs in the next six months.

I couldn’t believe this man who had half a dozen diplomas on his wall couldn’t tell me for sure what I had or if it would come back or how bad it could be. Turns out, predicting what MS does isn’t any easier than forecasting the weather six months in advance.

I also wished he had taken an acting class to at least look compassionate.

I went home from my worst doctor visit of all time and was depressed for days. My boyfriend, Sean, was incredible, but I was also preparing myself for the possibility that he would leave me at any moment. Who would want to hang around and deal with this Debbie Downer with a dire diagnosis? I knew I had to tell the people at work and was very nervous about it, because I had been on the job for only a year and I was still trying to prove myself. A close friend who was in the business told me not to tell anyone at Fox because that would

probably be the end of my career. But I have always felt I need to be honest. How could I hide this? I called my boss, the man who had hired me a little over a year ago, and told him.

“Roger Ailes, please.”

His secretary asked who was calling.

“It’s Janice Dean,” I said, trying not to cry.

She told me he was in a meeting and would call me back. And he did.

“Janice . . . what’s going on?” he said in his gruff Roger voice.

I tried to keep my voice steady and told him about the possible diagnosis. I had knots in my stomach. I think as soon as I said “MS,” the tears came.

He was very kind and understanding. Roger could be like that—sound very fatherly. He told me not to worry, to take my time, and to call if I needed anything. He also suggested I talk to Neil Cavuto. He was the funny, smart business anchor who hosted *Your World* on Fox. I didn’t know Neil well, but he loved to tease me when I did the weather with him on the air:

“Janice Dean, how do you guys still have a job when you’re only 50 percent right?”

“I could ask the same about your stock picks, Neil!”

“Nicely done, JD.”

Not only was Neil an anchor, but he had a fancy title after his name.

He was the senior vice president, anchor, and managing editor. He hosted three television programs on the Fox News Channel and our sister network, Fox Business. He was also a cancer survivor and, I now remembered, living with multiple sclerosis.

Neil would be my first phone call after I went back to work.

I was off for several weeks before I could go back. Unfortunately, I was one of the 32 percent of people who get something called a “spinal headache” after that dreadful spinal tap. My spinal fluid was leaking through the puncture site. It was one of the most painful things I’ve ever had in my life. I could not sleep, eat, or sit still. I had to go back and get something called a blood patch, which I will spare you the details of. As gnarly as it sounds, it worked, and that horrible piercing, bloodcurdling headache went away.

Thankfully, the steroids started working as well, and the feeling started to come back in my feet and my thighs. I remember booking myself for a pedicure at the nail salon near my apartment and quietly sobbing because I could finally feel the lady scrubbing my feet, something I hadn’t been able to feel a few weeks earlier. She asked why I was crying:

“Am I scrubbing too hard, miss?”

“No. Scrub as hard as you like,” I responded. “It feels fantastic.”

Now that I was feeling better, I decided to find another neurologist. I couldn’t bear going back to Dr. Detached. This took me a few tries, and I like to joke to other MS patients that finding your doctor is kind of like dating: you have to go on a few of them until you find your match. I’ve been told this is a common complaint with MS patients. Having a chronic illness, you crave compassion. I don’t necessarily need someone to hug me on every visit, but at least try to make eye contact.

In between my quest for the “one” (neurologist), I started reading every book I could get my hands on with a protagonist living with MS. The first was Richard M. Cohen’s book *Blindsided: Lifting a Life Above Illness; A Reluctant Memoir*. Richard spent his career as a journalist and a television producer. It was beautifully written, but it

scared the shit out of me. He warned against telling your employer you have MS. This was not what I wanted to hear. His struggles with the progressive side of MS were depressing and sometimes very angry. I ended up loving his wife, Meredith Vieira, even more after reading how wonderful a partner and caretaker she was.

I later got the chance to meet and talk to Richard when I interviewed him for an essay I was writing for Foxnews.com. We did a question-and-answer session at an MS function after I was newly diagnosed. Despite his challenges, he is funny and charming. We joked that doing these MS events all the time could lead to an MS flare-up, because as much as you want to help the cause, they can overbook you if you make yourself “too” available.

I also read Montel Williams’s book about his life living with MS and the funny, beautiful Teri Garr had a more uplifting read about her MS. I banned myself from googling anything.

I wanted to read about people who were doing well despite the illness. Why weren’t there any of these? The words “incurable,” “chronic,” “blind,” and “wheelchair” were all I was seeing.

Perhaps I was looking for stories of miraculous recoveries, which unfortunately don’t typically happen with MS.

When I finally went back to work, I could tell people had already heard about my diagnosis. I could read their faces when they saw me walking through the hallways. That sheepish “Hello” or “How are YOU doing?” I didn’t blame them; I would’ve probably been the same way.

I then called Neil Cavuto, who told me to come to his office right away.

He dropped everything, turned off the TV, brought a chair over, and sat next to me. He kept a stream of tissues in motion, consoling me while I just cried and told him all my fears. What would happen to my career? My personal life? My self-esteem?

Neil calmed me down, promised me I was going to be okay, and reminded me that I was working at a great company that would support us, even if that support included building his-and-hers wheelchair ramps for us. He told a few jokes, too, which made me smile despite the black tears streaming down my face from too much mascara.

I’ll never forget that day and what Neil did for me. And still does for me. He’ll drop me a line once in a while asking, “How are you doing, kiddo? Doing great out there. Can you tell me the forecast for New Jersey this weekend?” We also joke with each other that we will use our illness to get out of every chore possible at home. “No putting out the garbage for us, my friend. We have MS!”

Nowadays, I try to follow Neil’s lead and do the same for others. There have been several people over the years who have come up to me at Fox to tell me they’ve joined the MS club, and they weren’t afraid to tell their bosses because I was there—setting an example, being on TV, doing weather, laughing, dancing, and singing despite the war that was going on inside my body.

I remember a fellow MS’er saying she calls it the “My, you look so well” disease, because you can look normal on the outside and no one knows that you might be in pain or have a weird burning sensation somewhere or have vision issues.

I tried to find more people to talk to who were living with MS. It was the one thing that kept me going: seeing others who were not just functioning but thriving.

Back to my quest to find my neurologist match: after my first dreadful doctor date, I went on another, this time with an NFL sports neurologist that my dear friend Jane Skinner had set up for me. (Jane and I worked together at Fox for six years, and she also happens to be married to the commissioner of the NFL, Roger Goodell. Needless to say, they have some pretty good connections when it comes to physicians.)

Jane offered to pick me up at my apartment on the Upper West Side and drive me all the way out to Lake Success, Long Island, to visit this big-time sports neurologist. Unfortunately, Jane and I got lost (these were the days just before GPS), and we were an hour late. I was stressed-out to begin with—on top of my already stressful possible diagnosis—and we could tell that this guy was not pleased that we weren't on time. I went into the office and burst into tears as soon as he mentioned how busy he was, and he was doing someone a favor by seeing me. Once he saw my tears, he softened up a little bit, but not much. The one thing this doctor recommended despite his terrible bedside manner was that I should be on medication right away. He wrote out a prescription and shuffled me out with some instructions. I saw my beautiful friend Jane in the waiting room, and a new round of fresh tears came.

There is a moral to this story—other than it helps to cry. When I do MS events in front of a crowd of doctors, I tell these stories about how it's not only important for MDs to know their stuff, it's almost as important to be compassionate with their patients. We know your time is precious and you have many other people to see, and sometimes life gets in the way. Still, you have people who are emotionally broken in your office. Try to spend a minute or two looking them in the eye and let them know you're there for them.

My third date was successful. I found a kind neurologist named Mark Tullman. His partner, Nurse Practitioner Jen Smrtka, and I have since become good friends, and she's the one that let me in on the fact that Dr. Tullman is sometimes referred to as Dr. Mc-Dreamy. I mean, it doesn't hurt that he's handsome. Truthfully, I didn't care about what he looked like, since he was good to me. He took the time to explain things, and was sympathetic to my fears while taking my vitals. I fell in love with Jen, who I call my angel in a white coat. She would calm my anxiety and point out how far

we’ve come with this disease, telling me tales of strength and people overcoming challenges while holding my hand. Not only that, but we were around the same age and were able to gossip about dating, living in New York, and good skin care. God bless our nurses. I’ve met some great doctors in my life, but I’ve met some incredible, superhero nurses. That’s what Jen was. We’re still close even though she works with a different doctor and has moved to different cities over the years. She has been a source of goodness, light, and strength in a time of extreme darkness. And she still keeps up on the latest in skin care.

In 2007, I now had a great doctor and was getting the hang of the drugs I was on. Amazingly, I was still working full-time. I had to manage my sleep; keep cool, especially in the summertime; and I continued to have minor electrical malfunctions, but otherwise things were back to normal.

Maybe now was the time to tell my story. Perhaps I could share my diagnosis to help others. Maybe I could be the positive influence whom someone living with this unpredictable illness would look to—the person I had needed to see when I was first diagnosed.

I asked for a meeting with the VP of programming, to run my idea by him. Could I shoot a package of my doctors’ visits and MRI appointments and report on how I’m living pretty well despite having MS? It might help others. Not missing a beat, he told me:

“No.” He didn’t think this was the time to discuss a diagnosis on television, let alone make a production out of it.

I was crushed and too shocked to press him on why he didn’t think this was a good idea.

I decided that if programming didn’t like my pitch, perhaps the news department would.

I emailed my concept to our VP of news. Right away, he thought it was a great idea and gave the green light. I then got a producer and

camera crew together. They followed me to my MRI appointments, and we interviewed Dr. Tullman and my sweet friend Jen, for a report that would air on the news channel. Somewhere down the line the programming VP found out and wanted me to call him.

“Did you go behind my back and do this MS thing?”

I said I hadn’t gone behind his back; I just wanted to ask someone else what he thought, and the news department thought it was a great idea.

I think he hung up the phone afterward.

In the end, I was grateful someone thought my “MS thing” was worthy.

From there, I pitched *Fox & Friends* weekend and *Fox Report* weekend. I came in and told my story and showed how I was living with MS but still doing relatively well. By going public with the illness, I was finally doing something I would’ve loved to have seen on television when I was first diagnosed.

Afterward, I got so many emails and words of encouragement from coworkers, friends, and viewers. Maybe the reason I was given this platform of television wasn’t just to give weather forecasts but also to shed a little light on what’s going on behind the scenes in someone’s real life beyond the TV screen.

It was never my goal to be the poster girl for MS—although I don’t mind boasting I was the official cover girl for *Neurology Now* magazine a few years back—but I do feel a calling to be someone who can help others identify and live with the disease.

I don’t see Dr. McDreamy anymore. He lives in St. Louis with his family and is the director of clinical research at the MS Center for Innovations in Care.

Before he left me—and we had an amicable separation—Dr. Tullman kindly referred me to a friend and colleague he thought might be a good fit for me. Her name is Dr. Tracy DeAngelis, and I adore

her. She always greets me with a smile and a hug when I see her, and when she asks me how I’m doing, she does it by looking me straight in the eye. She takes time with me, never looking at her watch, and takes copious notes old-school-style with a pen and yellow notepad. I’m grateful for her care.

So far on this journey, I’ve done all right. There have been trying moments, painful situations, and moments of feeling sorry for myself. However, being diagnosed with MS has also made me realize the important things in life. The days of climbing the career ladder for self-fulfillment, gratification, and self-esteem are over. My health, my family, and their happiness are far more important.

People ask if I’m as “sunny” in real life as I seem to be on television. I think part of the reason I’m so happy is that I learned pretty early on that your life can change in an instant.

I also believe the challenges you are presented with in life are there to help you discover who you are. It’s the obstacles and adversity that make us stronger.

That and one of my favorite sayings: “What doesn’t kill you . . . makes you blonder!” Ha!