

Five Ways MS Has Changed the Past Five Years



There was no celebrating on the fifth anniversary of my diagnosis of relapsing remitting multiple sclerosis. Instead, I did some reflecting. After the reflecting was over, I made a list of the five ways—one for each year of the disease—MS changed the ways in which I move through and deal with the world.

1. High-maintenance

Remember that scene from “When Harry Met Sally” when Harry and Sally discussed low-maintenance people versus high-maintenance people? Harry said the “worst kind” of people are those who think they’re low-maintenance but are high-maintenance individuals.

I used to be one of the worst kind. I tried to act like I was a chill kind of person (I wasn’t), to pretend as though I easily rolled with whatever transpired (I never rolled easily), and that I was totally comfortable with my imperfections (a big fat no).

Now, I can’t even pretend to myself that I’m a low-maintenance person. Since my diagnosis, this illusion has been shattered because the disease itself can be very high-maintenance: heat sensitivity, frequently fatigue, leg spasms, intense headaches that make it impossible to read and occasional difficulties concentrating. Knowing that any of these symptoms can strike at any moment means I must admit I’m now (and likely have always been) high-maintenance.

2. Being flexible versus acting flexibly

Not to brag, but, some have called me [Gumby](#) during yoga classes because I can bend in myriad ways. But when it came to making plans with others, I've never been flexible or comfortable with vagueness. A fan of organization and predictability, I dislike when plans are suddenly changed for spurious reasons.

Then MS arrived.

Now, like it or not, all my plans are subject to change. At any time. And I need to be flexible. When I buy tickets to a play, concert or baseball game, I recognize that whether I can actually attend the event depends on the weather, the venue (will it be too hot or difficult to get to), and how I'm feeling at the time—things with which I didn't contend before my diagnosis.

MS is fickle, and its symptoms come and go like waves. Therefore, all my plans are provisional, regardless of whether I'm comfortable with that new reality.

3. [Spoon theory](#)

Writer Christine Miserandino created an apt analogy for what life is like with a chronic illness: the spoon theory.

For those unfamiliar with Miserandino's theory, here's a summary: when you have a chronic illness, each day affords you a finite amount of energy represented by a specific number of spoons. Each action you choose to do—shower, make a meal, walk the dog—costs you a spoon. When you run out of spoons, you're done with your activities for the day. If you use all the spoons by noon, you have to wait for another day in order to replenish your spoon supply.

Adjusting to this kind of periodic fatigue has been challenging. Pre-MS, I could just down another coffee (or seven), or another couple of cans of Diet Coke, and keep plugging away.

Post-MS, I recognize there's no magic elixir which will provide sufficient fuel to overcome the impenetrable wall of MS fatigue.

4. Strategic planning

When my family loves to go to the beach when we visit Cape Cod. Problem is, with my sensitivity to heat and humidity, I'm unable to join them on most warm and humid summer days. The weather makes me sick to my stomach, causes my vision to go blurry and my limited balance to go haywire.

If the weather is not insanely humid and hot by the end of the day, I will head to the beach while wearing a hideous cooling vest I bought. Sometimes, I'll retch during my walk from the car until I'm able to get in the water, where I cool off and start to regain my equilibrium. After

swimming, I can only stick around if there's a sea breeze.

I must be similarly strategic wherever I visit. Everything from if there are stairs, where the parking is, or whether just getting someplace will drain me of all my energy before the event has even begun. Over these past five years, I've had to think ahead, plan strategically, and lower expectations.

5. Scaled-down holidays

Speaking of lower expectations... part of living with MS means ditching sentimental notions of what "used to be." That includes jettisoning some traditions, such as making gargantuan, gourmet holiday meals like my mom and grandmother used to do.

Now, I use shortcuts, like ordering some premade dishes or asking my college-aged kids to quickly dust and vacuum before I host events. On gift-giving holidays, I mostly shop online. Sometimes, if it's a particularly busy period and we're hosting a holiday, I offer for us to eat the main meal in a restaurant and come back to our house for dessert.

Am I happy about all these changes? No, but I'm making the best of my post-MS life, and spending my time and energy on the things that matter most.