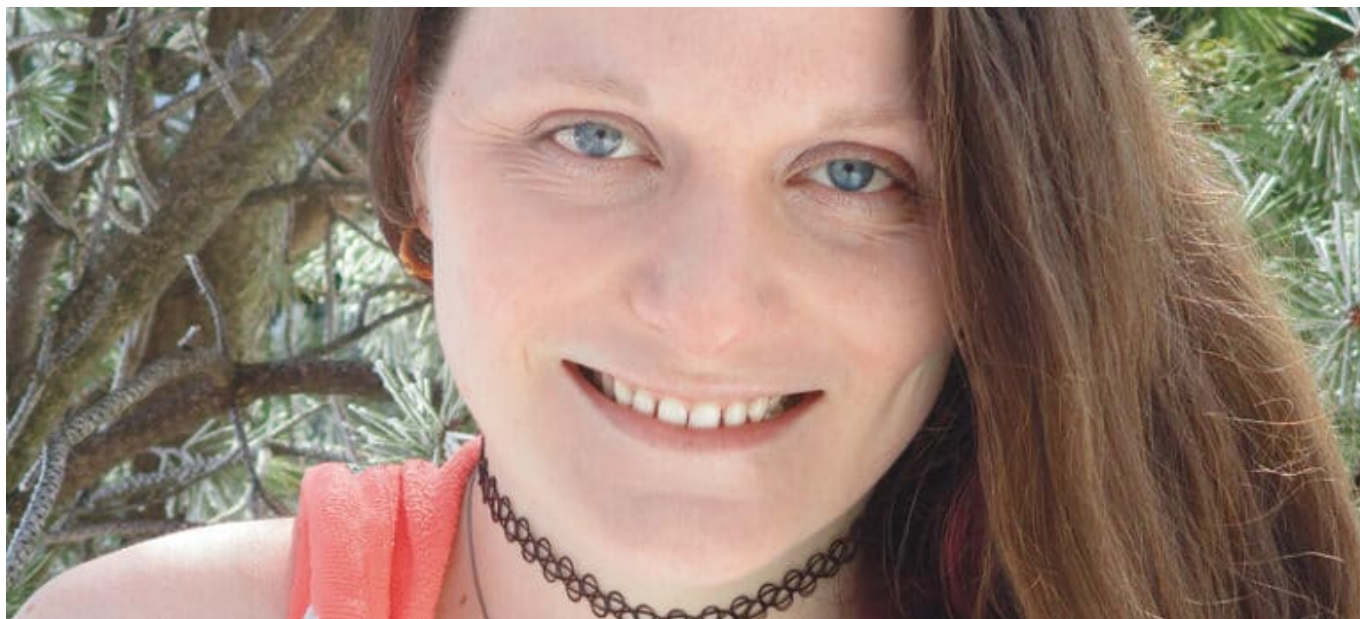


Four things I wish someone had told me after my MS diagnosis



I learned some valuable lessons on the path to my new reality.

by **Nicole Bradley-Bernard**

When I was first diagnosed with multiple sclerosis at age 16, I believed that God only gave us as much as we could handle. I was confident that I could “take it.” Really, I was only prepared for the physical challenges. No one prepared me for the emotional struggles of having an incurable disease.

My partner kept insisting that I needed to “accept my diagnosis,” and I would scream back in frustration that “I had!” But, in truth, the real question was—how do you accept something like this? Once I felt the full reality of my diagnosis, I spun into an emotional crisis as I tried to figure out how to function in a world where I was sick and everyone else seemed to be just fine.

It took years of resentment-fueled self-discovery before I was out of “crisis mode.” So, I’ve compiled a list of things that I wish someone had told me after my diagnosis. I hope they will help speed up the process for people struggling to face MS as their new reality.

1. You’re going to feel alone sometimes.

MS is such a personalized disease that even fellow “MSers” don’t always understand what you’re going through. And, while my family is my ultimate support system, their well-intentioned comments sometimes just leave me feeling isolated.

Being diagnosed so young also made it even harder for me to relate to my peers. And I found myself resentful of the people with MS who did understand my struggles, because most of them were middle-aged and I was bitter that they at least got to enjoy their youth disease-free—something I will never fully get to do.

While this may be one of the harder things to deal with after your diagnosis, it may also be the most fulfilling. There's not a lot that makes you feel more resilient and self-reliant than fighting a disease that's trying to "eat your brain" every day while feeling disconnected from the world.

2. The temperature struggle is real.

I didn't suffer from heat intolerance my first few years with MS. So, I honestly thought that everyone was being dramatic about it. Then, on one of the first days to hit 80+ degrees one year, I found myself collapsing into a chair at Starbucks after having only walked the short distance through the parking lot. I was exhausted, my limbs felt heavy, and I couldn't recall a time I ever felt so hot as I begged for ice water.

That was my first experience with heat intolerance, and it wasn't even close to how bad it became. Now, summers are basically four months of living as a half-naked shut-in because when I go out in the heat, I usually regret it. Luckily, Netflix has really changed the "stay at home" game, and there are still three other less horrific seasons.

3. You're going to have to mourn. Repeatedly.

When I was first diagnosed, I was in this exhausting cycle of relapse, recover and repeat. So, it was a year and a half before I even considered how I felt. Once MS sank in, I felt like I had lost a part of what made me "me." And, like you would mourn for a lost person (or, if we're being less dramatic, a beloved pet), I felt like I had to mourn for the healthy version of myself and the life that she had led. Then, I felt like I had to mourn for every lesion (and the new ones as they came) that made me feel like I had lost another small piece of who I am and what I can still do.

I think mourning is an important thing to do with this disease. Especially since it may happen again (probably repeatedly). After starting to take Ocrevus in 2018, I am doing much better. Before that, however, I was mourning for the drug therapy I was accustomed to. I also was mourning the fact that I had lost all enjoyment in going out because the heat intolerance was so bad that even being in a "normal" temperature room made me severely uncomfortable. But right now, I'm in a victory, and that's important to feel, too! For a long time, I thought the "Nicole" I was before MS was dead. But she wasn't dead—she just may have figuratively passed out from shock (or exhaustion; hard to say).

4. The world is going to be an even scarier place now.

Nobody prepared me for how terrifying it is to deal with what I refer to as the "dormant monster," AKA relapsing-remitting MS. Everyone acts like it's not even a concern once you're at a "good point," but I know the monster is still there. Biding its time. Waiting for an

opportunity to attack. And, I (and I'm sure, my fellow MSers, too) constantly try not to think about what it might take next.

No one prepared me for how intrusive and intimidating these thoughts can be. Although I have to say, dealing with them for so long tends to make you feel like you're at least a tad stronger than everyone else. I mean, half of them can't even seem to admit what could happen. In the terror, it's important to remember that "the dormant monster" can only change who we are if we let it.

If I could go back and talk to "newly diagnosed Nicole," the biggest thing I'd want to tell her is that I don't think a lot of us ever really "accept" an MS diagnosis. Let's get real about it; some of us don't accept it—we FIGHT it! And, like learning to live with the most annoying roommate ever, over time, we do find our own ways of living with it. Like life, MS is always changing. Sometimes it's good. Sometimes it's just awful (no sense in sugarcoating it). Either way, we learn to live alongside it. Hopefully, someday it will move out. Fingers crossed.

Nicole Bradley-Bernard is a freelance writer living in Moxee, Washington. She was diagnosed with MS in 2010.