

Making Peace with My New Normal



Coming to terms with having a chronic, incurable illness like MS doesn't happen immediately. It takes some time to reorient yourself to a different reality - to be able to accept that things have changed. Acceptance of a new normal, of peacefully coexisting with the new limits an illness has placed upon your life, is not instantaneous.

For me, the road to the uneasy peace I've tried to make with my course of relapsing-remitting MS has not traveled in a straight line. Despite all the reading and researching I've done, despite how much my awareness of the disease has been raised, I still have my blind spots. There are times when I am in denial about what living with MS means.

MS has made me sensitive to heat and humidity. It causes me to get nauseous and dizzy, to see spots in the corners of my eyes, and for my knees to buckle. A severe version of these symptoms sent me to the hospital by ambulance around the time I was diagnosed in the summer of 2014.

Despite what I learning how heat affects me and my MS, I occasionally don blinders and push my luck by trying to behave "normally," the way I would before I had MS. My periodic stubbornness, my refusal to abide by the dictates the disease has imposed on me, once resulted in me crumbling to the sidewalk in Cape Cod as I experienced dizziness and retched onto the grass. I had insisted on walking around on a largely shadeless street in 90+-degree heat and high humidity. That was not a smart move. I should have known better, known that I'd likely get sick. But, on that summer day, I was in rebellion against the constraints of MS and the disease won the battle.

This happens sometimes. More times than I'd like to admit. I allow my frustration to overpower my rational side and prompt me to do things I know I shouldn't, like how in December 2016, in a microburst of activity, I baked dozens of Christmas cookies and desserts, wrapped all the Christmas presents, and cleaned the house from top to bottom. The effort sent me to bed for days afterward as I tried to recover, rendering me unable to enjoy the holiday events.

On other occasions, it's not stubbornness that prompts me to forget or overlook that I have MS, but an unwillingness to acknowledge it to myself. For example, I recently learned that a writer who I greatly admire, Joan Didion, has MS. Her admission that she has MS was detailed in an essay in *The White Album*, a book I read a year-and-a-half after I was diagnosed. She detailed some of the same symptoms I have experienced, including nausea, vertigo, and migraines. Yet when I initially read it, I completely overlooked the fact that we both have the same disease. How could I have just ignored this fact, not even noticed it? Re-reading her essay now, when I'm in a much more emotionally stable place when it comes to MS, I wonder if back when I first read this material, I was simply not ready to see myself as a writer with a chronic illness. This new normal was too fresh, too frightening at the time.

Do these realizations mean I will not occasionally be pig-headed, that I will refrain from trying outdoor activities outside in the warm weather, or that I will never try to do too much and wind up in bed for days afterward? Probably not. I'm sure, in a moment of weakness, it's inevitable that I'll slip and try to fight against the involuntary limits of my MS. Hopefully, as time passes, that will happen less often. I don't call this peace I have with MS **uneasy** for nothing.