

Feeling Behind as a Young Person With MS



“It’s definitely MS.”

These were the words that came out of my neurologist’s mouth as I sat across from him in the exam room.

It was November 2013: I was 20 years old and about halfway through my second year of college. Earlier that summer, I began experiencing strange symptoms, such as sensitivity to heat and getting tired earlier in the evening. But the most frightening symptom was that the entire left side of my body became so weak to the point that I could no longer run or write with my left hand. I was at college away from home at the time, and the neurologist I was seeing had scheduled me for an MRI to get a clearer picture of what was going on. Sure enough, the MRI showed multiple lesions on my brain and spinal cord, confirming a diagnosis of MS.

At the time, I had no idea what MS was. In fact, it wouldn’t be until years later that I really began to research the symptoms of MS and how it affects the daily life of those who suffer from it. When I was first diagnosed, I was still very young. My mind was focused at the time on finishing my degree, landing a job, and (hopefully) getting married one day.

Now, I was hit with this massive roadblock that I didn’t understand. All I knew was that I felt pretty bad most of the time. I had significantly lower energy than I once did, and found myself taking naps almost every day after my morning classes. Although I lived in a dorm

with a couple of other guys, I spent most of my time alone, isolated from others, with an illness I did not understand. After all, if I didn't understand it, how was I supposed to try and explain it to others? I was only 20 years old, still trying to figure out who I was. But now, I had been totally blindsided by this disease, which had come out of nowhere and had seemingly taken over my life.

Thankfully, I was also able to quickly get on treatment, which I continue using to this day. Overall, this treatment has not rendered me completely symptom-free, but it has kept my MS stable and reduced the number of flare-ups of my symptoms. But for the rest of the time I lived in Dallas for school, I kept silent about my MS. I suppose it was beneficial that I didn't look sick on the outside. I wasn't in a wheelchair, and my walking appeared normal for the most part. From the outside, no one could tell that I was sick. On the inside, however, I felt absolutely horrible most days.

I spent the majority of my 20s trying to ignore the fact that I have multiple sclerosis. I tried to live as "normal" a life as possible, at least on the same level as my peers. Yet, while I tried my best to live in denial of this disease, I was always reminded in some way that MS was a part of me, and that I really wasn't able to do everything I wanted to do physically. I have felt like I was on the sidelines, watching everyone else at this stage of their lives passing me by.

As a young person, I have felt like I was watching everyone around me get ready for the next steps of life — finding success in their careers, buying a home, or starting a family—while I have spent most of the time trying to best manage a chronic illness. I can think of the many hours I have spent in an MRI facility or returning every few months for follow-up neurologist appointments, while many of my peers have never had to worry about such things.

I am not trying to throw a pity party here. I am learning to balance my life as much as possible, to manage my symptoms and rest when necessary, and to take each day as it comes. I have learned to grieve the loss of the person I once was, and the abilities I used to have. Yet at the same time, I refuse to give up hope. I refuse to let this disease define me.