

MS During Isolation



It's December 31, 2019, and I'm sitting in a hospital bed. IV of steroids, and I cannot feel my hands and body from my breasts down. A team of neurologists surrounds my bed with their heads heavily hanging.

"We're sorry, Ms. John. You have multiple sclerosis." I sat there, feeling more numb than my body. I could not comprehend what was said to me. I am 28 years old; how do I have multiple sclerosis? I was just fine a few months prior. I could not fathom that this was my reality—one bad flare took away my sense of security.

Fast forward three months later; New York was in a pandemic. Newly diagnosed and feeling so lost in the world, uncertainty was my way of life. Then one day, everything hit me like a mack truck. All the emotions I was suppressing came out. I cried from all the pain, I screamed from all the rage, and I felt defeated. The only way to explain the emotions was grief. I was mourning my past life and all that I could never accomplish. How could life be so cruel? Why me, what did I do to deserve this permanent disease? My life halted right when it was beginning.

It was odd going through the most challenging moment in my life without my family and friends nearby. We spoke on the phone and video chatted regularly, but it was not the same. I felt like a sideshow attraction. COVID-19 was the glass separating us. My vulnerability on complete display, yet no one could reach me. I could see their sympathy and want to help; they did not know-how. We knew nothing about MS. It was awkward interacting with others. No one knew what to say. Everyone was dealing with their own emotions around my diagnosis. I understood it was difficult for others, but that made me feel more alone. I felt the

need to comfort others instead of receiving comfort.

The isolation felt even worse, isolation emotionally and physically. It forced me to deal with my diagnosis in real-time. Day in and day out, here I was, left with my emotions. I fell into a deep depression and questioned if life was worth living. What will life be like going forward? The unknown was the scariest part. I could not feel the majority of my body. Would I be able to walk again without assistance? Will I gain feeling back in the body? How do I raise my son? He was two years old, too young to understand any of this. I could not feel it when he touched me. I couldn't play with him and changing him was almost impossible. I feared he was cursed with a mother who could not be any use to him. He would grow up learning to take care of me; we'd live reversed roles. So many questions, and no one had the answer. It was hard for my partner Nick to watch. Helpless in such a difficult moment for the woman that he loves. I thank him for understanding and allowing me the time I needed to process what I was feeling.

Looking back, I do not know how I coped with the world coming to a standstill and MS. It would have been easy for my emotions to spiral out of control. I had no control over my life, circumstances and body. I found some solace knowing I was not alone in this aspect of life. Everyone was dealing with this pandemic and all the feelings that came from it. With all that was going on, I needed to allow myself to feel. I went from moments of being emotionally sound to then breaking down. It took months, but I finally got to a point where I stopped crying. I was able to understand that my life was not over. Though life would be challenging going forward, it would not be impossible. I remained steadfast that I would be okay. My life was only beginning, and I have so much more to accomplish. Some days I still mourn. But for every bad day, I have several good ones. It's about finding the silver lining within MS!