MS Community

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Connecting with the MS Community

When I was first diagnosed with multiple sclerosis, everyone would tell me about the one person they knew who had MS. I thought this was strange because, at the time, I too only knew one person with MS.

I always felt strange because this happenstance made me the second person that everyone I knew and everyone would immediately begin telling me what I should expect to experience or how I should behave. After all, they already knew one person with this disease! And yes, it got annoying really quickly.

Rejecting the MS Community

I am sure that it was at least partly due to all that meddling and comparing that I decided, early on, to isolate myself from the MS community. I really wanted to distance myself as much as possible. I didn't like the pressure and the anxiety that came with having this disease. I felt branded when people would suggest that I go to MS groups, as though I was shoved into a community that I didn't want to be in and now people expected me to walk in and introduce myself. I felt like there was some kind of schedule or script that I should have been following and joining a group was the next step in the process of having a disease.

I am not a group type of person, and the thing about being diagnosed with a chronic illness; it doesn't change who you are, not really. I woke up and I was the same person the day after I was diagnosed that I was all of the mornings preceding it.

I am an incredibly social person, but I am not a person who enjoys being in organized groups. Those types of situations always seem so manufactured and false to me that I struggle with acting genuine while I am participating. I always feel like I am supposed to be filling some sort of role and not acting as I am. The long and short of it is, I was never going to go to a group discussion about MS. Trust me, I totally understand the irony of all of this. I do write for an MS forum after all!

A Change of Heart

What changed my mind? That is a tricky thing to answer, but I believe it can be explained through time and experience. I spent several years turning my back on this disease. I had felt that I just needed to go through the motions of treatments and medications and forge on forward. I believed that the world would blend in on the edges, as it should, and that everything would be fine. And 'fine' it was. I was able to move on with my life. I was able to find my way through on my own and within my family. I am a strong person and I was doing fine.

Years passed and it was during a visit with Dr. Repovic, my neurologist at the Swedish Medical Center in Seattle, WA that I began to change my mind. My six-month check up was wonderful and quick which left the two of us with plenty of time for small talk during the appointment.

We were discussing my day-to-day activities and I had mentioned that I was thinking of going back to work, but I didn’t know where I would like to go. Dr. Repovic had immediately suggested that I work there, helping other people with MS. I was surprised and deeply moved. I had spent so many years turning away from the community that it had never really dawned on me that I might be able to help. I walked away from the job offer, but I took his words with me.

Within a couple of months, a childhood friend and a relative were both diagnosed with MS. I was so saddened that they were being forced to join this fateful club. I thought about them often and I struggled with knowing if I should approach them, and how. Eventually, I reached out and spoke to them. It was important to me that they did not feel as alone as I had felt when I was diagnosed.

Next page: a feeling that hits close to home.

It Hit Close to Home

I remember the first call to my friend very clearly. She had shared many of the same struggles, the same fears. She was young like me and she had so much ahead of her. It was while we were speaking that all of my memories of the empty forward abyss reappeared. I became deeply and fully aware of how intensely my isolation had held me back.

I had wanted so badly for someone to reach out and grab me, to tell me that I was going to be OK. I needed to know that I was going to not only survive, but thrive! I had been seeking solace from people who could not know how to serve it up.

My family loved me, but they could not tell me how losing feeling in your hands actually deepened feeling in your soul. They could not tell me that there are going to be days when your body will give out in the freakiest ways, but it will still be all right. My family didn’t know what it was like to walk without feeling your feet hit the floor. They could not meet me in my torment and say, “Yes, but you are still you!” My family was there for me but they did not know my experience.

Experience leads to understanding. Understanding is the key to connecting with people in this world. We need people in our lives who can empathize with our experiences. We are not solitary creatures. We need people, each and every one of us.

Multiple sclerosis is a disease that slowly shuts off our experiences within this world. Our sight can disappear, leaving us without the ability to see our children grow. Our sense of touch can be stripped away. I once lived six months without feeling in my hands. I was no longer able to feel my toddler son’s silky hair with my hands. I used my wrists instead.

We can lose our mobility too. Walking in this world can become threatened by the loss of balance and movement in our legs. This disease is one that loves to whittle away all of those little fibers that draw our experiences closer. It will isolate us if we do not fight it. The best way to fight that isolation is to connect with the people who can find you and brighten you within that darkness.

Conclusion

I still have never joined an in-person group for MS warriors. I have, however, embraced the people in my life who fight this disease. I have also left my door open to anyone new who wants to connect and talk about their experiences.

It is important to find a way to accept who you are in this body that you have been given. We are not capable of curing our bodies of the effects of MS, at least not yet. But we are capable of curing our minds of our isolation and pain. We are a large community of people who were forced into this club unwillingly. We did not choose to join this club, but we can choose how we live within it. We don’t have to do this alone.