Coping with a Lack of MS Understanding

by LIBBY SELINSKY

When the People in Your Life Just Don't Understand

Multiple Sclerosis is a deeply personal disease. Each person has a different understanding of it. Those who have been diagnosed carry their own baggage. People who know someone who has the disease tend to view MS through the prism of their loved one. Some people only have knowledge of the things that you have shown them about MS. And others have no interest in knowing anything about it at all.

For the most part though, people are kind. They will try to be friendly and understanding. But even with the best of these people you are going to run into moments when they just don’t get it.

The truth is, no one will fully understand what it is like to be in your shoes. Other people who have MS will be better able to identify with some of your struggles, but even they will fall short in some areas.

This week has been a struggle for me. One of my oldest friends falls into the category of people who only know what I have shown them. But I am beginning to feel that she is also one of those people who has no interest in knowing anything at all.

Here is what happened. She was surprised to find out that I exercise. “Oh! You exercise!?” she asked. I was mortified and confused. I struggle with my weight, and MS adds to this struggle, but I always exercise. I am not a six feet tall and skinny, like she is, but I do take care of myself.

Then, later in the conversation, I invited her to join in on the MS Walk again this year and she answered me with an obvious and laughable lie. She joined in for the event last year and I really appreciated it, but I never thought that she was obligated to come again this year. I am honestly overwhelmingly grateful that she came last year, but her lie prevented me from showing her my further appreciation for the efforts that she has already displayed.

The Importance of Talking it Out

Friends are going to let us down sometimes. People are going to say hurtful things. I would like to say that I pulled a Taylor Swift and shook it off, but I didn’t. Instead, I carried it with me for the week. I was hurt that she didn’t see me for who I was. I am now aware of a space between us that I did not previously know existed. I am sad about that.

I am also sad that I became demure and ended up explaining my whole exercise routine instead of just asking her why she presumed that I didn’t take care of myself. I have to admit, I believe this distance is likely to remain between us. I don’t feel safe talking to her about it right now. We don’t have that kind of relationship.

Fortunately, I do have that kind of relationship with my husband. I love him deeply, but even he struggles at times. I am not the only person in my home who has to shoulder this disease. I have to remember, even on my darkest days, that this is a weight that he carries with him every day also.

He does not face the same physical limitations that I do. He is still strong and walks fast; something that grumpily I remind him of when I cannot keep up, but MS is a huge part of his life. Our marriage would not work if I did not give him the benefit of the doubt when he falls short from time to time.

I know that it is worth my time to reach out to him with grace because when I speak he listens. Sometimes I have to say things more than once. Sometimes I will become aggravated and yell, but he listens. My words and needs have value in his eyes. I need him in my life. He is a positive force and he always keeps trying.

Next page: breaking bonds, and carefully deciding who gets close.

Breaking Bonds

I have said it before and I will say it again. Living with MS is an uncertain art. MS has taught me how to put down boundaries. Boundaries always seemed like such a taboo before. I did not know my personal value and I gave to everyone around me with exuberant indifference to my own needs. Disease or not, we can't live like that.

I had to take a long hard look in the mirror when I got sick. I saw a broken, lonely, angry person. I had so many people telling me what to do and who to be all of my life. Until finally, there I was, alone with this disease and no one I knew had any idea of what to tell me.

At first I was afraid. I had no experience in living a life of my own design. Eventually, I figured out how to self soothe and I began to feel free. MS was a dividing force that broke the bonds between me and the people who had been holding me back all of my life.

We all have to do a dance in this world to get through life with the most joy, love and happiness that we can muster. MS has trained me to try to live the life that I always should have been living. If people are going to be worth my time then I will invest my time in them. If people are not worth my time, then I will create distance. I have made my interpersonal relationships a central focus since I was diagnosed. I only wish that I would have started doing this earlier in my life.

Carefully Choosing Who Gets Close

What I am saying is, it is important that the people you need in life are the ones who are worth needing. If you have someone who is close to you that is making zero effort to understand you then that person will be a drain on your life. I had little time for people who dragged me down before. I have no time and no resources for them now.

It is not always necessary or possible to cut all ties with people who don't understand you. It is just incredibly productive to make sure that you take the steps necessary to structure your life in a way that reduces your necessity for that person to understand you.

Sometimes all you may need to do is realize that a person will be a good friend up to a point. That they may not have the capacity to connect with you on all levels. This knowledge can foster your motivation to find people who have the capacity to meet you there, on all levels.

Other times you may have to take more drastic steps to ensure that you are not vulnerable to a person who is insensitive and lacks understanding. You may have to walk away from this person completely. It is a judgement call and it should be looked at on a case-by-case basis.

I try to look at my relationships as an exercise in sifting through and searching. Through doing this, I have found that I connect with the most unlikely people. Actively seeking out quality people has caused me to look more deeply at people than I used to. I no longer choose my friends quickly or easily. I have taken the reigns in my hands and I am no longer a victim of the people that I have randomly been handed in life.

Once I began to choose who was close to me, their understanding became a natural step in our relationship. I

was able to long for understanding less and live more.