The Devil Inside: Living with MS

November 18, 2014 By Nicole Lemelle

Part 1: Shaking the Devil

“Out of suffering have emerged the strongest souls; the most massive characters are seared with scars.” ~ Khalil Gibran

It can be hard to stay positive when so many negative things are happening around you. My cursed search for a meaning to the madness that is multiple sclerosis (MS) consumes my life.

Living with MS is a rollercoaster. Some days are up and some days are down. Happiness is here and then it’s gone, leaving a cloud of smoke behind. And just when I think I’m getting some relief and can finally breathe clearly, it strikes again.

It’s like the devil has found a home inside my body. Nipping at my faith. Growling. Constantly showing his teeth. Scarring my spirit. Marking my soul.

The power MS has over me is so strong, I start to believe I’m chained to it and there’s no escape. It feels so bad; I would trade anything for a cure. That’s when I can’t see beyond the fog of the disease and I wonder if the pain will ever let me go. Like nothing good will ever come again.

I hate how it affects me. It is mind-numbing the paranormal way it constantly tingles in my fingers, manipulates my thoughts, and destroys my confidence. I’ve cried so much, I feel like I’m drowning.

I just don’t comprehend what’s happening. If I keep getting weaker, what am I going to do? My mind says, “You can handle it,” but my body refuses to follow its lead. The worst part is, I’m beginning to sense there is nothing I can do about the progression. I listen to my doctors, but sometimes I feel stupid for taking all these different types of medicine. The side effects are draining. It’s like I’m killing myself as I try to kill MS.

Part 2: An Isolated Nightmare

It’s the stuff of nightmares.

But thanks to time and loved ones, I’ve been able to craft a new normal. Be it with a limp, cane, wheelchair, or scooter, I’ve managed to face and live through it all.

Still, I never imagined it would get this bad.

In the midst of losing my physical abilities, I'm also afraid of losing myself. I'm scared MS will take away me. But my competitive nature refuses to let that happen. It's become my goal to continue being me, in spite of MS.

One of the most aggravating things about MS is the social isolation it begets. As if society has forgotten about me.

It's just so hard to fit in when I can't drive. I have major fatigue issues, and sometimes I get confused during basic conversations. My limitations cause me to feel cut off, especially when I'm surrounded by a group of able-bodied people.

It's particularly hard at parties and gatherings. Normal interactions turn awkward or involve just a smile or a wave, but fail to develop into standard encounters. I'll sit in the middle of a room and people will walk by me like I'm not even there. Since I just can't do "normal" things, it's as if I've just disappeared, gone missing without a trace.

I think the problem is related to a lack of understanding. When I tell people I have MS, they look at me like I'm a unicorn. It's so misunderstood, most people shy away from spending time with me. They're not sure how to treat me or what questions to ask.

To counteract the loneliness, I continually reach out to people who are on a similar path as me. When I do, I always seem to have a great time. I find myself talking for hours and usually making some new friends.

My family, friends, and other people with MS provide that much-needed support and companionship. I even use them when they are not present. When my feet go numb, I think of them. When my fingers don't work, I think of them. When I try to walk and fall face first to the floor, I think of them.

Nothing else compares to the love of my family and friends. That love allows me to freely accept help and accommodations, ultimately giving me a better life.

Scared initially, I've now accepted my diagnosis and discovered how to incorporate MS into my life. I've learned to soldier ahead. Well, at least I try to. And as I look towards my future, I know there will be dark days, but I also can see the sunrise.

Despite the trials and tribulations, I choose to focus on the positives and leave the rest to faith. I can continue to harp on all the negatives or I can choose to be happy. I'd rather live my life no matter what obstacles come my way, have fun, and hope the universe hears my prayers while I try to stay positive about my life with MS.

Original article appeared on Healthline.

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