

Owning my MS



My diagnosis won't stop me from being happy.

by **Debbie Moyes**

I remember the day I was diagnosed with multiple sclerosis. I'd just returned from a weeklong hospital stay, limping as best I could on my half-paralyzed right leg, only turning to the walker they'd given me when I couldn't take it anymore. Forget using my arm—that was one of the first things to go. My scalp was bleeding in spots where I'd scratched it to death. Turns out that numbness can actually be really itchy. Go figure. Vick's Vapor Rub does amazing things for itching, by the way. I just about killed the MRI tech with all the menthol fumes emanating from me.

I regretted telling anyone about the diagnosis. Hearing endless exclamations of "I'm so sorry" and "I don't know what to say" started out as sincere and thoughtful but quickly turned into just plain annoying. If one more person asked me if I needed anything, I swore I'd go hide in a closet somewhere for eternity. Not because I was some thankless brat; it was simply because attention was being called to the disease. Although it was wonderful that people cared, it was a reality I wasn't ready to face. I hated the attention over it. I was done with it.

Get over the fear

For a while, my concerns shifted from embarrassment to fear. There was no question in my mind that I'd be disabled forever. That the right side of my body, almost completely paralyzed, would stay that way or close to that way forever. My whole life, gone. Goodbye, snowboarding! See you later, hikes with my four kids!

Now, my melodrama was unfounded—I did indeed recover, and almost completely. I count

my lucky stars for that. But the apprehension over my new stigma didn't fade. I may as well have been wearing some sort of scarlet "M" while I walked through the grocery store. "They know," I'd think to myself when I met new people. "They can tell I'm tainted."

Ridiculous. I knew it as soon as I began to look around: An acquaintance at church uses a wheelchair. My friend's son has Down syndrome. I didn't perceive them as "tainted" or somehow less vital than me.

I started to question what made me less of a person than someone without MS. I go "out of service" every once in a while, sure, but I usually bounce back and return to living a normal, boring life. But what if I didn't? What if my leg-gone-dead stayed that way for good? Would I somehow be banned from normalcy because afternoons leave me exhausted on the couch for no reason at all? Or because the heat is my enemy? I'm still me; the basics of who I am haven't changed.

Attack the conversation

Even so, I still tried to avoid any conversation that mentioned my disease in the slightest. This is how a typical one used to go for me. Let's just say the person's name is Fred.

Fred: You have multiple sclerosis?! (Eyes widen immeasurably. Voice drips in sympathy. Face twists up with pity for my situation.)

Me: (cowering, feeling ashamed) Um ... well ... yeah ... but ... it's not that bad. I—I'm really normal.

Fred: How are your kids? (Sighs sadly.) It must be terrible, right?

Me: Not really. I mean, it can be hard sometimes, but I'm fine.

Fred's entire persona oozes consolation.

Then I change the subject and hope he never brings it up again.

Eventually I realize that I never should have acted ashamed. I haven't done anything wrong, and I sure as heck am not a bad or tainted person. My immune system acts up sometimes and causes problems, just like a diabetic's pancreas behaves badly and causes them problems. Same thing, different disease.

The moment MS becomes an embarrassment is when we let it. But we don't have to. All we need to do is be confident. Don't let people treat you like you're broken or fragile. Show them that you can be a tough, awesome person, even if you're using a cane, a wheelchair or a scooter, and don't fit their image of "normal." You're still you, and having lived with MS is a part of what makes you, you. Accept it. Own it.



They have it, too

Everyone has their own thing. It may not be MS, but it's probably something they have to deal with, just like I deal with MS. The guy down the street who's got irritable bowel syndrome and can't be away from a toilet for more than 30 minutes at a time, the lady at church who feels her chronic back pain daily, the recovering alcoholic. They've got their own health issues that may follow them for life, sometimes invisible to the naked eye. Am I lesser than they are? No.

My body is difficult at times, but dang it, I'm just like you. Like him and her and them. Like everyone on this earth who has things go wrong.

I'm not ashamed, and I won't let it stop me from being happy. I've got MS, and I own it.

Debbie Moyes is a writer and stay-at-home mom in Glendale, Arizona. She was diagnosed with MS in 2013.

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