8 Examples of What Not to Say to Someone with MS

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8 Things MS Patients Don't Want to Hear

People react in all sorts of ways when you have a chronic illness. Some avoid eye contact and don't talk to you out of embarrassment or awkwardness, while some make a point of including you and making you feel welcome.

Others will offer well-meaning advice in an effort to "fix" the problem. I always feel mean if I'm inwardly groaning at these gems of wisdom, as people are genuinely trying to help – but there are certain things an MSer does NOT need to hear!

"You're so brave."

This is not only infuriating but also extremely patronizing!

I go to a local drama club with my daughter on a Monday and I usually ride my scooter down there to give her some exercise. The other day one of the grandmas made a point of telling me how brave I am for going out on my own on the scooter.

I know she means well, but what else am I supposed to do? I'm not brave or inspirational for using a mobility scooter to get around. I can't walk very well so would be lost without it, and the alternative is to stay at home out of sight and let my daughter miss out.

Interestingly, it's members of the older generation who usually make comments like this and I wonder if that's because younger people are more tolerant or disability aware, or do they think the same but know not to say it?

"That scooter looks like fun!"

Someone said this to me the other day and I couldn't resist replying, "Oh it is, but I'd much rather be able to walk."

I immediately felt guilty for making her uncomfortable and laughed it off as a big joke, but inside I was screaming! I miss being able to walk every day and the effort of getting out and about is immense sometimes. Although the scooter has changed my life and given me back some independence, I would much rather be able to do what everyone else takes for granted.

"I get tired, too."

This one's a classic and highlights just how ignorant of fatigue most people are. People with MS get tired, but the crippling fatigue most of us feel is not tiredness. It can feel like even the smallest action, like holding a knife and fork to eat, is a monumental effort. Every movement is like wading through treacle and rest will not necessarily help.

I've woken up after a long sleep and had to drag myself out of bed, feeling like I've had no rest at all. And it can hit you at any time, descending like a fog to ruin your plans. We call it tiredness but only because that's the closest "normal" human condition to compare it to.

Next page: five more things not to say to an MSer.

"You don't look ill."

My friend said that to me the other night when I complained of feeling exhausted with fatigue. I may not look ill but sometimes I feel dreadful and this must be worse for MSers who don't have obvious, visible symptoms like balance or mobility issues.

If fatigue is your main symptom people are never going to understand how bad you feel and will often suggest you have MS "mildly" compared to other people.

"I've got a weak bladder, too."

This is a favorite of a family member of mine who complains of having a weaker bladder after having two children. I sympathize with this, as I've had two children, too, but the difference is she can hold it long enough to get to the bathroom! She doesn't have mobility issues making it harder to physically get there on time.

Lots of MSers have at least one horror story of not being able to make it in time or not being able to go when they get there. We have to phone restaurants or bars in advance to make sure the bathrooms are accessible or not up a huge flight of stairs, and long car journeys are fraught with anxiety and panic!

"Oh, I know how you feel."

No, you don't.

"Disabled parking badge? You're so lucky!"

Lots of able-bodied friends say this to me and it makes me cross! Now that I have my scooter, a disabled parking bay nearer to the building isn't as important, but the fact they are wider is essential as I can't squeeze between parked cars to get in and out without the extra room.

The other day I parked in a bay that was on a slope and had such a nightmare getting my scooter out as it kept sliding downhill into oncoming traffic while I struggled to get on!

"Have you tried...?"

People do this to me all the time. Someone suggested I try acupuncture the other day and although I have heard it can help with some symptoms, it's not going to cure me overnight!

Someone else handed me an article on stem cell treatments. I'm aware of how close they're getting, but this is not available to me at the moment so don't need endless articles about it! When I can access the treatment let me know.

Despite all the ill-advised comments I receive, I usually smile sweetly and agree with people – I know they mean well!