

Helping Others to Understand



“I’m exhausted.”

“Oh, me too! I know exactly how you feel! I went to bed really late and haven’t had my coffee yet!”

How many times have you been stumped in describing how you’re feeling, simply because you don’t know how to respond in a way in which a non-MSer can relate?

We sometimes use metaphors like spoons or fuel tanks, and while those are fantastic visual representations, I long for more realistic examples similar to ones that people have experienced themselves.

There have been attempts at this. There was the [ALS ice bucket challenge](#), in which people would dump buckets of ice water over their heads and challenge others to do the same. I can see how, when done correctly with ice water that had been sitting for some time and while in the right mindset, it could be a helpful campaign in allowing people to experience—if only for a split second—the feelings of literally being frozen, smothered, suffocated and immobile that people with ALS live with all day, every day.

There was the “[Bike with MS](#),” which was built to cause the rider to expend a lot more energy on a much more uncomfortable and difficult ride with parts that were altered or faulty. This was an incredible project, but I would have liked to see people actually attempt to ride the bike in a timed distance race against other cyclists with unaltered bikes.

There was also an “MS House” that was built with features that demonstrated common MS symptoms: chairs set really low to the ground, jumbled computer screens, floors made out of air mattresses, television set to half resolution, heavy coffee mugs on an unbalanced tray, ankle weights, books with the same page printed over and over again, etc. This particular project, I think, is the closest thing I’ve seen to mimicking MS symptoms while also allowing the public to interact and experience them.

To describe fatigue, I have used analogies like walking the length of a football field in three feet of snow while carrying a backpack full of weights after a sleepless night. Still, I’ve struggled to describe what one of my attacks feels like.

In the past, I’ve described them by saying it is similar pain to when you first try to put weight on your tingly, numb foot after it falls asleep... only it’s much worse. It feels like a 200-pound weight is sitting on my arm and leg, causing painful electric shocks down my entire left side for anywhere between 30-120 long, agonizing seconds. But recently, I found a solid physical dupe.

I’ve been in physical therapy for the last couple months to rebuild the atrophy that has resulted from a broken leg and surgery. To get the proper muscles to activate, my therapist suggested that we use a piece of equipment called E-Stim. It electrically stimulates your nerves and forces them to contract your muscles.

I agreed to try it. I’ve used a TENS unit before and have never had an issue. The E-Stim was connected to the injured leg, incidentally the same one that has the tingly shocks shoot through it when I have a flare-up. I couldn’t handle the E-Stim for more than a few seconds. The sensation was so similar to the very start of one of my MS attacks. It’s hard for me to say whether it really was **that** painful, or if my body was just triggered enough to start panicking and bracing for something much larger and more unpleasant.

But that is the closest thing I’ve ever experienced to the onset of an attack.

What are your worst symptoms and how do you describe to others what you’re feeling? What do you use to help them understand?