

The “Normal” Paradox



Have you ever been in a situation where you park in a disabled stall and then act worse than you feel when you get out of the car? I know I have. It stinks, too, because I feel like I need to “look the part” if I don’t want to be judged.

Some days are worse than others, as we all know, but having to park on the other side of the lot in 90 degree heat would make this whole day a lot worse. I probably wouldn’t even bother making the trip. So I act “disabled.”

In a world of bullying and image issues, we all worry about being judged. It’s something that we pretend to not care about – but we do. It’s not just friends or people at the grocery store, either. It might be your employer or your insurance company.

I was recently denied my wheelchair request for insurance coverage. This may have been a “check the box” scenario for them, but for me it wasn’t a simple decision. I had to concede that I was no longer able to do the simple things I thought defined me as a dad and husband without help. I had to admit it to the whole world – starting with my doctor.

Sure, I have a cane. Truth be told, I have a bunch of them. The problem with MS, though, is that nothing works forever. I can’t walk a straight line to save my life. If I go more than 20 feet without collapsing, it takes a half-hour just to get to the point where I don’t look and feel drugged.

But, I can “ambulate” with a cane. This makes me ineligible to be covered for a wheelchair.

Last summer I took my family on a vacation. At one point, my boys wanted to go shopping on “the strip,” which we’ve done every year for the past several. I started the walk with them and turned back almost instantly. I knew I wouldn’t make it to the first shop and I didn’t want to deprive them of their fun.

Sure, I tried to enjoy myself and be positive about the situation, staying back and sipping my coffee. But I wanted to enjoy the day with my family.

It’s getting to the point where I can’t function without a chair. The further I try to walk with a cane, the more dangerous it becomes. I don’t even bother anymore.

But I can “ambulate.”

So when I visit my doctor, I’m excited to show him how well I’m doing – how I’ve kept in pretty good shape. I’m independent and remaining optimistic despite my prognosis.

And I can “ambulate.”

After having the difficult mobility discussion with him, he sent me to physical therapy to discuss my options. I was honest about my immediate needs – I won’t use it in the house. Why? Because it won’t fit and I can lean on walls and take a seat whenever I want. The safety of the carpet and cushions has limited my injuries to a bloody arm and swollen wrist at this point.

And I can still “ambulate.”

Getting into my office or picking something up from Target is a different story, though. That apparently doesn’t matter. I need to **not** act “normal” if I want to be treated like I have a disease. But wait... I **don’t** want to be treated like I have a disease – unless the insurance company asks, I guess.

It’s hard to be optimistic when you’re always hiding from something. So, I continue to manage my situation and not worry about image – even if it means “playing the part” for those that only see a box to check.