

Please Stop Saying That



The rhetoric used concerning wheelchair users has to stop.

Over the past year after a long hiatus, I joined several online support groups for MS'ers. It didn't take long before I realized why I stopped. I feel that wheelchair users are often looked down upon and using a wheelchair is often considered the gold standard of failure amongst MS'ers. I've read so many posts where people anguish over the thought of "ending up in a wheelchair" or make the statement "at least I'm not in a wheelchair."

These concerns are misplaced. We all have different goals and aspirations in our lives, but when confronted with a disease like MS, those can change. What do we want beyond good health? Do we want to be able to keep working, helping out in our children's classrooms, going to sporting events and concerts? If that's the case, the use of an assistive device may very well factor in at some point and there's nothing wrong with that. Maintaining good mental health by staying active and engaged in life is part of maintaining good overall health. The disease can't defeat you if you're still living the life you want, but maybe doing it in a different way than you had initially planned.

In my experience, part of the problem in how we talk about using wheelchairs comes from some healthcare providers. They will sometimes use "ending up in a wheelchair" as one of the worst-case scenarios to persuade patients to start using medications or to follow a certain treatment plan. When using this approach, it reinforces the thought that wheelchair use is bad and something to be avoided at all costs. I understand it can sometimes be challenging for doctors to convince patients to follow their advice, but using wheelchairs as an example

isn't productive.

I think a better tactic for providers would be to discuss the patient's goals and the overall benefits of a particular treatment plan. Instead of assistive devices being the scary elephant in the room, their possible use down the road should be seen as a positive part of a treatment plan, just another tool to use in the arsenal.

Imagine a visit with your healthcare provider wherein you discuss the many falls you have taken. Instead of it being a solemn affair, you would be presented with different options that would help you to get out and engage more fully in life, whether it be a cane, a walker or a wheelchair. "Okay," your provider would say, "we've discussed this possibility and we're prepared for it. You've taken several falls while at work and it's embarrassing and you feel it's hindering your job performance. Let's have a physical therapist properly fit you with a cane so you can feel comfortable at work." Instead of feeling defeated and worried about losing your job, you've got reason for hope. It's not as distressing because this was always presented as a possible part of your treatment plan.

The goal for people living with MS is so much bigger than staying out of a wheelchair. The goal is to be happy, to stay vital and to be productive. Anything short of that and you are severely limiting your possibilities.

Of course, we would all prefer to be ambulatory, clicking around in our high heels and going for jogs on the beach. It's the way our bodies were made to optimally operate.

Needing an assistive device can be a sign that our disease is progressing despite our best efforts and that can be difficult to handle. Assistive devices need to be seen as just another tool we all use to combat the effects of this disease, right along with diet, exercise, medication, etc. Those of us who use them aren't quitters, and we should not be symbols of pity or contempt. Instead of looking down on us and treating us like people who are less than, see us as the determined people we are. If you can't do that, then get out of our way. We've got stuff to do.