

Ending Up in a Wheelchair



“Not all patients with MS end up in a wheelchair.” I first heard this phrase the day I was diagnosed. “I don’t want to end up in a wheelchair,” is something I soon started telling myself with alarming regularity. The terror of this thought was what got me to the gym, got me giving myself painful injections, got me scared into action. You’ve heard the refrain, you may have said it yourself. It’s no coincidence we all express our fear of decline using identical language: end up in a wheelchair. It’s an unhelpful, toxic mantra that reinforces what society wants us to believe about disability, that it’s a fate worse than death.

The troubling reality of MS is that a wheelchair is not the worst possible outcome. Sadly, advancing disease doesn’t always stop with the loss of mobility. That’s the bad news. The good news is, a wheelchair is not, in fact, the end. Many people live fulfilling lives with the assistance of a chair and other devices. Of course, the best news is that with today’s treatments, many will never require the use of mobility aids, but that’s a headline that already gets a lot of attention. For those who will need one, who happen to ‘end up’ here, the feeling can be one of failure, of being beyond hope, of being cheated of the promise that this wouldn’t happen. MS is full of hard truths. But continuing to push this softer narrative has consequences beyond hurt feelings.

Stigma and Acceptance

There’s a stigma associated with wheelchair use that we’ve collectively created. We just don’t hear panicked cries of “I don’t want to lose lower limb function,” because there’s more to our fear than loss of mobility. There’s a judgment and social isolation that can come with wheelchair use that makes it difficult for people to accept them. Many would rather risk falls

and injury or choose not to participate at all than be seen using a chair.

By repeating the idea of ending up in a wheelchair, we're unwittingly contributing to the very stigma we wish to avoid. We make the wheelchair the enemy, something to look at with disgust, instead of recognizing it as a tool, a solution to a problem. An idea that's reinforced by well-meaning friends and family whose response to these concerns is a dismissive, "There, there. Most people with MS don't end up in wheelchairs", or, "Don't worry. That's not going to happen to you," when we could be saying, "This isn't likely to happen. We hope it won't.

Here's what we can do if it does."

Reality Check

Like most, I'm active on social media. I participate in several MS forums. Many times I've found myself reading some version of the unfortunate phrase, "I just hope I never end up in a wheelchair." Sometimes from high-functioning, even athletic people. Of course we're all entitled to express our worries. A diagnosis of MS carries with it a scary and uncertain future. But when we imagine worst case scenarios well in advance of them actually happening, we're not living in the present. What's more, doing so in public spaces can be hurtful. When I see a social media status like this, I'm aware that someone reading it might already be living it.

In some ways, **I'm** already living it and the idea that my life has been declared unlivable is maddening. Each person affected by MS has a unique course. We would all do well to deal with challenges as they come, without putting ourselves in a future that may or may not exist, or a future that belongs to someone else.

Research

Historically, MS clinical trials have focused heavily on the early 'relapsing remitting' stage. With the success of several therapies for this subset, attention is now shifting towards more advancing disease, that which we've labelled 'progressive.' Despite this, wheelchair use disqualifies patients from participation in many, if not most, major clinical trials of new therapies. MS may advance well past wheelchair use, but research that excludes this demographic has determined that the use of a wheelchair is indeed the end.

Nobody wants to be affected by MS to this degree. It goes without saying. I'm not suggesting we shouldn't express our fears. But we shouldn't feed them either. So yes, as an occasional wheelchair user I'm afraid of losing independence, of having to navigate a world that's still largely inaccessible. I'm afraid of the judgment and stigma and of society's neglect and ignorance of disability. I'm afraid of all the ways in which my life may be impacted by aggressive MS. But I will not be afraid of a wheelchair any more than I'm afraid of my physiotherapist. They're both there to help me. I will not participate in the idea that the use of a wheelchair is somehow the end.