The bouncer



A bar, a band and a bathroom

by Jessie Ace

During my time living with multiple sclerosis, I've learned there can be so much judgment from the general public. I can't think of a time where I felt more judged since I was diagnosed with MS in 2013. Seriously, it happens all the time.

Don't get me wrong — I get it, OK? I look like a "normal" person. A "normal" 28-year-old woman with no apparent disability.

One particular judgment happened somewhere I never expected.

Was it a parking lot? Nope.

The supermarket? Nope.

Where, then? A bar.

Have you ever known anyone who was refused entry to a toilet in a bar? Me, neither! It was the strangest experience I've ever had.

I was in London with the UK MS Society covering a hip-hop event at a bar. It was a nice bar called The Jazz Club, and we were there to see a guy called Masta Ace, who has MS himself.

When we walked in, the vibe was calm, sophisticated. I felt hopeful it was going to be a good night.

Until nature calls

Until nature called.

Now, I'd been walking around London all day. In and out of tube stations and train stations trying to find the bar. My body was exhausted and heavy. My legs were weak, and I was tingling all over. I was struggling even to stand, leaning heavily on a nearby table for support.

When I learned the main toilets were downstairs, anxiety set in.

"There's no way I can get back up those stairs!" I said in a panic to a friend, who was standing next to me.

"I'll seriously collapse and make a fool of myself. What am I going to do?"

"There is a disabled toilet on the other side of the bar, Jess, just use that," my friend suggested.

Off I staggered to find the disabled loo.

All the while, I was thinking, "Thank goodness this is here. I've never felt so grateful for an accessible loo."

As I approached, a bouncer greeted me at the door of a toilet for people with disabilities. That was a first for me.

Standoff with a bouncer

As I walked closer, I had images of being in a Wild West stand-off. The bouncer, who had no intention of letting me use the loo, fired questions at me. He told me I didn't look disabled enough to use the accessible loo and directed me to the toilets downstairs.

I calmly explained why I couldn't and started to tell him about MS.

He made it clear he thought I was lying and that I just couldn't be bothered to walk downstairs.

Seriously? Why would I fake a disability to get out of walking down a staircase?

It became an even more tense debate when he simply ignored what I was saying, looking me up and down and shaking his head.

Finally, I'd had enough. "Look," I said loudly.

"What do you want from me? Do you want to see my disabled permit? My MRI scans? What?! Because I am now desperate for the loo, and you are denying someone with a disability usage of the disabled bathroom."

He cocked his head to the side, squinted his eyes, pursed his lips and took a deep breath.

Then, he made a statement that filled me with anger.

"OK, miss, I'll let you in this time, but next time I might not be so nice."

I shook my head, rolled my eyes and pushed past him to use the bathroom.

Shocking encounter

I got back to my table and explained what had happened to my friends, who were all rightly shocked.

How different could that situation have been? What would have happened if my MS were more severe and I didn't have control over my bladder? What would have happened if I had an invisible inflammatory bowel disease like Crohn's disease or colitis?

After my encounter at the bar, I honestly felt like a fraud. I'd never been treated this way by anybody, let alone a person with a heightened sense of self who was the bouncer of a toilet.

It's times like this that I feel so grateful to have interviewed so many people on my podcast — the "DISabeld to ENabled" podcast — with different invisible illnesses, so I have more understanding of other people's difficulties. It has been my mission ever since to educate the general public on invisible illnesses.

It is so important to raise awareness of chronic invisible conditions to the general public, especially when, for some people, a common recognizable sign of disability is still a wheelchair.

Have you had any experiences like this? Contact me in the <u>ENabled Warriors Facebook group</u> and let me know. It makes me wonder what other strange judgments people living with MS experience.

Jessie Ace is the host of the "DISabled to ENabled" podcast and lives in Swadlincote, Derbyshire, in the middle of England, with her husband and her fur baby, Lucy.