

MS Transparency: How Open Should I Be?



Do I walk over and explain to the dude in the garage—the one who’s been giving me the stink eye ever since I pulled into a disabled parking spot—that, while I appear to be healthy, I actually have MS?

Do I tell my students what’s going on when I’m pressing my icy drink against my neck to cool me off while I’m teaching inside an overheated classroom, fretting about whether my MS heat sensitivity will flare up?

I face these situations quite frequently, wondering whether I should explain my MS to people so they will understand my actions and reactions, or if I should just keep quiet.

Four years into my MS odyssey, I haven’t yet found the sweet spot. I’m torn between the concept of total openness about my situation, and just wanting to live my life as best I can without making excuses or explanations for things I cannot control. It’s not as though I’ve hidden my MS from the world. I’ve had pieces published—and shared them on social media—discussing my experiences with the disease. But writing about it is not the same as telling someone in a moment when I’m experiencing something related to my disease, that *this* is what MS looks like for me today.

Do I need to tell the clerk at the grocery store that I’m not intentionally dropping item after item onto the conveyor belt as some sort of indication that I’m impatient with her work; I’m simply having a clumsy MS hands day. Or is that too much to share with someone who’s bagging your onions, orange juice and window cleaner?

I admit that my perspective on this subject may be skewed because I spend a lot of time

thinking about MS when it interferes with my daily life. People who know I have MS tell me the disease doesn't automatically come to their minds when we're interacting because I don't look sick most of the time. However, I worry that when I cancel plans at the last minute because of fatigue, they won't understand it's MS-related (and not laziness) unless I explicitly tell them. I don't want them to misinterpret the cancelation and think I just don't want to see them.

One of my close friends thinks I should be more open about MS, particularly with my college students. She suggests it would be a great life lesson for them to realize that, as I energetically discuss the day's news with them, I'm also living with a chronic illness that sometimes affects how I move about in the world. There was one recent day when I almost took her advice. The classroom was getting really warm and uncomfortable. I removed as much clothing as is socially acceptable and sucked down my cool drink (I always bring one to class.) Nevertheless, I started feeling lightheaded, weak, nauseous and as if the speed at which I was processing things mentally was slowing down. I considered explaining why I felt this way.

But I chickened out.

The students probably would have been fine with the disclosure and would have welcomed a short break. But as I played the scenario out in my head, I envisioned this MS revelation as potentially having a negative effect on teaching evaluations, as emboldening some to challenge grades based on my illness or to question whether MS was the reason it was taking me so long to review their work. In reality, I put in a lot of effort for my students and try to overcompensate for any obstacles MS puts in my way. So, would anything bad really have happened had I told them about the MS? Likely not. But you never know.

The closest thing I've done to being transparent about my as-of-now invisible disease is to print out two pieces of paper and slide them in the front windshield of my car whenever I use my disabled parking placard. One features a colorful orange "Multiple Sclerosis Awareness" logo, the other features the black and orange logo for the National Multiple Sclerosis Society, underneath which I've written, "I have MS." These thin pieces of paper represent the sum total of my attempts to dissuade any would-be nasty-note-writers from tucking a menacing missive beneath my windshield wipers.

I'm not sure there is one correct answer. I'm also not sure I should be worrying so much about what people are thinking when I experience an MS symptom or take measures to avoid triggering one (by taking an elevator up a single floor or utilizing disabled parking). However, I am sure of one thing: I am fortunate to have this choice because not everyone with MS does. Deciding what to do and how to react is a privilege.