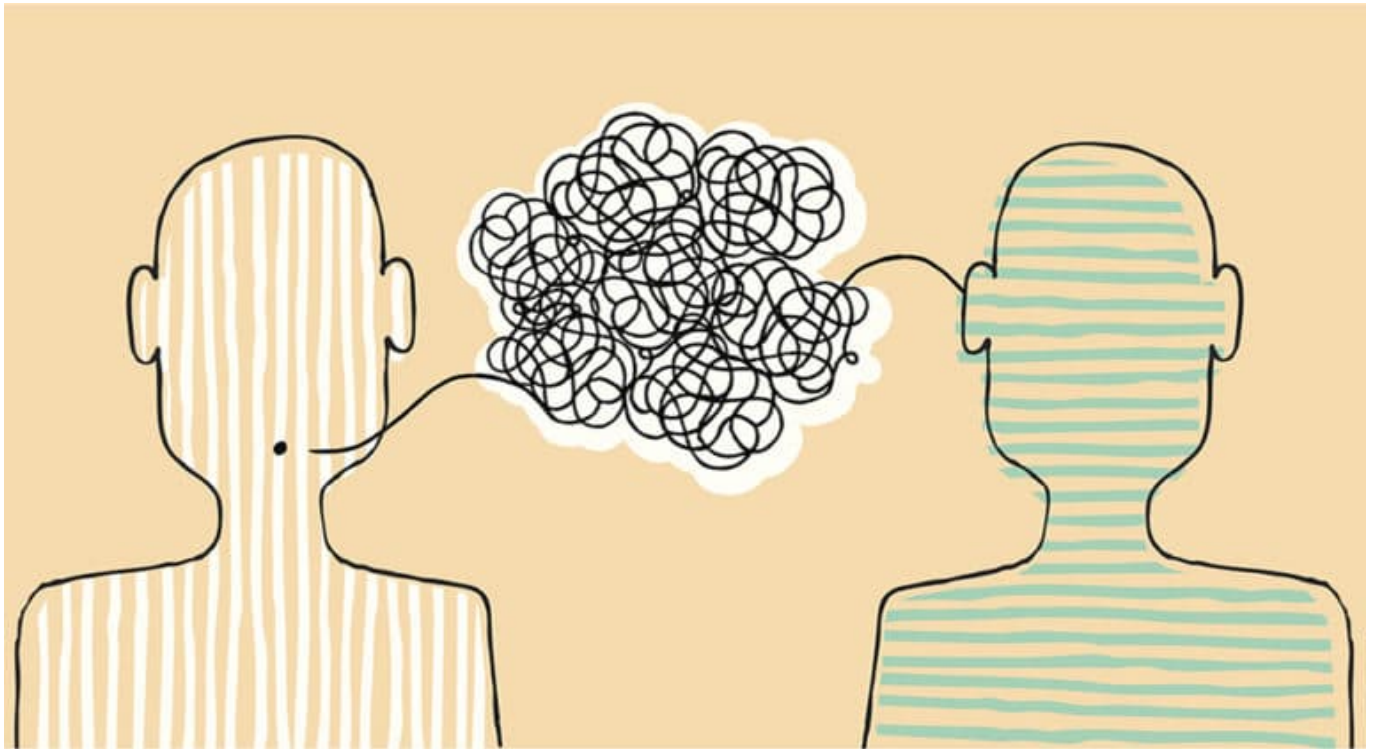


Tongue-Tied: 4 Things to Say



People can be awkward. When we're about to talk with a grieving person, someone who's lost a job, or is getting a divorce, we worry we'll say something stupid.

And when speaking with someone with a chronic, incurable illness like MS, it makes sense that people would be uncertain about what to say about it. Since people don't generally have a firm grasp of the disease, the comments we receive can vary from supportive and kind, to clueless and irritating.

After having dealt with awkward surrounding my relapsing-remitting MS, I can offer some advice if they're feeling tongue-tied.

Don't try to fix it. Just listen.

This could be called "the Scott rule," as my husband Scott struggles with this. He hears about what's happening inside my body, and he wants to fix it. He's a fixer, a person of action, and it comes from a good place.

But there are times when I'm just unloading my frustrations about a symptom and want to gripe about it. It isn't some passive way of getting him to figure out how to address the symptom.

I am just complaining, the way we all complain about things in our daily lives. Sometimes all a person wants is to know you've heard what was said.

There are times when I'm suffering from extreme fatigue, migraines, or muscle spasms and you wouldn't necessarily be able to tell (compared to when I'm experiencing heat sensitivity — which causes me to violently retch and/or vomit — it's clear that something's wrong).

You only need to say something validating and understanding, some version of: "That must stink," "I'm sorry you have to deal with that," or "How are you coping with that?"

Don't compare symptoms.

If I have honestly fielded questions about how I'm doing, people without chronic conditions, in a valiant attempt to relate, tell me they too have had whatever I'm describing.

My late-mother-in-law was a perfect example. When I'd admit to being fatigued — I never really described how bone-deep the fatigue was — she'd tell me she was tired too and that maybe I should just get more sleep. If I couldn't attend a family barbecue because it was a hot and humid mid-July afternoon and my MS symptoms would make me physically ill, she'd say, "The heat bothers me, too."

I know she meant well. I know she wanted me to feel as though I wasn't alone, but the quips made me feel as though my concerns were nullified. People who live with autoimmune diseases aren't trying to compete with people over who has it "worse" (FYI: Fatigue, to someone with an autoimmune disease, is not the same kind of fatigue otherwise healthy people experience.)

Ask before jumping into action.

A corollary to the aforementioned piece of advice: If an MS patient has just explained something that's happening to them and says something like, "Hey, I'm struggling with fatigue and need to lie down," that is not a greenlight to start ordering the person what they should do next; it's informing you about what's occurring.

Take action when the person with the symptoms asks for help: "Hey, I'm struggling with fatigue and need to lie down. Would you be able to make dinner?"

If you have the urge to do something to help, ASK the person if they want your help. And respect the answer, even when you think the person is being stubborn. I can be very stubborn, but when I need the help, I'll begrudgingly ask for it.

Nobody knows what's going to happen.

MS is an unpredictable, incurable disease. No one knows if or when relapsing-remitting MS will morph into a more progressive form. If you have a progressive form of MS, your rate of the decline doesn't necessarily travel in a straight line.

When you're caring about and for someone with MS, take each day as it comes. When/if new

symptoms appear, when/if the person with MS seems to need more assistance, that person will ask for it. If you think the person might, for example, benefit from a mobility device, you could suggest it, but don't force the issue.

For example, when I was having difficulties with maintaining energy and simultaneously coping with heat sensitivity when I was out of the house, it took me a long time before I felt comfortable applying for a disabled parking placard. Friends and family suggested it several times, but never pushed. I eventually got the placard when I thought it would enable me to do the things I needed to do.

If and when you goof up and say or do something that irritates your loved one with MS, not to worry. I know I've likely said and done many wrong things while communicating with people with other health issues.

Expressions of earnest concern will, at the very least, make the MS patient feel as though there's a community of people who care about them. That's worth its weight in gold.