

You want to know what?



People with MS get a lot of questions. Here's how you can answer — or not.

by Shara Rutberg

People living with multiple sclerosis face all kinds of questions — some serious, others out of left field.

“Whether to answer is entirely up to the person with MS,” says Anne-Elizabeth Straub, a Brooklyn-based social worker who was diagnosed with relapsing-remitting MS in 1983. “No one else has the right to your information,” says Straub, who often works with people living with MS in her practice and has run self-help groups for the National Multiple Sclerosis Society.

How you handle questions can depend on your relationship with the person asking the question — if you have one at all. Straub says: “Believe me, plenty of people on the street will ask you weird stuff. People have asked, ‘What’s wrong with you,’ I say, ‘Nothing.’ They’ve told me: ‘You’re too young to be in a wheelchair,’ and I say, ‘They didn’t tell me there was an age limit.’”

Humor helps, she says. Other times, “ignoring people is a fine response.”

Straub adds that talking with people who ask serious questions could help strengthen your relationship with them.

The nature of the questioner’s relationship to you matters, says Evan L. Smith, PhD, assistant

professor in the Department of Physical Medicine and Rehabilitation at the University of Michigan. Smith, a rehabilitation psychologist, is the attending psychologist for the university's MS Center, operating as part of the Department of Neurology. The MS Center provides care for more than 4,000 people living with MS.

He suggests thinking of it this way: You are the president, the CEO. Only certain people have access to you. Strangers are very much on a need-to-know basis. They don't have clearance-level access. "You never have to answer a question if you don't want to," he says. Consider "who is this person?" and "what level of clearance do they have?" You can always respond without actually answering the question, he says.

For example, "If I were to stumble and someone asks, 'Are you drunk?' I can say: 'I'm doing OK, I'm safe. I don't need any help right now.'" Or you can deflect. "If you're asked, 'Are you drunk?' you respond, 'Boy, I wish I were.'" It depends on your level of familiarity with someone."

Handy responses

It can help to keep a few responses in your back pocket for when you choose not to answer, Smith says. "It can be as simple as, 'I'm just not feeling up to talking about that right now,'" he says. "The temporal component 'right now' is important because everyone can relate to that. Or you could set a strong boundary with that person, 'I don't feel comfortable talking to you about this.' Then move on."

Smith suggests three steps for handling a nosy question or answering someone who offers to help you with something to help them understand your lived experience.

First, acknowledge their concern or attempt to be helpful. He explains that other people will feel more comfortable changing what they're doing if their attempt is acknowledged.

Two, explain what they're observing.

Three, direct that person in a way that will be helpful to you.

How much you explain, of course, is your choice. "What's MS?" is one of the most common questions. How you answer may depend upon your relationship to the questioner. It can also depend on whether you choose to expend the emotional energy to explain.

When it comes to educating others, it's helpful to ask permission first, Smith suggests. For example, say: "I live with MS. I could tell you more, but do you want to know more?" The other person may not be ready or interested in learning more. If they are, it can be empowering for the person living with MS to educate them. "It helps people experience autonomy and independence, flex their muscles of setting boundaries and be an advocate," Smith says.

Analogies help

When it comes to explaining the disease, analogies can help. Meredith O'Brien, a Boston-area journalism instructor and the author of "Uncomfortably Numb," a memoir about her MS experience, likes one she heard from a neurologist. "Envision a computer mouse with a cord stripped of its protective plastic lining. Now, spill some water on the cord. The cord is still attached, but the messages between the mouse and the computer may not be read correctly. The cord may be quirky and work sometimes but not others. It'll certainly work better when it dries off. The water represents a flare-up."

Another person explains it as "squirrels in the attic chewing on your wiring, depending on what wires they're chewing on and how much they chew, you could have all types of issues."

Other questions people living with MS face include: "Is there a cure?" "When will you get better?" and "Will you die from this?"

"I often tell people that MS is a brain and spinal cord disease with symptoms reflecting which nerves the disease has damaged," O'Brien says. "No two patients are the same. There is medicine I take to try to prevent any more damage."

People living with MS may also find themselves explaining why they often change or cancel plans because of their symptoms. The unpredictability of symptoms can be confusing for people not living with MS to understand, Smith says. Your goal here is to help them understand that canceling is not about them. It's about the unpredictability of the disease, he says. You might say: "I wish I were feeling better, too. It's unpredictable, and today, I'm not feeling well. I couldn't engage in the way I want to."

Mobility devices can also elicit questions and comments. Smith's patients have had people tell them: "I feel so bad for you; you have to use that wheelchair." He suggests reframing the conversation from its able-ist beginning. You might say: "My wheelchair is my freedom. It empowers me to go where I want when I want."

Straub's wheelchair has sparked questions from one group of people she never minds answering: children. "I'm pleased when a kid hasn't been raised with such able-ism that they're afraid to approach you. If they have a question, they're curious, not nosy," she says. She tells them: "I have trouble walking far, and this gets me where I need to go. For kids, they often look at me with envy and think it's cool."

Smile and nod

Sometimes, smiling and nodding at people's comments is the easiest option. "Some people have the misguided belief that one gets 'over' MS like a bad cold," O'Brien says. "Or there are people who perceive MS as a death sentence and think you're on death's door from diagnosis onward. People do not have a firm grasp of the disease because it presents so differently in each person, but that doesn't stop people from advising giving up certain foods or starting to eat certain foods or do this kind of workout." When someone recommends yet another diet to her? "I just nod and thank them for their information," she says.

Straub notes that the more accepting and comfortable you are with your disability, the easier it is to deal with what comes from outside. And handling odd and invasive questions can get easier with practice, she says. She suggests role-playing with a friend, family member or in a self-help group. "I'll take 'Inappropriate Questions for \$200,'" she says with a laugh.

What to say — and what not to say

DON'T SAY

MS person/patient/client

Person suffering from/afflicted with MS

When they were stricken with MS

Wheelchair-bound/confined to a wheelchair

Sufferer, afflicted, victim, invalid, crippled, stricken

Handicapped/disabled parking

Normal person/healthy person

DO SAY

Person with MS/who has MS

Person living with/affected by MS

When they were diagnosed with MS

Uses a wheelchair

Person with a disability

Accessible parking

Person without disability/able-bodied person

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