

Embarrassing MS symptoms



There are positive ways to cope.

by Olivia Cole

When Lisa Kemppainen, a psychotherapist in Colorado Springs, Colorado, meets with new clients, she tells them she has multiple sclerosis. That way, if they see her struggling to climb stairs or veering down a hallway like she's drunk, they'll understand why. And she lets them know she might have to abruptly interrupt them during a session and make a quick trip to the bathroom.

But despite these precautions, Kemppainen has defecated in her pants during sessions with clients. "Lots of times I have no warning it's coming, and then it really comes out," she says. "And when I try to change my clothes in the restroom, I'm unstable so I get poop on my hands, on the floor, on my clothes. It couldn't be more embarrassing."

But Kemppainen, who was diagnosed with MS in 1998, refuses to succumb to shame. "When something embarrassing happens, I have compassion for myself. And I tell myself it's not my fault," she says. "I'm completely the victim of my MS. People don't like to use the word 'victim,' but in this case it's true."



Ann Marie Johnson, traveling in India on a birthday trip last year, acknowledges she has bladder issues, and tingling that makes her scratch her skin. She has found ways to manage both problems. Photo courtesy of Ann Marie Johnson

She's seconded by Ann Marie Johnson, a human services professional in Brooklyn, New York, who was diagnosed with MS in 2002. Along with depression, bladder issues and problems with fine motor skills, Johnson has tingling in her upper body that makes her feel like things are crawling on her skin.

"I have long nails that look nice, but aren't so great when I'm scratching intensely. I have scratch marks on my neck and chest that look like I was attacked by a wild animal," she says. "It's so involuntary that I don't notice the type of harm I'm doing to myself."

Johnson was embarrassed about how she looked until she realized that wasn't productive. "I told myself those crawling sensations weren't going away, so I needed to learn how to handle the scratching. I can't control my MS, but I can control how I handle my symptoms."

Unlike more hidden symptoms like fatigue or heat intolerance, "bowel and bladder issues, cognitive changes, and problems with balance and walking can draw attention to you when you don't necessarily want it," says Peggy Crawford, PhD, a clinical psychologist in Cleveland. "They can take away the 'invisibility' of MS." These symptoms also create a Catch-22. "They can be so embarrassing that people don't even bring them up to their physician or nurse practitioner, who may actually be able to help them improve those symptoms," she says.

Here's how healthcare professionals and people living with MS suggest you not only cope with embarrassing symptoms, but also reframe them so they become less mentally and emotionally distressing.

Identifying the source

Basically, says Dr. Crawford, embarrassment is a form of anxiety. You may be anxious that people who don't know that you have MS will jump to the wrong conclusions or judge you. "For instance, people who have problems walking may be accused of using alcohol or drugs," she says. And then there's the anxiety that people who know you have MS may give you unwanted advice after they see a symptom that makes you—or them—uncomfortable.

Ironically, being anxious about something can actually increase the likelihood that it will happen, says Deborah Miller, PhD, associate professor of medicine at the Cleveland Clinic's Mellen Center for Multiple Sclerosis. That's why she recommends a three-step process to help alleviate that anxiety and embarrassment: Identify the issue, share it with others and work on problem-solving strategies.

Identifying the issue includes not only acknowledging your symptoms, but also examining how you react to them.

"Ask yourself, 'What's the worst thing that could happen if X, Y or Z symptom occurs? Has that ever happened? Do you know anyone that's happened to? What are the likely consequences if it does happen—someone makes fun of you at a party? Calls the boss?'" Dr. Miller says. "By thinking of the worst-case scenario and what you would do, you can make a plan that will help alleviate your anxiety. You might even start laughing at what you're imagining. After all, nobody has ever died of embarrassment."



Glenn Domilici, with his wife, Rhondell, in the Cayman Islands, is less embarrassed than he used to be by some of his MS symptoms, such as memory problems, because he knows he cannot control them. Photo courtesy of Glenn Domilici

Kemppainen says if she feels embarrassed to use a mobility aid like a cane or a scooter, she

creates a positive scenario in her mind. “Rather than thinking of strangers judging me, I visualize getting out of my car and walking to my office, and how my friends are walking by and looking at me with a lot of compassion, and celebrating how brave I am.”

Glenn Domilici, a New York City resident who was diagnosed with MS in 2005, has memory issues that sometimes make him lose his train of thought and appear as though he’s not paying attention to the person he’s talking to. But he’s learned to think of this and other symptoms as more frustrating than embarrassing.

“If I’m underdressed at a formal affair and I’m embarrassed, that’s my fault,” he says. “But with MS I have no control over whether my right hand works well, or if I stutter sometimes while I’m talking or if I have to go to the bathroom more often. These things are unavoidable, so it serves no purpose for me to be embarrassed.”

Acknowledging the issues

The next step is deciding when to discuss your symptoms with others, and how much you want to reveal. “It really depends on whether and how it’s intruding in your life—like if you dread going to work because you’re afraid people are noticing your bladder issues,” Dr. Crawford says. “And if other people are changing their behavior toward you, or if a symptom creates a safety issue—like cognitive difficulties that affect your driving ability—then maybe you should disclose.”

Kemppainen says there can be unexpected benefits from revealing your embarrassing symptoms. “I’ve found that people are really empathetic, and it builds trust with them.”

But that doesn’t mean you need to invade your own privacy, especially with someone who doesn’t know you have MS. “When people are embarrassed, they feel like they need to give a full-blown explanation, but they don’t really,” Dr. Miller says. “Don’t lie, but don’t feel like you need to go into detail. You can address the symptom, not the diagnosis.”

For instance, Drs. Crawford and Miller suggest using phrases like “I’ve lost my train of thought,” or “I have a weak bladder” or “I have a strained knee” or “My stomach hasn’t been right all day long.”

Or you can use humor, like, “Isn’t that amazing, someone my age wetting their pants,” Dr. Miller says. “Humor can reduce the other person’s anxiety of not knowing what to say.”

Overcoming the embarrassment

“It’s too simplistic to say ‘don’t be embarrassed’ when something embarrassing happens,” Dr. Crawford says. “But if you practice coping strategies, you can feel more in control of the situation. And you’ll feel less embarrassed if you know several options are available to you.”

She also advises to not let embarrassment prevent you from talking with your healthcare providers, who often can help manage your symptoms.

For instance, a physical therapist can help with gait or balance issues. Behavioral therapists can give you tools to deal with cognitive issues, like always putting your keys in the same place or developing a shorthand with your spouse when you need help finding a word you've forgotten. Bowel problems, including constipation, can often be treated medically.

Johnson says for bladder issues, she's learned to drink a glass of water or a cup of coffee relatively quickly, rather than taking occasional sips. That way, she stays hydrated but finds she has to visit the restroom less frequently. "Figure out how soon after you drink something that you have to go," she says. "And then make sure you're near a bathroom during that time period."

For her scratching issues, Johnson has discovered that cutting her nails and carrying lotion that she can rub on the itchy spot can help. And, although it can be challenging to treat these kinds of sensory symptoms, it's a good idea to discuss them with your neurologist. Johnson also shared her problem with her boyfriend, who has learned to take her hand when she tries to scratch, and rub the area himself.

"I had to let go of my ego and ask for help," Johnson says. "I've realized there are so many people who want to be on my journey with me, so I shouldn't be afraid to be vulnerable with them."

Johnson admits this wasn't easy in the beginning. Setting boundaries and maintaining dignity while asking for help with intimate issues can be challenging. "But if you don't tell people in advance what you truly need and instead leave it up to them to choose how to assist you, they may do it in a way you don't want," Dr. Crawford says. For instance, if you need assistance with going to the bathroom, but you don't actually need someone to stay in the stall with you, tell the person that.

Kemppainen has found that her close friends and family like being told how or when they can help. "There's so much guessing with MS that a lot of times people don't know what to do," she says. "I say something like, 'This is one of those moments that I dread. And I'm so sad that I need to ask you this, but can you help me?' And then I tell them what I need. If the person doesn't respond with compassion, you probably should get them out of your life."

The bottom line is that while experiencing a bladder, bowel, balance, gait or cognitive issue in public may never be easy, it doesn't have to be shameful either.

"One of the gifts of MS is that it has taught me that sometimes I just have to get over myself," Kemppainen says. "Nobody really cares if I'm peeing or pooping my pants. What they really care about is me."

Olivia Cole is a writer in Denver.

Learn about possible management strategies and treatments for the symptoms that you find

embarrassing. [nationalMSSociety.org/symptoms](https://www.nationalMSSociety.org/symptoms).

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