

Invisible symptoms in MS



How to help others ‘see’ your symptoms—and how they affect you.

by Vicky Uhland

World MS Day

This [World MS Day](https://www.worldmsday.org), May 30, raise awareness of the invisible symptoms of MS and the unseen impact of MS on quality of life. To learn more or download campaign materials, visit [worldMSday.org](https://www.worldmsday.org). Common invisible symptoms of MS include: [depression](#), [fatigue](#), [pain](#), [bladder issues](#), [mood swings](#), [mobility challenges](#) and [taste](#). Visit the [MSconnection.org blog](https://www.msconnection.org/blog) to learn more about the experiences of others living with MS.

Ann Borsellino was working as a high school teacher in Mamaroneck, New York, in 1997 when she was diagnosed with multiple sclerosis. Her initial symptoms included constant numbness or tingling throughout the right side of her body, cognitive issues and depression. For Borsellino, these symptoms felt debilitating. But many of her family, friends and acquaintances barely noticed.

“People couldn’t see what my body was dealing with,” Borsellino says. “Many times early on in my disease, I wished I had something people could see because then they would know what I was going through.”

Like Borsellino, many people with MS have symptoms that aren’t readily apparent to others.

These “invisible” symptoms can include fatigue, pain, cognitive challenges, mood changes, numbness or tingling, heat sensitivity, vision changes, balance and coordination problems, and bladder and bowel control issues.

And like Borsellino, many people living with MS struggle with how to explain these symptoms to people who know they have MS but may not understand how the disease manifests.

Invisible symptoms can play havoc with your relationships, says clinical psychologist Peggy Crawford, PhD. “Because you don’t fit their definition of ‘sick,’ others are apt to over- or underestimate your symptoms.” And that can result in misunderstandings, resentment and a feeling that you’re not getting enough support.

That’s why Dr. Crawford and other MS experts stress the importance of communicating your symptoms in ways that others can understand. This is often not an easy task, but a variety of resources are available to help you.

Consult your healthcare team

Borsellino didn’t realize how important it was to discuss her symptoms until her friends talked her into seeing a psychologist shortly after she was diagnosed. “I kept saying, ‘I’m not crazy, I don’t need a psychologist.’ But now I realize it’s the most important thing I’ve done regarding my disease.” That’s because Borsellino’s psychologist gave her a key tool for dealing with her MS.

“She told me the more up-front you are with other people about your MS, the more up-front you are with yourself. And that helps you accept the hand you’re dealt,” Borsellino says. She admits that before she saw the psychologist, she was worried that people might see her as weak if she talked about her symptoms. “But my psychologist said it’s not a sign of weakness; it’s a sign of strength,” Borsellino says. “Any time I can face this disease and say I’m not ashamed of it, it makes me feel in control. When I’m honest with people about my symptoms, it feels like a load off my back.”

That said, there is no one-size-fits-all strategy when it comes to talking about your symptoms—particularly the invisible ones. For instance, Maria Reyes-Velarde, a Long Island, New York, resident who was diagnosed with MS in 2001, says she only tells people—including close family members—about a symptom “if it interferes with something I need to do.”

Reyes-Velarde’s invisible symptoms include fatigue, pins-and-needles sensations in her legs and face, vision problems and cognitive issues such as forgetfulness and distractibility. She’s found that the most effective way to discuss her symptoms is to reveal them incrementally and in ways the person she’s addressing can relate to. For instance, her husband can get frustrated when she has trouble doing something that once was easy for her. “So I start by mentioning little things to him, like ‘I can’t do as much gardening this year as I did last year,’ rather than just all of a sudden not gardening.”



Illustration by Michael Morgenstern

Deborah Miller, PhD, a social worker at the Cleveland Clinic Mellen Center for Multiple Sclerosis, says therapists can help you sort out which communication style works best for you. “Support groups can provide a vital function, but they’re no substitute for working with a good mental health professional when it comes to dealing with this issue.”

Other professionals can also be of assistance. Borsellino found that many people confuse MS with muscular dystrophy, so she asked her neurologist for a simple explanation of MS that she could tell anyone. Dr. Miller suggests using printed materials from the National MS Society. “Having something published by a national organization, with explicit details about the disease, gives legitimacy to your symptoms [in many people’s minds]. And it opens the door to conversation.” It also helps educate people who may not understand why you’re using a handicapped space, or who make comments like, “You don’t look like you’re sick.”

After you’ve disclosed your symptoms to someone, Dr. Miller says it’s useful to tell the person the symptoms are intermittent, so he or she won’t worry you’ll constantly be affected. “And it’s really important to let people know you’re doing everything you can to manage your symptoms and are under a doctor’s care,” she says. This helps head off well-meaning but invasive or upsetting health advice from friends, family or acquaintances. And it also shows you’re not making excuses, giving up or being lazy.

Dr. Crawford tells the story of a patient whose husband thought she was using her MS-related fatigue as an excuse to get out of tasks she didn’t want to do. “So she invited her husband and her children to a session with me. They saw that I was her advocate and that I believed her,” Dr. Crawford says. “It was a real turning point for them to hear from a professional what she was going through.”

Counteracting the judgments

Along with professional help, there are several other approaches you can take to help your friends, family and acquaintances understand how your invisible symptoms affect you.

First of all, Drs. Crawford and Miller advise never using your MS as an excuse to get out of something you just simply don't want to do. Like the boy who cried wolf, if people discover your prevarication, they'll be less apt to believe you the next time you really can't do something because of a symptom flare-up.

It's also important to use examples when discussing your symptoms. "For instance, when people with MS tell someone they're fatigued, they often get responses like, 'Oh, I get tired, too,'" Dr. Crawford says. To help them understand MS fatigue is different, you could use phrases like "my legs feel heavy" or "lifting my hair dryer feels like I'm lifting a 25-pound weight." For vision issues, she suggests doing something as simple as putting Vaseline on someone's glasses to show them what blurred vision is like.

Dr. Miller notes that fatigue and cognition problems can be the greatest source of frustration for your loved ones. "Both symptoms can be interpreted as you're giving up if you don't explain them with regard to your immediate circumstances."

For example, Reyes-Velarde gives specifics to help her husband understand how her cognition and fatigue issues are affecting her at a specific time. "I tell him things like, 'When I was driving today, I got so tired I couldn't find my way home. And I couldn't focus enough to understand what the woman was saying on the GPS.' "

But sometimes, disclosing these types of details can make you feel uncomfortable.

Dr. Miller had a patient who would just say no when her family wanted her to join them on a visit to a friend, rather than admit her fear that she might have difficulty climbing the steps at the friend's house. Because she didn't explain this, her family felt like she was lazy. This spurred the woman to talk to Dr. Miller about how to build a vocabulary to describe her symptoms, and say no to things she didn't want to do, in a way that also made her feel comfortable.

Sometimes that might include nonverbal cues—especially if you're tired of discussing your symptoms. "I had one patient who put different colored Post-its on the kitchen door so her kids would know what to expect when they came home from school," Dr. Crawford says. "A blue Post-it meant she was having a good day.

"You can have a shorthand about what's going on in your life without talking about it for 45 minutes," she adds. "For instance, you could tell your partner, 'Today I feel more fatigued, and I may need you to stop at the grocery, but I will do my best to avoid that.' That way they know what to expect, and it doesn't look like you're slacking off."

Think outside yourself

It's also a good idea to tell people how they can help you manage your symptoms. "That's empowering for everyone," Dr. Miller says.

Dr. Crawford suggests modifying the approach a bit with casual acquaintances. For example,

if you don't want to get into an explanation of how your MS makes you feel fatigued in the afternoon, just offer to do the carpool in the morning rather than after school. If you have memory loss, simply saying, "I'm trying to think of a word," can encourage people to help without going into details.

Sometimes you may have to repeat yourself, Borsellino warns, because people don't always remember how your invisible symptoms affect you. "My secretary kept forgetting that because of my symptoms on my right side, it can be hard for me to write. I had to keep asking her to take notes for me," she says. "I've found that rather than getting annoyed, humor helps a lot in situations like that."

This can also be true with cognitive challenges. Dr. Miller says building habits and routines with your family, like always keeping the house keys in the same place, can spare all of you the frustration of asking and answering the same questions repeatedly.

Remember that symptoms may also affect your loved ones. For instance, Dr. Crawford says family or friends may be resentful when you have to cancel activities due to fatigue. So allow them to air their feelings, too, about how symptoms affect their lives. "Once a week, make sure to check in with your family and close friends," she says. "People are often scared their loved ones will get sicker, so they're looking for reassurances that you're taking care of yourself."

Vicky Uhland is a freelance writer and editor in Lafayette, Colorado.

For more on invisible symptoms, visit the following: [Invisible Symptoms in MS \(Part 1\)](#), [Invisible Symptoms in MS \(Part 2\)](#) or [But You Look So Good](#).