

# After an MS relapse



## **You've toughed it out. Now what?**

by **Vicky Uhland**

When Nerisa Misiata began having double vision and difficulty using her hands, she attributed it to the stress of being a 20-year-old college student working two jobs. But when leg issues caused her to slip and break her ankle, she decided to get checked out at a hospital.

While Misiata was waiting in the hospital, she collapsed. Doctors rushed to do bloodwork and other tests. "When the MRI results came back, they showed 21 lesions on my brain and 17 on my spine," she says.

Misiata's MS symptoms were so severe that she spent two months in the hospital and rehab, relearning how to walk, feed herself and perform basic hygiene.

"Doctors told me, 'You're never going to be able to walk; you're never going to be the same as before.' They said I could have fertility issues and not be able to have children. And I thought, 'Haha, you don't know me,' " Misiata says. "I went from a wheelchair to a walker to a cane, and now I'm a mother of four."

But Misiata's hard work and positive attitude weren't enough to completely slow her disease. In the 15 years since her diagnosis, she's had dozens of relapses, including seven times when she spent more than a week in the hospital.

"They know me at the ER," she says. "I'll come in and they say, 'MS setback?' "

The good news is that after years of feeling “like a guinea pig, trying a lot of different medications,” Misiata says, since she started on the disease-modifying therapy (DMT) Ocrevus in 2020, she’s only had one relapse and currently has only seven active lesions. “Because we have highly effective DMTs now, there are fewer relapses. And if someone does have a relapse, it’s usually less severe,” says Harold Moses Jr., MD, associate professor of neurology at Vanderbilt University in Nashville, Tennessee.

Even though her relapses have abated in recent years, Misiata knows she may have another at some point. She’s not overly concerned, though. Over the years, she’s developed physical, mental, emotional and spiritual strategies that not only help her weather a relapse, but also thrive afterward.

“I think of relapses kind of like a pebble in my shoe,” she says. “The first one was definitely scary, but nothing surprises me when it comes to my body anymore. I know the only thing I can control is my reaction to a relapse.”

Here’s what Misiata, other people with MS and healthcare professionals recommend for living your best life post-relapse.

### Relapses 101

The first step in coping with a relapse is [figuring out if you’re having a relapse in the first place](#). That may seem simple on the surface, but as with everything regarding MS, there’s



underlying complexity.

The standard definition of a relapse includes the following characteristics:

- You have a new symptom or acute worsening of existing symptoms
- It’s been at least 30 days since the onset of your last relapse
- The relapse lasts more than 24 hours
- It isn’t caused by a fever, infection or other stressors

- It has no other explanation

If a suspected relapse doesn't meet all these criteria, it's likely a pseudo-relapse and should go away within a day, says R. Alejandro Cruz, MD, who practices at the DHR Health Neurology Institute Neurology/Neuroimmunology & Multiple Sclerosis clinic in McAllen, Texas.

Heat, fatigue and stress can all cause a temporary worsening of symptoms, Moses says. So can urinary or respiratory infections, which is why your doctor may order a urinalysis or complete blood count to help determine if you're experiencing a relapse or a pseudo-relapse.

If your doctor decides you are indeed having a relapse, the standard treatment is three to five days of either intravenous or oral steroids. Cruz says 95% to 99% of the time, a course of steroids will help significantly ending a relapse. However, it may take a couple weeks after treatment for symptoms to return to where they were before the relapse.

Moses says there is high probability that symptoms that continue for more than 90 days may never resolve completely. But that doesn't mean those symptoms can never improve — some people with MS do resolve symptoms over a long period of time. And DMTs and specialists like physical therapists, occupational therapists, ophthalmologists, urologists or mental health professionals can help reduce the chance for relapse.

### **First steps after a relapse**

Cruz says he likes to schedule a visit with a patient a week or two [after a relapse](#) to evaluate their recovery. One of the first things he does is discuss medications. Was the relapse due to the person not taking their medication as prescribed, perhaps because of side effects? Or was the DMT simply not working? In either case, he considers switching them to a new medication.

Courtney Casner knows all about the DMT rollercoaster. She was diagnosed with MS in 2015 when she was 18 years old but believes her symptoms started as early as second grade.

Shortly after her diagnosis, she began taking a DMT. "Everybody was picking out their colleges and their dorm rooms, and I'm picking out immunotherapy drugs," she says.



**Courtney Casner eventually found the right DMT to help her manage her MS.** Photo by Keith Carlsen

Casner's first DMT made her feel like she had the flu. "I tried to go to college, but I felt so sick I couldn't make it to class," she says. She tried other MS drugs "but I felt like the therapies were poison — I was so afraid to take those things. So, I stopped."

In 2020, Casner lost her ability to walk and the use of her left hand. Doctors treated her relapse with steroids followed by intravenous immunoglobulin (IVIG) injections and persuaded her to begin taking a DMT again.

After six agonizing months, she was able to walk and use her hand again.

Today, Casner is a musician in a restaurant and bar in San Diego. "My left hand feels like I'm wearing an invisible glove, and my sensation of touch is off. I occasionally miss a note, but it's not a big deal," she says. "Plus, I can go to the gym again. The other day, I started crying, thinking about how once I couldn't walk and now I'm running."

### **Post-relapse physical recovery**

When a neurologist or MS specialist consults with a patient post-relapse, they often recommend physical therapy (PT) or occupational therapy (OT) for people like Casner and Misaita who have noticeable gait or balance issues or other serious problems using their limbs.

“Something that seems small from the neurologist perspective may still need to be looked at after a relapse,” says Evan Cohen, PhD, associate professor of physical therapy at Arcadia University in Pennsylvania. “The neurologist manages the disease; PTs and other specialists manage the consequences.”

Cohen calls these low-grade issues “occult” symptoms, which he explains is “something that doesn’t drastically change your function but is maybe a step down on the ladder and might make things more complicated later on.” These occult symptoms could include mild unsteadiness while walking, loss of flexibility in a joint, subtle problems with breathing and endurance, loss of dexterity in the hands, or a small change in vision.

“A lot of people early in their MS disease course, who appear completely healthy and functionally normal, have a fairly high occurrence of occult problems,” Cohen says. “They may not notice them, but these occult symptoms can cross the threshold to where they’re an issue. All it takes is a little bit of a difference, like a relapse, to turn something present into something problematic. These problems may be easily fixable, but they need the right set of eyes.”

Cohen says another benefit of PT after a relapse is that it can establish a baseline that will be helpful for both the patient and therapist later in life. Tests can measure your strength, flexibility, balance, oculomotor function and cardiorespiratory conditioning. They can also monitor bladder function, which may be improved with pelvic exercises and other strategies.



**Disease-modifying therapies have helped Misiata. She has had only one relapse since 2020.** Photo by Keith Carlsen

Mary Crumley, assistant professor of physical therapy at Washington University in St. Louis,



Missouri, who is a neurological physical therapist and a multiple sclerosis clinical specialist, says these evaluations can also determine if your daily performance is equal to your physical capacity. If not, PT can help with strategies like how to plan your day in ways that conserve energy, including taking physical and cognitive breaks.

“I see it as, ‘How can I make your life more optimal?’ ” she says. “What activity are you having a hard time doing, and how is that affecting participation in your community and what you want to accomplish?”

Other specialists can also address common post-relapse issues. A speech and language pathologist (SLP) can help if you don’t articulate as clearly as you did before the relapse, cough more frequently or have difficulty swallowing. An OT can help with your daily living needs. And vocational rehab counselors can step in if your relapse affects your ability to work.

Insurance companies may require a referral from a doctor to see these specialists. “But it may be up to you to advocate for that, saying, ‘This is different; it’s not like it used to be and I want to get it checked out,’ ” Cohen says.

Of course, if you’ve just undergone treatment for a relapse, you may be loath to spend more time with a specialist for what may seem like a small issue or one you think could improve or even disappear soon.

“Fatigue of working with medical providers can be a burden,” Crumley says. “Time, cost and access can all be issues.”

But not everyone needs to follow a traditional PT schedule of twice a week for two to three months, she adds. “At our first meeting, we can identify goals and what to work on, including exercises and home therapies. You might only need to come in as little as once a week for a month, and then have check-ins at three or six months or even a year later.”

### **Post-relapse recovery**

Relapses can have more than just physical effects. They can also impact cognition and mood.

Healthcare professionals can provide therapies and medications to cope with obvious mental and emotional effects of a relapse, such as memory issues or debilitating depression. But like occult physical symptoms, people with MS may not think it’s necessary to get help for common relapse-related thoughts and feelings like regret, guilt, fear or anxiety.

There’s no need to suffer in silence, though. Evelyn Hunter, PhD, associate professor of counseling psychology at Auburn University in Alabama, says working with a therapist, counselor, psychologist or psychiatrist can not only help you deal with these issues, but also identify coping skills and strengths so you can navigate a future relapse or other outcome of your disease.

After a new or existing patient has a relapse, Hunter begins by encouraging them to attend

to their physical health first.

“Some people want to avoid thinking about a relapse or pretend it didn’t happen,” she says. “But it’s hard to do psychological work if you’re distracted by your physical body.”

After that, it’s important to rebuild trust in your body. Hunter says this includes having gratitude for your body — but that can be difficult if you feel like your body has failed you during a relapse. Hunter says you can begin by confronting your negative feelings, like “I’m angry I have MS and these issues are coming up.” Then, identify the parts of your body that are functioning well.

“This can be hard to do, but sometimes shifting focus can be helpful to remember the ways your body is showing up for you,” she says. Doing something physical to illustrate what your body can do — rather than can’t do — may help. So can journaling or simply looking in a mirror and praising your body.

Hunter says that some people use an “extended family identity” for thinking about MS relapses, and there are healthy ways to do so.

For instance, she says, if your distant cousin comes to town, a healthy reaction is to treat them with respect, identify what they need while visiting and give it to them, and then stop thinking about them when they leave. The unhealthy reaction is to obsess over how much you hate it when your cousin visits and how miserable you are.

“A relapse would be that cousin coming into town,” she says. “Tell yourself, ‘I’m going to visit my neurologist, I’m going to engage in MS health behaviors. Then, I’m going to put that relapse out of sight and out of mind when I no longer need to deal with it.’ ”

Hunter also counsels patients who are concerned about having another relapse.

“For folks newer in their MS journey, fear of relapse is among the most significant psychological issues. You don’t know your body, you don’t know what form a relapse would take, you don’t know the long-term effect,” she says. “Fear of relapse also spikes at big life transitions like parenthood, changing careers or moving. People worry, ‘What if my MS gets in the way?’ ”

Hunter’s work with MS patients helps them acknowledge those feelings but also maintain balance with their disease.

“We want to identify the reality that is MS. Relapses may happen, may be low or high in severity and may disrupt some aspects of life,” she says. “But people in the MS community are resilient. Oftentimes, they just need to be reminded that there are parts of them that are strength-based that can help them navigate a relapse.”

### **Advice from those who’ve been there**

Although Casner isn't one of Hunter's patients, she's lived what Hunter teaches.

"One of the hardest things about having this disease is the uncertainty. You wake up every day and think, 'Is this the day a relapse is going to happen again?' " Casner says. "During my relapse, my mind went to dark places I didn't think were possible for me, for my character. But I found that after getting better from a relapse, it's less scary. I've proven that I can get through it."



**At one point, Casner couldn't use her left hand, but she is now back to playing the piano.** Photo by Keith Carlsen

Casner believes that having a support system was key in navigating her relapse and dealing with life post-relapse.

"My brother moved across the country to take care of me," she says. "I could talk about my disease with him, and he was always positive. He would try to get me outside to walk a few steps. The comfort of having family nearby was essential for me."

Casner also recommends connecting with other people with MS.



"I'd never seen someone get better from MS. Before my relapse, I only knew one person with MS, and I didn't really understand what relapsing-remitting MS meant. It would have been beneficial to see someone get better, to get their life back," she says.

Misiaita is also a big fan of support systems, both religious and secular. At least twice a week, she texts motivational quotes, leaves voicemails, emails uplifting memes or makes other contact with friends, family and coworkers.

"If they don't have a support system, at least they know someone cares for them and they're not alone," she says. "This was important to me when I was so down, so negative, and I didn't know how to lift myself up."

Misiaita also follows MS support groups on social media, posting funny videos, dancing reels and more.

"I like to make people smile, think outside of their frustration, show it's OK to not be OK," she says. "It makes me happy, and it makes other people happy."

Misiaita says after her first relapse, she felt scared and alone and didn't know what to do.

"But then I realized I've got to wear that MS on my chest like Superman and just fly through it," she says. "Sometimes when a storm is coming, we get scared, we're not prepared, but we have to look at that storm and say, 'Do your worst.' Going through this will make us stronger."

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

Learn more about [managing relapses](#).