All about MS relapses

What they are, what they aren’t and how to manage them

by Aviva Patz

When Gina Gentry was diagnosed with relapsing-remitting multiple sclerosis in 2015, she asked her neurologist how she’d know if she was having a relapse. “It will be in a different part of the body, and you’ll just know,” Gentry recalls her doctor telling her. One year later, when the 33-year-old from Minneapolis went numb in her torso, it was a new location and, she recalls, “I had a gut feeling.” By the time she reached her neurologist’s office, she’d lost sensation from the neck down.

Relapses — also called flares, attacks or exacerbations — are a hallmark of relapsing-remitting MS, the most common form of the disease, accounting for about 85% of initial diagnoses. They’re followed by periods of remission, where symptoms lessen or even disappear. Because MS affects everyone so differently, there’s no data on how often people with MS experience relapses. Relapses are more common in young adults — 20s and 30s compared to 60s — when the immune system is more active, says Maria Antonietta Mazzola, MD, a neurologist with Beth Israel Lahey Health in Burlington, Massachusetts.

Researchers are getting closer to being able to make individual predictions, but until that time, it’s critical for people with MS to recognize a relapse, so they can get the treatment that will speed their recovery. “Education is key for relapse treatment,” says Ahmed Obeidat, MD, PhD, associate professor in the Department of Neurology at the Medical College of Wisconsin. “If someone knows what to expect, if they’re informed, they’ll do better overall.”

What a relapse is and isn't

A relapse is new or worsening neurological symptoms in MS, in the absence of fever or infection, that last for more than 24 hours. The attack must occur at least 30 days after a prior attack to be considered a true relapse.

"A relapse is the clinical manifestation of a new inflammatory event in the brain and/or spinal cord that causes tissue damage," explains Mazzola. "When this happens, patients experience new neurological problems that can manifest with different issues involving strength, sensation, vision and balance."

Mazzola will often see patients with relapses experiencing double or blurry vision and pain with eye movement in one eye, or numbness and tingling in the arms and legs, as well as problems with coordination. Typically, patients experience symptoms they've never had before, but occasionally they can have acute worsening of older problems.

"We do distinguish between true relapse from pseudo relapse," she notes, which is why healthcare providers use MRI and/or lab tests to confirm. "A pseudo relapse is an exacerbation of old symptoms that becomes more prominent or bothersome. This can be due to external factors that increase stress in the body such as infections, heat or anxiety."

Becky Veverka, 56, of Williamsburg, Virginia, finds that stress and fatigue usually send her symptoms into high gear. Seven years ago, when her father died, and she began taking care of her mother, she started experiencing more intense bladder and bowel symptoms as well as terrible calf pain that lasted two to three weeks. Her neurologist upped her medication but did not recommend further treatment because it was not a true exacerbation.

“We need to make sure there’s not an infection going on, no fever, no unusual fatigue that’s making existing symptoms appear to be worse,” Obeidat says. “It’s important to make sure that this is an actual relapse we need to act on.”

For example, if he gets a call from someone with MS who knows they have optic neuritis in their left eye, and they say, “I was doing intense activity and then I felt my vision in my left eye go blurry, but I stopped doing what I was doing and it improved,” he’s pretty confident that that’s not a relapse.

And although an MRI that shows new lesions can help confirm a relapse, MRIs can miss things. “It doesn’t always show everything, so I’m listening to the story,” Obeidat says. “If someone with MS is telling us about cognitive symptoms that are impacting their life and I’m able to see that on a cognitive assessment, I don’t need an MRI to confirm it.”

Relapse triggers

There are no definitive triggers, but according to Obeidat, many people living with MS report that during stressful times or when dealing with an infection, they experience more or worsening symptoms.

“I know we just said if someone has an infection, they may not be having a relapse, but there’s a fine line,” he continues. “Infection can play both ways.” That’s why it’s important to tell your healthcare professional about any infection — such as a virus or pneumonia — that could be a trigger for new MS symptoms.

A recent upper respiratory infection triggered a worsening of symptoms for Michael Cavicchia, 54, of Jacksonville, Florida, who was diagnosed in 2005. “I have a weakened right side, so when I started getting this infection, my right leg got completely weak,” he says.

Hormonal changes may also play a role. Relapse risk goes way down in pregnancy, especially during the third trimester, but rises again after delivery — it actually triples or more, according to Obeidat. “The postpartum period is an important time to focus on getting proper treatment and make sure patients know about the higher risk so they can be proactive about it.”

There’s some evidence that fertility treatment, such as IVF could trigger relapses, but in Obeidat’s clinical practice, that’s only in cases of untreated MS. A recent paper in Neurology found no increased risk for women with MS who take disease-modifying therapies (DMTs). “That means people who are treating MS are lowering their risk for hormone-related relapse,”

Obeidat says.

Lastly, low vitamin D may be associated with higher disease activity and a higher relapse rate, which is why neurologists suggest that people with MS consider taking supplements.

Relapse symptoms
Generally, any new neurological problem may be a relapse symptom. “The nervous system controls everything in our body,” Mazzola says. “Relapse symptoms and their duration depend on the severity of the inflammation and the area in the brain or spinal cord that is affected.”

Though relapse symptoms can vary, lasting days, weeks and even months, Obeidat most commonly sees these:

- Blurry vision from inflammation of the optic nerve (optic neuritis) or double vision
- Sensory issues including numbness or tingling, or the sensation of a hand or leg feeling heavier than usual, swollen or painful
- Weakness, including inability to use an arm or leg, or dexterity issues in the hand
- Balance problems with or without falls
- Fatigue — pathologic fatigue, as in, you can’t get out of bed. A U.K. survey found fatigue to be the most commonly reported symptom of relapse
- Cognitive issues, including brain fog. “People say: ‘I can’t think straight, I can’t put things together, I can’t focus. I’m unable to do a task I did just a week ago,’ ” Obeidat reports.
- Bladder and bowel issues, including difficulty going and/or overactivity

Relapse treatment
Not all relapses require treatment. In the case of mild sensory changes, such as numbness, the best course of action may be to rest, eat well and hydrate, and treat individual symptoms as needed with medications, rehabilitation services and other targeted therapies.

For more acute symptoms that interfere with a person’s mobility, safety or basic ability to function, there are three main treatment options to bring down the underlying inflammation:

- Most neurologists start with high-dose intravenous cortical steroids for three to five days, such as methylprednisolone, or high-dose oral steroids such as prednisone, according to Mazzola. Possible side effects include stomach irritation, elevated blood sugar, water retention, restlessness, insomnia and mood swings. These symptoms should resolve after treatment is completed.
- For people who can’t tolerate high-dose steroid treatment or who have difficulty receiving IV medication, there’s H.P. Acthar Gel, delivered by injection, that stimulates the body to make its own steroids, according to Obeidat. This therapy isn’t used often because it’s expensive and not easily accessible.

Preventing relapse
DMTs, which work by lessening the development of new areas of damage in the central nervous system and slowing the accumulation of disability, have been shown to reduce the frequency and severity of relapses.

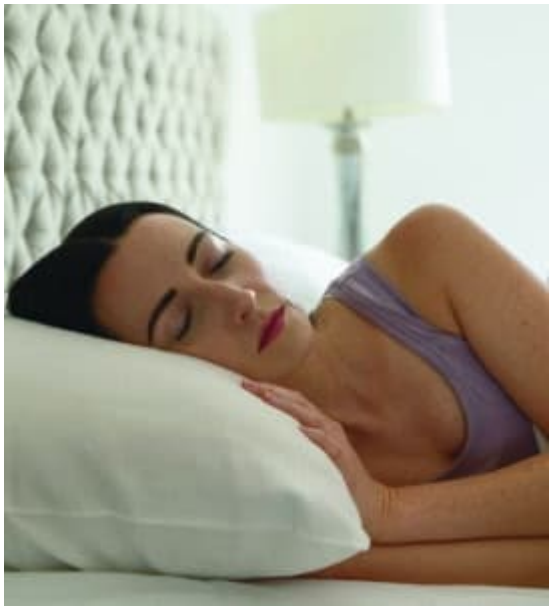
Scientists are also getting closer to having a proverbial crystal ball to predict relapses. Studies in people with MS show that before they relapsed and even before they presented with MS, there was a spike in their neurofilament light chain, a biomarker measured in spinal fluid or serum that indicates nerve damage, Obeidat explains. If doctors can detect a spike in that serum biomarker, they can act on it — perhaps with DMTs or different DMTs — before it becomes a major relapse.

Managing relapses
These self-care measures can help people with MS manage their relapse symptoms.

Make peace with fatigue. Good sleep habits, avoiding caffeine and alcohol, and moving regularly can head off routine MS fatigue, but when it's severe, honor it. Heather Malek writes on the Society Facebook page: "For me, the fatigue is the worst, as I cannot do anything about it, and I neglect life and myself while I'm in it. I have come to terms with not being able to control this symptom. I give myself grace. I also tell myself it's OK to take care of me when I have to sleep for days and cancel or seclude." It's also helpful to know when you have the most and least energy so you can plan your activities accordingly.

Ease spasms. Michael Cavicchia sometimes got spasms so severe that he couldn't sleep until his doctor put him on a regimen of 400 mg of magnesium, a vitamin D supplement and 3–4 ounces of tonic water with quinine before bed. Applying drops of sandalwood oil and lavender oil behind his neck help, too. Cavicchia also swears by yoga and meditation and twice monthly therapeutic massages. "That helps everything," he says.

Work around brain fog. Bernhard Nordentoft, 56, had a relapse in 2008 that affected his brain, erasing the memory of coworkers' names and neighboring towns. His capacity to remember new information hasn't fully recovered, so at his IT job, he writes everything down immediately and focuses on completing one task at a time.



Good sleep habits can head off routine MS fatigue. Photo by Beto Defreitas

Get help for tingling or pain. Neuropathic pain agents (gabapentin) have helped Becky Veverka manage her calf pain. “My neurologist gave me extra pills to use at times when nothing else helps,” she says. “I’ll also do hot baths to relax those muscles, and my husband will massage my calves. He bought me one of those massagers — it’s a miracle for muscle pain.”

Take control of anxiety and stress. Both can worsen and even lengthen a relapse, according to Obeidat, so get the help and support you need from your family and friends and know that hope can be powerful. “Have the mindset that yes, I’m going to get better — if not today, maybe in a month,” he says. He’s noticed that hope and optimism can be helpful in relapse recovery.

Beverly Kemnitzer, LMSW, writes on the Society’s Facebook page that after a terrifying relapse at age 53, she learned to hope and pray and take it one day at a time. “Only time will tell what will or won’t happen, but that is life anyway. So, I am learning to be patient with myself and hopefully roll with the MS punches when they come.”

Aviva Patz is a writer in Montclair, New Jersey.

For more information about MS relapses, visit Managing Relapses and Relapsing-remitting Multiple Sclerosis.