Managing MS relapses

MS flare-ups are unpredictable and discouraging, but you can learn how to cope with them.

by Vicky Uhland

In December 2017, Antonia Juarez fell off her horse. That wasn't unexpected for the avid 27-year-old equestrian, but the residual effects were. Juarez was used to recovering quickly from the bumps and bruises resulting from her falls, but three weeks later, she still had numbness in her left leg.

When that numbness spread up her entire left side, Juarez went to a hospital emergency room near her home in West Hollywood, California. She was diagnosed with relapsing-remitting multiple sclerosis (RRMS) and given a heavy dose of steroids.

Two months after Juarez left the hospital, she was sitting on a friend's couch and realized she couldn't feel her left arm when she touched it. Even though she had started a disease-modifying therapy (DMT), Juarez's doctor told her to return immediately to the hospital. An MRI showed that Juarez had a new lesion on her spinal cord, and she was diagnosed with a relapse.

Since she switched DMTs and started monthly intravenous immunoglobulin (IVIG) infusions in April 2018, Juarez hasn't experienced another relapse, and her MRIs have shown no new lesions. But that doesn't mean she's been symptom-free.

"A few months ago, I couldn't get out of bed because I was so fatigued. My legs were shaking," Juarez says. "The doctors said it wasn't a relapse, but it felt as bad as a relapse

because I was completely affected and hospitalized."

Living with the specter of relapse

Emily Zipps knows that feeling well. Zipps, who lives in Albuquerque, New Mexico, was diagnosed with RRMS in 2018 at age 30. Since then, she's had symptoms like constant neuropathy in her hands and feet that sometimes flare up.

Zipps' situation isn't unusual. The 2020 Global vs. MS online survey of 1,075 people with RRMS living in Australia, Canada, France, Italy, Spain, the United Kingdom and the United States reported that nearly half — 507 people — hadn't been diagnosed with a relapse in the last 12 months. About 28% — 300 people —reported one relapse during that period. Another 134 people had two relapses, and 134 had more than two relapses. But these statistics don't mean Zipps — or anyone else with RMSS — will go through their entire life without a relapse. A 2011 study published in the journal Neurologic Clinics reported that 85% to 90% of people with RMSS will have at least one relapse, flare or exacerbation at some point in their lives.

Managing expectations

That makes knowledge about relapses a key component in disease self-management. But, like everything else about MS, there's no one-size-fits-all relapse handbook. And that includes identifying if you're having a relapse in the first place.

Emily Zipps (left) and her wife, Hannah, enjoy walks with their dog, Kona. Photo by Gabriella Marks

“My first neurologist said you may have a relapse or you may not — we don’t know. Live your life, and let us know if something bad happens,” Zipps says. “The vibe I got from my friends with MS about relapses was ‘you’ll know it when you see it.’”

For some people living with RMSS, however, that’s not always the case. It can be difficult to know when worsening symptoms or even a new symptom is a relapse or due to other factors like an infection, stress or simply staying out in the sun too long. Even doctors — especially emergency room doctors who aren’t well trained in MS — can’t necessarily diagnose a relapse on the spot. As a result, many relapses can go unreported by both patients and physicians.

How to identify a relapse

There are tools that can help you understand how to identify a relapse, what to do if you have one and how to lessen your chances of having a relapse. Along with physical treatment options, there are tools to mentally and emotionally cope with a relapse.

Tool 1: Defining a relapse

MS is an unpredictable disease, and that applies to relapses. There’s no medical protocol — or crystal ball, for that matter — that can determine when you might have a relapse. But there are ways to rule out a relapse.

The standard definition of a relapse includes the following characteristics:

- You have a new symptom or worsening of existing symptoms.
- It’s been at least 30 days since your last relapse.
- This new issue lasts for more than 24 hours.
- Fever or infection doesn’t cause it.

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

Pseudo relapses are relatively common compared with diagnosed relapses. In 2020, during the first five months Cruz worked at the MS clinic, he saw 104 patients. Three had relapses, and about 10 had pseudo relapses.

To help differentiate between the two, Cruz asks his patients a series of questions. He begins by asking if the patient has experienced the same symptoms in the past. While a relapse can cause a worsening of existing symptoms — a new lesion near the same spot as an old one can exacerbate a symptom — if it’s a new symptom or in a new area of the body, that’s a red flag that it may be a relapse.

According to a long-term study of 806 people with RMSS published in 2010 in the journal Brain, the most frequent symptoms involved in a relapse are sensory, including numbness, tingling or pain. Visual symptoms are also fairly frequent, affecting 22% of relapse patients.

Other common relapse symptoms include balance issues, weakness in extremities, and bladder and bowel issues.

Cruz's second question involves what the patient was doing at the beginning of the suspected relapse. Were they overheated? Fatigued? Stressed? These metabolic issues can cause a temporary worsening of symptoms that can go away in 24 hours — meaning the patient isn't having a relapse.

Emily Zipps tries to alleviate concerns about relapses by learning more about her disease.
Photo by Gabriella Marks

Then, Cruz checks to see if the patient has changes in urination like burning or increased frequency, because urinary tract infections can exacerbate symptoms. Respiratory infections and fever associated with a virus or infection can also exacerbate symptoms. A urinalysis or complete blood count can determine whether fever or infection is causing a pseudo relapse.

Cruz will usually also conduct a neurological exam, assessing vision, strength, sensation, gait and coordination. Finally, "I can always get an MRI to check for new lesions, but for the most part, I don't wait for the MRI to determine if it's a relapse," he says.

Tool 2: Treating a relapse
Relapse symptoms can be different for different people and can last for a few days or several

weeks. In general, relapse symptoms gradually worsen over a few days before reaching a peak that's followed by recovery, says Lokesh Rukmangadachar, MD, assistant professor of neurology in the neuroimmunology and MS division at the Saint Louis University School of Medicine in St. Louis.

Since each relapse is different, a detailed clinical history and a neurological exam are essential. There's no validated tool or consensus on guidelines for how to assess the severity of an MS relapse, so doctors have to decide on their own. This is important because that decision usually determines the course of treatment.

The standard treatment for a relapse is three to seven days of intravenous or oral high-dose steroids to control the inflammation associated with the relapse. Doctors have differing opinions on which steroid delivery method is better, but clinical trials show outcomes are similar between oral and IV steroids. It comes down to which type you tolerate better.

Cruz points out that oral steroids can be taken at home, and thus are more convenient than going to a hospital or clinic to get daily steroid injections. But some doctors have found that oral steroids may cause more heartburn and gastric issues in patients. The more severe the relapse, the longer the steroid treatment, although five days is the most common.

But not every relapse has to be treated with steroids.

"I ask my patient how much their relapse is interfering with their life," says Harold Moses Jr., MD, associate professor of neurology at Vanderbilt University in Nashville, Tennessee. "Steroids shorten the time you deal with the symptoms of a relapse, so if the relapse isn't having a significant impact on the patient's life, sometimes we'll just keep an eye on how they're doing and see if we need to use steroids at all."

That said, Moses notes that steroids work better the earlier they're given. "It's OK if you want to wait a day or two to see your doctor if you think you're having a relapse, but don't wait too long."

Moses also cautions against going directly to the emergency room if you think you're having a relapse. "The doctors there may not be familiar with MS, and your care may be uneven," he says. "Try to communicate with your neurologist before heading to an ER."

Cruz says 95% to 99% of the time, a course of steroids will end a relapse. But not everyone can tolerate steroid side effects, including gastric issues, insomnia, blurred vision, restlessness and mood swings. People with diabetes may also have difficulty with steroid-related blood sugar increases.

In those cases, a doctor may prescribe IVIG therapy, like Juarez underwent, or adrenocorticotropic hormone (ACTH) gel injections. ACTH promotes the natural production of steroids in the body, but it's expensive and difficult to obtain. Another option for severe relapses that don't respond to steroids is plasma exchange, but this is rare.

If a relapse is severe, a patient may need to go to rehab after the symptoms are stabilized. A 2015 research review published in Neurology found that eight weeks' worth of weekly physical therapy sessions can help improve balance, disability and gait in people who can walk at least 16 feet without a mobility device post-relapse.

Tool 3: Assessing a relapse's effects

A review of 180 studies conducted over a 44-year period, which was published in Neuroepidemiology in 2015, found that people who have exacerbations that affect the bladder, bowels, or muscular system tend to have more disability after their relapse than those who have optic neuritis flare-up. Relapses that involve the brain have mixed outcomes.

The review found that women tend to have better recovery from relapses than men. Studies show that women are more prone to visual and sensory relapses, which are easier to recover from than the motor or neurological relapses that more often affect men.

Age also plays a role in relapse recovery. Research shows that people younger than 40 tend to have fewer residual symptoms after a relapse.

"There are different theories why," says Rukmangadachar. "The brain is more 'plastic' when you're younger and therefore may be better able to compensate after a relapse. The neurological reserve may be less in older individuals. And maybe earlier in life, the repair mechanism, remyelination, may be better."

Research shows that people younger than 40 tend to have fewer residual symptoms after a relapse. Photo by Gabriella Marks

Moses says there's some controversy about how likely relapses are to result in significant disability down the road. There's evidence that people who have five or more relapses in the first one to two years of their disease have a higher risk of disability progression five to 10 years in the future.

However, he says, many people will have few if any relapses, but will still move into a progressive phase of MS 15 to 20 years after their initial relapse.

And if you continue to have exacerbations in the same body system, such as your optic or motor system, you're at higher risk of symptom progression in those areas, Moses says.

Overall, 90 days after your relapse began, there's about an 80% chance that any remaining symptoms will continue for an extended period of time, Moses says. Fewer than 10% of people will see an improvement in some of their symptoms after more than a year, he says.

Tool 4: Reducing your relapse risk

The Neuroepidemiology review found that women are more likely to have relapses than men. People of color tend to have more relapses than white people. And you're also more likely to have a relapse if you're younger or earlier in your disease course.

"The chances are higher in your 20s and 30s because the disease is more active then. The relapse incidence comes down in your 50s and 60s," Rukmangadachar says.

All of these are factors you can't influence. But there are also relapse predictors you can influence.

The review found that people who smoke are more likely to have relapses than nonsmokers. Stress and mental and emotional trauma are significant factors in relapses, but, interestingly, physical trauma isn't. Relapses are less common during pregnancy. And your vitamin D levels may influence relapse frequency.

But more than any other factor you can control, being on a DMT has the most impact.

"DMTs not only help prevent relapses, but they also help prevent the accumulation of disability down the road," Rukmangadachar says.

A variety of studies equate DMTs with significantly lower chances of having a relapse. A 2013 Cochrane review of 44 studies found that DMTs can reduce the risk of relapse by 36% to 85%, depending on the type of drug. As Juarez discovered, different medications can have different effects on your relapse susceptibility, so it's best to work with your doctor to find the most effective one.

Tool 5: Finding coping strategies

There's no getting around the fact that relapses can be scary. Not only do you have no idea if or when they're coming, but you also don't know what effect they'll have on you now or in

the future.

But while relapses are serious, doctors are quick to offer reassurances. They note that because of DMTs, relapses are much less frequent than even a decade ago and more treatable. And even if you do have a relapse, that doesn't mean your disease outlook is worse.

As someone who hasn't had a relapse, Zipps feels like she's in a "wait and see" mode. She focuses on her tangible symptoms. "I think about things like what kind of fatigue will I have today? My wife would like to do more backpacking trips, and I worry, what if I have a bad day and can't hike out?" she says. "I'm a worrier, but it doesn't seem productive to worry about having a relapse because there's nothing I can do about it."

As someone who has had multiple relapses, Juarez agrees with that philosophy.

"Your body may not feel like it's yours, but you do have control over your mind. The more you panic about something, sometimes that thing will happen to you," Juarez says. "You have to learn to calm your mind."

Juarez does that through meditation and other relaxation techniques. Even though she now struggles to ride her horse, she makes it a priority because the exercise and equine-human connection soothe her both mentally and physically.

Juarez and Zipps also help alleviate their concerns about relapses by learning more about their disease through MS groups, classes and materials from the National MS Society. "I read a lot about MS, and it gives me hope because there are so many different stories," Juarez says. "My story doesn't have to be about just waiting around until I [have] another relapse."

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

Jessie Ace shares five fun activities to do during an MS relapse.