Recognizing a relapse

Learn how to spot the signs—and take action so you can recover.

by Elise Oberliesen

Carla Ramos learned to distinguish symptoms of an MS relapse from other conditions. Photo courtesy of Carla Ramos

Carla Ramos spent four days in the hospital in 2012 before she was finally diagnosed with

relapsing-remitting multiple sclerosis. Because this form of MS is characterized by occasional flare-ups of symptoms (also known as relapses or exacerbations), Ramos' neurologist warned her to expect them. "My doctor said, it's not a matter of if it's going to happen, it's a matter of when," the Portland, Maine, resident recalls. The casual nature of her doctor's remark left Ramos riddled with concern and fearing a trip back to the hospital. The unpredictability of MS symptoms—known for varying from day to day—only added to her anxieties. How would she recognize a relapse—and know what to do about it—when it happened?

Last summer, Ramos recalls, she was at a family gathering when she began to feel overheated. Then, overwhelming fatigue set in and prompted her to find an empty bedroom where she could cool down and rest. Was it a relapse or just her "normal" MS? Ramos, 59, even considered that her changing symptoms might be due to menopause. Her confusion is common, but there are ways to tell the difference.

The first criterion

"A relapse is the appearance of a new or worsening neurologic symptom, or a reoccurrence of a symptom the person may have had before. The key is that it has to last longer than 24 to 48 hours," says Dr. Barbara Giesser, clinical director of the Multiple Sclerosis Program at UCLA's David Geffen School of Medicine. While exacerbations are most commonly associated with relapsing-remitting MS, people with progressive forms of the disease can also experience them, though they tend to occur less frequently.

Keeping track of symptoms from the time they start until the time they end can be a tremendous help in distinguishing between a relapse and typical MS symptoms, says Dr. Giesser.

A person might wake up feeling more "tired, tingly or with more muscle stiffness" one day, she says, but if the symptoms vanish in less than 24 hours, chances are, it's probably not a relapse. Instead, it's possible that it's just the type of fluctuation that commonly occurs in MS symptoms. Or, it could be a "pseudoexacerbation," which feels like a true exacerbation, but results from a known trigger, most commonly a rise in body core temperature. It can occur after vigorous exercise, an infection, being outside on a hot day, or anything that causes a person to become overheated. "It could be a bladder infection, a cold or a sinus infection … Any kind of bacterial or viral infection can trigger a pseudoexacerbation," says Dr. Giesser. Once the infection or other cause of overheating is addressed and the body cools, symptoms generally subside, she says.

Preventing relapse in the first place is always the goal.

The symptom profile

Though Ramos' doctor believes her recent experience with overheating and increased fatigue was a pseudoexacerbation, likely caused by summer heat and humidity, she was smart to pay attention when the fatigue set in. About two-thirds of true relapses are associated with increased fatigue, says Dr. Robert Fox, a neurologist at the Cleveland Clinic's Mellen Center for MS. Still, fatigue can be caused by other factors, ranging from a hectic day to sleep disorders. For that reason, it's important to consider what other symptoms are present.

Dr. Fox says MS relapses most commonly affect three areas:

- **The spinal cord**, resulting in weakness or sensory issues in the arms and legs. Sensory issues can include paresthesia, which feels like numbness or pins and needles in the limbs, and may lead to coordination issues, says Dr. Fox. Some people notice tingling in the feet that moves into their legs or torso. "[With] paresthesia, typically the symptoms will start mildly and gradually progress, either worsening in severity or extending over larger areas of the body,"
  says Dr. Fox.
- **The brainstem**, affecting coordination and balance.
- **The optic nerve**, affecting vision. When a relapse affects the optic nerve, Dr. Fox says, some people report blurry or distorted vision, a condition known as optic neuritis. While some people experience double vision during a relapse, he explains that it's not the same as optic neuritis. "When the eyes are affected by coordination difficulties, it can result in double vision, which is caused when the normal yoking of the eyes breaks down and the two eyes go in slightly different directions," says Dr. Fox.

Though cognition isn't yet considered one of the primary areas affected by relapse, "about 40 percent of patients report thinking and memory issues associated with relapse," says Dr. Fox, citing research published in **Multiple Sclerosis and Related Disorders Journal** in March. Until we have more research, however, it's difficult to draw further conclusions about how the cognitive pieces fit into the MS relapse puzzle, adds Dr. Fox.

Making sense of steroids

The steroids that gain so much attention in the news are anabolic steroids, sometimes used by athletes. But the word "steroid" simply refers to a particular chemical structure of a substance—essentially, when there are multiple chemical rings of connected atoms. Here's a look at these two different types of steroids:

Anabolic steroids: These are synthetic compounds that target the male sex hormones and are used in certain medical conditions (such as delayed puberty or muscle-wasting diseases) by prescription. More notoriously, these are used illegally by athletes to build muscle and enhance performance, and have numerous risky side effects, including liver and kidney tumors, jaundice and high blood pressure.

Corticosteroids: Also known as glucocorticoids, these are anti-inflammatory agents that act on the immune system, and are commonly used for treating allergies and inflammatory conditions (including MS).

Treatment approaches

Medication, typically a course of high-dose corticosteroids, is the first line of treatment for relapses, and can be given either orally or intravenously. If you think you're having a relapse, Dr. Fox says it's important to seek out treatment instead of ignoring symptoms and hoping they vanish.

"The studies have clearly shown that treating a clinical relapse speeds the recovery, and there's some MRI evidence to suggest there's less injury—that it decreases the amount of injury to nerves in the area of active inflammation," says Dr. Fox.

Corticosteroids used to treat MS are different from the type of steroids that athletes sometimes use to build bigger muscles (see sidebar at right). Common side effects with corticosteroids include gastritis, insomnia, irritability and temporary weight gain, says Dr. Giesser. People taking steroids also should be vigilant for any changes in their moods, especially if they've previously experienced mood disruptions.

"Corticosteroids can prompt mood swings and mood changes, and might be more apt to do so in someone with a history of depression or manic episodes," says Dr. Giesser, although she says it's not considered "an absolute contraindication."

An alternative to corticosteroids is ACTH, also known as adrenocorticotropic hormone. It stimulates the production of cortisol, the body's own steroid hormone. It is typically self-administered by injecting it under the skin once daily for several weeks.

Preventing relapse in the first place is always the goal, however. "Some data suggest that increasing vitamin D levels can help protect against a relapse," says Dr. Giesser. "We don't know exactly what levels are best; the common practice is to keep the levels in mid-range." Since 2010, the Institute of Medicine has recommended that blood levels of vitamin D fall between 25 and 50 nanograms per milliliter when tested.

But, says Dr. Giesser, using a disease-modifying medication is the best strategy to minimize your odds of a relapse. That's what Ramos does, and based on results from MRIs, she has not had a relapse since her diagnosis.

And now she knows what to do if she suspects a potential exacerbation coming on. “I contact my neurologist’s office and discuss [my symptoms] with the MS specialist and seek appropriate treatment. And even if it’s just a pseudoexacerbation, I rest, take care of myself and try to stop worrying because it just adds to the stress of MS.”

Elise Oberliesen is a Denver-based freelance writer.

Learn more about managing MS relapses.