

# Specialist explains why multiple sclerosis can be misdiagnosed

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Every five minutes, someone in the world receives the life-changing news that they have multiple sclerosis, a chronic disease in which the immune system attacks the protective layer of the nerves and causes lesions, or scars, in the brain and spinal cord. If you're among them, you may be worried about the possible effects of MS, from vision loss to difficulty walking. You may even be wondering if you received the correct diagnosis, because many other conditions—from migraines to peripheral neuropathies—may be misdiagnosed as MS.

We asked Tyler Kaplan, MD, a neurologist and MS specialist with RUSH, to offer some advice for getting a second opinion on MS.

## **What symptoms can lead to a diagnosis of MS?**

There are two types of symptoms we consider: those that tend to be specific to MS and those that can occur in MS but are also common in other conditions.

To be diagnosed with MS, patients should have at least one of these classic, MS-specific symptoms:

- A type of painful [vision loss](#) in one or both eyes called optic neuritis
- Shooting, "electrical shock-like" pain on one side of the face called trigeminal neuralgia
- Double or blurred vision
- Vertigo, or a "spinning" sensation

- Weakness on one or both sides of the body from an inflammation of the spinal cord, known as transverse myelitis

A host of other symptoms can occur with MS that are also common with other conditions. These include:

- Fatigue
- Problems with thinking and memory
- Numbness or tingling sensations in the arms or legs
- Bladder or bowel problems
- Difficulty walking

Although these symptoms can occur with MS, they are not specific to MS. That is why it is important to see a specialist who can give you a thorough evaluation to rule out other conditions.

## **If I have some of these symptoms, which type of doctor should they see?**

You can start with a primary care doctor or a general neurologist. A general neurologist can recommend certain tests that you might need, depending on your symptoms. For example, if you are having some of the classic MS symptoms like optic neuritis or transverse myelitis, a neurologist can order a magnetic resonance imaging test, or MRI. Based on the findings of your MRI, your neurologist may refer you to a center like RUSH that specializes in treating MS.

## **Why should I get a second opinion if I've been diagnosed with MS?**

Although doctors follow consensus guidelines to help them diagnose MS, the guidelines aren't perfect. Not everyone who meets the criteria for

MS has MS. And not everyone can be certain they don't have MS based on the criteria alone.

There is still a fair amount of subjectivity that goes into making a diagnosis of multiple sclerosis. I have "undiagnosed" people who were diagnosed with MS by other neurologists. I have also told patients that I believed they had MS after another doctor told them they didn't. That's why I think it's reasonable for someone to seek a second opinion from a neurologist who specializes in multiple sclerosis.

MS patients are usually diagnosed between the ages of 20 and 50, and many are on medications for several decades. So, we want to be sure they are receiving the right treatment.

## **What other conditions can be misdiagnosed as MS?**

Migraines are a common condition that can be mistaken for MS because they can cause numbness and tingling, vertigo and visual changes.

Peripheral neuropathies, which are especially common among people with diabetes, also can be mistaken for MS. These disorders are caused by nerve damage and may trigger symptoms like numbness, tingling and burning pain in the hands and feet. Most of the time, MS flares don't cause pain. So, if people have this type of pain in their hands or feet, it's much more likely to be a peripheral neuropathy.

One rare condition that can have similar symptoms to MS and similar findings on an MRI is neuromyelitis optica spectrum disorder, or NMOSD. Only 10,000 people in the United States have that disease, compared with about a million people in the U.S. with MS. With NMOSD, doctors have specific blood tests they can use to diagnose it. That is not the case with MS.

## **If I've been diagnosed with MS, when is the best time to get a second opinion?**

The sooner, the better. There is very good evidence that the earlier that people are put on therapies for MS, the better their long-term outcomes. People who wait longer to get treated don't do as well, on average.

Some people may decide not to take medication if they aren't currently experiencing symptoms from MS. But that doesn't mean that the MS is totally inactive. They could have inflammation and lesions develop in the brain and [spinal cord](#) without having any actual symptoms.

So, we want to get patients started on active therapy as soon as possible. Of the 23 medications approved for MS, none of them can reverse damage, but they can prevent the development of new lesions or prevent them from becoming larger.

However, medications for MS do have potential side effects. So, if you want to be confident in the diagnosis and treatment plan, a second opinion can help with that.

## **How should I select a doctor for my second opinion?**

It's worthwhile to see a neurologist who specializes in MS at a Center for Comprehensive Care, a designation given by the National Multiple Sclerosis Society. These centers offer a full range of services for MS beyond medical care, including mental health, rehab and social services.

It also makes sense to go to a center that sees a high volume of MS patients and is familiar with the latest MS treatment options. If you are interested in [clinical trials](#), researchers at academic medical centers are often engaged in studies of promising new MS treatments.

## **What questions should I ask when getting a second opinion for MS?**

Some questions you might ask an MS specialist include the following:

- Do you agree with the diagnosis of MS?
- Do I need to take medication for MS? If so, which medications do you recommend? Why do you think they are the best option for me?
- Do you agree with the follow-up plan?

Getting a second opinion can also help you understand more about your condition. This information can be difficult to retain at the time of your initial diagnosis.

## **How do you work with patients who seek second opinions for MS?**

Our goal is to understand your clinical story: what symptoms you've had, when you first noticed the symptoms, what tests you have had and so forth. We ask that you bring a CD with any previous MRIs so that we can review your imaging with you. We also ask that you bring results from any prior bloodwork or spinal fluid testing if you have had those done.

During your second opinion appointment, we'll take time to review your diagnosis, suggest possible treatment options and answer any questions you may have about your current health and what you can expect down the road.

## **What should I do if the second opinion differs from**

## **the original diagnosis of MS?**

If I see you and you don't fully meet the threshold for a diagnosis of MS, I will usually recommend that you have another MRI in six months or a year. It's possible that you could be starting to develop MS, so we want to catch it as early as we can.

## **Will I offend my doctor if I get a second opinion from another doctor?**

I personally do not feel offended at all if a patient wants to see another provider for a [second opinion](#). I'm also happy to offer second opinions. Ultimately, my goal is to do what's best for the patient, whether that means potentially sparing a patient without MS from taking medications that they don't need or getting a patient with MS on a good, disease-modifying therapy as early as possible once a diagnosis has been confirmed.

Provided by Rush University Medical Center

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