

MS Learn Online Feature Presentation

Less Common Symptoms Featuring: Dr. Stephen Krieger

Trevis: The one thing I find about people living with MS is that we all want to be normal.

Walt: I have -- it's a smorgasbord of symptoms, MS is, and I have had every symptom I can think of.

Trevis: For about two weeks I had completely lost the ability to taste sweet, and then a year and a half later salt. I was trained classically as a chef, so, that was a very serious symptom for me.

Sally: I had a seizure four years ago and as I was eating my lunch the seizure happened.

Kathi: I don't have anything wrong with my eyes; mine seems to affect my hearing in my right ear.

Trevis: So, when you find yourself with a symptom that is relatively uncommon, you feel like you are taken away from the class, and then you're taken away from the group of the class that got taken away from the class.

>>Kate Milliken: For those of us who live with MS, we may all be too familiar with common symptoms, such as fatigue, spasticity and numbness. However, there are less common symptoms that people with MS may also be experiencing.

Hi, I'm Kate Milliken, and welcome to MS Learn Online. To discuss some of these uncommon symptoms, we have Dr. Stephen Krieger. Dr. Krieger is a neurologist at the Corinne Goldsmith Dickinson Center for MS, and an assistant professor at the Mount Sinai Medical Center, both in New York City. Welcome to MS Learn Online, Dr. Krieger.

>>Dr. Stephen Krieger: Thank you.

>>Kate Milliken: So, I'm kind of interested, I certainly am aware of symptoms that I have heard about that would be considered uncommon. I'd love to throw a couple out at you and see your response. I have heard that there are speech disorders in MS.

>>Dr. Stephen Krieger: So, speech disorders in MS are somewhat uncommon, as I think all of these things we're going to discuss will be. When we think about speech problems in MS, they are usually problems with speech articulation. Slurred speech, problems with getting words out. Sometimes this can sound like a stutter, for instance, or sometimes it can sound like someone who is intoxicated when they're not. Rarely, very rarely in MS are there speech problems, such as difficulty with word-finding, what we call aphasia. The speech problems that we see in MS at times are dysarthria, which is the difficulty in enunciating or articulating. This can be profound in a very rare minority of cases. Sometimes it's quite subtle and often the patient might not even be aware of it. But if speech problems begin to develop, we certainly would want to know about that, and that would need to be pursued.

>>Kate Milliken: Swallowing problems.

>>Dr. Stephen Krieger: Swallowing problems and speech difficulties in MS go together. Sometimes if MS has caused weakness or incoordination of the muscles of the face and throat, it can be difficult to get food going down the right pipe and swallow effectively. Often, speech problems from MS and swallowing problems from MS go together, because it's the same muscles that are responsible for producing speech and for handling fluids and food and swallowing them carefully. This can be a real concern in severe MS, where problems with swallowing can cause dysphagia, where the food goes down the wrong pipe and can get into the lung causing what's called an aspiration pneumonia. This is unusual, it's only -- occurs -- or it occurs most

often in very severe and longstanding cases of MS, but it is something that we have to stay vigilant about.

>>Kate Milliken: What about headaches?

>>Dr. Stephen Krieger: Headaches are extremely common in the general population, and headaches are perhaps even more common in young people, and more common in women than in men. Basically, more common in the people who get MS and who have MS. So, it is very difficult to attribute headaches to multiple sclerosis. And what I generally tell my patients is that they may have MS and headaches. Headaches, themselves, can take a lot of different forms, as we all know tension headaches, migraine headaches, and many other types. And headache in MS or irrespective of MS needs to be taken seriously and managed, and there are many different medications and techniques that can be helpful for both stopping a headache and preventing them if they happen commonly.

One way that MS can cause not headache precisely, but facial pain, is in something called trigeminal neuralgia. Trigeminal neuralgia is a situation where patients can experience very severe, shooting pain in and around the face and head, and this can occur both in MS and not in MS. It's not precisely a headache, but it is something that as neurologists we see and can certainly treat for patients who have MS.

>>Kate Milliken: What about hearing loss?

>>Dr. Stephen Krieger: Hearing loss is felt to be very uncommon in multiple sclerosis. There is a literature on subtle hearing changes in MS, but what I would tell you is if a patient describes to me that they have significant hearing loss, that always makes me question the diagnosis of MS. There are conditions that can seem like MS and involve hearing loss that require a detailed workup, but it's one of those red flags that neurologists think about as something that might reflect a different disease process.

That said, there are many reasons for hearing loss, and so patients who have MS may also get hearing loss for a variety of other reasons -- sinuses, etc. But it is something that we would need to do a bit of a workup for and not simply ascribe it to MS without pursuing it further.

>>Kate Milliken: Seizures?

>>Dr. Stephen Krieger: So, seizures are uncommon in the general population and uncommon in MS, but slightly more common in MS than in the general population. I think that seizures happen only a couple of times out of 100 in multiple sclerosis. So, the vast majority of people with MS live their lives seizure-free. Seizures themselves take many forms from the generalized convulsions that we think of when we think of seizures, to much more subtle and mild events that are still seizure in nature.

Because MS is a disease that affects the brain, lesions can potentially irritate parts of the brain and give rise to seizures, and seizures in MS are treated just like seizures without MS with anticonvulsant medications, which can do a wonderful job at getting people to be seizure-free or nearly seizure-free.

>>Kate Milliken: And breathing problems?

>>Dr. Stephen Krieger: So, breathing problems are very unusual in MS, especially in relapsing-remitting or early multiple sclerosis. But like trouble with speaking, dysarthria, or trouble with swallowing, dysphagia, breathing problems can occur in advanced and serious cases of MS, where the muscles that are involved in breathing and respiration, like the muscles that are involved in speaking and swallowing, can be affected. But it is quite unusual.

An MS sensory symptom, the "MS hug," where patients describe a squeezing, constricting feeling, can sometimes occur around the chest and thorax. And in those situations, patients may feel that they have difficulty getting a deep breath, because they feel a tight, squeezing feeling. But I think this is more of a sensory phenomenon in multiple sclerosis rather than a true difficulty with breathing and respiration.

>>Kate Milliken: Can you talk a little bit about why there are so many symptoms and all these different ones, some common, some not, and whether there is any way of knowing the frequency of how these symptoms happen?

>>Dr. Stephen Krieger: Well, MS is an incredibly varied disease, and as everyone who is watching this knows, no two patients with MS have exactly the same story. That can make it frustrating in a sense, because it's hard to know for a given patient what to expect or what their MS is going to be like. And it makes it challenging for the neurologist and for the physicians to know what is being caused by MS and what isn't. So, the common symptoms are common, and those are ones that we all recognize are likely due to MS.

But I think it is important for physicians to be aware of and vigilant about making sure that if someone presents with an uncommon symptom that it gets properly pursued, that it's not just written off as being part of multiple sclerosis. I often tell healthcare professionals, as we get better and better at taking care of people with MS, they are going to live longer and more normal lives, and therefore they are going to come down with things that affect everybody else. And we have to be careful not to just say, "It's your MS." So, that is something that's important.

It's important that patients talk to their doctors about the symptoms that they are experiencing and work with them to get to the bottom of them.

>>Kate Milliken: Well, that's what I was going to say. On the flip side, if a patient is having a symptom that could be MS or could not be MS, how do they know that it's MS related?

>>Dr. Stephen Krieger: Well, I think that, although we like to partner with our patients and work with them in a collaborative way, I think the burden of figuring out what is MS and what isn't MS shouldn't be on the shoulders of the patient. I think that needs to be on the shoulders of their doctors. I think what the patients need to know is that they are to feel very free to talk to their physicians and their neurologists and their nurse practitioners about the symptoms that they're having to give them the information they need to figure it out. They can sometimes be quite challenging. But I think that if a patient is experiencing something that seems unusual or different, particularly if it lasts for more than a day, they should call up somebody who is taking care of them and discuss it, and see if it gets up their concern.

But figuring out what is MS related and what is not MS related is a bit of a challenge. Thankfully, we have both the ability to examine patients and look at them neurologically and see if the symptom is causing something that we can recognize. And also workups including diagnostic imaging, like MRIs, and MRIs, although not perfect, can often show us if there are changes that MS is causing that are giving rise to particular symptoms. And so frequently, if someone is experiencing a new symptom, they may merit getting a new MRI, to see if the MS is causing it.

>>Kate Milliken: Dr. Krieger, thank you so much.

>>Dr. Stephen Krieger: My pleasure.

>>Kate Milliken: If you would like to get more information on symptoms of MS, go to nationalmssociety.org. This is Kate Milliken for MS Learn Online. Thank you for joining us.