



**National
Multiple Sclerosis
Society**

**MS Learn Online
Feature Presentation
Managing Symptoms: Pain
Nancy Holland, Ed.D, RN, MSCN**

Tom>> Hi, I'm Tom Kimball

Tracey>> And I'm Tracey Kimball. One of my sisters also has MS and sometimes we joke that the "multiple" in multiple sclerosis refers to the many different symptoms we can experience with this disease: fatigue, muscle spasm, spasticity, cognitive dysfunction, and the list goes on. For the longest time pain has not been recognized as an MS symptom.

Tom>> After all pain is pretty common for a lot of people who don't have MS and it takes on many different forms. Medical correspondent Rick Sommers sits down with the National MS Society's Nancy Holland, Vice President of Clinical Programs. She begins with a bit of history about the role pain can play in the overall MS picture.

>>**Nancy Holland:** Pain, along with fatigue and cognitive dysfunction, all of which are extremely distressing and can be severely disabling, were not recognized in MS, and I think this was because there were -- when there were no treatments for the disease course, people with MS were not seen very frequently by the neurologist. In fact, my mentor in this field, Dr. Labe Scheinberg, coined a phrase, "Diagnose and adios," because essentially what the neurologist said is, "Sorry you have MS, but I can't do anything to help you; learn to live with it." And so doctors didn't see people often enough or have enough conversations with them to really

recognize that these were very serious problems, pain being obviously one of them.

>> **Rick Sommers:** See, we learn something every day, because I always wondered where that phrase came from, "Diagnose and adios." When we talk about pain in MS, what kinds of pains are we talking, and is pain different than an ache? I have aches, but is that considered pain?

>> **Nancy Holland:** Well, I think it's how you describe it. People describe their pain in different ways. So, yeah, an ache is probably pain. Some people talk about discomfort, but it's pretty much the same thing. I think it has to do more with the degree of intensity than to whether it's pain or not.

The kinds of pain that we see in MS, there are two types. One is the primary pain that comes from damage from lesions in the central nervous system. This is also neurogenic pain. One of the most distressing types of pain that people experience is trigeminal neuralgia, with the French name of tic douloureux. This is very severe pain in the lower part of the face, and it can happen to anyone with or without MS, but it happens much more frequently in MS. In fact, the statistic is about 400 more times in the MS population, even though only about 4% of people with MS actually experience it. But it is such serious pain that it's worthy of mention, and it also tends to be one of the symptoms of MS that will recur after a few months.

It does generally respond to medication. Anti-seizure medications are used, and in extreme cases, if these medications are not working, sometimes hospitalization and intravenous medication is required. But this is very, very rare. It's just important for people to know about it, to know that there are options and that the pain will be treated and will be relieved.

Headache, which is common in the general population, is more common in MS than it is with those who don't have MS. About 58% of people with

MS experience headaches, and these tend to be the same ones that you see in other people -- tension headache, migraine headache.

There's another primary pain called dysesthesia, and this is when the individual experiences painful sensations. It can be a burning sensation, stabbing sensation, stinging sensation. These all fall under the category of dysesthesia.

There is one that people with MS have called the MS hug, and this is a feeling of uncomfortable, painful tightness around the rib cage, around the trunk, the entire torso, around the rib cage, and it's experienced, generally, as I say, it's uncomfortable, sometimes painful.

And there's another kind of pain called allodynia, and this is certainly not very common, and that's when a stimulus of some kind causes the pain. And it's usually something like touching the skin, clothing can do it, bedclothes can do it. And the good news is that it clears by itself pretty quickly. But there are things that can be done. Wearing loose clothes, having a bed cradle, which will keep the bedclothes off the legs, which is where it happens most often, can be helpful.

>> **Rick Sommers:** That's like the hypersensitivity that leads a lot of people to their diagnosis, is that tingling and that touch to the certain part of the body.

>> **Nancy Holland:** Well, the kind of sensory problem that leads people to their diagnosis is more often what you described, a tingling or a numbness rather than actual pain. But certainly pain can be the first symptom of MS as well. And secondary kinds of symptoms are not directly the result of damage in the central nervous system but are secondary to an MS problem.

Probably the best example is the pain from spasticity. The spasticity itself is caused by lesions in the central nervous system, but the pain that can result, not always and not even all that often, would be considered a

secondary symptom. And the management of that is to treat the underlying problem, in this case the spasticity, which can be managed generally with medication, which will then relieve the pain that results from that.

And the other secondary, or another secondary type of pain is musculoskeletal pain, and this results primarily from deconditioning, which lots of us are deconditioned. But people with MS just have a harder time staying in good physical shape because of fatigue, of difficulty moving, or whatever. And so you can get aches from that, and they're generally relieved by just over-the-counter kinds of things, like aspirin or Tylenol.

>> **Rick Sommers:** Let's talk about pain management. Different people have different MS, different people treat their pain differently. Is there one way, a high road, that you would recommend?

>> **Nancy Holland:** Okay, there is not currently a medication that is FDA approved for pain management, but clinicians have found drugs like Neurontin very, very effective for helping their patients relieve their pain. So, I would say that's probably the main treatment for primary MS pain.

>> **Rick Sommers:** How about over-the-counter?

>> **Nancy Holland:** Over-the-counter is useful for things like headache, and can be helpful, but tends not to. In fact, even the stronger medications, the opiates, tend not to relieve pain that's of neurogenic origin. You really need something that's going to target that kind of pain specifically, which is, as I say, generally the Neurontin.

So far as secondary pain, massage works very nicely for the muscle aches that people get. And the spasticity that I mentioned, there are several medications that work very, very well in relieving spasticity and secondary pain. And if at some point the drugs aren't working well or become too sedating, if the dose become very, very high, there is a procedure whereby a pump is inserted that delivers the medication directly into the spinal canal,

and so doesn't cause the sedation. This is actually not a big procedure to have done. It's pretty comfortable and really allows the person to have very significant relief of spasticity. But this is really talking about very severe spasticity that has not responded or is no longer...

>> **Rick Sommers:** So, there is an upbeat, there is help out there.

>> **Nancy Holland:** Yes, definitely.

>> **Rick Sommers:** And you should discuss it with your doctor or your primary care, whoever it is, that you deal with with your MS.

>> **Nancy Holland:** Yes. Pain, fortunately, is a symptom of MS that can be managed.

Tracey>> Pain is not usually one of the symptoms that one associates with MS but it certainly has been for me.

Tom>> Once again it is so important to tell your doctor about all of your symptoms whether you think they are MS related or not. Keep in mind there are a number of ways to manage the pain.

Tracey>> That's right. Your doctor can help determine the right course of treatment for you.

Tom>> Thanks for joining us on MS Learn Online.