Pain, pain go away

MS pain is real. Learn the experts’ top methods for managing it.

by Vicky Uhland

Andrea Williams was 36 years old and had been living with multiple sclerosis for six years when she began having back pain. At first, it was mild, with numbness and tingling, so her general practitioner recommended physical therapy. That didn’t relieve the pain, so he gave her a dose of oral steroids. No success. Finally, her doctor recommended a magnetic resonance image (MRI). She was diagnosed with nerve pain (known medically as neuropathic pain) caused by MS and given a prescription for gabapentin, a seizure medication also used to treat nerve pain.

The medication took a few days to kick in, and then for a few glorious months, Williams’ back pain disappeared. But then it returned with a fury—a burning, radiating pain in her lower back and tailbone. Over the next three years, doctors gradually upped her dosage of gabapentin to the maximum allowed. When that offered minimal relief, Williams visited two different pain management clinics near her home in McHenry County, Illinois. A clinic doctor prescribed two narcotics: oxymorphone and fentanyl. When those weren’t effective, he recommended a pain pump—a device that is inserted into the abdomen. The pump delivers pain meds continuously to the spine through a catheter. But problems arose for her during the trial period to see if the pump would be effective, so she discontinued it.

Williams started doing daily Internet searches for anything—no matter how farfetched it sounded—to relieve her pain. She discovered a process called cooled radio frequency, in which electrodes are inserted near the irritated nerves. The electrodes heat and then cool the surrounding tissue, decreasing pain signals. She convinced one of her doctors to try it and got two weeks of relief. But then the pain returned.

“At that point, my doctor threw his hands up in the air,” Williams remembers. “He said, ‘It’s MS pain. There’s nothing I can do.’ ”

Today, six years after her back pain started, Williams takes the maximum daily dose of gabapentin, along with two opiates—tramadol during the day and morphine at night, so she can sleep. “Some days my pain is as low as a 2 or a 3 [on a scale of 1 to 10], but most days it’s a 6 to an 8,” she says. “It affects every part of my life—even my marriage. It makes me crabby, and my husband gets the brunt of that.”

Though Williams remains optimistic and is exploring other pain management strategies, she wonders if her doctors really take her pain seriously. “I haven’t found it to be addressed by physicians as urgently as it needs to be,” she says. And she’s not alone in that opinion. Discussions on the National MS Society’s online MS community, MSconnection.org, are punctuated with stories from people who feel like their doctors downplay their pain or even refuse to acknowledge it as a symptom of MS.

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Feeling the pain

But MS pain is real. A new study of 115 people with MS—published in April in the **Archives of Bone and Joint Surgery**—found that 88 percent had pain, and 54 percent said their pain interfered with their daily functioning. The average pain severity was 3.8 on a scale of 10.

Another study, published in June in **Pain Medicine**, found that of 650 people with MS, 67 percent had pain, and their aches had a significant impact on their quality of life. Nearly 30 percent of the people with pain also had depression, and the researchers found high levels of anxiety as well.

“Pain may be so great that it prevents a person from leaving his or her home, causing social and emotional withdrawal from activities and people that, prior to the pain, may have brought great joy,” says Amanda Rohrig, a physical therapist with Horizon Rehabilitation Centers in Omaha, Nebraska, and a consultant to Can Do MS.

But that doesn’t mean that people with MS are doomed to a lifetime of agony. There are some interventions that have been found, both in studies and anecdotal reports, to be effective at either alleviating or lessening MS-related pain.

Like Williams, many people with MS use a variety of approaches to relieve their pain. A study of 125 people with MS, published in July in **Disability and Health Journal**, found that 90 percent had tried multiple pain treatments—an average of nine different treatments per person. Overall, 75 percent of the study participants said they had visited a healthcare provider in the past six months looking for pain relief. And not just once; they made an average of 10 visits during that six-month period. Eleven percent even went to the emergency room because they were in so much pain.

The researchers noted in the report that “few [treatments] were rated as providing pain relief” by the study participants. This may be because, like the disease itself, MS pain is difficult to diagnose and treat. “MS pain may be more complex than other types of pain because of the assortment of potential causes and the fact that the pain can change from day to day, hour to hour or minute to minute—similar to other symptoms of MS,” Rohrig says. “A good detective is often needed to determine the cause and exacerbating factors of the pain.”

Explaining MS pain

Dr. Alexander Rae-Grant of the Cleveland Clinic’s Neurological Institute admits “there hasn’t been as much research done on MS pain as there probably should be.” But he says scientists suspect that some MS-related pain is caused by problems with sensory neurons. These nerve cells transmit information from your senses to your brain, which translates that message into the appropriate response.

But because MS damages nerves, sensory signals can get distorted. “Think of it as a cable that’s not totally connected to a TV,” Dr. Rae-Grant says. “The signal gets blurred.” As a result, your brain may misinterpret sensory signals. And one of those misinterpretations can be pain. So even though your sensory neurons may not be transmitting that your back hurts, your brain may be interpreting it that way.

Dr. Gordon Ko, assistant professor in the University of Toronto’s Division of Physical Medicine and Rehabilitation, and a member of the editorial board of **Practical Pain Management** journal, says there are three main types of MS-related physical pain: neuropathic, musculoskeletal
and psychological.

Neuropathic pain most often feels like electric shocks or burning. But it can also include sensations of pins and needles, itching, numbness or tingling. According to a report by Heidi Maloni, PhD, national clinical nursing director at the Multiple Sclerosis Center of Excellence in the East Veteran Affairs Medical Center in Washington, D.C., this type of pain can have varying degrees of severity. It may be constant or intermittent, and can be caused by something as simple as the weight of a blanket or a cold breeze. It may be worse at night, during temperature changes or as a result of exercise.

Dr. Ko says about 25 percent of people with MS have whole-body neuropathic pain. There are three common types of specific neuropathic pain associated with MS:

- **Trigeminal neuralgia**. This sharp, stabbing pain in the cheek or jaw can be an early symptom of MS, especially for younger people.
- **L’hermitte’s sign**. Bending the neck forward can induce this brief, stabbing sensation

that can feel like repeated electric shocks from the back of the head down through the spine.

- **Dyesthesia**. This type of pain can include burning, aching or a constricting feeling in the legs, feet, arms or chest. When a squeezing sensation is felt in the torso, it’s often called, somewhat ironically, “the MS hug.”

Musculoskeletal pain is usually an ache and can be triggered by movement. Dr. Ko says in people with MS, spasticity is a common source of this type of pain. Musculoskeletal pain can also be the result of MS-related posture issues, muscle imbalance, or compensation for gait or balance challenges, according to Rohrig. This can cause back, knee, ankle, hip, wrist or other types of non-nerve-related pain.

Psychological pain doesn’t mean phantom or imagined pain, but rather mental and emotional factors that can affect the severity and intensity of physical pain. “Stress, anxiety, depression, not enough support from family members, not enough sleep—they all contribute to pain,” Dr. Ko says.

Pain killers

Dr. Rae-Grant says there are no medications approved by the U.S. Food and Drug Administration specifically for MS-related pain. So doctors prescribe drugs that are used for other conditions in the hope that they will also be able to stop MS pain.

For neuropathic pain, Dr. Ko says doctors frequently prescribe anticonvulsant drugs to help stabilize the nerves and the signals from the brain. These medications include carbamazepine (Tegretol), oxcarbazepine (Trileptal), lamotrigine (Lamictal)—and gabapentin, like Williams takes.

Corticosteroids also help reduce nerve inflammation that can cause pain. And Dr. Ko says sometimes people with neuropathic pain are given antidepressants, which can dampen pain signals sent by damaged nerves to the brain.

Duloxetine (Cymbalta), an antidepressant medication, is increasingly being used for MS nerve pain. A study published this spring in the **International Journal of MS Care** shows that people with MS who took duloxetine had 29 percent less average daily pain than people who took a placebo. In addition, Dr. Rae-Grant says pregabalin (Lyrica) is thought to work similarly to duloxetine in people with MS pain, but through different and complementary mechanisms. “It can change how the nervous system handles pain, and how it interprets the signals after nerve firing,” he says. The two types of medication can be used together for neuropathic pain if necessary.

None of these medications are effective for spasticity and other musculoskeletal pain, Dr. Ko says. Instead, doctors tend to prescribe muscle relaxants like diazepam (Valium), baclofen (Lioresal) or tizanidine (Zanaflex). Epidural cortisone shots can also be effective.

To alleviate her MS-related leg pain, Heather Stull, of Boise, Idaho, takes Botox and does daily stretches. Photo courtesy of Heather Stull

Dr. Ko is a fan of another type of muscle relaxant—Botox injections. So is Heather Stull, a Boise, Idaho, resident who has had MS-related leg pain since 2010. “It’s a constant dull ache, mainly in my calves. It makes walking difficult, and I can’t sleep,” Stull says. “It tends to go in waves—I’ll have it for a while, it will fade away for a month, and then it will come back really bad for a few weeks.”

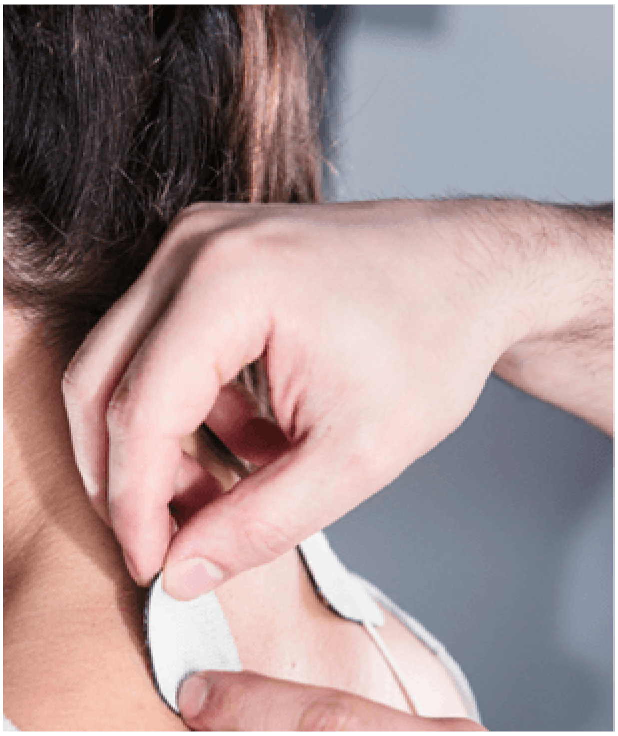
Her doctor prescribed baclofen and the opiate hydrocodone for her leg pain, but that didn’t work. Then Stull tried Botox—which is approved by the FDA for spasticity—and got instant relief. Every three months, she gets 10 to 12 small injections of Botox in her legs. “By the middle of the second month, the pain starts creeping back, but it disappears again when I get another set of injections,” she says.

Stull also does 10 to 15 minutes of daily stretches for her leg pain, but she hasn’t tried any other type of non-drug treatment. “My mom’s an RN, so I’ve always believed in medications,” she says.But some medications may actually be counterproductive, especially when it comes to opiates. “There’s some pretty good evidence that [in the long run] narcotics make pain worse,” says Dr. Rae-Grant. “They can sensitize the nervous signals, which creates more nerve pain.”

So what should you do instead? “If you want to make improvements in your pain management, you usually have to go beyond the medication paradigm," says Dr. Ko.

Yes, we CAM

Dr. Maloni and others believe the answer to chronic pain may be through a "biopsychosocial approach" that encompasses not only the body, but also the mind and spirit, she says in her report. Complementary and alternative medical (CAM) approaches to pain management encompass non-drug therapies such as electrical stimulation and acupuncture, natural substances such as dietary supplements and cannabis, psychological interventions such as meditation and stress management, and lifestyle modifications such as diet adjustments and behavioral therapy.



Transcutaneous electrical nerve stimulation offers pain relief with low-voltage electrical current.

Electrical stimulation devices. Transcutaneous electrical nerve stimulation (TENS) and interferential current (IFC) block pain transmission and sensory neuron interpretation from the spinal cord to the brain, Rohrig says. A review of four studies, published in May in **Multiple Sclerosis and Related Disorders**, found that TENS therapy safely reduces chronic pain in people with MS.

TENS and IFC therapy can be self-administered via a battery-powered machine about the size of a cellphone. The machine powers two electrodes that are placed on the skin near the painful area. Rohrig says a physical therapist can show you how and when to use the machine, and can suggest devices that are eligible for insurance coverage.

Radial shockwave therapy. Physical therapists or other healthcare professionals apply a wand that emits high-energy sound waves to painful parts of your body. These sound waves (scientifically known as shockwaves) are thought to reduce the muscle hypertonia (tightness) that contributes to spasticity-related pain. One study, published in Multiple Sclerosis in April, found that radial shockwave therapy reduced ankle pain in people with MS.

Acupuncture. There is quite a bit of evidence that this ancient Chinese healing modality can alleviate pain. Acupuncture involves placing fine needles along meridians, or channels, in the body to unblock vital energy, also known as chi or qi. Acupuncturists say blocked energy can contribute to pain, along with a variety of other mental and physical conditions.

The evidence is limited on acupuncture and MS pain, however. A June 2014 review of MS-related acupuncture studies, published in **Evidence-Based Complementary and Alternative Medicine**, found only two studies having to do with pain. One study involved only one woman. In the other study, researchers found that biweekly acupuncture treatments for six months significantly improved pain-related disability. However, the researchers didn’t report whether the participants used pain meds in addition to acupuncture.

Acupuncture generally needs to be ongoing to successfully treat pain, making it too costly for some people with MS. “I’ve never tried it because it’s not covered by my health insurance,” says Williams. Some insurers do pay for acupuncture treatments, though, so check with your provider.

Vitamin B12. All of the B vitamins have been shown in a variety of studies to improve neural health, but Dr. Ko says B12, in particular, is known as the nerve vitamin. He suggests asking your doctor to check your B12 levels to make sure you’re not deficient.

Cannabis. Clinical trials show promising results for medical marijuana’s ability to manage pain. However, it’s still illegal federally and in many states. That’s why Dr. Ko prefers synthetic cannabinoids, such as the FDA-approved Marinol or nabilone (Cesamet). “I’ve been prescribing cannabinoids for 20-plus years, and I’ve found that not only do they help relieve pain, but they’re less addictive than opiates like oxycontin,” he says.

The American Academy of Neurology released evidence-based guidelines in 2014 that rated complementary and alternative treatments for MS symptoms as either level A, B or C. Oral cannabis extract scored a level A for spasticity and non-neuropathic pain. However, with regard to cannabis plant material, Dr. Rae-Grant points out that the data’s “not great” in terms of how specific strains affect MS pain. Consequently, “it’s our last line of defense,” he says.

Meditation and hypnosis. "You can't just tell yourself not to think about pain," Dr. Ko says. "You need instruction in how to do that." A 2011 study showed that people with MS who practiced self-hypnosis either with or without cognitive behavioral therapy had statistically significant decreases in pain. A variety of classes and books teach these techniques.

Exercise. For some people, exercise can lessen pain. But for others, it can make it worse. Rohrig recommends checking with your doctor or physical therapist before beginning an exercise program.

Nutrition. A diet that's high in sugar and simple carbohydrates like white bread and pasta can increase inflammation—which can increase pain, says Dr. Ko. Supplementing with omega-3 fatty acids may help with pain and nerve function, he adds.

Sleep. Dr. Rae-Grant says this is a Catch-22: Pain can prevent sleep, and lack of sleep can contribute to widespread pain throughout your body. If you're having trouble sleeping, Dr. Ko suggests a sleep study to address conditions such as sleep apnea and restless leg syndrome, often seen in people with MS.

Stress management. Dr. Ko recommends meditation techniques as well as talk therapy—whether it's with a group of other people with MS pain, with your family and friends, or with a professional counselor.

Because MS pain can be as individual as the symptoms, Dr. Ko and others say it's important to be open to trying a variety of therapies, often at the same time. That message certainly resonates with Williams.

"I'm bound and determined not to give up," she says.

“I know there’s pain relief out there somewhere.”

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

Visit MSconnection.org to talk to others about how they manage MS-related pain.

You’re not alone. Pain is one of the most common symptoms in multiple sclerosis. Recent studies are investigating why and how pain occurs as part of MS.

Read more about managing pain and MS from the National MS Society’s resources.x