

# Pain and MS:

## Options exist to manage this difficult symptom

by Avril Roberts

The first time she felt sharp pains shoot up her legs and arms, Janet Liston thought she imagined it. When the pain returned from time to time, she considered it an annoyance. “The pain was short-lived and didn't interfere with my life so long as I kept myself distracted.” Janet was familiar with painful muscle spasms, but she didn't know that this shooting pain was also an MS symptom and that there were treatments for it.

Pain is a serious issue in multiple sclerosis. More than 50 percent of people with MS will experience some kind of pain. It occurs equally in relapsing-remitting and progressive MS but is as variable as any other MS symptom. It may be mild or severe, short-term or long-lasting, spontaneous or triggered by external factors like heat, movement or touch. People also experience it in a variety of forms: leg cramps; stiffness; spasms; sensitivity to heat, cold, touch; burning; pins and needle sensations; joint pain; a feeling that something is crawling under one's skin.

For some people, pain is their worst symptom next to fatigue, stealing a part of their lives, flatlining their careers and wreaking havoc on their relationships with family and friends. “When it's intense, it can be all you can think about and make it hard for you to function normally, interact with people, feel sympathy, be personable or polite,”

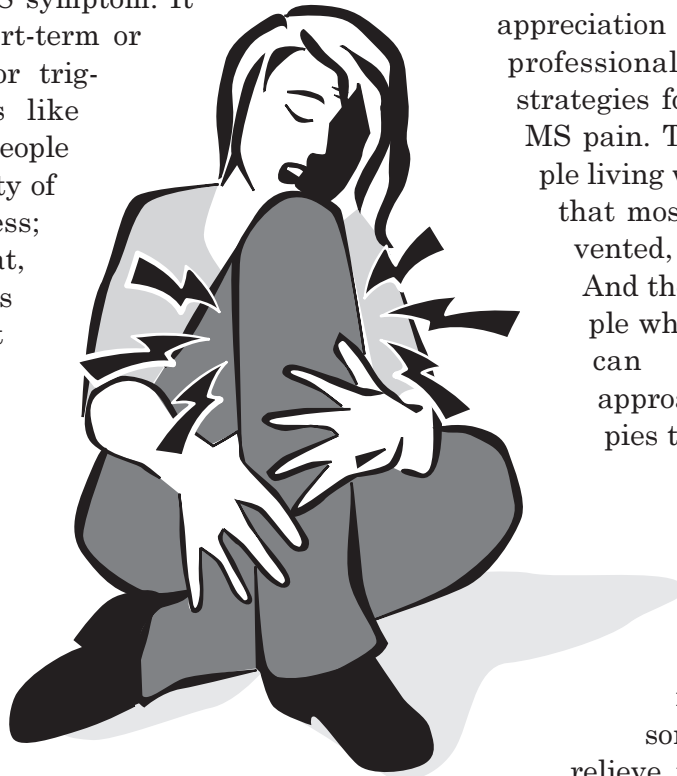
said Janet, who lives in Carp, Ontario. “It's difficult to do any of those things when you are so focused on yourself and your discomfort.”

In the past – and occasionally still today, MS pain was sometimes discounted by health professionals or misdiagnosed. Thirty-seven years ago, Lyn Thompson of Winnipeg had pain in one eye then the other. After experiencing a variety of baffling symptoms, including pain, Lyn was eventually diagnosed with MS in 1991.

### Managing pain in MS

Today, with a better understanding of the reasons for pain in MS and a greater appreciation of its complexity, health professionals have developed new strategies for assessing and treating MS pain. This is good news for people living with MS because it means that most pain in MS can be prevented, eliminated or improved. And the small percentage of people who experience chronic pain can try multidisciplinary approaches and newer therapies to manage their pain.

Managing pain in MS involves being aware of the different treatments for pain, combining treatments and therapies and, if necessary, adding personal elements that work to relieve pain. Also important are setting realistic goals for pain management, recognizing that this is a part of multiple sclerosis – and everything is subject to change.



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The treatments for pain in MS are determined by the *cause* of the pain – whether it is directly or indirectly related to MS and the *quality* of the pain – how a person experiences or perceives pain.

A person with MS may have pain caused by another illness, such as fibromyalgia or arthritis, which a physician can identify or rule out.

There may be pain that is indirectly related to MS. “If somebody is in a wheelchair, or if they have altered mobility because of MS, they can get musculoskeletal pain, problems with the bones, joints and muscles just from muscle imbalance, prolonged sitting or sitting with a poor posture,” explained Dr. Mary Lou Myles, an Edmonton MS neurologist.

And there is the pain that is a direct result of the MS disease process – the attack on myelin, the damage to nerves and the disruption of nerve pathways, particularly those related to pain and sensation.

Some types of nerve pain in MS have a paroxysmal quality, meaning the pain is sudden and intermittent. This pain symptom is due to short-circuiting along nerve fibres stripped of myelin. “The best example of that is trigeminal neuralgia,” said Dr. Myles. It’s a stabbing, electric shock-like facial pain experienced by up to seven percent of people with MS.

Trigeminal nerve pain is Lyn Thompson’s worst MS symptom right now. “It starts at the midline on the top of my scalp and goes down the left side of my face. It’s never exactly the same each time.”

“Sometimes, it feels as though someone’s trying to sand the skin off my nose on one side. Other times, it feels like someone’s sticking a cattle prod in me and it’s like an electric shock. Sometimes, it will fire intermittently, zap, zap, zap. Other times, it just starts and it holds, and it can go on until

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I’m in tears.” A light breeze, brushing teeth or chewing can trigger it. It can also happen right out of the blue.

Murray Sawler of Fredericton, New Brunswick has had five or six encounters with another type of paroxysmal pain called l’hermitte’s sign. It feels like an electric shock crackling down his neck and back when his head is flexed forward.

“It goes down to the end of my spine, down each arm and leg and out to my fingertips and toes. When it happens, it will almost knock you down. It’s very painful, afterwards.”

Some people experience paroxysmal limb pain as a sharp, shooting pain in the legs or arms. Others may describe it as more of a burning, aching, itching kind of pain that comes and goes.

### Finding pain solutions that work

The treatment of choice for paroxysmal pain is anticonvulsant medication – usually carbamazepine (Tegretol), gabapentin (Neurontin) or one of a number of other similar medications – to block the short-circuiting of nerve signals. In the most extreme cases, nerve block surgery may be recommended to alleviate the pain.

Dysesthetic pain is a type of nerve pain associated with abnormal or distorted sensation. For instance, a persistent, burning, aching, prickling or creepy-crawly sensation, usually in the extremities. Or a tightness around the abdomen, a feeling some people call the MS hug. “It can fluctuate in severity but it doesn’t have the same lightning-type properties as paroxysmal pain. It’s a more constant pain,” said Dr. Myles.

“The most common experience is burning pain and other hypersensitivity. For example, a feeling that some part of the body is too hot or too cold, even though it isn’t. Or perceiving what would usually be a non-painful touch as very painful.” Murray Sawler finds that at times, his scalp hurts when he brushes or combs his hair and “to even wear a cap is almost unbearable.”

This chronic dysesthetic nerve pain is experienced by about 30 percent of people with MS. It often gets worse at night, after exertion and in hot weather. It is believed to be a direct result of the loss of myelin from the sensory pathways of pain and temperature.

Treating and managing chronic nerve pain is particularly challenging, possibly because of the added emotional stresses of living with constant pain. In the absence of official clinical guidelines for managing neuropathic pain, physicians take a step-by-step approach to treating it.

The first line of treatment is often tricyclic antidepressants – usually amitriptyline (Elavil) – to reduce pain, sedate, and help with sleep. These drugs block serotonin, one of the chemicals necessary for communication between nerve cells.

If the antidepressant fails or if a person cannot tolerate the side-effects, then gabapentin (Neurontin) or another anticonvulsant is tried.

For people who don't respond well to the antidepressants or anticonvulsants, opiates – narcotic-based painkillers, including methadone – may be prescribed, usually in combination with other drug therapies. "Opiates alone usually aren't enough," Dr. Myles said. Also, opiates can affect bowel function, which, in turn, can affect bladder function, making opiates a less attractive option for people with MS.

Now there is Sativex, a spray containing two of the active ingredients of cannabis – tetrahydrocannabinol (THC) and cannabidiol. It was approved by Health Canada in April 2005 for treatment of MS-related pain. Chemicals in the mari-

juana plant appear to prevent neurons from becoming overactive and causing neuropathic pain. Sativex is sprayed under the tongue or inside the cheek and the dosage can be adjusted.

Pain from muscle spasms and spasticity is common in MS but about 10 percent of people

will have painful involuntary muscle contractions, typically involving the muscles on the one side of the body, known as painful tonic spasm. In tonic spasms, a muscle contracts suddenly causing a violent, painful extension or flexion of a limb; it feels like an extreme cramp. Some people experience it mostly at night. Tonic spasms are distinct from the spasms caused by spasticity and are treated differently – usually with anticonvulsant medications.

Anticonvulsants are not typically used for spasticity or the spasms that occur along with it. Pain from spasms or spasticity is best managed with antispasticity medication such as baclofen (Lioresal), dantrolene (Dantrium) or tizanidine (Zanaflex); and a regular program of stretching exercises or physiotherapy. Botox injections can relax spasms in specific areas.

People with multiple sclerosis pain can apply as well for a permit to possess

or grow marijuana for medicinal purposes, under the federal government's medical marijuana access program. For details on how to apply for the permit, visit the Health Canada website: <http://www.hc-sc.gc.ca>. Go to the A – Z Index. Click on C, scroll down to Cannabis and click on Medical Use of Marijuana.

### **Tips for communicating with health care professionals about pain**

- ◆ Keep a diary of your pain. Record:
  - location of pain
  - severity of pain
  - time and extent of the response
  - time of day
  - what the pain feels like
  - what improves or worsens the pain:
    - activities
    - heat/cold
    - certain positions
  - any changes in the pain over time
  - any new pain symptoms
  - any treatment side-effects
- ◆ Take a list of medications (prescription and herbal) and complementary therapies.
- ◆ Discuss realistic expectations for managing your pain.
- ◆ Discuss your satisfaction / dissatisfaction with your pain management strategy.
- ◆ Seek a second opinion from your neurologist, if necessary.
- ◆ Ask for a referral to a pain specialist, if you don't think your doctor understands the impact of your pain.

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For lower back pain, usually due to strain on weakened muscles, a combination of physiotherapy and non-steroidal anti-inflammatory medications (NSAIDs) such as ibuprofen can provide relief. An occupational therapist can assess proper seating, posture and movement in the home or work environment.

Corticosteroids and NSAIDs can treat pain from optic neuritis, which is inflammation or demyelination of the nerve that transmits light and visual images from the retina to the brain.

Non-drug treatments for pain in MS include exercise, to release the body's natural pain-reducing chemicals; nerve stimulation, through acupuncture or transcutaneous electrical nerve stimulation (TENS); massage, to stimulate blood flow throughout the body, which may promote relaxation and relieve pain; and other alternative and complementary therapies. Psychological counselling can be useful to learn coping strategies for living with pain.

### **A multi-faceted approach**

Dr. Myles encourages her patients to take a multi-faceted approach to managing chronic pain. "Pain is such a complex symptom that, more than many other symptoms, you have to approach from a number of different angles. It's usually not a matter of just taking a pill."

Murray Sawler's prescription for pain relief includes an array of medications, classical music, reading upbeat or educational materials, massage, physiotherapy, occupational therapy and keeping a positive attitude.

He is so enthusiastic about the benefits of massage that he helped set up a program where people with MS receive massage therapy from students training at the Atlantic College of Therapeutic Massage in Fredericton. After a single massage session, he can cut back on his pain medication for three to five days.

Sheer determination gets him out of bed everyday. "I give it all I've got when I get up in

the morning. I don't ignore the pain if it's there. I recognize it but I know that if I do too much, the pain will get worse tomorrow. So I do as much as possible today and maybe tomorrow I will have to let nature take its course and have a more relaxing day."

Lyn Thompson's facial nerve pain is so severe that she has visited a pain specialist and she has had nerve block surgery five times over the past 10 years. She now takes a drug cocktail every day – a mix of anticonvulsant, antidepressant and

other medication – to keep pain at bay. "Right now, it's not preventing my trigeminal nerve pain. What it's doing is holding it at a level I can live with most of the time and it's stopping many of the major spasms." The deep breathing exercises of yoga help keep her calm when pain threatens to take over her world.

Sometimes she worries about the health effects of being on such aggressive drug therapy. "If I take these drugs, are they going to have side-effects? Is it perhaps even possible that they're going to shorten my life span?" Then she remembers the advice she gives to people in the MS self-help group she facilitates: "Quality of life is important. *Carpe diem*. Seize the day. While you're here, do whatever you have to do to get through."

*Avril Roberts is a Toronto-based health writer with an interest in neurological disorders.*

Pain is such a complex symptom you have to approach it from a number of different angles.

Want to learn more? Call your division office at 1-800-268-7582 and ask for a copy of the booklet *Living for Today: Managing MS Pain*.

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