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Getting a Handle on MS Pain

by Rachel Adelson
Illustrations by Dan Page
Living with MS can be a real pain: an aching, burning, stabbing, numbing, cramping, tingling, sometimes overwhelming and often unpredictable pain. While people with MS attempt to blunt the pain with traditional and non-traditional approaches, scientists are hoping to create drugs that can actually block it.

According to recent research, nearly half of all people with MS are thought to live with some level of chronic or recurring pain. Perhaps one in every four people with MS-related pain say that it’s severe enough to hurt their quality of life.

Although pain can’t be measured with objective tools, this symptom of MS is just as real as any other. Just ask the people who have it. Some say their legs feel heavy or numb, or as if they’re being cut off or impaled on hot pokers. Some say they constantly ache, as if with perpetual flu, or they feel bruised, or they feel a suffocating pressure around the chest. Yet they don’t have the flu, there are no knives or pokers, and they haven’t been beaten or crushed. So what on earth is going on?

It’s all in your head, sort of

In a way, pain really is all in the head—but that doesn’t mean it doesn’t hurt. That’s because pain has many dimensions, being the body’s response to a physical threat and the mind’s awareness of that pain response. It’s as much a perception as it is a feeling.

Evolved to protect us from harm, pain tells us to yank our fingers out of fires. Pain on the inside, from a burst appendix or a busted ligament, is also a warning sign.

Pain starts when threat-sensitive nerve cells (called nociceptors) sense danger, be it sharp, hard, hot, cold or chemical. Through long, stringy fibers called axons, these nerve cells send a message up the spinal cord to the brain. A biochemical chain reaction then prompts the brain to do two things: first, create a deeply unpleasant awareness we call pain; second, tell the endocrine system to produce extra stress hormones to heighten senses and reflexes. It’s both a warning and an evacuation system.

But the pain system isn’t perfect. It makes mistakes. For example, even after injury heals, some people find themselves in chronic pain. An over-stimulated nervous system makes extra nociceptors, and it doesn’t take much for them to holler, “Ouch!”

Sometimes they signal pain when nothing’s there. Sometimes they amplify real but mild sensation. And sometimes they throw all the switches, turning warmth into a stabbing sensation or post-workout fatigue into a heavyweight barrage of blows.

MS pain does “all of the above” because MS pain is central; it works from the inside out. Lesions in
the brain and spinal cord and the inflammatory toxins they release damage or destroy the fatty coat of myelin that protects nerve fibers, a process called demyelination. That leads to two problems: first, abnormal creation of nerve-pain impulses; second, amplified pain signals. Both occur anywhere along the pathways of pain. Moreover, the same abnormal signalling may produce “funny feelings”—sensations that might not necessarily be painful, but if intense enough become bona fide, genuine, honest to gosh, man that hurts pain.

It’s not known at what point lesions and inflammation are able to trigger acute or chronic pain.

It’s also hard to link the size and location of lesions to the intensity and location of pain, although lesions below the cervical spine tend to result in lower-body pain.

“Even an MRI is not sensitive enough to predict how lesions lead to pain,” said Barbara Green, MD, director of the West County Multiple Sclerosis Center in St. Louis, Mo.

“But if lesions affect the same nerve tract over and over, for example a tract that conducts sensory information, that can cause ‘wrong information’ to be conducted,” Dr. Green said. “Sometimes that’s pain.”

Tell me where it hurts
Go ahead, complain! Pain must be discussed so it can be diagnosed and treated.

“Just because we can’t see pain, we should not ignore it. It is real and it can affect quality of life,” said pain researcher Stephen Waxman, MD, PhD, Bridget Marie Flaherty Professor of Neurology, Neurobiology, and Pharmacology; director, Center for Neuroscience & Regeneration/Neurorehabilitation Research, Yale University School of Medicine and VA Connecticut. Still, some doctors minimize pain in MS because they “don’t know how to handle something they can’t see or measure, so they dismiss it or say it’s not from the disease at hand,” said Dr. Green.

Some people think they can—or should—tolerate the pain, but “if it becomes limiting or affects other symptoms, it’s time to do something about it,” said Dawn Ehde, PhD, a professor in the Department of Rehabilitation Medicine at the University of Washington MS Rehabilitation and Research Center.

“Even more important,” she pointed out, “early intervention may help people practice self-management strategies sooner and avoid learning bad ways of responding to pain.”
**Talking points**

An accurate history comes first. “Doctors have to determine if it’s MS pain or not and rule out structural causes,” said Dr. Green. “Don’t immediately blame MS for a pain if it’s different or new. Either way, a doctor needs to look into it.”

To get that attention, people need to speak up—which isn’t always easy. “Communication style is so important,” said Rock Heyman, MD, chief, Division of Neuroimmunology/Multiple Sclerosis at the University of Pittsburgh School of Medicine. “For example, some doctors might tune out a patient who seems very emotional.” He suggests people put pain front and center by using statements such as:

- “One of the biggest problems I want to talk about is pain.”
- “One of my priorities in this visit is pain.”
- “My number one thing today is pain.”

Go to the appointment with a list of all symptoms, including itching and burning. Use descriptive wording like dull, throbbing, radiating, stinging, and so on. Also note on the list when the pain gets worse, such as late in the day or when it’s warm. To help the doctor check for drug interactions, bring a list of all prescription and over-the-counter drugs, as well as vitamins, herbal teas and other supplements you are currently taking.

If, despite all the prep, pain still isn’t taken seriously, “Move on to a new doctor willing to work with you,” said Dr. Green.

“Don’t let anyone tell you that there is no such thing as pain in MS because it just isn’t true!” said Tammy Malkowski of St. Clair Shores, Mich. Malkowski keeps a blog (www.picktammysbrain.blogspot.com) about her experiences with MS.

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**Handling pain from spasticity**

**Spasticity** includes stiffness, cramping, joint contraction and muscle spasms (whether brief twitches or short, sharp pain) and requires a special approach. Spasticity comes from spinal-cord damage that hurts motor pathways, said Bruce Cohen, MD, professor of Neurology at Northwestern University Feinberg School of Medicine. Too much muscle tone can make joints stiff and limbs (often the legs) heavy and hard to move. MS can also cause clonus, which makes limbs (again, usually the legs) shake rhythmically.

“People tend to just say, ‘It hurts,’” said Dr. Cohen. “It helps to know the circumstances under which it hurts.” Medical therapies for spasticity include baclofen and tizanidine, which treat a range of spastic movement disorders; muscle relaxants; and benzodiazepines. However, many “benzos” (often used for anxiety) are sedating and can result in dependency. Anti-inflammatories, both prescription and over-the-counter, may also help.

Important therapies for spasticity include stretching, avoiding known triggers such as heat or fatigue, physical therapy and localized warmth, if tolerable. The buoyancy and water resistance of aquatic exercise help people with weak muscles. People can also learn to balance their water intake with adequate sodium and potassium to avoid muscle cramps.

For severe spasticity, doctors may recommend a more permanent solution such as an implanted baclofen pump, which bathes the lower spinal cord in very low levels of the drug. On the plus side, pumps provide finely tuned doses, and today’s pumps are more reliable than in the past, with longer battery life and time-of-day rate controls. On the minus side, surgery always involves a risk of infection and dysfunction. —RA
For help communicating with your doctor, call us at 1-800-344-4867. We can offer communication strategies and resources on pain to share with your health-care provider.

How to make it go away
Pain management in MS should be comprehensive and multimodal. In other words, you and your health-care providers should explore everything until something works. Although there have been no big breakthroughs in recent years, there are more drugs to try and a better understanding of the positive role of complementary approaches.

“We’ll keep making educated guesses on therapies until the pain stops,” said Anthony Reder, MD, professor of Neurology at the University of Chicago Medical Center.

Neurogenic, or nerve, pain is often treated with anticonvulsants. Acute nerve pain can include trigeminal neuralgia, a searing facial pain that can occur with MS; Lhermitte’s sign, a shocking sensation that runs from the back of the head down the spine when the neck is bent; and stabbing eye pain possibly caused by optic neuritis. These “paroxysmal” pains tend to come and go independent of the course of the MS.

Anticonvulsants and/or antidepressants may also improve the odd and painful sensations known as dysesthesias. One example is called the “MS hug, a terrible term for something that creates the brutal feel of constriction,” said Dr. Green. Her patients sometimes tell her that when they eat, they hurt, because of that so-called “hug.”

Anticonvulsants and antidepressants may also calm the burning, aching, numbing, prickling or “pins and needles” sensations called paresthesias. Paresthesias may worsen after surgery or broken bones; and chronically numb areas should be inspected frequently for infection and injury.

Complementary treatments include wearing a pressure stocking or glove, warm compresses, and over-the-counter pain relievers.

There’s no hard evidence yet that low-dose naltrexone (LDN), which is FDA approved for drug and alcohol dependence, eases MS pain, said Dr. Green. In fact, she is concerned that people may use it instead of standard disease-modifying therapies. However, a Society-funded study in 2010 suggested that LDN helps mental health and pain control. Dr. Reder said there are hints that LDN may work by boosting responses to the brain’s natural feel-good chemicals. Further research is recommended.
Finally, some pain responds only to narcotics. Dr. Reder prefers prescribing a sustained low dose only. Narcotics only blunt but don’t stop pain, he reasons, and they can cause fatigue, constipation, bladder problems, a need for ever larger doses and even addiction.

Devices called “dorsal column stimulators” are still being evaluated for their use in chronic pain and have not been studied in MS neurogenic pain. Dr. Green suspects the stimulation could backfire in people with MS, making symptoms worse. She advises a trial period first.

Musculoskeletal pain is not directly caused by MS. In a way, it’s a side effect of daily coping with disability. It stems from inactivity, incorrect use of mobility aids, or the struggle to balance and walk in the face of MS symptoms. Examples include chronic back pain from sitting for long periods; hip trouble from limping; and even osteoarthritis from a chronically hyperextended (the opposite of bent) knee. “Plus people with MS tend to fall, which leads to pain from fractures, sprains, and dislocations,” said Dr. Green. Musculoskeletal pain is treated with anti-inflammatory drugs, physical therapy, heat (if well tolerated), massage (if it is comforting), ultrasound, and treatment for spasticity.

Going green? The questions about cannabis
The National MS Society has recently issued new recommendations about the use of cannabis. Although a medical team concluded that cannabinoids (the active substances in cannabis) have potential to manage MS pain and spasticity, there’s no sign that they work better than existing treatments. MS specialists worry about the impact on cognition, mood and balance, which may already be affected by MS. Until more is known about side effects, systemic effects and long-term effects with data from controlled clinical trials in people with MS, cannabis is not recommended by the team. In Canada, however, a prescription cannabinoid mouth spray called Sativex is approved and legal for treating nerve pain and spasticity.

Cannabinoids may be most promising as neuroprotectors able to prevent nerve damage in the first place. If that’s true, they could become a key part of early MS treatment. Clinical trials of cannabinoids for nerve cell protection in MS are now in progress in the United Kingdom.

Make it go away with complementary approaches
Instead of being “the court of last resort,” complementary therapies are now integrated into pain treatment plans from the start. They help people cope with pain more effectively, often reducing medication use and thus minimizing side effects such as sedation or constipation.
“The randomness [of MS pain] is hard on people,” Dr. Edhe noted. “They never know what they’re going to have to deal with day to day.” The unpredictability and the fatigue from sleep loss make other issues worse, including mood disturbances, anxiety and social relationships. Cognitive-behavioral therapy (CBT) can help.

CBT is a talk therapy that uses the mind’s ability to change emotions and how symptoms are perceived by challenging habitual thought patterns and behaviors. It has been found to help in many painful ailments. It might not make pain go away, but it can foster behavior that minimizes the impact.

For example, Dr. Ehde explained, thinking “oh this is awful” or “I can’t stand this” are typical responses to pain that actually make pain worse. “People with MS can employ more helpful or constructive thoughts instead, such as ‘I may be

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Medications used for MS pain

Pain management is a two-step process: First, careful assessment to select appropriate medications; second, adding mental health support and/or complementary therapies such as yoga and meditation. The chart below lists some examples of drugs that may be used for different types of MS pain.

<table>
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<tr>
<th>Type of Pain</th>
<th>Class of Medication (with generic examples)</th>
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<tr>
<td>Neurogenic pain (nerve pain), chronic or episodic, such as burning, tingling, pins and needles in the extremities, often at night.</td>
<td><strong>Antidepressant agents:</strong> Tricyclic (amitriptyline, nortriptyline, desipramine…); SSNRI (duloxetine, venlafaxine…)</td>
</tr>
</tbody>
</table>
| Intermittent, paroxysmal neurogenic pain that is sharp, searing stabbing pain such as trigeminal neuralgia and painful tonic spasms. | **Antiepileptic agents:** carbamazepine, oxcarbazepine, lamotrigine, gabapentin, pregabalin, valproic acid, phenytoin  
**Antispasticity agents:** baclofen  
**Benzodiazepine agents:** clonazepam (avoid in combination with opioids)  
**Weak opioid agent:** tramadol |
| Continuous, steady neurogenic pain such as painful extremity dysesthesias     | **Antidepressant agents:** amitriptyline, duloxetine  
**Antiepileptic agents:** gabapentin, pregabalin, lamotrigine, carbamazepine, topiramate, levetiracetam  
**Weak opioid:** tramadol  
**Strong opioids:** buprenorphine, fentanyl, oxycodone |
| Mild/moderate nerve pain, such as dysesthesias.                              | **Antiepileptic agents:** gabapentin, pregabalin,  
**Topical agents:** capsaicin, lidocaine, diclofenac, methylsalicylate |
| Painful spasms                                                              | **Antispasticity agents:** baclofen, tizanidine, diazepam, dantrium, botulinum-A |
| Musculoskeletal pain/joint pain                                             | **Nonsteroidal Anti-inflammatories (NSAIDS):** ibuprofen, naproxen sodium, celecoxib, aspirin  
**Analgesic:** acetaminophen |
| Moderate/severe pain; opioids for when non-opioids don’t work.              | **Opioid Agents**  
**Weak opioid:** tramadol  
**Strong opioids:** buprenorphine, fentanyl, oxycodone, methadone, hydrocodone, morphine sulfate |

Chart courtesy of Heidi Maloni, PhD, ANP-BC, Clinical Nursing Director, MS Center of Excellence East at the VA Medical Center, Washington, DC.
in pain but I can manage it,’ ‘This is a sign that I should meditate,’ or ‘I’ve been through this before, I can get through it again,’” she said.

CBT isn’t “happy talk” or “positive thinking.” People are taught relaxation and breathing exercises; visualization and “mindfulness” meditation (living in the present moment); they explore new approaches to activity; and learn to use more focused self-evaluations of pain and its impact. Acknowledging the pain actually helps people manage it. Even better, CBT may alter the perception of pain by altering how pain is processed in the brain.

The therapy helps people concentrate on how to get on with life in a way that’s meaningful to them and, through this process, to feel less pain.

“We used to think that depression came before pain, but we’ve found it’s more likely the other way around,” Dr. Ehde said. “Pain can lead to depression because it gets in the way of a happy, productive life. Pain is also socially isolating because it’s such a private experience.”

Paradoxically, research also suggests that although social support is vital, overly solicitous or protective behavior from partners and family members may actually heighten a person’s experience of pain. Dr. Ehde counsels loved ones to “validate the pain, but don’t make it central.”

Exercise
Exercise clearly helps break the cycle of pain and inactivity. With MS, any exercise program must take into account heat intolerance, individual preferences and physical issues. People with more severe disability will need an exercise helper. But otherwise the science is in. Movement actually releases pain-relieving endorphins, reduces stress, relieves muscle tension and helps people sleep better. Exercise also helps to shore up strength, posture and balance and improves mood and overall health.

“Pace yourself and don’t overdo,” said Dr. Cohen. Heat intolerance can be addressed by exercising in the cooler parts of the day (or in the basement!), by wearing light clothing, by precooling with a soak in a cool tub and by drinking cold water before a session.

“Swimming helps me, along with kicking my legs or walking in the pool,” said Suzanne Cramer of Orangeburg, S.C. Swimming in a cool pool is a true heat beater. In the winter, Cramer uses a video-based exercise game, rides a stationary bicycle, and walks her trusty dog, Sparky.

And many more complementary options
Complementary therapies include biofeedback, various breathing techniques, music therapy, aromatherapy, self-hypnosis and meditation. Massage may comfort stiff muscles but it can also be over-stimulating. Acupuncture may be helpful, although the evidence for its effectiveness in MS remains anecdotal. Even so, the list keeps growing. Today’s pain management teams focus on improving quality of life by combining medication with complementary therapies that work for the individual.

“Maybe as soon as five years from now,” Dr. Ehde believes, “we’ll look back and see a variety of improved medical and psychosocial treatments for pain.”

Rachel Adelson writes about health science, especially neurology and neuroscience, through her company Live Wire Communications.