

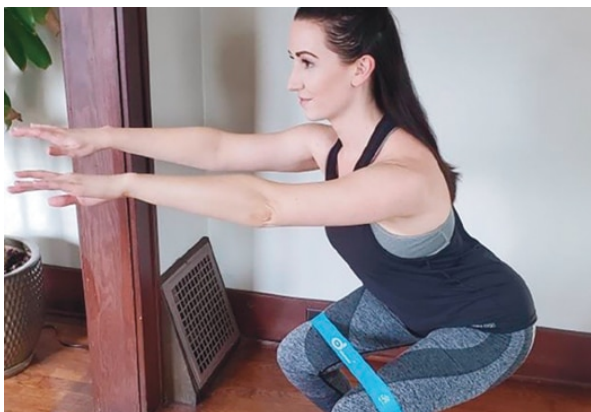
A handle on pain



New approaches mean more people with MS are taking control and getting their lives back.

by Aviva Patz

After a relapse of her multiple sclerosis in 2016, Gina Gentry was in such agonizing pain that she'd curl up in a ball on the couch and cry. "It felt like the bones in my mid-back to my knees were in a vice that kept getting tighter — it was a pressure and a throbbing pain," she says. The 30-year-old from Minneapolis started taking medication and was up to nine pills a day without much relief when she began discovering a handful of effective treatments — an anti-depressant, medical cannabis, physical activity and a healthy diet. "I do feel pain every day, but I get through it," says Gentry, who works full time as an MS Navigator with the National Multiple Sclerosis Society.



Gina Gentry tries to fit movement

into her daily schedule to treat her MS pain. Photo courtesy of Gina Gentry

Up to 80% of people living with MS will have a painful condition during the course of their illness, according to a 2013 article in the journal *Pain*. “A lot of people with MS have mixed types of pain — some neuropathic pain, like achy legs or tingling, discomfort or burning, and also some musculoskeletal pain, like back pain, hip or knee pain,” explains Dawn Ehde, PhD, Nancy & Buster Alvord Endowed Professor in Multiple Sclerosis Research at the University of Washington School of Medicine.

The pain can be significantly disabling, potentially leading to social isolation, mood disorders, mobility problems, loss of employment, and even increased pain and a worsening of other MS symptoms, according to the Society. It can be incredibly challenging to treat because neuropathic pain, caused by damage to the central nervous system that’s a hallmark of MS, doesn’t respond to traditional painkillers.

The U.S. Food and Drug Administration has approved exactly zero medications for MS pain, and the ones prescribed off-label can have unpleasant side effects. The good news: Fresh research and treatment approaches are offering new hope. “We don’t have a cure for chronic pain,” Ehde says, “but there are a lot of things people can do that will be helpful.”

Defining pain in MS

There are two main types of pain in MS:

- Neuropathic, from the damage caused in the central nervous system from MS
- Musculoskeletal, from disability caused by the disease

“If it’s central nervous system pain, we look for qualities associated with that — burning, tingling, prickling, pins and needles, pain with touch, electrical shocks,” says John Rose, MD, Chief of the Division of Neuroimmunology at the University of Utah. Rose notes that the pain can be intense, and that people may have more than one type of pain and in more than one part of their body.

Musculoskeletal pain usually involves dull throbbing or aching. It can come from muscle weakness, extra stress on bones and joints, changing one’s gait, or from health issues that affect the general population and could be unrelated to a person’s MS, Rose says. He tells the story of a 67-year-old man with MS who had pain while raising his leg. It turned out that he had nerve compression and needed hip surgery — neither problem was related to his MS. When both of those issues were addressed, his pain went away.

The experience of pain in MS

Julie Fiol, director of MS Information and Resources at the Society, says the types of pain people living with MS may typically experience include:

- Headache
- Burning, prickling, stabbing, ice cold or electrical sensations in the extremities
- Trigeminal neuralgia (a stabbing pain in the face or jaw area)
- Lhermitte's sign (a brief, stabbing, electric shock-like sensation that runs from the back of the head down the spine and often into the arms or legs when the neck is bent forward)
- Spasticity (muscle stiffness and involuntary spasms)
- Squeezing or tightness around the torso (the MS hug)
- Itching without a rash or other skin issue

Chronic pain in MS can be life-altering. Barbara Reed, 51, of Fishers, Indiana, had to quit her job and go on disability in 2010 because the pain from her MS was so crippling.

"I was heartbroken," Reed says. "I loved my job."

Reed says her pain "feels like being stabbed or having constant muscle spasms or charley horses. Then there is the deep aching, tingling, numbness, touch sensitivity, temperature sensitivity, not to mention the tremors."

Reed has to decide every day whether it's worth the pain and effort to get up and try to do something. And she says people aren't always sympathetic. She has a friend who "doesn't understand the effort it takes just to get ready, and then the effort it takes to do whatever when we are out. I think this is one of those things that can't be judged by anyone other than a person with MS."

Diagnosing pain in MS

There is a formal pain scale on which people rate their pain from 0 to 10, and your healthcare provider will ask questions and do exams to look for signs that align with the sensations you describe, Rose explains. But he and his team are working on developing a pain reporting tool that would be more detailed and specific. "It's opened our eyes to the fact that these patients are putting up with pain we need to know about," he says. "Seven on a pain scale regularly? That's too high to be tolerating."



Chronic pain from her MS affects Barbara Reed each day. Photo courtesy of Barbara Reed

Revelations from the latest research

Medications can be helpful, including anti-seizure and certain antidepressant medications prescribed off label. However, results are limited. One study found that on average people living with MS and pain use nine different strategies to manage their pain, “with very few reporting effective relief of that pain despite those strategies,” Fiol says. One of the remedies reported to be most effective in that study was hypnosis.

Newer approaches to treatment

Hypnosis is just one of the mind-body therapies getting more attention and research dollars. “They used to be looked at as strange, but now they’re considered a best practice,” says Pearl B. Werfel, PhD, Chair of the California Psychological Association CARE Program. Besides not having negative side effects, psychological interventions give people a sense of control. “That’s what people want, because it’s scary to be in pain,” says Werfel, who is lead author of the book, “Multiple Sclerosis: Advances in psychotherapy, evidence-based practice.”

“You don’t know how or when it’s going to end,” Werfel adds. “It’s easy to think, ‘I’m in pain, I’m always going to be in pain.’ But that panic actually makes the pain and inflammation worse.”

Mind-body interventions work because damage in the body is only one piece of the puzzle when it comes to the amount of pain people experience. “Think of it like the volume on a stereo: Some thoughts, feelings and actions can turn the volume up on pain and lead to more danger signals being processed,” Ehde explains. “There are other thoughts, feelings and actions that can turn down the volume on pain, reducing the number of pain signals

processed in the brain and the amount of pain you feel.”

Treatments beyond medication

Here are some approaches to reducing pain for people with MS that don’t involve taking medication, according to the experts:

- Physical activity, whether it includes formal physical therapy or a home or community exercise program, is “somewhat of a panacea,” Ehde says. “It may modulate how pain is processed in the brain, and it makes you feel good because it gets you out and around other people, so there’s the social connection and feeling of self-efficacy.” The movement also conditions your muscles to support your back and joints, which helps prevent discomfort and musculoskeletal pain. Gentry bikes every day, works out with resistance bands and a kettlebell every other day, and also practices yoga a few times a week. “If I don’t keep moving, my pain gets so much worse,” she says. “If I miss just two days, the pain comes back, and it comes back strong.”
- Relaxation training, which could involve breathing, imagery and progressive muscle relaxation, can bring on the body’s natural relaxation response — a combination of slower breathing, lower blood pressure and a feeling of increased well-being, according to the National Institutes of Health. “Strategies like relaxation cause changes in the brain that dampen or decrease pain sensations as well as our emotional, physical and cognitive experience of pain,” Ehde says. Relaxation is immensely helpful for people who live with chronic pain, whose brains are almost “too good” at processing pain and need to be desensitized. Werfel has seen great success with imagery, in which a focus on pleasant images replaces negative or stressful feelings. She tells the story of one woman who would wrap a patterned scarf around her leg where she had shooting pain. “When she’d get into the intricacies of how beautiful the scarf was, she would relax and have less of the signal pain,” Werfel says.

Pacing helps reduce pain

Pacing or energy management helps you more evenly plan your days to avoid the cycle of overdoing it and then needing to recover from increased pain. A 2015 clinical trial showed that among people taught “pacing” skills by telephone over eight sessions, about 50% had a meaningful reduction in pain and fatigue.

Cognitive behavioral therapy (CBT) changes the automatic thought process that can ramp up pain. Although it’s reasonable to think the pain is “terrible, I can’t stand it, I don’t know what to do,” Ehde explains, “you can learn ways to reframe those thoughts. We’re not saying be a Pollyanna — ‘everything is amazing!’ — but how can you develop an alternative thought?”

For example, you might think: “I’ve gotten through this before. I can practice my meditation, my relaxation. I have things I can do to feel better. This doesn’t mean my MS is getting worse.” In an eight-week study for those newly diagnosed with MS, published in 2016 in *BMC Psychiatry*, CBT helped drastically reduce the high levels of depression and anxiety that we

know to heighten the experience of pain.

Mindfulness meditation teaches you to become aware of pain and view it differently, and it's very effective. A 2018 study in the International Journal of MS Care shows a "strong and significant association between greater mindfulness and lower levels of pain interference." In a 2019 study in the journal Pain Reports, MRI scans show precisely how the practice alters brain function to reduce the experience of pain. Earlier studies show that it can also reduce measures of depression, pain-related anxiety and physical disability.

Self-hypnosis can change response

Self-hypnosis training helps you take advantage of the power of your mind to control how you feel in your body. Ehde says it can change the way your brain responds to pain signals, so you feel less pain all the time. It also teaches you how to enter a state of relaxation when you need it. "Most patients report that when they learn to do this, they feel immediate pain relief, and that this relief can last for hours or longer," she says. In a 2014 study in American Psychologist, hypnosis not only effectively reduced chronic pain but also had "clear effects on the brain and spinal-cord functioning." Werfel confirms that after an online self-hypnosis program she conducted with the Society, participants reported taking much less pain medication and even seemed more clear-headed over time.

Somatic experiencing was initially used for trauma because it can work with the autonomic nervous system to decrease inflammation, which decreases pain, Werfel says. Here's how it works: Find a place in your body that's comfortable and focus on that, even if it's your hair or the tip of your nose. "Make the brain aware that there's a part of your body that's comfortable," she explains. For a second, pay light attention to the uncomfortable spot, then switch back. "People can begin to notice the discomfort without triggering a stressful reaction that increases inflammation," Werfel says. "The goal is to have pain not interfere as much with what you're doing, bringing it to a point where it's tolerable enough so you can go about your day."

Diet could be a powerful weapon against pain. Several studies show an association between pain and healthy lifestyle habits including diet quality, says Dr. Ilana Katz Sand, MD, Associate Director of the Corinne Goldsmith Dickinson Center for MS at Mount Sinai Medical Center. The center is conducting studies on diet and MS, and hopes to develop dietary guidelines in the future. In the meantime, it can't hurt, and it may help, to eat cleaner. "A big part of what inspired me to pursue research on diet in MS was my observation that my patients who followed a healthy diet seemed to fare better than those who did not," Katz Sand says.

Gentry sticks to a plant-based diet with lots of fruits and vegetables, nuts and seeds, and some fish for the omega-3 fatty acids. She avoids dairy, meat, gluten, added sugar, saturated fats and foods high in omega-6 fatty acids, such as that from canola oil. "I've come to a point where I see food as medicine," Gentry says. "What I put in my body is either going to help or hinder me."

Working with your healthcare professional

Besides experimenting with medication, one of the first steps to reducing pain is understanding the role the brain plays. “Sometimes people think pain is physical, so why are we talking about my thoughts?” Ehde says. But they’re connected. “Thoughts influence feelings, which influence behavior, which influences physical pain.”

Ehde’s first line of defense is mindfulness meditation or relaxation because it delivers the most benefit early in the treatment. Then, she might explore ways to boost physical activity and improve sleep and teach some cognitive behavior therapy skills, all while having people track their symptoms. “They start to notice patterns of how they respond to pain — what makes it worse, what makes it better — and use that information to create a toolkit,” Ehde says.

Concerns about treatments

With all medications, there are risks of unpleasant side effects, Rose says, including cloudy cognition, fatigue and balance issues. Some anti-depressants might cause irregular heartbeat; others pose a risk of swelling of the limbs and depression. Another issue is that a medication might not reach its full dosage for a few weeks, and meanwhile, people get frustrated and stop taking it.

Neurologists tend to avoid opioids because of the risk of addiction, though they might help some people and can be convenient and inexpensive in small doses. And CBD (cannabidiol, a non-intoxicating chemical compound found in cannabis), while anecdotally helpful, is still largely unstudied and unregulated. Gentry swears by the sublingual cannabis spray she’s used for two years. However, more work needs to be done to establish its safety and efficacy, Fiol cautions.

Physical activity, energy pacing and the mind-body interventions appear to be universally safe, though there’s some trial and error involved as you discover what works for you. As Gentry tells the newly diagnosed, “This is your body, your disease, and you can make the choices that will make you feel better.”

Aviva Patz is a writer in Montclair, New Jersey.

Watch a [video on managing pain and sleep](#).