

Warm up to winter



Frigid temperatures can make some people with MS freeze up. Learn ways to cope.

by Aviva Patz

For Dawn Wheeler, winter is torture. “Right now in Wisconsin, it is below zero, and when I had to get gas the other morning, my fingers felt like they’d been run over by a truck,” says the 49-year-old maintenance systems coordinator. “I had tears in my eyes when I got to work.”

For Wheeler, who was diagnosed with multiple sclerosis in 1993, cold weather is more than just unpleasant—it exacerbates her MS symptoms, causing “stabbing pain” in her elbows, fingers and legs, throwing her muscles into spasm, and making her joints feel immobile, as if they were packed full of cement. “The cold is prickling, biting, as if you put your arm in a freezer and just left it there,” she says. “It’s so awful. I basically don’t leave my house anymore in winter if I don’t have to.”

She’s not alone. While heat intolerance is a well-known and well-understood symptom of MS, cold intolerance is much less acknowledged. “Cold intolerance is understudied and even written off by some healthcare providers,” says neurologist Dr. Robert Bermel, medical director of the Mellen Center for Multiple Sclerosis at the Cleveland Clinic. “And yet it’s definitely reported by many patients.”

That becomes very clear if you head to online chat rooms and blogs, where dozens of posts detail flare-ups of MS symptoms in cold conditions. “The pain gets worse for me during the winter—some days it’s unbearable. All my joints hurt, my muscles get tense, and my mood shifts greatly,” writes Aida Tahrihi on the National MS Society’s Facebook page. On an

[EverydayHealth.com](https://www.everydayhealth.com) forum, “MSsoldier” writes: “I have lived in colder temps, and this is when my symptoms have gone off the charts. I lose feeling and mobility of the entire left side of my body, severely affecting my ability to walk and pick up objects.” User “dwayne” adds: “Over the last winter when the temps would drop 15 degrees, I would be unable to move. I’ve been putting on more layers, but it doesn’t cure it. I’m glad I found this post—I’ve been going crazy wondering if it was just me!”

What we know

There are no statistics on how many people with MS experience cold intolerance, and no published studies on why it occurs or how to remedy it—yet. What we do know is that cold intolerance seems to be temporary—symptoms subside when you warm up (though it can take a few hours), and although it may feel like it’s making your disease worse, it actually isn’t. “Cold intolerance doesn’t trigger inflammation, create new lesions or cause additional demyelination,” that eroding of protective nerve coverings that occurs in MS, Dr. Bermel says. “If you have specific symptoms as part of your MS—we’re talking spasticity, stiffness—they may get dramatically worse in the cold.”

Dr. Bermel’s patients have described feeling their muscles “locking up” or “freezing up;” others describe the sensation as “burning pain.” Amanda Rohrig, a physical therapist with Horizon Rehabilitation Centers in Omaha, Nebraska, and consultant to Can Do MS, says some of her clients experience powerful stiffness, spasticity, spasms, muscle pain, difficulty walking and difficulty transitioning in and out of chairs or cars in frosty weather. In addition, muscle stiffness and spasms also increase the risk for falling. “The cold can influence a person’s movement to the extent that he or she requires more assistance than usual,” says Rohrig. One of her clients uses a wheelchair in winter when cold aggravates her symptoms, and then goes back to using a cane or walker come spring. “When it’s tough to move around,” Rohrig adds, “it’s also tougher to generate warmth, so it can become a vicious cycle of feeling cold and having cold-related symptoms.”

Cold intolerance is likely to get worse as MS progresses, especially for people who already have stiffness and spasticity as symptoms. “The two go hand in hand,” Dr. Bermel adds.

Heat intolerance, however, does not seem to be linked to cold intolerance. In fact, the two problems are totally unrelated, Dr. Bermel says.

A cold case

Neurologists aren’t 100 percent sure what causes cold intolerance, but they know what doesn’t, and that’s a change in core body temperature.

With heat intolerance, a rise in core body temperature—even just a half a degree—can interfere with nerve impulses. “If you heat the body up, movements become slower,” explains Dr. Bermel, citing research done on eye movements. But the dynamic is totally different when core body temperature drops. “If you cool the body down, movement improves—often even better than baseline, so cold is not likely to slow down nerve activity.”

Here's what neurologists think is happening instead: MS is known to cause problems, in some individuals, with the autonomic nervous system—the part of the nervous system that controls key involuntary functions such as movements of the heart muscle and the muscles of the gastrointestinal tract. It's this system that helps the body adjust to changes in ambient temperature—making us sweat if it's too hot, for example, or shiver if it's too cold. It can make our blood vessels dilate or constrict, and our blood pressure rise or fall as needed to stay a comfortable 98.6 degrees Fahrenheit (individual temperatures vary). “These natural compensation mechanisms may not work right in people with MS,” Dr. Bermel explains, “so they might not shiver to send extra blood flow to the limbs when they're cold, as people without MS do.”

Compounding the problem is that many people with MS also have Raynaud's phenomenon, a condition in which the small blood vessels in the extremities—the fingertips, toes, nose or ears—constrict when exposed to cold temperatures, causing them to feel painfully cold, along with sensations of pins and needles, numbness or throbbing.

Matt Allen G., who writes the blog [Matt's MS](#), remembers the moment, on a 32-degree day, that he first suspected he had secondary Raynaud's phenomenon, meaning the syndrome was linked to his MS. “I started noticing very quickly that my fingers were becoming extremely cold, to the point that they hurt,” he says. “It felt as though I had held my hands in ice water till they were numb and then dunked them in hot water.”

Coping mechanisms

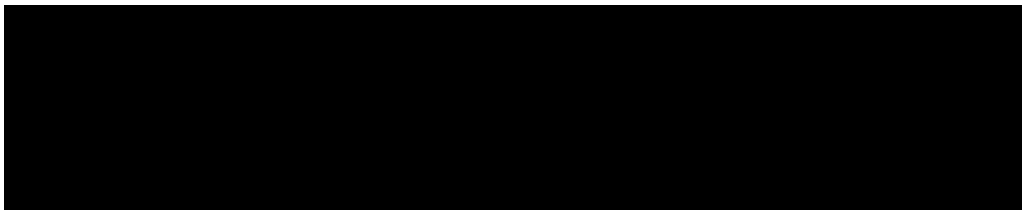
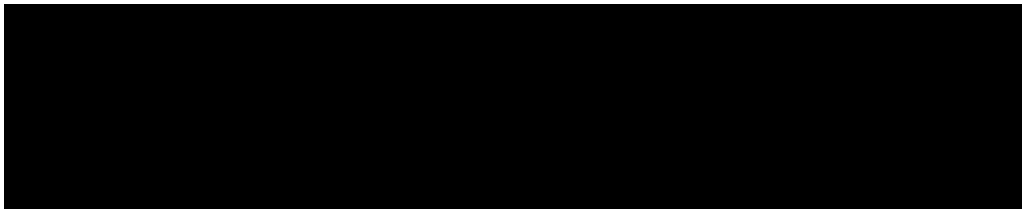
At this point, there are no medications on the pharmacists' shelves for cold intolerance, so to avoid it, you have to find ways to stay warm.

The primary goal is not to boost your core body temperature, as you might think to do when you're trying to stay warm during skiing and other winter activities. “It's more about keeping skin covered to limit cold sensory input,” Dr. Bermel explains. “So if you're at a tailgate party and there's a cool wind, for example, drinking a warm beverage isn't going to help.”

What **will** help: insulating your extremities, particularly your neck, wrists and ankles, because key veins and nerves travel through them. Rohrig recommends dressing in light layers, rather than tight thermal layers, which can cause spasticity for some people. She's also a fan of hand warmers, warm packs (with a cloth around them to prevent accidental burns to the skin), hats and headbands, gloves and scarves. Keep extras in your car and office for emergencies. “Just as people with heat tolerance develop their own strategies to manage heat, people with cold sensitivity have to figure out what works best to manage cold,” Rohrig says.

Warming trends

These accessories promise to keep you toasty when the mercury dips below your comfort zone.



Dawn Wheeler has found success sleeping with wool socks, slippers, leg warmers and a hoodie sweatshirt with the hood up. To stay warm in her office, she runs a space heater, and in her car, she's added a furry steering wheel cover for extra insurance against cold hands. A car strategy Rohrig recommends is to use a remote starter so you can start cranking the heat before you have to drive.

A good exercise program can also help the body stay warm. "Movement may help the body stay warm by improving circulation, and that, in turn, can minimize some of the stiffness or spasticity aggravation that can be the result of the cold," Rohrig says.

An online user named PNut posted on the forum at [MSWorld.org](https://www.msworld.org): "Lately I've been working out and I now can tolerate going into the refrigerated section at the grocery store." Talk to a physical therapist to devise a workout program that's right for your MS, as well as for your sensitivity to cold or heat.

Ultimately, if you find cold weather excruciating, you might consider relocating. One of Dr. Bermel's patients was so bothered by the cold—he would feel sensations of burning, prickling and icing in his hands and feet, and he had trouble walking because of the leg stiffness—that he moved to a warmer climate, where his symptoms have improved dramatically. Wheeler, whose daughter is going off to college this year, is seriously considering leaving frigid Wisconsin winters for someplace warmer, possibly Arizona.

If you experience cold intolerance, tell your doctor. Not only can he or she offer advice that's specific to your MS, but also you'll be helping to raise awareness that could lead to the development of potential treatments for cold intolerance down the line.

Aviva Patz is a freelance writer in Montclair, New Jersey.

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