Conquering the cold



Despite winter weather, you can still make the most of the season.

by Vicky Uhland

After a searing summer, winter weather can feel like a relief to many people living with multiple sclerosis. The high temperatures that play havoc with demyelinated nerves and lead to a temporary—but often agonizing—worsening of symptoms are no longer a worry.

But before you breathe that cool sigh of relief, beware that winter comes with its own set of woes for people with MS.

"As with everything in MS, symptoms that are impacted by the cold are unique to each person. However, generally speaking, sensory symptoms such as numbness and tingling or pain, spasticity and fatigue are exacerbated by the cold," says Mandy Rohrig, a physical therapist with Horizon Rehabilitation Centers in Omaha, Nebraska.

Snow and ice can cause problems for people with MS. Snow can disguise uneven surfaces, creating treacherous walking conditions for people with balance issues. It can also make walkers, wheelchairs and scooters difficult to maneuver. And, of course, slipping on ice is a potential peril for everyone.

Humidity also is a concern in winter just as it is in summer. "Rain or snow can have the same effect on MS symptoms as heat, even when it's nice and cool outside," says Herb Karpatkin, a physical therapist and associate professor at Hunter College in New York City.

When you combine all of these elements, it's no wonder that people with MS may choose to stay inside as the temperatures plummet. But winter shut-ins risk cutting themselves off from the activity and socialization that are vital for staying physically, mentally and emotionally healthy.

This winter, don't get a case of cabin fever. Here's how to get out, get moving and make the most of the season.

Feeling the cold

It's a no-brainer that you need to dress warmly when you go outside in freezing temperatures. But for people with MS, that sounds easier than it might actually be.

For example, people who have sensory issues might not get the physical cues that they're not dressed warmly enough for the weather and are in danger of frostbite.



People with MS who experience sensory issues might not get the physical cues that they're not dressed warmly enough for the cold weather and may risk getting frostbite.

"I work with one woman who just loves the cold weather because it allows her to walk more," Karpatkin says. "One day when it was 25 or 30 degrees, I saw her walking outside in sandals with no socks. Because she had no sensation in her feet, she couldn't feel that they were ice cold."

Christopher Rodney, who was diagnosed with primary progressive MS in 2004 when he was 35, spent 20 years in Maine as a young man, so he's used to cold weather. But now that he uses a power chair to get around, he's had to make some adjustments when he ventures outside his Freehold, New Jersey, apartment.

"I believe in getting 15 minutes of sunshine every day, so I try to get outside every day the sun is out in the winter," he says. But like Karpatkin's sandal-wearing patient, Rodney says he doesn't feel the cold as much after his diagnosis. "I'll be out thinking it's a beautiful day and not realize I'm cold until I come inside and get warm. So I have to be careful how long I spend outside."

Rodney says because sitting in a chair doesn't generate as much body heat as walking, he makes sure to wear boots with a good tread whenever he goes outside in the winter. "The tread part might sound silly when you're in a chair, but you have to transfer," he says. "And you need the warmth that boots provide."

Karpatkin said sensation issues may also cause people to wear too many clothes and overheat, which, ironically, leads to the symptom exacerbation common with summer weather.

The key is to dress in layers, so you can adjust with the temperature. Those layers should be lightweight, Karpatkin says, because bulky clothing can restrict movement. It also adds weight—and the heavier you are, the more energy you use, making it more difficult to be active in winter weather.

Your inner layer should be thermal socks and underwear, Rohrig says. Then you can add warm outerwear like flannel-lined jeans and a cardigan, or a wool or lightweight down vest or coat. She also suggests wearing scarves, hats or gloves both indoors and outdoors if you're particularly sensitive to cold.

Navigating snow and ice

Rodney says his heavy power chair can provide stability in snow less than 6 inches deep, but it can slide on ice. "If it's icy and you're on ground that's at a slight angle, your chair will go in that direction, and you can't control it. You have to always be aware of the angle of the surface you're traveling on."

Rodney recommends only going outside in winter with a buddy, who can call for assistance if there's a problem. His girlfriend also uses a power chair, but they're careful to travel a safe distance apart. "It can be dangerous to have anyone in front of you when you're in a power chair in case you slide into them," he says.

You can protect yourself from slipping on ice or getting stuck in snow by adding chains to the wheels of a chair or scooter, but they can be a pain to take on and off. An easier option is to swap out your wheels with all-terrain versions for the winter, just as you replace the regular tires on your car with snow tires.



Christopher Rodney's power chair can provide stability in snow but can slide on ice. He carries a bag of sand and sprinkles it in front of his chair as he moves. Photo by Riku Foto

Rodney says one simple solution is to carry a small bag of sand and sprinkle it in front of your wheelchair as you move along. You can also spray windshield deicer (available at auto supply stores or websites) on the path in front of you.

If you go outside on a scooter, it should have a wide wheel radius to provide extra stability, Karpatkin says. He recommends checking with the manufacturer to find out about a scooter's snow or ice capability.

Even if you don't normally use a mobility device, trekking poles, a cane or a walker can be good options when you're walking outside in the winter. You can find traction tools for canes by doing an internet search for "claw crampon for cane," "crampon tips" or "cane ice tip attachments." Because crampons can tear up carpets or floors, Karpatkin recommends having separate indoor and outdoor canes so you don't have to waste time and effort removing the crampons when you go inside.

Karpatkin doesn't recommend crampons or traction devices for shoes because they're easy to trip over—especially for people who have trouble lifting up their feet as they walk. Instead, he suggests buying shoes with a sturdy tread.

Finally, being inactive due to fear of falling on snow or ice may actually be worse for you than the fall itself, Karpatkin says. "People with MS have worse outcomes from being sedentary than from falling."

Of course, that doesn't make the fear any less real. One way to overcome it is to practice gentle falling techniques with a physical therapist, such as rolling to the side, or falling uphill or in a sitting position—along with strategies for getting up after a fall. (The National Multiple Sclerosis Society's <u>"Free From Falls" DVD and brochure</u> also teaches these skills.)

Outdoor activities adapted for MS

Simply going for a winter walk can have significant mental and physical benefits. So can zipping through the scenery in a snowmobile. But if you want to up the ante even more, there are a variety of winter activities that have been adapted for people with MS.

Sit-skis and -snowboards allow people with mobility issues to glide down the slopes or crosscountry ski while seated, steering themselves with poles that have miniature skis on the end. These "outrigger" poles require less balance and upper-body strength than standard poles because they slide rather than having to be planted. For extra safety, sit-skiers or snowboarders can be tethered to an instructor who skis behind them and helps control their speed and turns.

If you like to ice skate, there are walker-type devices available that have plastic nubs on the legs so they can glide along the ice in front of you. There are also adaptive poles for snowshoeing. And there's even sled hockey, in which participants sit upright on a metal sled that has a pair of specialized hockey skates attached to the bottom. The players use adapted hockey sticks to propel themselves around the ice and shoot pucks.

To find these and other adaptive winter sports programs in your area at no or minimal cost, visit <u>disabledsportsusa.org</u> or <u>usaparalympics.org</u>.

Indoor winter physical fun

Jerry Noble, a New Jersey resident who was diagnosed with MS in 2008 at age 40, finds that the combo of MS; arthritis in his knees, feet and hands and cold weather can make his joints and muscles hurt more than usual. "My ability to move is not as good in the winter," he says.

Noble relies on an electric scooter to get around when he's outside and an electric wheelchair inside his apartment. But when ice and snow make him feel unsafe using his scooter, he uses a New Jersey Transit program for people with disabilities called Access Link. Many city transit systems have similar options; call an MS Navigator at 1-800-344-4867 to see what's offered in your area.

Noble uses Access Link to attend church and MS support group meetings, and to visit his local rec center. "I like to sit in the sauna at the rec center. Even just 20 minutes warms me up and alleviates the pain in my joints," he says.

He also does exercises at home, including lifting 1- or 2-pound hand weights and working out on a Cubii Under Desk Elliptical, which is a type of seated treadmill. "I'm also looking to buy a foot massager to stimulate blood flow in my calves," Noble said.



Christopher Rodney's home workout program includes grip exercises and an exercise ball to strengthen his core. Photo by Riku Foto

Rodney has a vigorous home workout program as well, including grip exercises and using an exercise ball with handles to strengthen his core.

Rohrig says other home exercise options include online exercise groups like <u>MSforward</u>, <u>MS</u> <u>Workouts</u> or <u>the MS Gym</u>. "These groups can provide structured exercise, guidance and interaction with others who have MS," she says. You can also find online videos for MSfriendly exercises like yoga, Pilates and seated workouts. As always, check with a physical therapist or other healthcare professional to find out if an exercise video or program is right for you.

"Another often forgotten resource is the community library," Rohrig says. "Often, libraries have exercise videos or DVDs that can be checked out for free."

Avoiding cabin fever

"January and February are long months. The majority of my time is spent in my small apartment," Rodney says. "But I don't look at it as being stuck inside. I look at it as an opportunity to pursue things normal people don't have the time for."

For instance, Rodney, who was a chef for 20 years, spends time freezing, fermenting and pickling the produce he grew in his community garden during the summer. He researches new recipes and bones up on the latest health and nutrition information. He also maintains an indoor herb garden.

"Green in my house is very, very important," Rodney says. "I have an amazing garden 3 feet in front of me."

Noble makes an extra effort to be social during the winter, which helps him feel less shut in. He invites members of his church men's group and choir to his apartment, and chats with his housekeeper when she comes by once a week.

"I also take the opportunity to make phone calls and catch up with people," Noble says. "When you have a disease like MS, you run the risk of getting disconnected from the community."

Above all, Rodney says, find ways to avoid the winter doldrums.

"I mitigate the emotional roller coaster of MS through writing poetry or short stories," he says. "Just because my body is stuck in this apartment doesn't mean my mind is. I travel around the world in my head every day."

Free ways to stay active indoors

- **Throw a dance party.** Research shows dancing—either standing or seated—can be beneficial for people with MS. One fun option is freeze dancing: Designate someone as a DJ. When he or she stops the music, everyone freezes until the music starts again.
- **Have a scavenger hunt.** Hide "treasures" around your house or apartment and get a group together to search for them. You'll get exercise walking from room to room, not to mention fun and socialization.
- Host an indoor Olympics. Invite friends or family to compete in indoor sports like broom hockey, beanball tossing, balloon volleyball, hallway races or whatever else you can dream up.
- **Hula hoop.** If you don't have balance issues, try a few rounds with a hula hoop. You can do it in a small space, and it's a great way to strengthen your core.
- **Clean your house.** You'd be surprised how many calories you expend cleaning your residence or even a single room. And you'll get pleasure from your spick-and-span surroundings. To lessen the drudgery, listen to music or a podcast while cleaning.
- **Rearrange the furniture.** Moving the couch might be a bit taxing, but shifting some chairs or end tables will keep you active and change your perspective.
- Learn a craft. Sewing, quilting, painting, cooking, playing a musical instrument, building a birdhouse and other creative endeavors keep you physically, mentally and emotionally active.
- **Walk and shop.** If you live in an area with a mall, there's likely a mall-walking group you can join. Or start your own with your neighbors.
- **Phone in your workout.** Move around while you're chatting on the phone. Depending on your level of mobility, you can walk, do arm exercises or try a few stretches.

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Learn more about <u>temperature sensitivity</u>.