Beating the heat

Sweltering temperatures can make MS symptoms worse. Give them the cold shoulder with these sizzling ideas.

by Vicky Uhland

A ‘cool’ product guide

For clothing, gear and devices that can help you stay cool in any environment, check out our Web-exclusive product guide.

Bambi Lint’s family and friends often urge her to go outside and enjoy the fresh air on hot summer days. “They’ll say it’s just for a little while, but they don’t understand that even a little while can be too long,” says Lint, an Appleton, Wis., jewelry designer and gardener who was diagnosed with multiple sclerosis in 2001.

Lint started noticing problems with heat the first summer after she was diagnosed. “I was building a rock garden for one of my neighbors and the fatigue hit me like a brick. The heat caused so much spasticity and weakness in my legs that I just couldn’t go on anymore,” she says. “And it seems to have gotten worse every year. Now, if I’m outside and the sun is pounding on me and it’s warmer than 75 degrees, I can’t last more than 15 minutes.”

Heat intolerance is such a pervasive symptom in people with MS that the “hot bath” test

used to be one of the main ways of diagnosing the disease. In the l9th and early 20th centuries, doctors immersed people whom they suspected had MS in water that was around 105 to 110 degrees. If neurologic symptoms appeared or worsened, the doctor concluded that the patient did indeed have the disease.

With the advent of magnetic resonance imaging, spinal taps and other modern-day diagnostic tools, the hot-bath test has become an antiquated anecdote. But that doesn't mean that heat sensitivity is any less of an issue. Researchers estimate that 60 to 80 percent of people with MS have a temporary worsening of their symptoms when they become overheated. In a 2004 international survey of more than 2,500 people with MS, 70 percent reported that heat worsened their MS symptoms. And a 2011 Swedish study of 265 people with MS found that 58 percent had heat sensitivity that significantly increased their fatigue, pain, concentration or urination urgency.

Raising the thermostat

Known as Uhthoff's phenomenon, after the physician who first discovered it in 1889, heat sensitivity affects people with MS and other demyelinating diseases. Basically, says Teresa Frohman, PA-C, who co-authored a 2013 paper published in Nature Reviews Neurology on Uhthoff's phenomenon, as little as a half-degree increase in body temperature makes it harder for nerve impulses to operate normally. "Heat changes the amount of energy the body needs to keep the nerve impulses going," she says.

This in turn creates pseudoexacerbation—a temporary worsening of physical and cognitive symptoms. So people who experience weakness, fatigue, balance issues, spasticity, blurred vision, concentration problems, memory difficulties or other MS symptoms are likely to feel them more acutely if their body temperature is raised, whether due to heat, exercise, fever, infection, or even psychological stress or, for women, menstruation.

The good news is that a pseudoexacerbation is not the same as a relapse and disappears once the body's temperature reverts to normal. "It's usually very short in duration—less than 24 hours—and totally reversible," says Frohman, who is a clinical specialist at the Multiple Sclerosis Clinic at the University of Texas Southwestern and co-author of the National MS Society's book, Multiple Sclerosis for the Physician Assistant.

But knowing that it's not permanent doesn't make a pseudoexacerbation any less real or distressing when it's happening. "I may be feeling great, and then I go outside in the heat and do some planting in the garden, and bam! I can hardly move," Lint says. "The heat exacerbates the fatigue and other symptoms and nearly incapacitates me. One of the most frustrating parts is there are no warning signs. What I could tolerate yesterday, may or may not be the same as what I can tolerate today."

Understanding the thermostat

Evidence suggests that heat sensitivity becomes more common as the disease progresses, but researchers aren't sure why some people with MS are relatively unaffected by hot temperatures. And while many people with MS report that the old adage "it's not the heat; it's the humidity" is particularly true for them, Frohman says there's no scientific evidence that high humidity exacerbates MS symptoms more than high heat. It is true, however, that when humidity is high, sweat does not evaporate as efficiently, so it has less of an ability to cool the body. So people may perceive that their symptoms are worse.

Frohman says people with MS may be particularly affected by heat because they tend to have resting body temperatures that are lower than the usual 98.6 degrees. "In our patient population of over 5,000, we've discovered that the average temperature is 96.9 to 97.5 degrees, so someone presenting at 99 degrees could actually have a fever," she says. A 2010 paper published in the Journal of Applied Physiology reported that this may be because MS affects areas of the brain and nervous system that regulate core body temperature.

This faulty internal thermostat may also affect the body's sweat glands, according to the study. The researchers found that people with MS don't tend to perspire as much as the rest of the population, which can lead to overheating because sweat helps the body cool itself. In addition, the researchers noted that people with MS-related bladder problems may restrict how much they drink, which also reduces sweating.

Certain treatments can increase or decrease heat sensitivity as well. People who take anticholinergic medications—a specific type of treatment sometimes used for bladder issues in MS—may have reduced sweating, Frohman says. Conversely, potassium-channel blockers such as 4-aminopyridine, or 4-AP, which are taken for relief of many MS symptoms, may improve heat-related fatigue or cognition problems.Frohman says she and her colleagues have found that Ampyra, a type of 4-AP approved by the Food and Drug Administration for gait-related issues, is also effective for Uhthoff's phenomenon, although it's not specifically approved for that use.

Lowering the thermostat

Keep Moving

You can still enjoy your favorite summer activities—with a little adaptation.

The faster you decrease your body temperature, the faster you reduce the accompanying symptoms. Frohman says the body has numerous points that act as heat conductors, so it doesn't matter which one you choose to cool—targeting your wrists and neck, for instance, is no less effective than focusing on your core. Here's a look at the most efficient ways to lower your body temperature, from the tried-and-true to the novel.

TIMING IS EVERYTHING

Lint loves to garden, but knows that even in the relatively cool Wisconsin summers, she can fight off fatigue longer if she does her planting and weeding closer to dawn and dusk. If she works in her garden from 6 to 7 a.m., she'll have enough energy left over to do another half-hour stint shortly before the sun goes down. And if she focuses on beds that are in the shade, she can last twice as long as she would tending a sunny plot. If she does get overly fatigued, she lies in shade on the cool soil until she can safely move again. "And I make sure my husband is home to help me inside if I need it," she says, because balance issues are her primary heat-related symptom.

Lint doesn't always follow her own rules perfectly, though, and sometimes finds herself exposed to the noontime sun. She's a big baseball fan and likes to attend games but makes sure to take her wheelchair in case the heat leaves her overly fatigued. For activities where restricting others' views isn't an issue, umbrellas can provide portable shade—and some even have UVB and UVA protection to block the sun's rays.

YOU ARE WHAT YOU EAT—AND DRINK

"My No. 1 weapon to deal with the heat is decaffeinated, ice-blended coffee beverages; nothing makes a bigger difference in cooling me down," says Michael Gerber of Los Angeles. Gerber, who has secondary-progressive MS and has used a wheelchair for almost four years, says high temperatures cause overall weakness and an inability to lift his arms, but Frappuccinos and similar drinks "reduce my symptoms almost instantaneously. All my friends know to call before they come over and ask, 'Does Michael need a drink?' "

Cold beverages are a great way to cool down, says Ashley Uyeshiro, OTD, OTR/L, assistant professor of clinical occupational therapy at the University of Southern California. Gerber is smart to choose decaf, she says, because caffeine and alcohol are diuretics that can reduce sweating. They also decrease the overall water content in your body, impeding your body's ability to regulate its temperature. Ideally, ice water is the best coolant, Uyeshiro says, because it's free of non-nutritional additives like sweeteners, and doesn't require energy expenditure to digest. Sports drinks aren't really necessary, because, although they replace electrolytes you may lose from sweating, everyone but hardcore athletes can get those lost nutrients from food, she adds.

Uyeshiro says chilled foods like yogurt, hummus, sherbet, juicy fruits, and frozen grapes or blueberries help you feel cooler but generally don't drop your body temperature as quickly as water. She recommends eating smaller, more frequent meals rather than a heavy meal that makes you feel sluggish.

CHILL OUT

Air conditioning is often the most powerful—and expensive—way to make summer heat bearable for people with MS. If you can't afford it, check with your utility company, Uyeshiro

says; some offer rate discounts if you have a note from your doctor. In addition, air conditioning units or systems may be covered under your health insurance or could be deductible on your taxes, so check with your insurer and accountant.

In the workplace, you can ask for an office with an individual thermostat, or for a fan or air conditioner at your workstation, according to the Job Accommodation Network. You can also ask your employer for flexible scheduling or the ability to work from home on particularly hot days, especially if you have a long commute.

To avoid stifling cars, consider installing a remote starting system that will also activate your vehicle's air conditioning. Kits are available for as low as $50 at electronics or auto accessories stores or websites. Or go the low-tech way and have a friend or family member start and precool your car.

THE WATER'S FINE

Handheld spray misting bottles—some come with built-in fans—are a quick way to simulate sweat's cooling effect on your body. Keep them in the refrigerator for extra impact.

Simply putting hands or feet under a cold faucet also is an effective way to cool off quickly, Uyeshiro says. Frohman suggests packing a cooler with ice water and rags and applying the rags to your arms and legs if you anticipate being out in the sun for a long period of time.

Whichever method or device you use to keep your cool during sweltering summer days, one thing is key: Know your limits. "I'm a Type A person, so I tend to overdo things," Lint says. "But I've learned to slow down when the temperature goes up."

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Need help paying for A/C or other heat-related assistance? Call the National MS Society at 1-800-344-4867 for information and resources. And read "Blowing hot and cold" for more information on assistance with air conditioning costs.

What's your favorite strategy for keeping cool? Start or join a discussion at MSconnection.org.