

Acing temperature control



How to cope with heat sensitivity

by Vicky Uhland

Samir Chandiwalla loves to play tennis. But after he was diagnosed with multiple sclerosis in 2005, he gave up the sport. The heat and humidity in Augusta, Georgia, where he lived, affected him so much that he was barely able to go to his office in the summer—let alone the tennis courts.

“I have spasticity in my back, legs and chest that became worse each summer in Augusta. I’d have full body spasms just crossing the parking lot into work. Sometimes I couldn’t even walk,” Chandiwalla says. “I got so anxious about whether the heat would exacerbate my MS symptoms that I think that made my symptoms worse. And then that would give me even more reason not to go outside in the summer.”

Chandiwalla is one of the 60 to 80% of people with MS whom researchers estimate have a temporary worsening of their symptoms when they become overheated. In fact, heat sensitivity is such a common symptom of MS that in the 19th and early 20th centuries, one of the main ways of diagnosing the disease was to immerse people in water around 105 to 110 degrees and observe if neurologic symptoms appeared or worsened.

Like most people with MS-related heat sensitivity, Chandiwalla tried the common coping strategies. He cranked up the air conditioning in his home and car. He drank cold beverages. He wore cooling vests but found that even the ones filled with ice packs weren’t effective in the Georgia humidity. And the vests caused other problems as well. Chandiwalla and his wife, Sarah Taufique, who wears a hijab, are Muslim. When they visited a butterfly show in a

greenhouse, a woman pointed them out to police because she mistook Chandiwala's bulky cooling vest for an explosive device.

Chandiwala decided he would need to take more drastic measures to beat the heat. He works as an engineer at a large manufacturing company with multiple U.S. locations, so he asked for a transfer to a cooler climate. There was an opening in Cincinnati, so Chandiwala and his family packed up and moved in 2007.

Cincinnati summers are hot, but Chandiwala has found there are breaks in the heat that allow his symptom exacerbations to subside. He also switched his medications, which he believes has had an impact on his heat sensitivity. And he started swimming and lost 15 pounds. He says weighing less helps him feel cooler on hot days.

Thanks to all these changes, it's been three years since Chandiwala has used a cooling vest when he's outside in the summer. He was recently able to take a beach vacation in Hawaii. And last year, he started playing tennis again.

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"I don't know anyone else who has as much heat sensitivity as me, but now I feel like I can cope. The heat is no longer something I have to work my whole life around," he says. Here's what Chandiwala and medical experts recommend to beat the heat when simple strategies aren't cutting it.

Remember, it's temporary

The most important thing to know about summer heat is that it won't make your MS worse. But it can make your symptoms feel worse. That's because, according to research, raising your body temperature by even as little as half a degree can affect how your nerve impulses operate.

"Demyelinated nerves are already not doing a normal job of conducting electricity, and heat impedes electrical transmission even more," says Barbara Giesser, MD, a professor of neurology at UCLA.

This can create what's known as pseudoexacerbation—a temporary, reversible worsening of physical and cognitive MS symptoms that is caused by a known precipitant, such as heat or an infection. "You feel crummy, but it's important to know that you're not going to have any more nerve damage," Dr. Giesser says. So when your body temperature returns to normal, your symptoms should revert to the level they were before you became overheated.

"I have patients ask me: 'Do I need to move because living here is going to make my MS worse?'" says Jonathan Carter, MD, a neurologist with the Mayo Clinic in Phoenix. "I tell them they're not going to develop new lesions in their brain or spinal cord because they live in Phoenix. They're not harming themselves or making their MS worse by living in a hot climate."

But because MS is unpredictable, heat sensitivity can vary from person to person, he says.

Evidence suggests that heat sensitivity becomes more common as the disease progresses, but not in everyone. If you have fairly mild symptoms, you may be able to tolerate the heat better than someone with more severe symptoms, Dr. Carter says. And he points out that people who already have difficulty walking may find that their mobility worsens dramatically after as little as a few minutes in high temperatures.

“People with more mobility issues tend to have more nerve damage, so it’s like you’ve got less to work with when you get overheated,” Dr. Giesser says.

In some cases, it’s also possible to temporarily develop symptoms you haven’t had before. “If you have an area of damage that’s functioning normally under normal conditions, it could get worse with heat. But those symptoms should disappear when your body temperature is cooled,” Dr. Giesser says. So, for instance, you could have lesions in a “silent area,” like the part of your brain that affects cognition, which could produce symptoms only when you get overheated.

Track the heat index

The old adage “it’s not the heat; it’s the humidity,” can be particularly true for people with MS.

“When it’s humid, it’s harder for your body to cool down,” Dr. Giesser says. “This affects everybody, but if you have MS, you tend to feel the humidity more.”

One theory is that sweat—the body’s natural cooling system—doesn’t evaporate well in humidity, so it can make MS symptoms like fatigue, leg heaviness and lack of energy feel worse. The key is the word “feel,” though. Researchers don’t know how much of this is attributable to the disease of MS itself, says Kathy Zackowski, PhD, an occupational therapist and senior director of patient management, care and rehabilitation research for the National Multiple Sclerosis Society.

Dr. Carter says what you really need to pay attention to is the heat index—the weather report that tells you how hot it feels outside. For instance, when it’s 110 degrees in Phoenix, the heat index is the same as when it’s 97 degrees in Nashville, Tennessee, because Nashville’s average summer humidity is double that of Phoenix.

The higher the heat index, the more risk of pseudoexacerbation of previous symptoms—in most cases. “I’ve found that humidity has as great an impact on mobility symptoms as temperature alone,” Dr. Carter says.

Summer shut-ins

Dr. Carter works with retirees and other patients who are able to leave Phoenix for cooler climes in the summer. But that’s not financially or logistically possible for many others with MS. These people can become summer shut-ins, afraid that even a few minutes out in the hot

sun can worsen their MS symptoms—particularly the ones that have the potential for social embarrassment.

“For instance, many people with MS time their bathroom visits when they go out. But if you’re walking slower because of the heat, it may take you too long to get to the bathroom. Or if the heat increases hand numbness, you may worry about how you’ll wipe yourself after a trip to the bathroom. And people with cognition symptoms may feel like they’re slower with their thinking, or they’re not as quick to respond to others,” Zackowski says. “So it’s no surprise that many people think the safest solution is to just not leave the house in the summer.”

But Dr. Carter says holing up in your home for months on end can create its own issues. The isolation can make you feel depressed and lower your quality of life. And you may exercise less, which could impact energy levels, fitness and mobility.

If you have an MS clinic nearby, one solution is to participate in a daily or weekly wellness program.

“We keep the gym so cold here that the therapists wear sweatshirts and sweaters,” says Ian Flannery, therapy manager at the Shepherd Center’s MS Rehabilitation and Wellness Program in Atlanta. “Some people come here in the morning and say it’s the only time they leave the house during the summer. Not only do they get a chance to exercise, but they get the social component, too.”

Another option is to walk or swim in a cool, shallow lake or a swimming pool. Chandiwala’s wife called local gyms and recreation centers and asked the temperatures of their lap pools. After she found one lower than 80 degrees, Chandiwala started to visit regularly.

“At first, I was very afraid to exercise because I felt like I would overheat,” he says. “So I started out basically just walking around and worked my way up to swimming. I work from home a lot in the summer, and I’ve found that the pool exercise is good for me both mentally and physically.”

Zackowski also recommends visiting air-conditioned senior centers or other community centers where you can interact with others. If that’s not possible, she suggests using a computer at home to become part of a virtual community or play games. “You can do that safely, and it helps keep you from being isolated,” she says.

Finally, Flannery recommends venturing out in the heat with a friend or family member until you understand how your body reacts to various temperatures and humidity levels.

“You may find you can’t go out if it’s warmer than 75 degrees. Or you only have 45 minutes outside until your cooling techniques fail,” he says. “But that still means you’ve got 45 minutes. If you do some planning, you can accomplish a lot during that time.”

Simple strategies to beat the heat

Here's what Samir Chandiwalla; Kathy Zackowski, PhD; and Jonathan Carter, MD, recommend to lower your body temperature and reduce symptom exacerbation when the heat and humidity skyrocket.

Start with pre-cooling. If you know you're going outside on a hot day, Zackowski suggests drinking some ice water beforehand. And then take regular sips from a thermos of ice water when you're out in the heat.

Of course, this can create other problems if you have bladder issues. Chandiwalla is a big fan of sports drinks like Powerade. "I feel like I don't have to pee right after drinking," he says. Experiment to see what works for you, but it's best to avoid alcohol or caffeinated beverages. Both are diuretics that can reduce your sweat levels and hamper your body's ability to regulate its internal temperature.

Keep your environment temperate. Air conditioning is the most powerful—and expensive—way to make summer heat bearable. If you can't afford it, check with your utility company or your state's public utilities commission. Some offer rate discounts for people with disabilities.

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 accounting service. You can also contact an MS Navigator (ContactUsNMSS@nmss.org or call 1-800-344-4867) to discuss other cooling options and resources.

Do some device shopping. Cooling vests are effective "to some degree," Dr. Carter says. But he says his patients rarely ask about them—perhaps because so many are cumbersome and unattractive.

However, with a little searching, you can find lightweight, unobtrusive cooling vests. A good resource is activemssers.org, which is operated by Dave Bexfield, who was diagnosed with MS in 2006. Bexfield has tested a variety of cooling vests in various situations and offers unbiased reviews.

Chandiwalla keeps an ice-filled cooling vest in a small cooler in his car. He puts it on as soon as he gets in the car, and it keeps him comfortable until the air conditioning kicks in. And if he knows he's going to be outside in the heat for a while, he dips an undershirt made of a wicking material, like Under Armour, in water and wears it as a base layer.

Handheld misters or fans can be surprisingly effective, says Zackowski, as can cold, wet towels applied to your wrists, neck or other parts of your body.

Ask your doctor about your medications. Chandiwalla found that his ability to tolerate

heat and humidity improved when he switched from Rebif to Copaxone. Rebif is a beta-interferon, which research shows may temporarily increase body temperature about six hours after injection.

It's also worth discussing with your MS care provider any secondary medications you may be taking. There is some evidence that anticholinergic medications, which are sometimes used for bladder overactivity in MS, may reduce sweating and the body's ability to cool itself.

Vicky Uhland is a writer and editor in Lafayette, Colorado.

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Check out our [summer guide to managing heat](#).