Keep moving with MS



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

by Vicky Uhland

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Hundreds of studies show that exercise is physically beneficial for people with multiple sclerosis. Hundreds more report that sunshine provides a psychological boost for virtually everyone. So what could be better than biking, hiking, playing a game or just running around on a summer day?

If that last sentence made you cringe, you're likely one of the estimated 70 percent of people who have heat sensitivity related to MS.

Lisa Green, a psychotherapist in Colorado Springs, Colo., is well acquainted with this phenomenon. "I think I came out of the womb hating heat," she says, a trait that leads her to believe her nervous system may have been "going crazy" well before she was diagnosed with MS in 1997. As her MS has progressed, so has her sensitivity to heat. "It turns me into a wet blanket," she says. "Everything slows down, fatigue sets in, and my strength is zapped. It's what anyone would feel in 96-degree heat, but 10 times more."



Lisa Green, diagnosed with MS in 1997, has always been athletic. To accommodate her sensitivity to heat, she rides a modified bike that allows her to use less energy while riding.

Photo courtesy of Lisa Green

Green could just spend her summer indoors, but she feels that would be even more torturous than the heat. Prior to being diagnosed, she ran an average of 5 miles a day and was a regular hiker. She says she was so fit that when she went to a gym, "people would ask me if I was a trainer."

When heat started interfering with her exercise regimen, Green devised a plan that allows her to still enjoy her favorite outdoor activities in the summer. "First, I had to grieve the fact that I can't do what I used to do. I can't exercise to the point of sweating anymore, and my 80-year-old mother outruns me," she says. "Once I got through that, it was all about finding resourceful and creative ways to keep my body moving."

Running, biking, hiking

Green replaced outdoor running with a treadmill workout. While she goes to her physical therapy clinic to use a specialized treadmill, called the Alter G, which holds her up and reduces the effects of fatigue and balance issues, standard treadmills are also widely available at local health clubs and city rec centers. These facilities may also have indoor tracks. You'll get the benefit of air conditioning while being able to run or walk at your own pace.

Wherever you choose to run, Noriko Yamaguchi, PT, DPT, with University of Southern California Physical Therapy Associates, recommends starting with run-walk cycles, which are

short bouts of running mixed with walking or a full pause when you need a rest. These types of drills help you gauge how much the heat is affecting you and allow you to quickly adjust your workout based on your energy levels.

If biking is your preferred sport, several alternative bicycle designs can help you expend less effort and energy on hot summer days. Tandem bikes allow you to ride while a partner does more of the work; recumbent adult trikes help with balance issues and also enable riders to lean back; and power-assisted bikes have an electric motor that kicks in if you get tired of pedaling.

Green is a fan of the BerkelBike, which is a hybrid between a recumbent bike and a handcycle. "I can use my legs and arms or just my legs or just my arms, and because I'm sitting I can really push myself," she says.

"I often wear a cooling vest, a visor or headband with cooling beads, and I plan extra time in case I need to stop and rest and spray myself with water."

Physical therapists also recommend wearing bike helmets with extra or larger-than-usual vents to help keep your head cool, and carrying a cellphone with you in case you overexert yourself and need to call for help.

BerkelBikes are pricey—about \$6,500—but Green hunted around for money to pay for hers, scoring grants from a pharmaceutical company and a local organization. The <u>Challenged Athletes Foundation</u> is also a good resource for equipment grants. Last year, it awarded over \$2 million in grants to more than 1,100 people with disabilities. The program is closed until September 2014, when it will begin accepting grant applications for 2015.



Dave Bexfield, an avid hiker, takes frequent breaks on a collapsible stool to avoid overheating.

Photo by Chip Simons

Dave Bexfield, who was diagnosed with MS in 2006 and runs the nonprofit website ActiveMSers.org, still enjoys cycling and other summer activities despite balance, leg weakness and eyesight issues that are exacerbated by exercise and heat. For summer hiking, Bexfield switches out his cane for forearm crutches, which give him more balance and stability on uneven surfaces. Yamaguchi says even if you don't use an assistive device for walking, you might want to consider hiking poles—particularly when you're hiking downhill, which demands more muscle strength for shock absorption and balance. Bexfield's wife, Laura, carries a small portable stool, and every 15 minutes, he sits in a shady spot to cool down, sipping ice water from a hydration pack he froze the night before. He also wears a cooling vest and, often, a wide-brimmed hat. Following this regimen allows him to hike for a couple of hours, or two to three miles.

Time of day also matters. Bexfield, who lives in Albuquerque, N.M., restricts his hiking and biking to the cooler morning and evening hours—a strategy that medical professionals recommend for exercise in the heat. "You can achieve your fitness goals even by exercising in increments, so consider breaking up your workout into smaller, more manageable sessions," says Mandy Rohrig, PT, DPT, with Horizon Rehabilitation Centers in Omaha, Neb.

Getting wet

Water dissipates heat about 25 times faster than air, so water activities can be ideal for people who have heat sensitivity. Water-based aerobics, walking and tai chi; water polo and volleyball; and swimming and snorkeling can feel very freeing if you have weakness, spasticity, pain, or balance or gait issues, Rohrig says.

However, she recommends caution if you've never exercised in the water before. "You're moving well, without becoming overheated or fatigued. In this situation, it can be very easy to overdo things. Then when you get out of the water, and suddenly gravity's back, your symptoms may temporarily feel more pronounced," she says.

Start conservatively, she recommends, with water walking or a gentle swimming stroke. Watch for warning signs like shortness of breath or muscle soreness, and keep your rate of perceived exertion at an intensity of 1–2 for warm-up and cool-down, and 3–4 for your "exercise zone," on a scale where 10 is the maximum effort. The pool temperature should be 80 to 84 degrees to minimize overheating. She encourages clients to confirm that the local pool is in this temperature range, as some pools are transitioning to warmer water for people with arthritic conditions.

If you find swimming monotonous, you can listen to music, even while you swim. "My partner got me a waterproof iPod that clicks onto my goggles," says Green, who started swimming last year. "It makes a huge difference for me."

Bexfield points out that tandem or group kayaking, rafting and canoeing can be good options for people with MS. Not only are you able to sit and rest your legs, but there's someone to help if needed. Plus, if you get overheated, you can dip your hands, hat or neck scarf in the cool water.

Rohrig says these are excellent strategies, but notes that being on the open water can lead to a significant amount of sun exposure. "Potential ways to manage this include paddling shorter courses or courses that allow for 'pulling over' in the shade," she says, "or using an umbrella or canopy-type system for some shade" on the watercraft. If water-sports enthusiasts find that wearing a life preserver creates additional heat, Rohrig recommends that they have cooling devices available and stay well hydrated.

Research shows that a preworkout shower or bath can also be a powerful coolant. Ideally, immerse your legs in about 70-degree water for 20 to 30 minutes before you're going to be exposed to heat. "Precooling allows the lower limbs to effectively serve as heat 'sinks' in order to blunt internal temperature increases and decrease reliance on ... sweating," wrote researchers in a 2010 study published in the **Journal of Applied Physiology**. If you can't stay in water that cold for that long, a 5- to 10-minute pre- and post-workout shower that's as cold as you can comfortably tolerate can also prove to be somewhat effective, Rohrig says.

Green likes to cool off after exercise in a 10-foot-wide inflatable pool that she places on her shaded patio and fills with cold water. "I can sit in water up to my neck and read a book," she says.

Keeping active in the summer

Dave Bexfield enjoys a range of outdoor activities and stays smart about adapting to the heat.



Other outdoor options

Tennis, particularly with a partner, can be a good choice for a cooler summer activity if you have adequate hand-eye coordination, Yamaguchi says. The U.S. Tennis Association has adaptive programs specifically for people with challenges like MS, and can match you with local players with similar skills.

Softball and baseball offer frequent opportunities to rest in the shade, but require some arm power and ability to sprint short distances. If you have adequate balance to swing a club, Yamaguchi recommends golfing. Using a cart helps with fatigue and, because you play in pairs or foursomes, there's also a social aspect.

To evaluate whether a type of exercise is right for you, Yamaguchi recommends paying attention to your symptom patterns. "It can be helpful to keep a workout log listing what you did, how you felt immediately afterward, and how you felt later in the day or the next day," she says. And be sure to check with your physician before starting any new exercise regimen. Once clearance is granted, a physical therapist with experience treating individuals with MS could help structure your program.

One thing to keep in mind: A 2013 study published in the **Multiple Sclerosis Journal** reported that people with MS who do 30 minutes of endurance exercise have significantly

greater increases in heat-related symptoms compared with people who do the same amount of resistance exercise. Endurance exercise includes aerobic activities like walking, running, biking and swimming, while resistance exercise focuses on weight lifting and strength training.

Of course, as the temperatures spike, none of these options can seem very attractive. Green realized that if she waited until she felt like exercising on hot days, she might never leave her couch. So she came up with a solution that she calls her 10-minute rule. "I do an activity for 10 minutes and then listen to my body. I check in and see if the feeling of wanting to continue follows," she says. "Often, after 10 minutes the feeling has kicked in. If it hasn't, I stop and try again the next day."

Vicky Uhland is a freelance writer and editor in Lafayette, Colo.

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