

Ready, set, snow!



An entire industry has evolved to make skiing, skating and other winter sports possible for people with MS-related challenges.

by Vicky Uhland

As a teenager growing up in Vermont, John Pierce fell in love with downhill skiing. Not only did he enjoy the physical activity, but it also helped him endure the frigid Northeastern winters. “It makes them seem shorter because you’re not just sitting at home waiting for spring,” he says. Pierce’s devotion to skiing continued throughout his 20s and into his 30s. And then, in 1985, when he was 38, he was diagnosed with multiple sclerosis. For the first decade after his diagnosis, his symptoms were mild enough that he was able to continue skiing. But as his disease progressed and his balance and coordination eroded, he began to rely on a walker or a cane for everyday mobility, and he decided it was no longer safe to hit the slopes.

Over the next 15 or so years, Pierce mourned the loss of one of his favorite activities. But then, in 2010, he discovered Vermont Adaptive Ski & Sports—one of hundreds of programs throughout the U.S. that provide winter and summer activities for people with disabilities, including MS. (For more information, see sidebar below, “Adaptive winter sports resources.”)

Adaptive winter sports resources

- **USA Paralympics** Visit findaclub.usparalympics.org for a list of the hundreds of USA

Paralympic programs in downhill and cross-country skiing, snowboarding, sled hockey, biathlon and wheelchair curling. You'll find nonprofit programs offered by ski areas, local rec centers, colleges and universities, volunteer organizations and Olympic training centers, along with a list of adaptive sports teams in your area.

- **Disabled Sports USA** Disabled Sports USA chapters in the Northeast, Midwest and West offer adaptive downhill and cross-country skiing, snowboarding, snowshoeing, biathlon, sled hockey and wheelchair curling programs at no or minimal cost. For a list of chapters, visit disablesportsusa.org/chapters.

Volunteer ski instructors at Vermont Adaptive outfitted Pierce with a sit-ski, which is basically a padded plastic chair mounted onto a metal frame that holds the skier's legs horizontal. The entire apparatus is then attached to one or two skis. A skier is secured in the chair with safety straps, and can control the skis' movement with ski poles and by shifting his or her weight from side to side in the chair—similar to the way a person moves in conventional skiing. Pierce uses “outrigger” ski poles, which have miniature skis on the end and require less balance and upper-body strength than standard poles because they slide rather than having to be planted.

Some people sit-ski solo, but because Pierce's motor skills have lessened enough that he can't make the quick shifts in body weight that are necessary on a ski slope, he skis with an instructor. The instructor is tethered behind Pierce, helping him turn, stop and control his speed.

Today, Pierce regularly cruises down intermediate slopes in his sit-ski. And once again, he celebrates winter instead of dreading it. “People with MS have to give up so many things, so to be able to do one of the things you love is delightful,” he says.

Indeed, many people find winter's chill more enjoyable than summer's swelter and are looking for ways they can resume—or start—a winter sport. The increased strength, stamina and cognitive improvement that come with exercise add to its appeal.

“There's no doubt that when you get fresh air with a little bit of movement, there's a tremendous lift to the mind, body and spirit,” says Amanda Rohrig, DPT, a physical therapist with Horizon Rehabilitation Centers in Omaha, Nebraska. “But more people with MS are reluctant to do winter sports activities than summer sports activities, and that's almost entirely due to one thing: fear of falling.”

Learning to slip and slide

Considering that heat intolerance is common in people with MS and can be exacerbated by exercising in the summer, cold-weather activities could offer a welcome alternative. But frigid temperatures pose their own challenges, Rohrig says: They can aggravate spasticity, numbness and tingling in people with MS—increasing their risk of falls.

“For an individual who does not feel his or her feet or legs well because of numbness or tingling, a slick surface or an icy patch on a sidewalk or grass can pose quite a balance challenge,” Rohrig says. Strap on a pair of skis or ice skates, and those balance issues are amplified. So it’s no surprise that fear of falling makes many people with MS reluctant to try winter sports.

While a bad fall on ice can certainly have serious consequences, that doesn’t mean you should avoid exercising outdoors in the winter. A better approach is to manage the risk of falling. Susan Kushner, a PT and academic coordinator of clinical education at Pennsylvania’s Slippery Rock University, recommends practicing 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 MS Society’s “Free From Falls” program, available in person in some regions, and in a DVD and companion brochure format everywhere, also teaches these skills.)

Pierce practiced falling sideways in his sit-ski on a beginners’ ski slope, aided by a Vermont Adaptive instructor who helped him get back up. “After falling a few times, I came to realize it wasn’t as dangerous as I thought, and I wouldn’t hurt myself,” he says. Helmets can protect the head in case of a fall, too, and are now widely available in many styles and colors.

Many adaptive sports programs have teachers who are taught specifically how to work with people with MS. “I’ve found that these instructors are very well trained, very cautious and conservative,” Pierce says. “If anything, they assumed my disability is actually worse than it is, and that was reassuring.”

Along with being cognizant of falling issues, many instructors watch their clients with MS closely for signs of fatigue or weakness. “We encourage shorter runs with more breaks between,” says Kelsey Moody, program coordinator for Maine Adaptive Sports & Recreation.

Kushner recommends that anyone with MS who embarks on an outdoor activity pair up with a buddy in case safety issues arise. “If you’re snowshoeing or cross-country skiing, gauge your distance very conservatively so you can get back safely,” she says. And make sure you stay hydrated and carry high-protein snacks to keep your blood sugar, and thus your energy levels, optimal. To protect yourself from the cold and from overheating during exercise, dress in layers, Kushner recommends. And stop to stretch if you feel any worsening of spasticity, Rohrig advises.

More photos of people with MS enjoying winter sports

ngg_shortcode_0_placeholder**Winter fun on a budget**

Aside from physical issues, some people with MS also avoid winter sports because they can be expensive. However, many adaptive sports programs receive grants, donations and scholarships that allow them to provide their activities at little or no cost.

Thanks to a grant from the Multiple Sclerosis Foundation, Common Ground Outdoor Adventures in Logan, Utah, is able to offer its skiing and sled hockey programs for free. In sled hockey, players sit upright on a metal sled with their legs extended, parallel to the ice. A pair of specialized hockey skates is attached to the bottom of the sled. The players use adapted hockey sticks to propel themselves around the ice and to shoot pucks.

Maine Adaptive also hosts free ski and snowboarding programs, courtesy of its annual Ski-A-Thon fundraiser and in-kind donations for lift tickets from Sunday River ski resort and host mountains. “We get a lot of people who come here with their families on vacation. They’re thrilled that they can all ski together,” Moody says. In fact, last January, several people enjoyed an “MS camp,” complete with lodging, food, a guest speaker and free ski lessons at Sunday River, provided by Maine Adaptive and the MS Cure Fund. “This year we are blocking off an entire day (Jan. 12, 2015), and we hope to have 15 or more people with MS skiing together,” Moody says.

Similarly, in 2014, people living with MS and their support partners were invited to ski together using adaptive equipment with professional ski instructors at Vertical Express, an on-mountain ski fundraising event in Vail, Colorado, hosted by Can Do Multiple Sclerosis. In 2015, Can Do MS plans to add more adaptive ski experiences to its roster of Vertical Express events in different parts of the country, says Rohrig, a programs consultant with the nonprofit. (For more information, visit mscando.org.)

Navigating snow and ice

Snow, ice and cold weather can pose mobility challenges for people with MS. Physical therapists Amanda Rohrig and Susan Kushner offer the following tips to stay safe and mobile during the winter months.

- Consider adding rubber gripper systems (such as Yaktrax) or ice cleats to your shoes to navigate slick surfaces and improve balance. You can find these devices at outdoor stores like REI or websites like backcountry.com. Snow boots with cleat-like soles are also widely available at outdoor stores and websites.
- Carry a can of windshield de-icer (available at auto supply stores and websites) to spray on ice in your pathway.
- Make your cane or walker legs more stable on ice by attaching pieces of sandpaper to the bottom. You also can attach pronged ice grips to canes.
- Outfit your wheelchair or scooter with thick-tread tires that can plow through snow. Look for these all-terrain tires at websites like sportaid.com.
- If cold weather affects your grip, add Velcro strips to your gloves or mittens and to the handle of your cane or walker.

Choose your sport

Whether you're a beginner or an expert, there's likely to be a winter sport that fits you and your physical abilities. Here's a look at cold-weather activities geared toward people with MS.

Downhill skiing. Also known as alpine skiing, this is the most developed and popular of the adaptive winter sports. "It's been around since shortly after World War II, and today there is an entire adaptive certification system in place for instructors from the Professional Ski Instructors of America & American Association of Snowboard Instructors," says Julia Ray, programs manager for Disabled Sports USA, which has more than 100 adaptive sports chapters nationwide.

Adaptive downhill skiing is done either upright or in a sit-ski, and trained PSIA-AASI Adaptive Alpine-certified instructors can work with either type of skier. Instructors are certified on a progressive system, so Level III instructors are generally more skilled and knowledgeable than Level I instructors. In addition, instructors can specialize in instruction related to specific types of disability such as visually impaired skiers, sit-down skiers or stand-up skiers.

For beginner or anxious adaptive skiers, instructors "start very basic," Moody says. "We explain what the parts of the ski are, [help them] slide around on their skis, and then ski with them by holding their hands for balance, for example. Every person has an individual lesson plan."

At the chair lift, skiers—whether standing or using a sit-ski—begin by watching how other people load and unload. "Then we stand behind them and do a countdown—3-2-1—and push a regular chair behind them on number 1 so they can see what it feels like, and after we will ride the actual chairlift," Moody says. Instructors sit next to skiers once they're on the lift, and lift operators are often asked to slow down or stop the lift for any skier who feels uncomfortable getting on or off. Sit-skis can also be equipped with a pump that raises the chair, allowing the skier to sit on the lift while still in the chair.

Like Pierce, more advanced upright or sit-skiers may choose to ski with an instructor who is tethered to them via a long leash that attaches to a belt around their waist or on the tips of their skis. The tethered instructor helps the adaptive skier maintain control, assists with decision making and aids in turning—particularly for people with vision deficits who may have trouble discerning bumps and ruts in the snow.

Skiers who want to be upright but who have balance or weakness issues can use outriggers or snow sliders (also called ski walkers) instead of poles. "Ski walkers are like walkers with full-length skis on the bottom. Instructors ski on both sides of you to help you turn," says Heather Timins, northern program coordinator with Vermont Adaptive.

Another option is "four-track" skiing—so named because it uses two outrigger poles that have cuffs from the elbows to the wrists to provide extra balance and support, plus two skis, leaving four tracks in the snow.

Sit-skiing can be done on one or two skis. One ski requires greater balance and core stability and strength, Rohrig says.

Cross-country skiing. Also known as Nordic skiing, cross-country skiing is usually cheaper and more accessible than downhill skiing. Often, you can just strap on your skis and go for a jaunt around the local park.

That's how Jane Schmieding got started. An avid handcyclist and kayaker who was diagnosed with MS in 1978, Schmieding was taking an adaptive fitness class at the University of Wisconsin seven years ago when she learned that an engineering department faculty member was developing an inexpensive cross-country sit-ski.

Schmieding and her husband helped UW students construct some of the sit-skis, which consist of a low chair with a webbed back and seat that is clipped into bindings mounted on a pair of standard cross-country skis. Volunteers with the Central Cross Country Ski Association, a Wisconsin-based regional organization governing cross-country skiing in 10 states, eventually built about 300 of the sit-skis. The association donated them to ski areas and city and state parks nationwide, where disabled skiers can use them for free.

Of course, after Schmieding helped build one of the skis, she had to try it out. "It's nothing I ever thought I'd be doing," she says. "But I've found that it's a fun and crazy way to get exercise, make friends and not spend the winter sitting around hibernating."

Schmieding opted for a sit-ski rather than standard Nordic skis because she has balance problems and numbness and tingling in her feet that necessitate the use of a walker indoors and a scooter outdoors. But she's fairly strong in her upper body, which allows her to push her skis along with poles. Sit-skiing also requires good core strength, Rohrig says. She recommends cross training with handcycling to build upper-body strength.

Originally, Schmieding tested out her sit-ski in flat parklands, with her husband snowshoeing beside her. "The first thing I did was fall on my side and break the ski," she says. "But falling usually isn't a big deal because my husband is there to help get me upright."

Soon, Schmieding graduated to cross-country ski trails, and for the last four years, she's competed in the prestigious American Birkibiener marathon that's held each February in Wisconsin. Schmieding skis a challenging three-kilometer portion of the Birkie that is geared specifically to skiers with disabilities.

For cross-country skiers who prefer to stand when they get out on a trail, snow sliders and outrigger poles are available.

Snowboarding. Adaptive snowboarding is relatively new, Timins says, but its popularity seemed to skyrocket after it debuted in the 2014 Sochi Paralympics. As a result, look for more equipment and instructors in coming years.

Like skiing, snowboarding is applicable to a variety of ability levels, but it takes longer to learn the basic skills, Moody says. An instructor can tether himself or herself to a snowboarder via a waist belt or a device that looks like a hula hoop. Alternatively, some snowboards come equipped with a handlebar that the rider can hold onto for extra support, and ski poles with outriggers can help with balance.

Ice skating. Adaptive-sports program coordinators say ice skating isn't very popular with their participants, probably because of the fear of falling. That's a pity, says Jeffrey Gingold, a speedskater who lives in Milwaukee. Gingold, who was diagnosed with MS in 1996, walks with a cane and has issues with cognition, stamina, fatigue, balance, vision and numbness in one leg. "But my cane stays in the car when I go to the ice arena," he says. "It's wonderful. When I speedskate, I feel like I'm flying."

Gingold says his walking motion requires a bent knee and lifted toe and heel, which for him, necessitates the use of a cane. But he can leave his cane behind when he's on the ice because "speedskating is a matter of shifting weight rather than doing deep knee squats."

Skating also offers other advantages for people with MS. Gingold had to drop all of his summer activities because of overheating, but speedskating "never lets my core temperature rise," he says. "Being surrounded by ice has a natural cooling effect."

Gingold was an accomplished speedskater before he was diagnosed with MS. For those with less experience, he recommends senior or beginner figure and speedskating programs at local rinks. "People skate with walker-type devices that have plastic nubs on the legs so they can slide on the ice," he says. "I've never seen anyone go down when skating with a walker." Others use poles or hold hands with someone else as they skate.

"I've found that in ice arenas, people are very supportive of any tool you need," Gingold says. "MS doesn't mean that you can never do something like skating again; it means you need to figure out a new way to do it."

Snowshoeing. If you can walk—even with a cane—you can snowshoe, Timins says. "It has less of an impact on joints than skiing, so you can go longer, as long as you take breaks when you feel tired, and use hiking or ski poles to help with balance."

Snowshoeing is a good aerobic and strength-building activity, and has the added advantage of being social. It moves at a slow-enough pace for chatting, and people without any specialized skills can join you. "You can get out with your friends and family and build relationships," Timins says.

When it comes to any winter activity, the key is to not let fear or inexperience hold you back. "Even if it's just sitting in a wheelchair and throwing a snowball with your kids, I encourage people with MS to enjoy the outdoors in winter whenever they can," Rohrig says.

Vicky Uhland is a Lafayette, Colorado-based freelance writer.

To request the “Free from Falls” DVD and brochure, or to find out if the Society offers the eight-week course in your area, call 1-800-344-4867.