

Fun in the sun



Outdoor activities offer people with MS a chance to have fun and connect with others.

by Robert Lerosé



Elyse Palmer joined First Descents, an organization that offers activities like white-water kayaking, modified for people with MS.

Elyse Palmer was active in sports from a young age, playing soccer with her dad and older brother and running track at Allegheny College.

“Sports were always a container for my intensity,” the 34-year-old Pennsylvanian says.

When Palmer started experiencing severe fatigue as the mother of six-month-old Lena and 2-year-old Les, it was dismissed as routine exhausted parenthood, even though her paternal grandfather had multiple sclerosis. But after Palmer lost sensation in her feet, legs, arms and hands, she was diagnosed with MS in March 2017.

After retiring from her job as a second-grade teacher and wondering who she was now after building an identity around sports, Palmer found her answer. “I’m exactly the same person. With a little flexibility, I could find ways to continue doing things that are fulfilling.”

Summer is a prime time for people with MS to learn a new sport or participate in outdoor activities while connecting with others who have similar interests, abilities and perspectives.

Palmer got involved with First Descents, an organization offering free outdoor programs for people aged 18 to 45 who are living with MS.



Mackenzie McGrath is director of programs for First Descents, a program that hosts outdoor activities for people with MS.

“First Descents’ programs normalize and destigmatize a diagnosis through a shared experience, in a safe and comfortable environment,” says Mackenzie McGrath, director of programs. “We know that adventure and community foster healing. Our programs reduce anxiety, depression and social isolation, and strengthen self-confidence, self-efficacy and

social connection. Participants feel hopeful about their future.”

During a week-long trip to Montana, Palmer tried white-water kayaking for the first time. Nervous about spending time with strangers doing an intense activity, she flipped her kayak on the second day — and broke out in a huge smile.

“I was no longer carrying the weight of trying to be perfect,” Palmer says. “I was surrounded by people who had my back.”

New England Disabled Sports offers year-round customized sports programs with trained instructors.



Dana Roberts is operations manager for New England Disabled Sports, which offers customized sports programs with trained instructors.

“There are so many adaptations now that you can still independently engage in the community, whether you identify as a biker, kayaker, mountain biker, whatever it might be,” says Dana Roberts, operations manager. “For social and emotional well-being, that makes a huge difference for people.”

Sailing escape

JR Hardenburgh pursued a lifelong interest in sports — particularly sailing, which he got hooked on at the age of 12. He was in the middle of a successful career at AT&T when his left side went numb as he was walking down a train platform in Boston. He was diagnosed with MS in June 1995. He stayed with AT&T until 2003, then became a consultant until 2012, when he began to experience cognitive issues. He also started using a wheelchair.

At a loss for direction, Hardenburgh found purpose in sports when two buddies suggested he explore adaptive sailing. Hardenburgh found Y-Knot Sailing on Lake George and was soon piloting a Martin 16 sailboat that accommodates people with a disability and can be sailed singlehanded or with a companion.

“We got invited to the Clagett Regatta — the U.S. parasailing championship — and that’s when I knew I had arrived,” says Hardenburgh, 66. “I took a bronze medal with a buddy with MS in the first race we entered, beating the Canadian team who took the gold medal at the Rio Olympics.”

Hardenburgh hopes to get funding for MS Sailing Days, an effort to give people with MS more opportunities to get out on the water at four different locations: Community Boating in Boston; Y-Knot Sailing on Lake George, New York; Sail to Prevail in Newport, Rhode Island; and the WaterFront Center in Oyster Bay, New York.



Caroline Craven, diagnosed with MS in 2001, has always been passionate about the outdoors.

“Sailing is a 100% quality-of-life endeavor. You get to leave your disability on the dock,” Hardenburgh says.

Rediscovering the natural world

Caroline Craven had always been passionate about the outdoors — fishing, rock climbing, even jumping out of airplanes. For about five years, she experienced numbness and tingling that didn’t bother her. But on a trip to Guatemala with friends, she began to lose her balance, vision and ability to eat. She was diagnosed with MS in 2001.

After a career in marketing and IT, the 55-year-old now blogs about health. She lives with her

parents and can only drive locally, making travel more difficult. On her first trip to South Africa after her diagnosis, Craven cried because of her limitations. But she soon learned that preparation can make for smoother sailing: A trip to the Galápagos Islands two years later was much more enjoyable because she trained for it beforehand with slow walks in her neighborhood.

Resources

To find out more about adaptive sports and recreational activities around the country, check out:

MS Sailing Days

Contact: jrhardenburgh@gmail.com

Move United

moveunitedsport.org

Outdoors For All

outdoorsforall.org

First Descents

firstdescents.org

Then, after meeting some women at a local fly-casting club, Craven found the confidence to go on her first trip without the support of her family or friends since her diagnosis — a fly-fishing excursion in 2014 to Hot Creek Ranch in the Eastern Sierra of Mammoth Lakes, California.

Craven prepared by wearing cooling vests, SPF shirts, gloves and neck wraps. She was candid with her companions about her concerns, such as how she would manage if her legs gave out or if she got separated from the others.

But coming up with options in advance alleviated her worries.

“Everyone needs to remind themselves to have compassion towards themselves,” she says. “You did nothing to cause this disease, but you can still look for opportunities.”

Being in the sunshine made her aware again of the beauty of the natural world and kept a valuable part of her identity alive. It also showed her how to manage her energy for the best result.

Pushing through

As a vice president of sales for a contract food group, Jenivie Leschber was on a plane almost weekly and led an outdoorsy life. She had been fishing with her family on their boat off the

Texas coast when she felt numbness on one side of her face and a terrible headache, which she attributed to a pinched nerve.



Jenivie Leschber, diagnosed with MS in 2019, enjoys exploring national parks and is an advocate for adapting activities to suit your needs.

An MRI showed lesions that confirmed an MS diagnosis on July 4, 2019 — one day after her 39th birthday.

She had to take disability leave from her job in December 2020 because of cognitive issues, and is still getting accustomed to her new limitations.

The spasticity in her legs has been hard to manage, and headaches can make it impossible to get up, but she aims for some type of daily activity. On a 2021 Christmas road trip in her RV to visit a friend in California, she and her two kids — 7-year-old Reece Karen and 6-year-old Levi Walter — visited seven national parks. “I try to push through because I know if I get out and do some form of exercise, whatever my MS symptoms are that day will be better,” she says.

Learning to adapt is essential. Leschber was mountain biking with her husband in summer 2020 when she realized that she was having a bad time with her depth perception. She crashed but adjusted by switching to a paved path and riding easier.

“I’m a big advocate of getting people outdoors,” she says. “I found out that you can get a disability pass from the national parks, so you can enter any national park and not pay the entrance fee. Tap into folks who’ve been doing this for a while, but find something you enjoy

and that is easy to access, even if you have to adapt.”

Robert Leroose is a writer based on Long Island, New York.

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