

Social season



Even when summer seems to melt routines away, people with MS can still meet others and stay socially engaged.

by Marcella Durand

Summer, with its slower rhythms and less-structured routine, is a time many people look forward to all year long. But that very lack of routine can keep people with multiple sclerosis from staying connected with each other: School lets out, programs and classes go on hiatus, and offices empty as colleagues leave for vacation. Summer might feel isolating, especially for people with MS who stay indoors to avoid heat triggering their symptoms.

But with a little creativity, people with MS can find activities that will help them stay connected and engaged throughout the hot months.

In your backyard

Kendra L. Williams was a senior travel editor for Midwest Living before she was diagnosed with primary-progressive MS in 2014. “It was the first summer I wasn’t working full time,” she says. So she planned instead to spend more time with her 8-year-old son, Colin, and explore activities near her home in West Des Moines, Iowa. “A lot of times with MS, your financial picture changes and [even if] travel isn’t an option, you can try a state park or a local restaurant. That way, you start meeting people and having experiences that don’t cost a lot, but that can change your whole outlook,” says Williams, who now writes a blog, mstravels.org.



The Ferris wheel at Chicago's Navy Pier stands as a bright backdrop for Kendra Williams, left, and her childhood friend, Jennifer Coletta.

Photo courtesy of Kendra Williams

Summertime entertainment events, such as outdoor concerts and minor-league baseball games, are great places to socialize and take advantage of accessible seating, she says. "I have found that I end up bonding with the other people who are sitting in the accessible section," she says. "We don't even talk about what our disabilities are; it's just a shared understanding." Williams recommends calling ahead to ensure that venues are accessible. "That makes me more confident about venturing to a place I'm not familiar with."

Another of Williams' favorite summer activities is visiting her local farmers market, where she can interact with people each week. "Being able to make friends with the vendors may be a small thing, but it means a lot to us," she says. "They love to talk about the food they grow and simple ways to cook it," which she finds helpful because, "I'm not able to cook the way I used to be able to."

Many city and state websites provide listings of public pools, park programs and cultural events such as yoga classes, street festivals and live performances. If daytime heat is an issue, look for events, such as movie screenings or concerts, during evening hours or indoors. Many of these activities are free or low cost. Try using search terms, such as "accessible" plus "events," "recreation" or "arts and culture," to find out about them online. Public libraries and local Y branches are also great resources for finding summer activities for people with disabilities.



Antoinette-Marie Williams, left, with friend Ruth Robbins at the 39th Monte Carlo Backgammon World Championship cocktail party in Monaco. Williams was a finalist. Photo courtesy of Antoinette-Marie Williams

Cruising to connection

Antoinette-Marie Williams (no relation to Kendra) was diagnosed with secondary-progressive MS in 1987. After she had made several connections through an exercise class offered by the National MS Society, the New Yorker decided to arrange monthly luncheons where she and her new friends could simply socialize. This summer, she is hoping to offer something special—a luncheon and tour aboard a cruise ship docked at one of New York City’s ports.

Williams is asking the cruise line to demonstrate its accessible facilities. Last summer, she took a cruise to Nova Scotia and loved it. “You see people at meals, you run into the same faces, you say hello—I think it’s a great way to open up.” What’s more, the cruise was accessible. “Most people who use motorized equipment wouldn’t think of a cruise as an accessible option,” she notes. But any ship docking in domestic ports must comply with the Americans with Disabilities Act (ADA); however, some may offer more disability-friendly amenities than others. Visit cruisecritic.com and search for “accessible” to find information about accessible cruises and reviews of specific cruise lines.

Dancing to well-being

Summer nights can be a great time to get outside, be active and socialize while the air is still warm, but without the fierce heat of the sun. Many cities and towns offer summer-only concerts, dance events and even dance classes.

Alexander Ng, PhD, an associate professor in the department of physical therapy at Marquette University in Milwaukee, has been studying the potential benefits of dance for people with MS. “It becomes a social event as much as a physical event. People seem to genuinely form friendships. And there’s value in that,” Dr. Ng says. “I believe it’s time to start looking at recreational activities where you can get the same [physical] benefits but have fun at the same time.”

Afford your fun

Summer is a great time to find low-cost or free activities. You can often find an impromptu performance or free yoga class in local parks. And if daytime heat is an issue, many public spaces hold free events, such as movie screenings or concerts, during evening hours or indoors. Check local listings in newspapers, public libraries, community gardens and parks, or state and city websites, and call ahead to ensure that the event is fully accessible.

The Plus One Foundation provides financial assistance to children and adults with a neurological injury, disorder or disease, including MS, for activities such as aquatic therapy, therapeutic horseback riding, therapeutic camps and summer programs. Visit plusonefoundation.org to learn more.

Also contact your health insurance to see what benefits it offers for health and wellness programs.

Call the National MS Society at 1-800-344-4867 to find out if assistance may be available for MS-related recreation and wellness expenses.

Physical therapist Amanda Rohrig, PT, DPT, at Horizon Rehabilitation Centers in Omaha, Nebraska, confirms that value of connection: “Participating in an adaptive program for people who have similar challenges provides comfort and a sense of inclusion and belonging. That security may then provide greater feelings of confidence and self-worth,” she says.

Dr. Ng was so encouraged by the results of his studies, which are currently being written for potential publication, that he is partnering with the Society and a Milwaukee dance studio to offer classes to people with MS. “It’s not part of our research, but we want to create sustainable programming to offer to the MS community,” he says. And what would this programming look like? “We want to offer summer classes, under the stars,” he says.

Adapting experience

Can Do MS is also offering programming that incorporates connection—and fun. “We’re developing what we’re calling ‘adaptive experiences,’” says Anne Lee Gilbert, programs manager at the Colorado-based nonprofit. These experiences include hiking, walking, water activities, cycling or ballroom dancing. Can Do MS’s first summer adaptive experience

launched in 2014 with a golf tournament. She expects full programming, which Can Do MS hopes to offer nationally, to roll out in 2016. “Through these experiences, people with MS can meet others and build on shared interests. We encourage participants to get together with other people with MS to have fun and be active. Hopefully they can take what they learn through these adaptive experiences and apply them to their everyday lives,” she adds.

Other organizations, such as Disabled Sports USA, provide adaptive sports opportunities nationwide, including aquatics, rafting, kayaking, stand-up paddleboarding, canoeing, surfing, day camps and more.

Your healthcare provider or a physical therapist can also help you decide what activities will work best for your level of ability. Rohrig points out that many adaptive programs are not specific to people with MS, so she recommends talking to instructors to make sure they understand the disease. And you should always check with your healthcare provider before beginning any new exercise program.



Kathleen Elder is the proud aunt of first-year medical student Kurt Marc Isaac-Elder, shown at right, on “white coat day”—marking the beginning of his education—in the summer of 2014. Isaac-Elder is at George Washington University Medical School in Washington, D.C. Photo courtesy of Kathleen Elder

A year-round commitment

Kathleen Elder, who was diagnosed with progressive MS in 1993, makes sure to keep her connections going year-round—even when her routines change with the seasons.

“When our indoor pool is closed for summer maintenance,” says the Reston, Virginia, resident, “we swim in one of the outdoor pools.” The city’s public pools have lifts that lower Elder, who uses a scooter for mobility assistance, into the water, and lifeguards are available to assist.

The “we” to which Elder refers is a group of people who meet year-round to take an aquatics exercise class for people who have MS or arthritis. “We are a community of fighters supporting each other,” she says. “This community is probably more important to me than the physical exercise than I get. It’s all about sharing and encouraging.”

Elder adds, “All of us in the class are frightened of the future, but by talking with each other, it lessens our fear.” Elder says that’s why it’s so important to her to not let those vital connections lapse during the summer. “The same thing we do during the rest of the year, we do during the summer— support each other—because MS is a daily struggle.”

Marcella Durand is a frequent contributor to Momentum.

Call an MS Navigator at 1-800-344-4867 to ask about summer programs in your area.