

Get moving



People with mobility issues can benefit from exercise, too.

by **Brandie Jefferson**

Exercise is recommended for everyone: people with multiple sclerosis, people without, people who walk miles a day and people who use wheelchairs daily. Most people — with or without a chronic disease — don't get enough.

“Most Americans don't get enough physical activity,” says Deborah Backus, PhD. And when it comes to having access and support to get in a good workout, “people with mobility limitations face much bigger barriers.”



Deborah Backus, PhD,

is leading a clinical trial that studies how exercise can be made easier and more accessible for people with MS. Photo courtesy of Deborah Backus, PhD

Today, healthcare professionals think differently than in the past, when exercise was not recommended for people with MS. Physical activity has been shown to have positive impacts on everything from strength and fatigue to bladder function and cognition in people with MS.

Backus, the director of multiple sclerosis research at the Shepherd Center in Atlanta, is working to make exercise easier and more accessible for people with MS.

Backus leads the multisite STEP for MS trial funded by the Patient-Centered Outcomes Research Institute, with co-principal investigator and creator of the novel exercise intervention, Rob Motl, PhD, of the University of Alabama at Birmingham. Participants are put into one of two exercise groups: one randomly assigned to do exercises at a facility or from home using teleconferencing, and the other allowed to exercise wherever they want. Both groups have access to coaching.

The trial is ongoing, but Backus has already gained some insights. “Being able to exercise in a way that fits your lifestyle, just like for all of us, is going to be meaningful,” Backus says, because everyone is more likely to stick with something they enjoy.

The coaching is key. “The coaching is what’s going to probably lead to best outcomes because people need support, so they can build confidence dealing with MS,” Backus says.

6 tips for getting more exercise

1. **Make it a habit.** Try to do something active every day.
2. **Look into different types of exercise classes.** Try exercise classes designed for the elderly, which are often adapted in ways that suit people with mobility limitations.
3. **See a physical therapist.** If you have insurance, make use of a physical therapist. Insurance typically pays for a limited number of sessions, says Kathy Zackowski, PhD, senior director, patient management, care and rehabilitation research at the Society. She suggests using them to learn exercises you can do at home, then checking in as insurance permits to perfect your form and learn new routines.
4. **Educate your trainer.** Prepare to work with a trainer. Offer a potential trainer/coach

the Society's "Intro to MS" for fitness and wellness professionals.

5. **Participate in step for MS.** Join the STEP for MS trial if you are in one of the participating areas, or look for another study in your area. You can find some current clinical trials at nationalmssociety.org/Research/Participate-in-Research-Studies/Participate-in-Clinical-Trials.
6. **Keep it local.** Visit nationalmssociety.org to find health and wellness programs in your area.

Exercising with mobility aids

It can be frightening for people with MS to exercise because they might be nervous about experiencing a fall, fatigue or pain. A person may not know how or if they should continue a program when these issues come up. Coaches with specific knowledge of MS can help people navigate those uncertainties.

Navigating the exercise terrain can be even more challenging for people who use wheelchairs. The first challenge is learning to use them.

"People with MS are often given wheelchairs, but they're not taught how to use them," says Stephanie Silveira, PhD, a postdoctoral fellow in the Exercise Neuroscience Research Lab at the University of Alabama, Birmingham. Her research focuses on exercise interventions for people with MS who use wheelchairs. Specifically, she asks, what are people interested in?



In her research, Stephanie Silveira, PhD, focuses on exercise adaptations for people who use wheelchairs. Photo courtesy of Stephanie Silveira, PhD

Silveira says there isn't much research when it comes to exercise for non-ambulatory people, and much of it is developed for people in the aftermath of an injury. She and her team started by interviewing 20 people, most with primary or secondary progressive MS.

The people Silveira surveyed were most interested in cardio and strength training, but their reasons were specific to their symptoms. For instance, she says, "A few people mentioned that if they got stronger, they'd be able to stand a bit more."

But the answer to one question, in particular, points to the differences inherent in exercise programs for people who use wheelchairs after injury versus those who have MS. And it can create problems down the line.

"When I ask, 'How did you decide to get a wheelchair?' some people say, 'I just decided to buy one and use it.' "

That's just what Laurie Monserrat did.

Monserrat was diagnosed with MS nearly 30 years ago. She was getting tired throughout the day, and she had difficulty walking. At the time, she was working with people who had spinal cord injuries. "They said, 'You're going to fall. Get a wheelchair, save your energy, walk when you can.' " After convincing her insurance to cover one, she went to pick up her new chair.

"I just wheeled out of the place where I picked it up," Monserrat says.

"If you don't know how to use it, you're going to be disinclined to exercise," Monserrat adds. "If I'm exhausted because I don't know how to use the chair, by the time I get to my car to go someplace to exercise, I'm done."

Making sure she gets some exercise every day is a lesson Monserrat brought home from four days that she says changed her life. Twenty years after her MS diagnosis, she went through the Can Do MS health and wellness program (candoms.org), a retreat where she had personalized coaching and therapy for everything from exercise to diet to mental health.

"They kept saying, 'The answer to disability is mobility,' " Monserrat recalls. "It's been the most impactful program I've done.

"I have terrible days where everything hurts, but every single day I do something," she says. From going on a walk with crutches when she can to lifting a book up in the air after reading a page when she can't. "Every single day."

The National Multiple Sclerosis Society is a Can Do partner. Olympic skier Jimmie Heuga, who was diagnosed with MS in 1967, founded the organization. "Doctors told him not to exercise," says Kathy Zackowski, PhD, senior director, patient management, care and rehabilitation research at the Society.

Heuga began the program to help people with MS stay active. “Research shows that people with MS are far too inactive, overall,” Zackowski says. “And it’s essential to acknowledge that physical activity is different than exercise, and we need to do both.”

The benefits of staying active

Physical activity is the daily accumulation of leisure, occupational or household activities that require moderate intensity. This includes activities such as vacuuming and parking a little farther away from the store. Exercise is a form of physical activity but it is performed on a repeated basis over an extended period of time. Think yoga, walking, or cycling. “It’s important for people to know the difference,” Zackowski says, “in part, because we need to incorporate both types of activity in our lives. And doing this is empowering.”

It’s also important to know the effects exercise can have. Research on the benefits of exercise for people with MS has borrowed from spinal cord injury therapy, as well as from stroke studies. “In a stroke, you form a lesion in your brain from a blood supply issue. In MS, the lesions in your brain or spinal cord are caused by different mechanisms,” Zackowski says, “but the symptoms people feel and their recovery from these symptoms have some similarities.”



Michelle, diagnosed in 2001. Photo by Keith Carlsen

We hear it often when it comes to stroke patients, but it’s true for people with MS as well, Zackowski says: “The brain can change over time. The idea of staying as active as you can, trying in a careful way to use a limb that isn’t working well can have benefits.”

As part of her goals leading a wellness research work group, Zackowski plans to publish

guidelines and adaptations for people across the spectrum of disability. She hopes people can use it to advocate for themselves, taking the guide to a physician, physical therapist, occupational therapist or trainer and saying, “I need you to walk me through this so that I know what I’m doing.”

People with particularly limited mobility, however, may not have that option, as spaces with adaptive machinery are few and far between.

“It’s been exciting to have an option for an exercise study that people who use wheelchairs can participate in,” said Lara Pilutti, PhD, at the University of Ottawa. She is working on a Society-funded pilot study looking at the impact and enjoyment of exercise for wheelchair users. “There’s been excitement about the adapted exercises they can do.”

Her research is in the early stages. “We’re trying to characterize responses and understand safety,” she says. “In designing the study, we’re thinking about how we can adapt certain exercises while also considering logistics,” such as specialized equipment to allow people to remain in their wheelchairs or to help people stay secure while exercising.

The trial uses tools like upper-body cycles and recumbent steppers operated by a person’s arms as well as legs. There are also high-tech interventions: functional electrical stimulation exercise, which involves mild electric stimulation, for instance, to a leg muscle while exercising that muscle using a specialized cycle.

Pilutti wants her work to have an impact beyond the participants and academic circles. “Hopefully, we can provide research that supports the use of these interventions,” she says. “And it transfers to the community.”

Community involvement could make all of the difference when it comes to access to exercise for all people with mobility limitations. “The equipment we use is expensive,” Backus says. “For someone to have an \$18,000 bike in the home is expensive. A specialized center is expensive. How do we make this affordable?”

The Shepherd Center has collaborated with the YMCA on some adaptive programs. Backus plans to work with Motl to package the results of the STEP trial in a way that people can use to self-advocate.

“I would like to make exercise more accessible to people with disabilities who need it the most,” she says.

One thing that can change is people’s attitudes.

“A shocking number of times, I’ve tried to go to a gym, and the trainer said, ‘We can’t do that,’ ” Monserrat says.

But self-advocacy paired with an open mind can lead to significant changes.

“I wanted to take a yoga class to help with balance,” Monserrat says. She asked the teacher if he could help. He was honest; he didn’t know, but he’d try.

“He adapted poses. He does this adaptive yoga now, and it’s cool. I can do some of the poses lying down. The important thing is I’m still doing something,” she says.

“It was a big step for me to ask, ‘Can you do that? Can you help me with this?’ It wasn’t easy, but it paid off.”

Brandie Jefferson is a writer in St. Louis, Missouri. She was diagnosed with MS in 2005.