

## Obstacle course



### **Researchers look for ways to help people with MS be more active.**

by **Lori De Milto**

People living with multiple sclerosis who exercise regularly can feel better, move better and live better. But studies show that fewer than 20% of people with MS in the United States get enough physical activity to see these benefits. While exercise helps lessen depression, fatigue and difficulty walking, these symptoms also make it hard for people with MS to be more active. And a variety of other obstacles can prevent people from beginning an exercise program and sticking with it.

Exercise physiologist Robert Motl, PhD, explains that many people with MS “lack knowledge about how to appropriately and safely exercise. Some are afraid that exercise will worsen the disease.” Motl is associate director of research for the UAB/Lakeshore Research Collaborative and professor of physical therapy at the University of Alabama at Birmingham. The cost of joining a gym or buying exercise equipment and having a safe and comfortable place to be active also can prevent people from being active.

Some groups face additional barriers as well, according to the studies. Some African Americans and other racial minorities with MS said they don’t have safe sidewalks in their neighborhoods for walking. Some minorities also said they don’t feel represented in exercise programs. “It shouldn’t be acceptable that you open an informational packet for an exercise program and you don’t identify with the people in it,” says Dominique Kinnett-Hopkins, PhD, a research assistant professor in the Department of Physical Medicine and Rehabilitation at the Feinberg School of Medicine at Northwestern University.

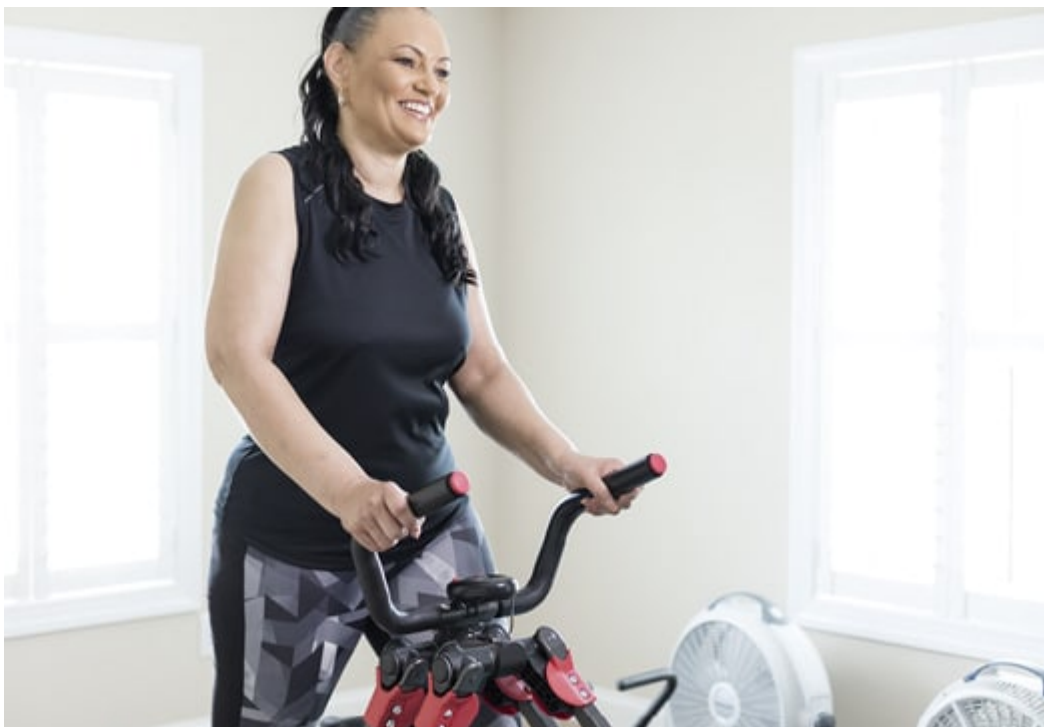
For children and teens with MS, lack of confidence in their ability to exercise and not setting goals are key barriers, according to research by Dr. E. Ann Yeh. Yeh is a professor of pediatric neurology at the University of Toronto. Yeh also is director of the Pediatric MS and Neuroinflammatory Disorders Program and senior associate scientist and a staff physician at the Hospital for Sick Children.

### **Ways to make exercise easier**

In their studies of exercise for people living with MS, these three researchers have found ways to overcome barriers and make exercise easier and more accessible. Motl suggests following the physical activity guidelines for adults with MS (see “Get moving” sidebar below), which call for aerobic exercise and strength training twice a week each. You can exercise at a gym or at home. But before starting to exercise, see your neurologist or primary care provider to make sure it’s safe for you.

“Walking is the most popular form of aerobic exercise in people with MS. It has the most benefits for physical outcomes as well as cognitive outcomes and brain health,” says Motl. If you can’t walk, try riding a stationary exercise bike. For strength training at home, Motl recommends resistance bands or even lifting a can of food in each hand.

“Small changes over time lead to great results,” Kinnett-Hopkins adds. “Start with going for a walk twice a week for five minutes or doing laps inside of your home. You may also order a resistance band and begin doing strengthening exercises at home.” Slowly increase how long and hard you exercise as you work toward meeting the guidelines.



**Judy Boone’s routine includes using an aerobic walking machine and twice-weekly strength training workouts.** Photo by Riku Foto

For children and teens with MS, Yeh recommends decreasing screen time and increasing movement in everyday life. Ways to do this include taking the stairs instead of the elevator or walking to school instead of getting a ride. Social interaction also facilitates exercise. “Find things to do with friends that will encourage you to be active,” like biking, skateboarding and dancing, Yeh says. Parents can help by providing a supportive and positive environment and leading by example.

### **Improving knowledge about how to exercise**

Helping people with MS learn how to exercise — and get encouragement from their doctors — is a key focus of Motl’s current work. He and his research team have found that people with MS want their neurologists to help them exercise. Neurologists are willing to do this, but they need training, tools and help from others. “We’re working on a framework for neurologists to help patients exercise safely,” says Motl. The framework will include training on how to guide patients in choosing the right types and amount of exercise based on their MS symptoms, and tools such as posters, pocket cards and patient handouts.

But many people living with MS don’t see a neurologist regularly. Primary care providers can also encourage exercise and provide resources.

Whether neurologists or primary care providers encourage exercise and provide the initial education, most doctors don’t have time for regular follow-up and support. Other healthcare providers and community support are needed to help people stay active over time. “Patients need resources to keep going,” Motl says. A nurse, for example, could provide more information about different ways to exercise or appropriate exercise programs. The Society’s services staff or community health providers can connect people with MS who want to exercise with resources to help them get started and continue to stay active. Find out more by calling 1-800-344-4867, or by emailing [ContactUsNMSS@nmss.org](mailto:ContactUsNMSS@nmss.org).

Motl’s research uses behavior change theory to help people living with MS learn skills and tricks to start and keep exercising. Through goal setting, action planning and self-monitoring, people can “see how much they’ve changed, and how easy it is to change,” he says. Motl also has worked on exercise guidelines, including the Canadian Physical Activity Guidelines for Adults with Multiple Sclerosis.

### **Exercise tailored to racial minorities**

Kinnett-Hopkins began studying exercise in people living with MS when she worked in Motl’s research lab during college. “I fell in love with how exercise could be used to combat a disease we don’t have a cure for,” she says. Kinnett-Hopkins’ research focuses on how MS is different for African Americans and other racial minorities who may have a higher risk of poverty, social exclusion, discrimination and violence than other people. When she started focusing on this, little research was available on MS in such disadvantaged populations.

In one study of 40 African Americans, Kinnett-Hopkins found that participants wanted to see people like themselves in educational and motivational content for exercise programs. They

also wanted to work with coaches who were African American and have faith-related content. Participants preferred weight/resistance training exercises and easy walking. Kinnett-Hopkins published these results in *Multiple Sclerosis Journal: Experimental, Translational and Clinical* in 2019.

Under a fellowship from the National Multiple Sclerosis Society (2019–2020), Kinnett-Hopkins is using data from the Chicago Area Patient-Centered Outcomes Research Network to identify the most disadvantaged people with MS in Chicago. Then she'll compare their use of healthcare services and disease characteristics to that of people with MS who have more advantages and identify differences between the two groups. Kinnett-Hopkins will also assess the needs of disadvantaged people with MS, including for exercise. She hopes to identify neighborhoods where providing exercise and other MS programs can help the most people.

### **More physical activity for children and teens**

Yeh is developing and testing an app called ATOMIC (Active Teens with Multiple Sclerosis) linked to a Fitbit activity tracker that helps children and teens with MS be more active in their everyday lives. While group exercise programs for children and teens have shown benefits, it's difficult for them to get to these programs. "We wanted to design something flexible that would enable kids to change their behaviors without requiring them to go any place," she says. Yeh and her team used input from children and teens with MS when they designed ATOMIC.

A pilot study showed that kids were interested in using ATOMIC, and that the program was feasible. Fifteen children and teens with MS, with an average age of 16, participated in the 12-week study. They received coaching (a monthly call and weekly text messages) and education, and used the Fitbit to monitor their progress toward their goals. Participants could choose the type of physical activity that worked for them. Suggested activities included skateboarding, scootering, dancing, throwing a frisbee, biking, hiking, taking the stairs and walking to school. Before each coaching call, participants increased their activity. Yeh calls thoughtful coaching "the secret sauce" to ATOMIC.

Based on the results of the 12-week study, the Society has funded a bigger three-year study of ATOMIC at three centers: the Hospital for Sick Children, the University of Alabama at Birmingham and Children's Hospital of Philadelphia. Fifty-six people with MS ages 11–21 will either receive the app and coaching on physical activity or a nutritional information program. Motl, who has helped Yeh develop clinical trials for children and teens with MS, will be part of the study at the University of Alabama at Birmingham. Much of Yeh's other research focuses on wellness, physical activity and lifestyle in pediatric MS and other neuroinflammatory disorders.

# Get moving

A doctor, physical therapist or a trainer with experience working with people with MS can help you choose the right types and amount of exercise based on your MS symptoms.

For adults ages 18–64 with mild to moderate disability, at least:

- 30 minutes of moderate intensity aerobics twice a week
- Strength training for major muscle groups twice a week

**Type:** Aerobic Exercise

**Frequency:** Gradually work up to 30 minutes

- Arm cycling
- Walking
- Leg cycling
- Elliptical trainer

**Type:** Strength training

**Frequency:** 10–15 repetitions of each exercise; Gradually work up to doing this twice (2 sets)

- Weight machines
- Free weights
- Cable pulleys
- Elastic resistance bands

Source: Canadian Physical Activity Guidelines for Adults with MS

**Lori De Milto is a Sicklerville, New Jersey-based freelance writer.**

Learn more about [MS research](#).