

Free to be fit



New guidelines highlight the benefits of exercise for all people with MS — regardless of ability.

by Matt Alderton

Exercise is the golden rule of health and wellness and has been for millennia. Nearly 3,000 years ago, for example, the ancient Indian physician Sushruta became the first doctor to recommend moderate daily exercise, which he believed could provide resistance to disease and “physical decay.” Just a few centuries later, the ancient Greek physician Hippocrates of Kos became the first physician to give a written exercise prescription, which he gave to a patient suffering from consumption. Since then, everyone from Jane Fonda and Richard Simmons to Bruce Springsteen and Michelle Obama has hailed the benefits of physical activity.



Anqunette Jamison, diagnosed in 2013, and her husband, Richard Sarfoh, stay active with regular walks. Photo: Keith Carlsen

If there's one person who hasn't always been on the exercise bandwagon, however, it might have been your neurologist. That's because, for a very long time, doctors advised against exercise for people with multiple sclerosis.

"Until fairly recently, the conventional wisdom was that people with MS shouldn't exert themselves," says MS specialist Barbara Giesser, MD, a neurologist at the Pacific Neuroscience Institute in Santa Monica, California. "This may have stemmed from the observation that when somebody with MS exercises and gets overheated, they can have a temporary worsening of symptoms."

"The problem with MS, of course, is that the nerves are scarred. They don't conduct electricity properly. If you take a damaged nerve and heat it, you get a temporary conduction block. The heat temporarily impedes the nerve's ability to function, but it doesn't cause more damage," Giesser says.

In fact, not only does exercise fail to make MS worse, it actually might make it better. In 2019, the National Multiple Sclerosis Society convened an international and interdisciplinary group of MS experts, researchers and clinicians, including Giesser, to create a new set of exercise and physical activity guidelines for people with MS. Published in April 2020 in the *Multiple Sclerosis Journal*, its work breaks new ground by making physical fitness accessible and attainable for all people with MS.

The merits of movement

Exercise physiologist Robert Motl, PhD, calls exercise a “potent stimulus” that has “clear pleiotropic effects.”

“That means it has effects on nearly every single system within the human body,” says Motl, a physical therapy professor at the University of Alabama at Birmingham and one of the coauthors behind the Society’s new exercise guidelines. “When you look at MS specifically, exercise can affect the expression and degree of inflammatory immune cells. For example, exercise can decrease pro-inflammatory immune cells and increase anti-inflammatory immune cells. Exercise also is known to stimulate nerve growth factors, which can help reduce damage within the brain caused by multiple sclerosis.”

Exercise is especially stimulating to the hippocampus and thalamus, areas of the brain with critical roles in memory and learning, and speech processing and motor function, respectively.

“Exercise has cellular-level effects ... that translate into changes in brain structure and function, which in turn translates into other benefits like reducing fatigue, improving cognition, improving walking and, ultimately, improving quality of life by enabling people to be employed and engage in social activities,” Motl says.

Exercise also is beneficial for its impact on other illnesses that can exacerbate MS, according to occupational therapist and guidelines coauthor Kathleen Zackowski, PhD, the Society’s senior director of patient management, care and rehabilitation research. “When someone who has a chronic neurological disease isn’t active enough, they can develop comorbidities like diabetes and obesity, which can be very impactful not only to the person’s life but also to the progression of MS,” she says.

Exercise even has mental and emotional benefits. “We know that mood is significantly impacted in people with MS and that staying active helps mood,” says clinical psychologist and guidelines coauthor Rosalind Kalb, PhD, a consultant to the Society as well as to the MS education organization Can Do Multiple Sclerosis. “People who exercise feel better, and people who feel better manage their symptoms more effectively.”

Making activity attainable

Exercise is healthy. The problem is: Many people with MS don’t know how to fit it into their lives.

“People with MS often know that exercise and physical activity are important and beneficial for their disease and their overall health,” says guidelines coauthor Amanda Rohrig, a physical therapist at Horizon Rehabilitation Centers and senior programs consultant at Can Do Multiple Sclerosis. The challenge occurs when movement becomes more difficult or feels unfamiliar because of MS, to the extent that participation in exercise and physical activity

declines, Rohrig explains. “Previous forms of exercise and physical activity become challenging, unsafe or unenjoyable, so people significantly reduce or stop participating.”



Jason Webb, diagnosed with MS in 2002, incorporates functional exercise into his daily life. Photo: Embry Rucker

The Society’s new exercise guidelines were born of that realization, according to coauthor Kathleen Costello, the Society’s associate vice president for healthcare access, who conceived the guidelines with Kalb, Motl and Zackowski. “What we needed and did not have was one place where a person with MS or their healthcare professional could go to see what types of things we’re talking about when we say exercise is good,” says Costello, a nurse practitioner specializing in MS care. “I was looking for something incredibly practical that synthesized the research and put it into a format that people could use. That’s what we as an organization developed.”

Based on current evidence and expert opinion, the new guidelines — which have been endorsed by the Consortium of Multiple Sclerosis Centers — are tailored by disability level using the Kurtzke Expanded Disability Status Scale (EDSS), a method of measuring neurologic disability in MS. The scale ranges from EDSS 0 (no disability) to EDSS 9.0 (confined to a bed). Wherever they fall on the EDSS, people with MS can participate in some form of exercise or physical activity. The guidelines recommend completing at least 150 minutes per week of exercise and/or 150 minutes per week of lifestyle physical activity.

The distinction is essential. “Exercise is doing something repetitive over a period of time and with a specific objective (for example, higher intensity) whereas lifestyle physical activity can

be accumulated as part of your daily activities, including work, household or leisure time,” Zackowski says.

In other words, exercise is structured and prescriptive, while lifestyle physical activity tends to be unstructured and spontaneous. Exercise for people with mild impairment, for example, might include running, walking, weight training and yoga. Exercise for wheelchair users might consist of strengthening the lungs using a spirometer or strengthening the arms by way of arm cycling. Lifestyle physical activity, on the other hand, might include gardening, cleaning, or pushing a grocery cart for people with mild impairment, and folding clothes, seated dancing or manual propulsion for wheelchair users.

Although exercise typically is more effective than lifestyle physical activity at building aerobic capacity, muscle strength and balance, each yield similar benefits for people with MS with regards to symptom management and disease progression, according to Motl, who stresses the guidelines’ flexibility. Individuals don’t have to accumulate 150 minutes of exercise and 150 minutes of lifestyle physical activity. They don’t have to accumulate it all in one bout or session. Instead, they can do a mix of exercise and lifestyle physical activity that they accumulate in small increments.

“Start slowly and listen to your body,” Motl advises. “If you’re not used to being active, don’t immediately try to do 30 minutes of walking five days a week at a moderate intensity. That’s going to do more harm than good. Instead, start with just 5 minutes two or three days a week.”

Rohrig agrees and suggests consulting a health professional before escalating your physical activity. “Specifically, physical therapists and exercise specialists can help guide people safely toward this recommendation,” she says.

Doctor’s orders

The authors wrote the guidelines as much for clinicians as they did for people with MS.



Chris Grubbich, diagnosed in 1993. Photo: Ray Ng

“The key is educating both the healthcare provider and the patient that exercise and physical activity are an integral part of their treatment plan, just like taking medicine is,” explains Giesser, who says providers — including neurologists — can use the guidelines as an icebreaker. “A neurologist isn’t necessarily the person who can prescribe a comprehensive exercise regimen, but a neurologist can certainly start the conversation.”

Zackowski agrees. “I would love to see physicians, including neurologists, make a point of asking their MS patients how active they’ve been — and if they’re not active, what the barriers are that they’re facing.”

As the authors acknowledge in the guidelines, barriers can be:

- Physical (e.g., rural vs. urban environments, unsuitable home environment, lack of community facilities or transportation)
- Social (e.g., limited support, dependence, cultural factors)
- Medical (e.g., fatigue, fitness level, symptom fluctuation, comorbidities, treatments and medications)
- Financial (e.g., gym membership, equipment costs, childcare fees)

Some of the most common barriers, however, are emotional, according to Kalb, who says people with MS often experience fear, anxiety and apathy about exercise.

“We call all the negative messages that people with MS send themselves ‘brain chatter,’” Kalb explains. “When you work with a specialist, you can negate some of that brain chatter by learning different ways to adapt.”

For example, providers can give someone concerned about exacerbating their MS symptoms

strategies for managing them — anti-spasticity medications can help with muscle spasms, for example, a cane with ambulation issues and a cooling vest with heat sensitivity.

“Ideally, physicians would make it clear to their patients that activity is important,” Zackowski says. “It would then be great if the physician could talk to other patient providers such as a nurse or physical therapist, who can help the patient find resources that help them safely increase their activity and exercise.”

Resources might include:

- Starting a take-home exercise program with resistance bands and other equipment
- Getting a referral to a physical or occupational therapist
- Calling an MS Navigator (1-800-344-4867), emailing ContactUsNMSS@nmss.org or visiting nationalMSSociety.org/navigator.
- Watching online videos that the Society has created to demonstrate stretching, aerobic and breathing exercises for people with MS at all ability levels.

Whatever resources their providers share, the message the guidelines’ authors most want people with MS to receive is that everyone should exercise — and that everyone can.

“All people with MS, regardless of ability level, can participate in exercise and lifestyle physical activity,” concludes Rohrig, who reiterates that all movement, such as folding clothes, picking up kids’ toys, working in the garden, doing yoga, riding a bike, counts. “In the simplest terms: People with MS should try to move as much as they can, as often as they safely can.”

Get moving

The National MS Society recommends that all people with MS get 150 minutes per week of exercise and/or 150 minutes per week of lifestyle physical activity.

People with MS who have a mild impairment ranging from no restrictions to limited endurance, unsteadiness, and impaired information processing and memory:

- Aerobic exercise such as walking, rowing, running, jogging, swimming or stair climbing.
- Resistance/strength training using weight machines, free weights, resistance bands or body weight exercises.
- Flexibility training encompassing standard stretching or yoga.
- Neuromotor activities, such as Pilates, dance, yoga, Tai chi or equine-assisted therapy. Examples include walking, gardening, road cycling, hiking with poles, individual and team sports, and dancing.

People with MS who have restricted ambulation, including people who have limited walking

ability, people who are prone to falls and people who use mobility aids:

- Exercise your core by doing seated isometric ab exercises, and/or moving or stationary seated balance and posture exercises. Examples include walking as able, manual wheelchair propulsion, power-assist cycling, swimming, water therapy, adaptive sports, seated dancing, yoga, boxing and active weight shifting.
- Breathing exercises using a resistive breathing apparatus, such as a spirometer.
- Flexibility training via stretching.
- Work out upper extremities using weights or resistance bands, or by doing arm cycling.
- Exercise lower extremities by walking with a walker, doing sit-to-stand exercises, doing power-assist cycling or doing body weight treadmill training.

People with MS who use wheelchairs:

- Breathing exercises using a resistive breathing apparatus, such as a spirometer.
- Flexibility training wherein you stretch all affected upper and lower extremity joints, with assistance if needed.
- Work out upper extremities using weights or resistance bands, or by doing arm cycling
- Exercise lower extremities by standing with support and using a standing frame.
- Exercise your core by doing seated isometric ab exercises, moving or stationary seated balance and/or posture exercises. Examples include activities of daily living (e.g., cleaning, grooming, laundry, shopping), water activities, bed mobility exercises and pressure relief (e.g., front/lateral press-ups).

People with MS who are confined to a bed or chair:

- Breathing exercises using a resistive breathing apparatus, such as a spirometer.
- Flexibility training via a passive or active range of motion of all joints, as able.

Matt Alderton is a Chicago-based writer and editor.

Learn more about the new exercise and physical activity guidelines and watch demonstration videos at [ntlms.org/ExerciseRecommendations](https://www.ntlms.org/ExerciseRecommendations).