

October 2021 Newsletter



Get in the Groove with MS

It's a well-known fact that exercising regularly has many benefits, including weight management, strengthening muscles and bones, and decreasing the risk of cardiovascular disease. Until recently, doctors recommended that people with MS avoid too much physical activity, believing that it could



make fatigue and other MS symptoms worse. However, research has revealed that exercise can, in fact, improve MS symptoms. A [2016 review](#) concludes that exercise is associated with a reduced relapse rate, lower lesion volume, slower progression of the disease, and improved performance on neurological tests in people with MS. According to a [2019 review](#), aerobic exercise and physical therapy can improve many areas of life for people with MS, including physical symptoms, mental health, and social functioning. A [2020 review](#) found that physical exercise can significantly reduce fatigue in people with MS. Having established the fact that physical activity also helps people with MS, a number of questions remain. For example, what are the best exercises to do and how can they be done safely and effectively?

It's important to consult a doctor before starting an exercise program. They may recommend working with a physical therapist who can design an individualized exercise program based on a person's specific symptoms and goals. A physical therapist can also provide guidance on how to perform exercises correctly to avoid injury. Dr. Gretchen

Hawley is a physical therapist and MS specialist that runs an online physical therapy program for people with MS called the [MSing Link](#). In her words, “It’s very important for people with MS to exercise because it can help those with weaknesses or imbalances get stronger. I tell all of my clients to start as early as possible, even if the weakness they experience is minimal. The goal is, ideally, to get as strong as you can so if symptoms do progress, you might not notice it as much since you’re starting off at a much a stronger point.”



There are many different **types of exercise**, each of which holds unique benefits.



Aerobic exercises are activities that increase the heart rate. This form of exercise is especially good for improving lung capacity, strengthening core muscles, and improving balance and coordination. A [2017 review](#) suggests that low- to moderate-intensity aerobic exercise can also boost energy levels, mood, heart health and quality of life in people with MS who have mild to moderate disability.



Progressive strength training involves lifting light weights and doing minimal repetitions at first, and slowly increasing the amount of weight or the number of repetitions over time. [Research](#) shows that strength training improves strength, balance and mobility in people with MS.

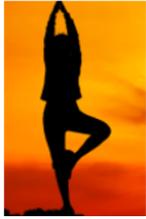


Flexibility and stretching exercises help to lengthen muscles, increase joint mobility, and improve balance and posture. [Researchers](#) in Iran found that flexibility exercises such as stretching the muscles may lessen spasticity and prevent painful contractions in people with MS.



Balance exercises involve shifting one’s center of gravity from side to side. There is [evidence](#) that this type of activity improves balance and reduces the number of falls in people with MS.

Research shows a number of **other physical activities** also help improve function and quality of life for people with MS.



Yoga is a mind-body practice that incorporates various breathing, stretching, and meditation exercises. Yoga improves flexibility and strength while relieving stress and promoting a calmness. A small [2017 study](#) found that an 8-week yoga program improved physical performance and quality of life for 14 adults with MS.



Tai chi is a martial art that focuses on deep breathing and slow, gentle movements. A [2017 review](#) concluded that Tai chi improves quality of life and functional balance in people with MS. Authors also suggest there is evidence that it helps with flexibility, leg strength, gait and pain.



Kick boxing is a form of martial art that combines boxing with elements of karate, in particular kicking with bare feet. A small [2012 study](#) showed a 5-week kick boxing program significantly improved gait speed and balance in people with MS who have mild to moderate levels of disability. No changes in health-related quality of life were observed.

According to Dr. Gretchen, “When someone asks me what’s the best exercise to do, I ask them what they are working toward. Is it improving [foot drop](#)? Is it finding more ease in tasks like getting in and out of bed? Their answer will determine what they need to do for exercise. It all depends on their personal goal.”

As we discussed in our [April 2019 newsletter](#), neuroplasticity is the brain’s ability to form and reorganize connections between brain cells in response to new tasks. Dr. Gretchen believes that neuroplasticity is the reason that someone with MS actually can improve their strength, balance and walking. In her words, “Demyelination is a common cause for weakness. When a nerve does not transmit a signal to its intended target, that muscle will not work. Neuroplasticity is key because it prompts your brain to find a new way to make that muscle work. Understanding what neuroplasticity is and how it works is the first step to



exercising effectively, otherwise it's hard to stay motivated and consistent - increasing the likelihood that you'll give up before you see results. The second step is making sure that your exercises are functional. People often exercise and feel like they're getting stronger, but their function doesn't improve. That may be because they're doing the wrong exercises. For example, if someone's goal is to improve their walking, you need to take the activity of walking and break it down into as many different movements as possible. Each of those movements are now your exercises. In order to take a single step forward, you first need to be able to shift your body weight forward, bend your knee, scoop your toes up, bring your knee up toward the ceiling, straighten your knee, put your heel down, and while you're doing all of that you're standing on one leg. That's seven different movements. Therefore, that's seven different exercises. In order to get neuroplasticity to work, for your brain to find and strengthen new pathways, it requires repetition. What that looks like is: doing those exercises as many times as possible cumulatively throughout the day. They can be done while standing, sitting or lying down. To maximize their functional effect, first determine the correct exercises to do and then find a position that they can be done successfully. That's going to be a little bit different for each person."



As a word of encouragement, Dr. Gretchen shares, "Trust the process. It can be difficult to believe in this process when you're doing all the right things and you still don't see progress or you don't feel anything happening.

[Research](#) shows that neuroplasticity does happen in people with MS. You really just have to trust and know that with every repetition you're doing what it takes for your brain to find a pathway that works, resulting in more strength or improved mobility. And it takes time." According to Dr. Gretchen, there are two common habits that can prevent a person with MS from improving. "Number one is touching furniture or walls while you're walking. People often don't even realize they're doing it. The second habit is using your arms to help lift your leg. People often do this because their leg is weak. However, by using your arm for that movement, instead of your leg, you are telling your brain that your leg doesn't need to work and you're perpetuating the weakness. I tell people to attempt to use their leg muscles twice. If it still doesn't work, go ahead and use your arms."

Safety is of prime importance while exercising, not just for people with MS, but in general. It's a good idea to avoid exercising in places with slippery floors, poor lighting, throw rugs, or other tripping hazards. It's often helpful to use a wall, railing or a piece of furniture (something that won't tip over) for extra stability when performing balance

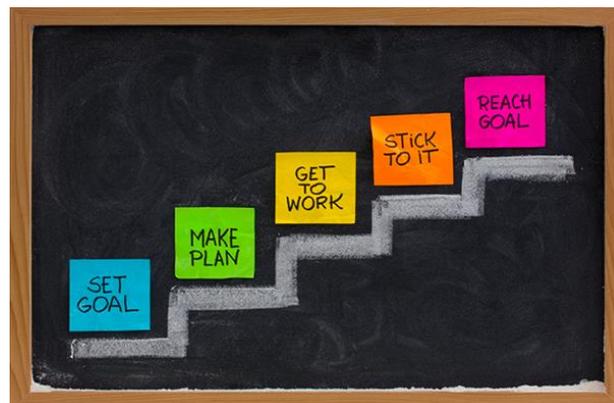


exercises. Choose activities that won't make it likely to fall or try exercising from a seated position. According to Dr. Gretchen, "This still works your core and leg muscles, but you're seated so it takes balance out of the equation and it's just as effective." It's important to warm up by stretching and ease into an exercise routine. Knowing when to quit is also key. Anyone experiencing excessive fatigue, lightheadedness or dizziness, overheating, confusion, loss of balance or coordination problems should slow down or stop exercising completely. Cool down at the end of a workout to allow heart rate, body temperature and breathing to return to normal.

Overheating during exercise is a common problem for people with MS because it can make their MS symptoms worse. To avoid this, one can exercise in the early morning or in the evening, when it's cooler. Staying hydrated can also help in this regard. Other helpful strategies include the use of cooling devices, wearing light exercise clothing, using fans or air conditioning to keep the exercise area cool or taking a lukewarm bath or shower before and after exercising. Exercising in water also helps prevent overheating and the feeling of weightlessness, combined with the mild resistance of the water, creates an excellent environment for low-impact exercising. Beyond swimming, it's possible to perform many types of exercise in the water, including weightlifting, balance training, walking and stretching.



Exercise is an effective means of rehabilitation in people with MS. It's important for those living with the disease to communicate with their healthcare team about physical limitations or disabilities that may be limiting the things they would like to do. With the guidance of a physical therapist, one can develop an individualized exercise program to get stronger and, possibly, overcome them. Success depends on consistency and repetition. With both, future goals may just be in reach!



An Unpleasant Embrace

The MS hug is a type of pain associated with MS that goes by the medical term [dysesthesia](#). Because it feels like something is tightly wrapped around the torso, this unpleasant sensation is also known as banding or girdling. As with other MS symptoms, the MS hug is unpredictable. Not everyone experiences it and those that do experience it differently. It can be a first symptom of MS or occur years after diagnosis. The MS hug often resolves without treatment, however, if it is persistent or painful, there are a number of ways to find relief.



An individual experiencing the MS hug may feel a variety of sensations, such as burning, pain, pressure, tickling, tightness, tingling, or vibration, stretch around their body, or just on one side. This most often occurs between the neck and waist. When these sensations occur around the chest, they may feel so tight that it's painful to breathe. Some people with MS experience dysesthesia around their feet or hands, making it feel as though they are wearing tight boots or gloves. It may also occur around the head. The MS hug can last a few seconds to a few hours, and in rare cases, a few days.

Dysesthesia also occurs in other inflammatory conditions, for example [transverse myelitis](#) or [costochondritis](#). It is caused by demyelination in the brain and spinal cord. The disruption of nerve signals can lead to sensory changes and muscle spasms in the [intercostal muscles](#) (the small muscles between the ribs), which help expand the chest when breathing. In general, these sensations are not a sign of damage to the areas where they are felt. Rather, the damage is in the nerves that communicate to the brain what's happening in another part of the body. However, it's important to note that anyone experiencing pain or tightness in their chest should have it evaluated immediately to be sure it's not a heart or breathing problem.



The MS hug often resolves with no intervention. If it persists, there are a number of natural ways to ease it. It's important to look for and avoid triggers, if possible. These might include fatigue, changes in temperature, eating a large meal, illness, or being stressed. If the cause isn't obvious, it may help to keep a diary to learn what sets it off. During an episode of dysesthesia, applying pressure to the area with the flat of the hand or wrapping the body with an elastic bandage may bring relief. This helps the nervous system translate the unpleasant feelings of pain or burning into pain-free pressure. The fit of one's clothing can also make a difference. Some prefer tight clothing, because its grip on the skin distracts the brain in a similar way that an elastic bandage would. In other cases, loose, lightweight garb or, when the situation allows, taking off items of clothing is most helpful. Applying hot or cold compresses can also help with these sensations. Just like tight and loose clothing, the opposites of temperature seem to help different people. Many people with MS find that, when the hug happens, it also helps to move, stretch, or try a different position.



Relaxation techniques like deep breathing, [mindfulness](#), meditation or having a massage can sometimes ease the discomfort caused by the MS hug. [Researchers](#) in Scotland found that acupuncture is effective at reducing pain in people with MS and may be a way to help manage dysesthesia. There is also [evidence](#) that hypnosis is helpful in this regard. [Transcutaneous electrical nerve stimulation](#) (TENS) may be another option. A TENS unit is a battery-operated device that delivers small electrical impulses through electrodes that are attached to a person's skin. The electrical impulses flood the nervous system, reducing its ability to transmit pain signals to the spinal cord and brain, and also stimulate the body to produce natural pain relievers called [endorphins](#). Certain vitamins and minerals, such as [vitamin D](#) and [magnesium](#), are also known to reduce muscle spasms and may help ease MS hug symptoms.

If natural remedies are not effective, a number of drug treatments are available to treat dysesthesia. If it is a symptom of an MS relapse, [steroids](#) might help speed up recovery. Muscle relaxants ([diazepam](#), [baclofen](#)), anticonvulsants ([gabapentin](#), [pregabalin](#)) and antidepressants ([amitriptyline](#), [duloxetine hydrochloride](#)) are also used. Many of these

medications were originally approved for other conditions and are used off-label for MS, the exact way they work against MS hug symptoms isn't clear. It may be a process of trial and error to determine which one, or if a combination, of these treatments is most effective.

The MS hug is often unpredictable, tiring and stressful. There are a number of non-drug approaches to treat this uncomfortable MS symptom. If they are not effective, a variety of medications can help. The MS hug is not dangerous in and of itself, however anyone experiencing it should have it evaluated immediately. The symptoms can mimic other health conditions that require immediate medical attention, like heart or breathing problems. If other MS symptoms come on suddenly at the same time, the MS hug may be part of a relapse. In this case, it is best to consult a neurologist as soon as possible to see if steroids would help.



October 2021 iConquerMS Spotlight

Encouraging news about COVID-19 vaccination in people with MS!

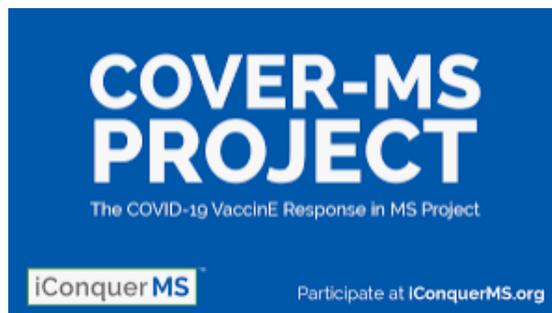
Many thanks to all that contributed data to the COVER-MS study. The initial results are in! In summary, having MS **does not appear to increase** the likelihood of experiencing COVID-19 vaccine reactions, and the frequencies of different types of reactions are similar to those reported in the vaccine clinical trials.

719 participants were included in this analysis, over half (57%) received the Pfizer vaccine, followed by Moderna (36%), Johnson & Johnson (4%) and Oxford/AstraZeneca (3%). The most common vaccine reactions were pain, fatigue and headache. These reactions were more likely in younger people, women, those with a prior COVID-19 infection and those who had a reaction after the first shot. Factors that **did not** correlate with vaccine reactions included being on disease modifying therapy, the type of MS an individual had, or how long they had MS.



A [summary](#) of the initial results, including a breakdown of demographics and MS disease modifying therapies used, can be found on the iConquerMS website. A more detailed analysis has been accepted by a medical journal, and we look forward to sharing that with you as soon as possible. For those interested, COVER-MS data analyst Dr. Farren Briggs describes what we've learned to date in an [Ask an Expert webinar](#) that was hosted by the National MS Society in September.

COVER-MS is open to anyone who has received a COVID-19 vaccine or plans to receive one. If you are an iConquerMS member that has received a COVID-19 vaccine, please [login](#) today and share your experience by clicking on “Participate in the COVID-19 Vaccination Study.” Have you received an additional dose of COVID-19 vaccine recently? Please let us know about it! We’re also interested in learning about any new or changed MS symptoms you’ve experienced and if you’ve had a breakthrough case of COVID-19. We appreciate you keeping your information up to date! If you’re not yet a member of iConquerMS, please [join](#) the network and start powering MS research today!



RESEARCH OPPORTUNITIES



A New MS Aging Study

Our research partners at the Albert Einstein College of Medicine in New York City are conducting a study of aging and walking in MS.

What is the study?

The goal of this research study is to evaluate how the brain is involved in walking in older adults with and without MS. The results will provide valuable new information about how brain structure and function affects the ability to walk and influences the risk of falling. If successful, the findings may lead to possible new treatments that could improve brain control and efficiency of walking.

What is involved?

Participation begins with a telephone interview to see if the study is a good fit for you. If it's a good fit, and you agree to participate, you will have two study visits around 3 hours long at the research center at Albert Einstein College of Medicine. You will be asked to fill out some questionnaires, complete a few tests that assess cognitive functions (e.g., memory, attention), participate in some walking tests, and have one MRI.

The research team will arrange free private transportation to and from the research center for each visit. You will be paid \$100 for each visit for a total of \$200.

The research team strives to make your experience a positive one and has put in place several precautions to ensure your safety during the pandemic. The staff is vaccinated, always wear masks, and maintains appropriate distance. Study visits are conducted with only one person at a time.

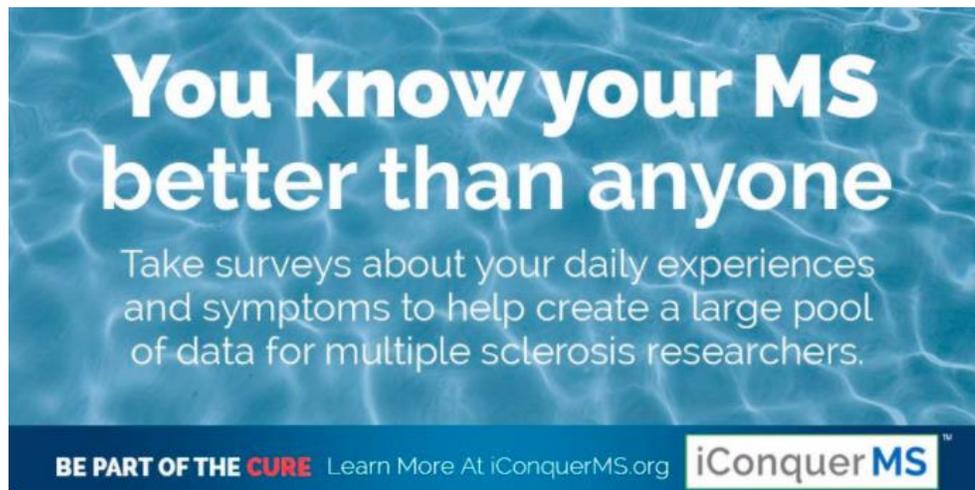
Who can participate?

The researchers are looking for people who:

- Are at least 60 years of age
- Have been diagnosed with relapsing remitting MS (RRMS) or secondary progressive MS (SPMS)
- Can walk 20 feet without assistance or with a single-point cane
- Have been on the same MS disease-modifying therapy for at least 6 months
- Meet additional study criteria

Interested in participating?

[Complete this form](#) to let the research team know of your interest. You can also call or email them at 718-430-3972 or holtzer.neuropsych@gmail.com



Complete your REAL MS surveys!

In the summer of 2016, the iConquerMS initiative launched REAL MS (Research Engagement About Life with MS), a longitudinal study of MS. Participants complete questionnaires online twice each year on a variety of subjects, including health history, diet, exercise and their experience with MS. **The next round** of REAL MS surveys is available now through the [iConquerMS portal](#). Completing these surveys is one of the simplest ways

you can accelerate MS research. The information collected will play a pivotal role in helping scientists and clinicians gain a better understanding of the health and quality of life over time for people with MS. REAL MS is just one of the many ways iConquerMS is facilitating research on topics of importance to people affected by the disease. If you are not already a member, please consider [joining](#) iConquerMS, the only people-powered research network for MS!