

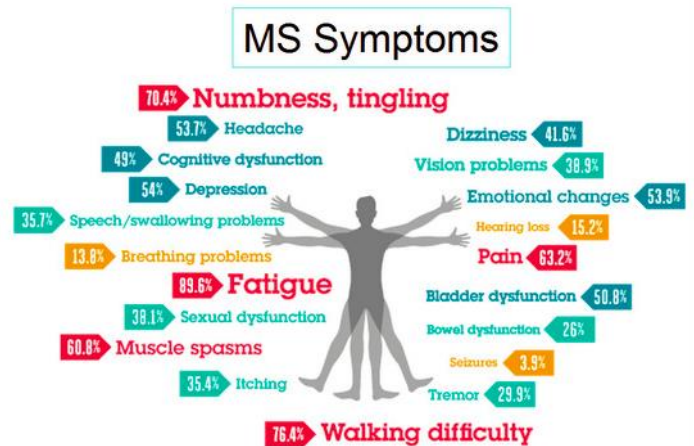
February 2021 Newsletter



Exploring Some Less Common MS Symptoms

MS is an autoimmune disorder where the system designed to keep the body healthy (the immune system) mistakenly attacks the nerves in the brain and spinal cord. The resulting nerve damage can cause a myriad of symptoms that can be variable and unpredictable. It's not unusual for people with MS to experience such things as fatigue, numbness and tingling, muscle spasms, walking difficulties, bladder and bowel dysfunction, vision problems and cognitive changes. There are a number of other MS symptoms that aren't seen as frequently.

Approximately 25 to 40 percent of people with MS have problems with their speech, particularly later in the disease course and during periods of extreme fatigue. [Scanning speech](#) is commonly associated with MS. This is when spoken words are broken up into separate syllables, often separated by a noticeable pause, and spoken with varying force. People with MS may slur words ([dysarthria](#)) due to weakness of the muscles of the tongue,



lips, cheeks and mouth. Nasal speech and [stuttering](#) can also occur. Sometimes speech volume is affected ([dysphonia](#)) due to weakness in the diaphragm, making it difficult to be heard. As discussed in our [November 2019 newsletter](#), a speech-language pathologist can provide useful exercises to treat speech abnormalities or suggest [assistive devices](#) and/or [smart phone apps](#) that may help with communication, if necessary.



Difficulty chewing and swallowing ([dysphagia](#)) are sometimes observed in individuals with MS. Manifestations of these problems might include saliva, fluid or food going down the “wrong pipe”, choking during mealtime, or having residual food in the mouth after swallowing. While more frequent in advanced disease, these difficulties can occur at any time. Chewing and swallowing each require a number of muscles in the mouth and throat to work in a coordinated way. In MS, damage to the nerves that control these muscles can cause weakness and incoordination that make eating more challenging. Numbness of the mouth and throat can also cause these problems. These issues are usually diagnosed and treated by a speech-language pathologist. Treatment typically consists of strategies for safer chewing and swallowing, dietary changes, or [exercises](#) designed to improve swallowing.

[Tremor](#), or uncontrollable shaking, may happen in different parts of the body due to nerve damage along the pathways that are responsible for coordination of movement. Tremor can be classified in two main categories. Resting tremors occur when a limb is at rest and the muscles are relaxed (for example, a person with MS may experience a resting tremor when their hands are resting on their lap). This type of tremor decreases with movement. An action tremor, on the other hand, occurs with voluntary movement of the affected body part. An intention tremor is the most common and generally the most disabling form of action tremor that affects people with MS. It generally occurs with purposeful movement toward a target, such as lifting a finger to touch the nose or reaching to pick up an object. Typically, the tremor will become worse as an individual gets closer to their target. A postural tremor may occur when an individual with MS holds a position against gravity, for example holding their arms outstretched. People with MS may also experience [nystagmus](#), which affects the eyes, causing them to flick rapidly from side to side, up and down or in a circular fashion. Tremor can make simple activities very challenging. It can also have



emotional and social impacts as those experiencing tremor may be embarrassed and choose to isolate themselves as a result. It is a difficult symptom to treat. Lifestyle changes such as avoiding stress, getting plenty of rest and not drinking caffeinated beverages may help those who suffer from mild tremors or help prevent them from beginning in the first place. Many of the [medications](#) used to treat MS-related tremor are not FDA-approved for this purpose and must be used [off-label](#). An occupational therapist can provide advice about [assistive devices](#) to aid with activities of daily living that may be impacted by tremor, such as writing, dressing, and cooking. Physical therapists can help when tremor makes mobility challenging and increases the risk for falling.

Breathing difficulties may also occur in MS. Just as a person can experience muscle weakness in the arms or legs, weakness can occur in the muscles of the chest and abdomen that are involved in breathing, resulting in an individual having to work harder to inhale and exhale. Difficulty breathing can also interfere with speech, making it much harder for a person to carry on a conversation or speak loudly enough to be heard. These issues may be caused by damage to the nerves controlling the respiratory muscles, or they can be the result of inactivity (bedrest or a sedentary lifestyle). Individuals experiencing the [MS hug](#) may also have difficulty breathing because of pain and tightness in the chest. Symptoms of mild respiratory issues may include shallow breathing, shortness of breath, hiccups, cough or frequent sighing. For minor problems like this, [breathing exercises](#) may be helpful. In more severe cases, individuals may experience labored breathing or feel like they have a weight on their chest. Individuals experiencing difficulty breathing should be treated promptly, whether or not they have MS. This is usually done by a healthcare professional with special training in this field.



Approximately 6 percent of people with MS experience hearing loss due to damage to the related nerve pathways in the brain and the brainstem. Symptoms range from ringing in the ears ([tinnitus](#)) to sudden deafness. This can occur as the first symptom of MS (although this is very rare) or during an exacerbation. Most hearing deficits caused by MS tend to improve. Because it is so uncommon, people with MS that experience hearing loss should be evaluated by an [audiologist](#) to rule out other causes.

Seizures, which are the result of abnormal electrical discharges in an injured or scarred area of the brain, are possible (but rare) in MS. They are estimated to occur in 2 to 5 percent of people with MS, compared to 3 percent of the general population. Seizures are classified into [two forms](#). Generalized seizures affect both sides of the brain and focal (or partial) seizures are located in just one area of the brain. Seizures are usually diagnosed by clinical history and an electroencephalogram (EEG), which is a recording of electrical activity in the brain. Most seizure disorders can be well controlled by use of the appropriate [anticonvulsant medication](#) and continuing medical supervision.

People with MS may experience a number of other uncommon symptoms, such as [headaches](#). Treatments for headaches include a variety of [medications](#), physical therapy and lifestyle changes. Sudden, intense itching ([pruritis](#)) can also occur which often worsens with scratching. The itching associated with MS is often paroxysmal, meaning it comes on suddenly with great intensity, but is temporary (lasting anywhere from a couple of seconds to minutes). Because this type of pruritis is neurologically based, it does not respond to topical treatments. [Anticonvulsants](#), [antidepressants](#) and the antihistamine [hydroxyzine](#) are typically used to treat it instead. Individuals with MS may experience vertigo (feeling as if the room is spinning). This is often treated by an audiologist, or with a number of [medications](#). MS can also cause emotional instability, known as the [pseudobulbar affect](#) (PBA), due to lesions in the areas of the brain that control emotions. This is characterized by sudden, uncontrollable laughing or crying. This can be embarrassing and cause people to isolate themselves from others. [Nuedexta](#) is the only medication that is approved to treat PBA, however low dose antidepressant medications are also used to reduce the severity and frequency of emotional outbursts.



Most of the less common symptoms of MS can be treated successfully with medications, or with non-drug approaches like specialized exercises or lifestyle changes. As discussed in our [July 2019 newsletter](#), people with MS often have other illnesses (known as comorbidities). It

is very important to have any new or unusual symptoms thoroughly evaluated to determine if they are associated with MS or caused by some other health condition. This distinction is essential in determining the most effective treatment and achieving the best outcome.



Does MS Affect Your Taste?

Taste, the sense that adds flavor to life, is a complicated process.

The tongue has small bumps (called [papillae](#)) scattered across its surface, many of which contain taste buds. Taste buds send messages to the brain about how something tastes. There are five primary types of taste: bitterness, sourness, saltiness, sweetness and umami (or savory), each is associated with a different area on the tongue. The number and pattern of taste buds on a person's tongue is determined by genetics, making everyone's taste inherently unique. Numerous factors can affect this important sense, including aging, illness, and more.



According to the National Institute on Deafness and Other Communication Disorders (NIDCD), there are three types of [taste disorders](#). A complete loss of the sense of taste is called **ageusia**. **Dysgeusia** causes a persistent taste in the mouth that can mask other tastes and make all foods taste the same. **Hypogeusia** is a reduced ability to taste things. It's important to note that the sense of smell significantly affects one's taste. An individual may have partial or total loss of smell ([anosmia](#)) which may influence the flavor of food. [Research](#) shows that 95 percent of the time there is a loss of taste, it is associated with a reduced sense of smell.

Taste bud function can be impacted by numerous factors, such as smoking, [vitamin deficiencies](#) and some [medications](#). As a person ages, their taste buds not only decrease in number, but their function also changes, making it harder for them to perceive taste.

Upper respiratory infections can cause nasal congestion and a runny nose. These symptoms often reduce the sense of smell, which in turn can impact the perception of



taste. A [recent study](#) shows a sudden loss of smell occurs in approximately 40 percent of people with COVID-19 (without a runny or stuffy nose), and is often accompanied by altered taste. Interestingly, [research](#) suggests this often happens prior to other COVID-19 symptoms (suggesting these sensory deficits may be early symptoms of the virus).

Any medical condition that affects the brain, nose or mouth can impact one's ability to taste. Nerve damage anywhere along the pathway from the mouth to the brain, whether

from injury or an illness like MS, can affect one's palate. A [2016 study](#) suggests that one in four people with MS may experience a diminished sense of taste. Investigators administered taste tests to 73 subjects with MS and 73 control subjects. Participants received small drops of liquids (sweet, sour, bitter and salty) on their tongues and were asked to identify the tastes. Interestingly, women outperformed men on all taste measures regardless of MS diagnosis (more research is needed to understand why). Among participants with MS, results showed that approximately 15 percent exhibited a loss in bitter taste, 22 percent a loss in sour taste, 25 percent a loss in sweet taste, and 32 percent a loss in salty taste, compared with the controls. Participants also underwent MRI brain scans that showed these taste deficits were associated with MS-related lesions throughout the brain.

Losing the sense of taste, even partially, can be very distressing as tasting food is an important part of life's experience for many people. The following tips may help make these a reduction or loss of taste more tolerable. Seasoning food more strongly with herbs, spices, and flavorings may make them taste better. Trying new foods (particularly those with intense flavors) may reveal ones that are more appealing. There is [evidence](#) that the temperature of food affects how it tastes. If the option of heating something up exists, rather than eating it cold, the heated food will likely be more flavorful. The texture of food is another important factor to consider. Try foods with a variety of textures (crispy, crunchy, creamy, etc.), as some may be more appealing than others. The appearance of food can also make it more or less appetizing. Preparing foods in a variety of colors and adding garnishes may help. Keeping a detailed food journal can help determine which of these options made the greatest difference. Be sure to record all of the ingredients in dishes, paying special attention to the amount and type of seasonings that were used and noting how they tasted. The end result will hopefully be a more appetizing list of food options.



As we discussed in our [April 2019 newsletter](#), changes in neural connections may occur with “mental exercises,” such as learning new things or memorizing new information. This ability to change is often referred to as [neuroplasticity](#). These new nerve networks are reinforced and strengthened through behavior. In light of this, keeping the senses active may help bolster and preserve them. For individuals experiencing a loss

of taste, it may help to practice tasting foods from different categories of taste, such as chocolate (sweet), lemons (sour), coffee (bitter), and pretzels (salty). Strengthening one's sense of smell (which is linked to taste) by sniffing foods that have a strong, characteristic smell may also have a positive effect on taste (for example, cinnamon or fresh garlic). Smelling aromatic items like baby powder or a scented candle may also help in this regard.

Relishing a delicious meal is an enormous pleasure for most people. Not being able to enjoy the taste of food steals that experience and significantly reduces quality of life. A diminished sense of taste can also impact appetite and make it harder to stick to a healthy diet. There are a number of ways to make meals more appealing. However, it's important to keep nutrition in mind while experimenting with different foods. A well-balanced diet combined with other healthy lifestyle choices is the foundation of good health not only for people with MS, but also for the general public.



February 2021 Research Spotlight

EVENTS



People Powered MS Research With CEO of ACP, Sara Loud

RealTalk MS is a weekly podcast well worth listening to for anyone who is affected by MS. Hosted by Jon Strum, it provides a platform to stay up to date on the latest information about MS. Jon packs a wealth of information into each 30-minute podcast. He covers a wide range of topics, from groundbreaking MS research to legislation surrounding healthcare issues. Sara Loud, CEO of ACP, is featured on the first episode of 2021. [Tune in](#) to learn more about iConquerMS and hear how the initiative is contributing to the expansion of MS research to include and amplify the voices of people affected by the disease. If you're not already a member, please consider [joining iConquerMS](#) to add your voice to MS research. People-powered MS research ensures people affected by MS drive, shape, and accelerate research on topics that matter most to them. It can't happen without *your* participation!

RESEARCH OPPORTUNITIES



Coming Soon! Share your experiences with COVID-19 vaccines.

ACP, through its people-powered research network [iConquerMS](#), will soon begin collecting information from people affected by MS related to their experiences with COVID-19 vaccines. The data collected will be securely shared with researchers studying the effects of COVID-19 vaccination on people affected by MS. Already a member of iConquerMS? You'll be the first to know when the study is launched! Not yet a member? Please [join](#) iConquerMS now and stay tuned! In the meantime, please share your experiences related to the pandemic through the newly launched *COVID-19 Recent Experiences* survey [now available](#) on iConquerMS!



UNIVERSITY OF GEORGIA

Researcher studying fatigue in MS would like your help!

Have you ever wondered about the connection between physical and emotional aspects of fatigue in MS?

Fatigue is one of the most frequently reported symptoms in MS, but not enough is known about how tiredness, physical sensations, and emotions lead to feeling fatigued and happen during fatigue.

You can help understand this important question!

A PhD student from the University of Georgia who is investigating this topic is inviting people with MS to join her research study. She is looking for people who are physically active, between 18 and 65 years old, and have reliable Internet and phone access.

Participation involves taking a survey online and (optionally) having a phone conversation with the researcher to answer additional questions. The survey will take up to 45 minutes and the optional phone conversation will take an additional 1 hour.

Research study participants will receive a summary of the findings at the end of the study.

Are you interested in helping with this research study?

Please contact Megan Ware by email at mew77577@uga.edu or by phone at 423-260-5045.

Thank you!



Call for Participants with Multiple Sclerosis

Have you been diagnosed with multiple sclerosis for 2 years or less?

Are you older than 18 years of age?

If the answers to all these questions are **yes**, investigators at the University of Alabama invite you to take part in a voluntary study ‘Social Cognitive Correlates of Physical Activity in Adults with Multiple Sclerosis in the United States.’

What will you do?

You will be asked to complete questionnaires about your health beliefs and physical activity.

Why is this research important?

Previous research reports significant relationships between social cognitive variables such as social support, self-regulation, motivation and physical activity in adults from the general population. This study is a novel investigation of various social cognitive factors that may be associated with levels of physical activity in persons with MS.

What’s in it for me?

You will be helping researchers at the University of Alabama by providing invaluable feedback that will be used to help inform future multi-level physical activity interventions for persons with MS.

If you are interested in completing this survey, please click [this link](#) or email Trinh (Lexi) Huynh at enrl@uabmc.edu.



New Year, New You

Study Title: Step for MS (Supervised versus Telerehab Exercise Program for People with Multiple Sclerosis)

Study Purpose:

New research shows that exercise is good for people with MS and may decrease symptoms and improve health and walking ability. An exercise study called *STEP for MS* will compare the outcomes of a 16-week exercise program conducted at home to a program conducted in a gym. The researchers conducting the study hope that the findings will make exercise and its benefits more available to people with MS who have problems walking.

This Study Involves:

Participants will exercise two times per week for about one hour each session for 16 weeks. A trained “coach” will help participants learn how to exercise and will provide encouragement throughout the program. Participants will take assessments before starting the program, two months into the program, at 16-weeks when the program ends, and at 6 and 12 months after starting the program.

Eligibility:

If you are between the ages of 18 and 65 years and you have Multiple Sclerosis you may qualify if you:

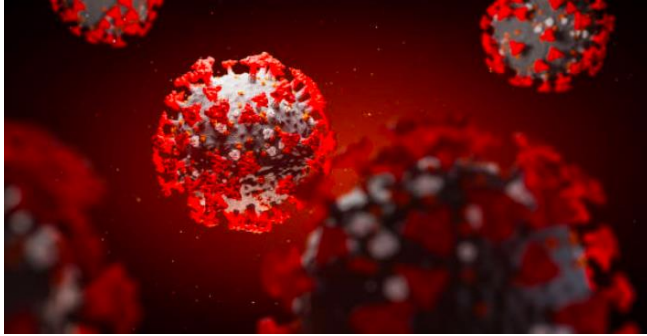
- Can **walk** but you have **some difficulty**, with or without a device
- **Do not exercise** regularly
- Have not had a **relapse** in the past month
- Can commit to **train 2 times a week for 16 weeks**
- Can **drive to study site** for assessments and potentially for exercise training
- Have reliable **internet access**

Participating Locations:

- Massachusetts General Hospital, Boston, MA (**new site now open!**)
Contact: Dr. Plumer 617-724-3103/ PPlummer@MGHIHP.EDU
- Shepherd Center, Atlanta, GA
Contact: Erica Sutton at 404-367-1305
- Cleveland Clinic, Mellen Center, Cleveland, OH
Contact: Darlene Stough at 216-445-5877/ stoughd@ccf.org
- University of Colorado, Denver
Contact: Alexa Vareldzis: neurologyresearchpartners@cuanschutz.edu / 303-724-4644
- University of Alabama, Birmingham
Contact: Petra Silic at 205-975-1306/ petra09@uab.edu
- University of Georgia, Athens
Contact: Megan Ware at 423-260-5045/ megan.ware20@uga.edu
- Marquette University, Milwaukee, WI
Contact: Heidi Feuling at 414-288-6209/ Heidi.feuling@marquette.edu
- University of North Carolina, Chapel Hill
Contact: Rachel Keen at 704-877-5636/ rayray@live.unc.edu

For more information, please visit our

website: <https://www.iconquerms.org/welcome-step-ms>



Update your experience with COVID-19

As a supporter of Accelerated Cure Project, you know one way to deal with the uncertainty of MS is to **act** – to be proactively involved in research and to contribute your insights, expertise, and information so that key questions about MS may be answered.

The COVID-19 crisis has added an additional level of complexity and urgency for those affected by MS.

We have launched a follow-up survey on iConquerMS to update how people affected by MS are dealing with the COVID-19 pandemic and what their personal experience has been with COVID-19 over the past 11 months.

We are interested in responses from all – those with and without MS, whether or not you have been diagnosed with COVID-19 – and hope the information gathered through this survey will help people affected by MS and their doctors during the current pandemic and in the case of future viral outbreaks.

Participating in the COVID-19 in MS study is easy. If you are not already a member, please consider [joining iConquerMS](#). Your voice matters! Already a member? Please [login](#) to your account and complete your COVID-19 survey. Thank you for your participation!