

August 2020 Newsletter



The Senior Moments of MS

For most people, difficulty with thinking and memory are a natural part of growing older. For those living with MS, cognitive changes may also occur as a direct symptom of the disease due to the loss of myelin surrounding nerve fibers in the brain. Some may notice problems with their memory, particularly finding words or remembering events from the past. Others find they have trouble doing more than one thing at a time (multitasking), or they take longer to process information. Some people find they have problems learning new tasks, while others may struggle with organization, planning or prioritizing. For many, the cognitive effects of MS represent its greatest challenges. The subject of cognitive impairment in MS is discussed extensively in our [March 2019 newsletter](#), including its risk factors and effects, how it is measured and different ways of coping with it. In this article we primarily focus on cognitive issues in people with MS in the context of aging.



[Cognition](#) refers to the wide range of mental functions involved in learning and comprehension. In MS, some are more likely to be affected than others. These include memory, attention and concentration, information processing (dealing with information gathered by the five senses), executive functions (planning and prioritizing), visuospatial skills (the ability to identify visual and spatial relationships among objects) and verbal fluency (word-finding). Interestingly, a number of functions are less likely to be affected in people with MS, such as general intellect, long-term memory, conversational skill and reading comprehension.



Cognitive dysfunction is common in MS, especially in older people with the disease. An individual may experience difficulties in only one or two areas of cognitive functioning or in several. For most, the changes are mild and limited in scope.

For some, however, cognitive dysfunction may be more widespread and challenging. A [2019 study](#) compared cognitive impairment in older and younger people with MS. They found 77 percent of individuals with MS over the age of 55 experience difficulty thinking, compared to 43 percent of those who are younger. Information processing speed (IPS) was the most impaired cognitive function, followed by verbal learning, executive function, and visuospatial learning. Another [study](#) concluded roughly half of elderly people with MS have decreased cognitive processing speed and verbal fluency (subjects in the study had a mean age of 62).

[Researchers](#) at the University of Alabama studied changes in cognitive function with aging in 129 individuals with MS with similar results. Subjects were assigned to one of three age groups (young, middle-aged, and older). Results showed older subjects with MS demonstrated significant impairments in cognitive function compared to younger ones, and these differences were not explained by a person's amount of physical activity, years of education, years since diagnosis, or race. Specifically, older subjects had significantly worse IPS, verbal learning and memory than young and middle-aged subjects. Older and middle-aged participants also demonstrated significantly worse visuospatial learning and memory than those in the younger group.

There is evidence that cognitive impairment can occur in all [forms of MS](#), but is slightly more likely in progressive MS (which typically occurs later in life). According to a [recent study](#), slow IPS and occasional memory deficits are typically observed in clinically isolated syndrome and relapsing-remitting MS (RRMS). Executive functions (in particular verbal fluency) may also be impaired.



Individuals with relapsing forms of the disease are more likely to experience cognitive dysfunction during a flare. More frequent and severe deficits in memory and IPS are reported in secondary progressive than in RRMS. People with primary progressive MS typically experience a wide range of cognitive deficits in IPS, attention, memory and executive functions.



Cognitive changes in people with MS generally progress slowly, however they are unlikely to improve significantly once they have begun. [Researchers](#) at the University of Buffalo studied the rate of cognitive and motor decline over time in subjects with MS. They evaluated the ability to walk, upper extremity function, IPS and memory in 698 people with MS (aged 29–

71 years) and 226 healthy controls (aged 18–72 years). Results show the progression of physical disability in subjects with MS accelerates with age. Cognitive difficulties affecting IPS, attention and memory were present in most older subjects with MS, however rates of decline in these areas did not vary and appeared to be similar to rates of decline in normal aging. This study team concluded accelerated cognitive impairment in older adults with MS may be due to the presence of other age-related cognitive pathologies. [Researchers](#) at Pennsylvania State University also concluded individuals with MS do not appear to show accelerated rates of cognitive decline with aging and they adjust well, particularly if they have sufficient social support.

MS is an autoimmune disorder characterized by [neurodegeneration](#) and [brain atrophy](#). In general, difficulty with thought processes correlates with the amount of brain atrophy and the number of [lesions](#) seen on MRI. Other cognitive impairment conditions affecting older individuals, such as [Alzheimer's](#) and [Parkinson's disease](#), involve the same degenerative processes. Researchers at the University of



Buffalo looked at the differences between these different conditions and the possibility that they may co-occur. This [study](#) compared brain changes in 112 older subjects with MS, 108 older people with Alzheimer's, Parkinson's, or [amnesic mild cognitive impairment](#), and 184 age-matched control subjects. Participants had MRI scans to look for structural changes in their brains that might help explain declines in cognitive function.

Comparisons of MS and Alzheimer's brain scans revealed the low brain volume seen in MS subjects was comparable to that seen in subjects with Alzheimer's disease. It's important to note further study is required to understand whether these changes are due to a worsening of nerve damage in MS or a comorbid occurrence of other neurodegenerative diseases.



Cognitive dysfunction substantially impacts the lives of people with MS and their families. It may also place significant additional strain on an individual's caregiver, who has an insider's view of its effects on their loved one's life. A [recent study](#) compared the amount of cognitive decline in people with MS as measured with a standard clinical evaluation with the perception of decline from the patient and caregiver's perspective. Forty-nine people with MS and their caregivers were included in the study. Results show patients and their caregivers disagree on the presence of cognitive difficulties. The caregiver's perception of their loved one's cognitive deficit showed stronger correlations with standardized testing than the patient's perception. This difference in perception was directly related to the patient's age and severity of cognitive impairment. These findings suggest that as individuals with MS age, they may become accustomed to their cognitive difficulties, and thus become less aware of them. They also stress the importance of the caregiver's point of view and open communication with clinical professionals for accurate evaluation of cognitive function.

MS is a complex disease with many psychological aspects. Adjusting successfully to the changes the disease imposes over time requires understanding and addressing its often-hidden mental changes along with the more obvious physical ones. Because the disease can affect any part of the brain, almost any cognitive function can be impaired, and symptoms may range from having a mild impact to more pervasive changes which affect a person's quality of life. Employing a number of [strategies](#) to increase attention and memory can

help minimize the effect of cognitive difficulties on daily life. Reaching out for [help](#) when needed can also help a person with MS and their family continue to live life to its fullest.



Helpful Therapies for MSers of All Ages

A variety of medications are used to treat MS. There are a number of other treatments available to help manage the bothersome symptoms the disease may impose and increase quality of life no matter what age an individual with MS may be. Some are non-drug approaches that are part of standard medical care and others are less traditional.



As discussed in our [November 2019 newsletter](#), rehabilitation therapy is an essential component of MS care. Unlike some of the disease modifying medications, these non-drug therapies are potentially available to people with all kinds of MS. Rehabilitation therapy involves multiple specialties working together as needed. These specialties include physical therapy, occupational therapy, speech therapy, cognitive therapy and counseling. Rehabilitation specialists can provide education and strategies to address or prevent many complications of MS, such as decreased mobility and independence, fatigue, pain, bladder or bowel dysfunction, trouble swallowing, impaired communication, or problems with thinking and memory (to name a few).



Some types of exercise can be helpful in managing MS symptoms and are also important for general health and wellbeing. Exercise doesn't have to be rigorous to provide benefits. Any physical activity done on a regular basis (walking, gardening, or even cooking) has the potential to reduce stress and improve

physical and mental health. It's important for people with MS to check with their doctor before starting any exercise program. It needs to fit an individual's capabilities and limitations and may need to be adjusted as changes occur in MS symptoms. Many exercises can be done at home and modified if they cannot be done in the "traditional" way. Be aware that any exercise can elevate the body's core temperature and temporarily aggravate MS symptoms. Periods of exercise should be carefully timed to avoid the hotter periods of the day and prevent excessive fatigue. Some find that exercising in water is especially beneficial. Water helps people with MS move in ways that they may not be able to on land and keeps them cool while they are exercising.

Therapeutic exercises

[Yoga](#) combines poses with proper breathing and thought processes to bring peace to the mind, body and spirit. Every pose can be simplified and practiced in a variety of positions for those who may be less able. Practicing yoga can help increase core strength and flexibility, while providing relaxing benefits that are helpful for releasing tension. One [study](#) also showed yoga helps improve fatigue and mood in people with MS.

[Tai Chi](#) is a martial art that combines slow, deliberate movements, meditation and breathing exercises. Tai Chi is said to be gentler than yoga. Many of the positions can be done while sitting. There is [evidence](#) that Tai Chi helps leg strength, walking, balance, coordination, flexibility, anxiety, depression and pain in people with MS. Another [study](#) suggests it may also help with fatigue, however the evidence is less clear.

[Pilates](#) is a low-impact exercise which focuses on building core stability and muscle strength by performing a range of exercises in smooth succession. The exercises are based on six fundamental principles: concentration, control, centering, flowing movement, precision and breathing. Pilates can be practiced on the floor with a mat or with a range of

equipment, such as weights, resistance bands or an exercise ball. There is evidence that doing pilates is beneficial for people with MS. One [study](#) concluded pilates and physiotherapy are equally effective at improving balance and mobility. Another [study](#) of 30 people with MS also showed pilates significantly improved their ability to walk. This form of exercise is also effective and feasible for people with MS who use wheelchairs. One [study](#) found pilates can improve sitting stability and posture, and decrease back and shoulder pain. Participants with MS in this study also described psychological and social benefits.

[Whole body vibration therapy](#) (WBVT) involves standing, sitting, or lying on a machine with a vibrating platform. As the machine vibrates, it transmits energy to the body, forcing muscles to contract and relax dozens of times each second, leaving a person feeling as if they had exercised. A [2013 study](#) looked at WBVT in combination with a standard rehabilitation program in people with MS. Results suggest that exercising using a vibrating platform may improve lower limb strength and mobility, especially in those with lower levels of disability. Other positive effects were seen on fatigue, mood, coordination and balance.

Many people with MS turn to [music therapy](#) for management of their MS symptoms. Doing repeated movements to a rhythmic beat can improve coordination and, in turn, also affect endurance and improve one's walking gait. [Research](#) also shows it can help with social skills, improve cognitive functions, decrease the severity of depression and anxiety, improve sleep and decrease pain in people with MS. Verbal communication may also benefit. Words that are hard to verbalize can sometimes be easily communicated when put to music.

Relaxation and stress management are important for managing MS symptoms. Everyone manages stress differently. In general, keeping a positive attitude and minimizing stress producers in life can help one feel better. Sharing thoughts and feelings with others can help relieve stress. Managing expectations is also important. MS is changeable and flexibility in expectations is the key to keeping stress levels low.



Helpful Relaxation Techniques

Many people with MS get regular [massage therapy](#) to help them relax and reduce stress. [Researchers](#) at the University of Miami suggest message therapy significantly lowers anxiety and depression in people with MS and also significantly improves self-esteem, body image and an individual's image of disease progression. However, they did not draw any conclusions about physical symptoms. Another [study](#) suggests receiving massage therapy helps improve self-efficacy in people with MS (the belief that one can competently cope with a challenging situation). The [AMBER study](#) found abdominal massage to be more effective in treating bowel problems in people with MS when combined with standard bowel care than standard care alone.

[Aromatherapy](#) is the use of fragrances in the form of oils, known as essential oils, as they contain the essence of the plant from which they are taken. These oils can be used in the bath, as a steam inhalation, in an oil burner or with a compress. Aromatherapy is sometimes used with massage (a few drops of the required essential oils are added to massage oil). It can also be used as part of a sleep routine. Although there is no research evidence about the effects of aromatherapy on MS symptoms, it can promote relaxation and wellbeing.

[Meditation](#) is a mental exercise that involves relaxation, focus and awareness. There are many types of meditation. Some do it in a seated position with their eyes closed. Walking can be a form of meditation. Knitting, gardening, observing nature or any other activity that causes a person to narrow their focus can be meditative. [Studies](#) show that meditation can help improve quality of life, stress, anxiety, depression and various types of pain in people with MS. However, [research](#) also shows these benefits are not long lasting. Results suggest one must keep meditating in order to experience any benefit.

As discussed in our [April 2019 newsletter](#), [mindfulness](#) is a meditative technique that involves learning to focus attention on emotions, sensations and thoughts in an accepting and non-judgmental way. Mindfulness is a well-established therapy, with considerable research-based evidence for its benefit in people with MS. Various studies show that mindfulness helps to decrease [pain](#), [stress](#), [fatigue](#) and [depression](#) in people with MS. There is also evidence that it helps with sleep.

[Hypnotherapy](#) is a state of focus and concentration, typically achieved with the help of a clinical hypnotherapist, however it can also be self-induced. In this state, people are more susceptible to suggestion. The therapist then makes suggestions that are of therapeutic value to the individual with the hope that their thought and behavior patterns will be sufficiently modified on waking to effect positive change. Two studies ([one](#) and [two](#)) suggest self-hypnosis may provide pain relief in people with MS.

[Visualization](#) is based on the premise that the mind is the body's most powerful tool. A session can be led by a therapist, recorded or self-administered. Participants are helped to create positive mental images of desired outcomes or states and through visualization techniques persuade their body to translate these images into reality. A [small study](#) comparing visualization to a journaling exercise for people with MS found small improvements in fatigue, mood and quality of life. However, a large number of subjects dropped out of the study, leaving behind only the ones who enjoyed or benefited from the technique. [Researchers](#) in London, however, concluded visualization and relaxation can boost the immune system.



Although there's no special “MS diet,” what a person eats can make a difference in how they feel. As discussed in our August 2019 newsletter, different [diets](#) have been proposed as treatments, or even cures, for MS symptoms. While there are proponents for each, most have not been studied adequately, and the few that have been studied have produced mixed results. Several [dietary supplements](#) are said to be beneficial in managing MS symptoms. It’s important to note that supplements can cause side effects or harm when taken in combination, at high doses, or instead of prescribed medications. Because supplements are not regulated in this country, being educated and careful about their use is very important.

Complementary and alternative medicine (CAM) refers to medical products and practices that are not a part of standard medical care. These can be either in addition to treatments (complementary) or as alternatives to the orthodox approach. There is evidence that a number of these approaches may be helpful for people with MS.

It's important to note that people with MS should consult with their doctor before starting any new therapy. The treatments a physician prescribes are the ones that have been evaluated in controlled clinical trials or accepted by the MS medical community as safe and effective therapies. In contrast, most alternative treatments have undergone very little scientific study to evaluate their safety and effectiveness. When considering alternative treatments, it's important to find out what the treatment is, what's involved and how it works. It's also important to ask about side effects, risks, effectiveness and cost.



CAM Options for People with MS

[Acupuncture](#) is an age-old healing practice of traditional Chinese medicine in which thin needles are placed at specific points on the body. It's primarily used to relieve pain but also has been used to treat other symptoms. The goal of acupuncture is to release the flow of the body's vital energy or "chi" by stimulating points along energy pathways. This is thought to release natural painkillers and may boost blood flow and change brain activity. Acupuncture needles are very thin, and most people feel no pain or very little pain when they are inserted. Some people report relief of symptoms like pain, muscle spasms, or bladder control problems, however the scientific evidence that it works for people with MS is mixed. A [recent study](#) found acupuncture improved walking difficulties in people with MS. However, a [2014 review](#) of 12 studies in MS concluded that although many of the studies included suggested that acupuncture was successful in improving MS symptoms, poor study designs made it difficult to draw any firm conclusions about its true effectiveness. Despite there not being enough evidence to make claims for or against the use of acupuncture in MS, it is generally considered safe when provided by an experienced, trained practitioner using sterile single-use needles. For those that don't like needles, [acupressure](#) may be an option. This involves pressing or massaging the acupuncture points to stimulate energy pathways.

[Reiki](#) is used by people with MS to help relieve various symptoms. This technique was developed in Japan in the 1920s. The word itself is Japanese for "universal life force energy." The whole body is treated rather than a specific symptom. The underlying principle of treatment is that "energy flows" through the body can be altered by placing

one's hands in a series of positions, on or over the body. Each position may be held for several minutes and the process can last up to an hour and a half. Although there is no research evidence supporting the use of reiki in MS, studies have shown it helps with a number of other related conditions. [Researchers](#) in Brazil found that reiki combined with massage reduced levels of stress by 33% and anxiety by 21%. In cancer, there is [evidence](#) that reiki is particularly effective at reducing pain and decreasing levels of anxiety and fatigue. It has also been found to improve wellbeing and mood during chemotherapy treatment.

[Reflexology](#) is a complementary therapy that involves having gentle pressure applied to the soles of the feet, hands or ears. It's thought that different points on these areas are connected to different organs and body systems. Reflexologists believe stimulating these points can encourage natural healing. As well as providing the calming effects of touch, reflexology can promote relaxation and improve wellbeing. One [study](#) found reflexology improved paraesthesia (abnormal sensations such as pins and needles), bladder symptoms, muscle strength and spasticity in people with MS. More recently, three separate studies ([one](#), [two](#) and [three](#)) concluded reflexology was an effective technique for relieving fatigue, pain and psychological symptoms (anxiety, stress and depression) in women with MS.

[Magnet therapy](#) is an alternative therapy that uses magnets or magnetic fields to treat illness, relieve pain and promote health. Thin metal magnets are attached to the body alone or in groups. These magnets may be worn for just a few minutes or for weeks at a time. The magnetic fields produced from the negative pole of the magnet are thought to have healing powers. [Pulse Electromagnetic Fields](#) (PEMF) is the most popular version of magnet therapy. Results from a [clinical trial](#) looking at 117 participants with MS suggest that PEMF can alleviate symptoms of MS. However, more research is needed to confirm these results.



As discussed in our [September 2018 newsletter](#), there is much controversy surrounding the therapeutic use of [marijuana](#) for MS. Some people with MS say that smoking or ingesting marijuana brings relief of many MS symptoms. However, scientists aren't clear on how it works and who should use it. Marijuana is a complex substance that may contain many different components affecting the body. Production of marijuana for medical use is

not standardized or regulated, therefore the effects of different batches of marijuana may not be the same. While many people are using marijuana, the FDA still hasn't approved it as a treatment because there haven't been enough studies to prove that it's safe and effective. This research is necessary to understand whether or not the benefits of marijuana use outweigh its many side effects. If you live in a state where medical marijuana is legal, it's important to consult with your doctor about the use of marijuana in your particular situation.

There is a wide range of treatment options available to people with MS to help relieve troublesome symptoms and improve quality of life. It may take a few attempts to determine which type of therapy works best. Some find it helpful to keep a journal tracking changes in treatment, symptoms, frequency of relapses and anything else that is



out of the ordinary. Sharing such information with one's healthcare providers can be very helpful in guiding treatment decisions. Talking to others who have used a given therapy may also help. With non-traditional therapies, it's especially important to research the provider's background. Find out about their credentials and how long they've been offering the treatment. People with MS should be sure that the provider is willing to work with their doctor and be fully informed about the total cost of the treatment (most are not covered by insurance). Be wary of outrageous claims and "secret" formulas (make sure all ingredients are listed). It's important for people with MS to weigh the pros and cons of any treatment under consideration and discuss this important decision with their doctor before proceeding.

August 2020 Research Spotlight

EVENTS



A New Podcast Series for People with MS

EMD Serono, in collaboration with Accelerated Cure Project, has released the first three podcasts in a 5-part educational podcast series, hosted by Jon Strum, called “Uncovering Sex in MS: A Dialogue About Sex, Parenthood and Hormones.” The topics covered in the podcast series were developed based on input from the [iConquerMS](#) community – another example of how iConquerMS members are driving and shaping MS research and care!

Women are nearly 3 times more likely to develop MS than men. Because the majority of these women are diagnosed during their childbearing years, clinicians and patients are encouraged to incorporate family-planning discussions into their ongoing MS management conversations. Optimal patient care involves coordination among a woman’s neurologist, obstetrician/gynecologist, and primary care provider to ensure alignment on the woman’s individual family-planning choices and preferences.

[Episode 1](#) features 3 unique perspectives on preconception planning for women with MS: Dr. Lori Travis, a neurologist who specializes in treating patients with MS; Dr. Erkan Buyuk, a reproductive endocrinologist, and Ms. Shannon Green, a pregnant woman living with MS.

Family planning is not just a concern for women with MS. Men with MS also need to be involved in these discussions. They have different concerns about fertility and pregnancy than women with MS. Thus, optimal MS care involves coordination and communication

among a man's neurologist and other care team members, such as reproductive endocrinologists and urologists.

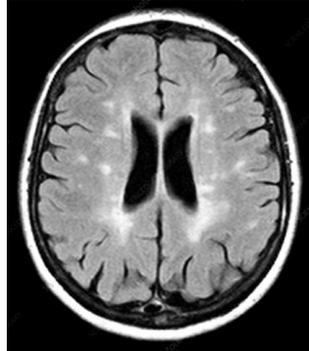
[Episode 2](#) features 3 unique perspectives on preconception planning for men with MS: Dr. Lori Travis, a neurologist who specializes in treating patients with MS; Dr. David Ryley, a reproductive endocrinologist with experience in treating men with MS; and Mr. Josh Evitt, a male patient with MS who has experienced fertility concerns during the family-planning process.

For pregnant women with MS, preparing for the birth of a child can be a time of excitement and anxiety. Each woman should work closely with her neurologist and other care team members to determine how best to manage her MS in the postpartum period. In addition to postpartum disease management, postpartum depression should also be assessed, because although the data are limited, it appears that new mothers with MS may have an increased risk of postpartum depression.

[Episode 3](#) features 3 unique perspectives on postpartum planning for new mothers with MS: Ms. Melanie Huff, a nurse practitioner who specializes in MS; Dr. Adam Kaplin, a mental health specialist; and Lindsey, a mother with MS who has first-hand experience with the postpartum period.

Stay tuned for future episodes!

RESEARCH OPPORTUNITIES



Do you have access to your own MRIs?

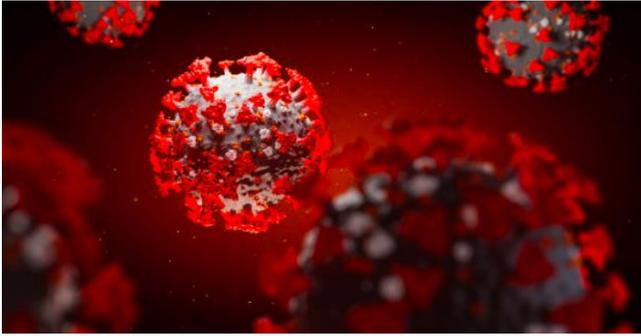
If you've been diagnosed with MS, you've probably had at least one MRI, if not several. Have you ever received a copy of your MRI files for your own use? We're interested in knowing and invite you to take a short [survey](#) on the topic. The survey has up to 20 questions and is expected to take around 10 minutes to answer. Your answers will be collected anonymously. You can click the link above or go to <https://www.surveygizmo.com/s3/5624803/iConquerMS-MRI-Access-Survey> to participate.

We'd like to know whether people with MS have access to their own MRI files and if they're interested in viewing, understanding, and/or sharing their MRIs. This will help us learn whether it might be feasible to conduct future research studies that involve MRIs.

The survey results will be shared with a company called Icometrix. Icometrix has developed software and services that help healthcare providers view, store, and analyze medical images such as MRIs. They would like to know how people with MS feel about viewing their own MRIs and whether they have access to their own image files.

If you have any questions, please email us at info@iconquerms.org. Thank you for your help and your input!

The iConquerMS Team



Share 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.

In response, we have launched a survey on iConquerMS to learn more about how people affected by MS are dealing with the COVID-19 pandemic and what their personal experience has been with COVID-19.

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!