

July 2020 Newsletter



Does MS Weaken With Age?

The immune system protects the body from harmful substances (called [antigens](#)), such as bacteria or viruses. It can distinguish between normal, healthy cells and unhealthy cells by recognizing a variety of "danger" signals and responding to address a threat, when necessary. If an immune response cannot be activated when there is a need, problems like an infection may occur. On the other hand, when an immune response is activated without a real threat or is not turned off once the danger passes, different problems arise, such as allergic reactions and autoimmune diseases (like MS). Inflammation is an immune response that occurs when tissues are injured. The damaged tissue releases chemicals that cause blood vessels to leak fluid into them, causing swelling. This helps isolate the foreign substance and prevent its spread throughout the body.

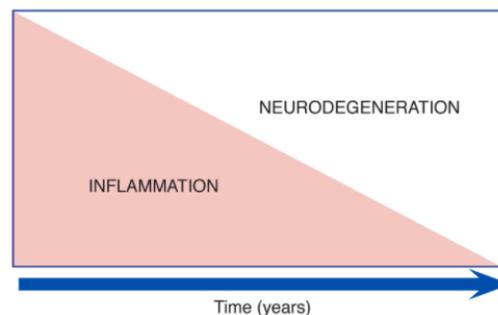


MS is a condition in which the immune system attacks the nerves in the brain and spinal cord, causing [demyelination](#). Approximately 85 percent of people living with the disease are initially diagnosed with relapsing remitting MS (RRMS), in which they experience flares in their symptoms (new or existing), lasting anywhere from a few days to a few months. Afterward, symptoms improve or resolve completely for periods of months or years. Over time, RRMS may progress to secondary progressive MS, in which an individual may experience a slow, steady progression of symptoms – with or without



relapses. If relapses do occur, they usually do not fully remit. Approximately 15 percent of the MS population is diagnosed with primary-progressive MS, where individuals experience a steady worsening of symptoms from the start, and do not have periodic relapses and remissions.

The MS disease process is a complicated one and it evolves over time. An immune response occurs in which the body's own white blood cells attack the nerves in the brain and spinal cord, causing inflammation. This, in turn, damages the protective covering surrounding the nerves (demyelination). [Nerve degeneration](#) may also occur, which is the breakdown or death of nerve cells. The body attempts to repair the damaged myelin ([remyelination](#)), however this process is often incomplete, which results in scarring within the central nervous system at the sites of damage ([glial scar](#) formation). [Research](#) shows the efficiency of remyelination naturally declines as part of the aging process. As a result, the ability to repair damaged nerves decreases, eventually reaching a point where it is too slow to prevent nerve degeneration (which is when MS enters the progressive phase). In RRMS (early in the disease process), inflammation is typically the primary driver of the disease process. Over time, in progressive forms of the disease, the disease involves increasingly less inflammation and more neurodegeneration.



The immune system functions less effectively as a person gets older, which is a complex process called [immunosenescence](#). As a result, elderly individuals are often more at risk for infections and have a decreased response to vaccinations. A number of environmental

and lifestyle factors have been shown to affect this rate of decline. For example, [research](#) suggests the amount of exercise an individual gets influences their immune function over time. Another typical aspect of aging is the development of a chronic, low level of systemic inflammation, often referred to as [inflammaging](#). There is evidence these abnormal immune responses lead to the development of many conditions, such as [cardiovascular disease](#), [cancer](#) and a worsened disease course in [MS](#). Everyone living with MS experiences disability progression at varying rates. A [recent review](#) suggests levels of iron increase in the brain and spinal cord as one gets older and this causes oxidative stress and cell death (which contributes to neurodegeneration and the formation of lesions). The reviewers concluded the processes of immunosenescence and inflammaging contribute to unhealthy aging and disease progression.



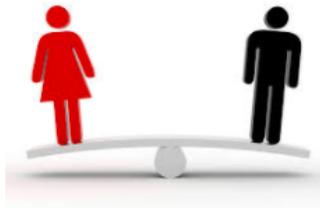
As mentioned in our [June 2020 newsletter](#), there is evidence the number of relapses a person with MS may experience decreases with age. [Recent research](#) suggests young adults show higher levels of MS disease activity. Exploring this phenomenon further, a [2008 study](#) followed 2,477 RRMS subjects for an average of 20 years from the onset of their MS symptoms. Results showed relapse rate decreased by 17 percent every 5 years. Subjects who were older at disease onset experienced a more rapid decline in relapse rate. More than three quarters of subjects experienced a 5-year relapse-free period during the RRMS phase. Interestingly, women and those whose first MS symptoms were sensory in nature had higher relapse rates.

People with MS, and in general, are more likely to develop other health conditions as they get older. As discussed in our [July 2019 newsletter](#), there is evidence that these other health conditions, also called comorbidities, play a significant role in MS disease progression over time. For example, [research](#) suggests people with MS and vascular comorbidities such as hypertension, diabetes and hyperlipidemia are more likely to experience ambulatory disability sooner compared to those without these comorbidities. Results show these risk factors are associated with decreased brain volume, as well as an increased number of lesions. [Researchers](#) at the University at Buffalo also found cardiovascular risk factors are associated with an increased number of lesions and more advanced brain atrophy. An additional issue with



comorbidities relates to treatment of them. Attempts to treat the multiple conditions a person with MS may experience with various combinations of medications often results in “polypharmacy” (taking more than 5 prescriptions at a time). A [2014 study](#) shows that taking so many different medications is associated with increased fatigue and memory/cognitive problems.

A [recent study](#) of 57 people with MS found individuals may get better at dealing with the disease over time. The research team divided participants into three different age ranges: 35 to 44, 45 to 54 and 55 to 65. Participants completed several tests to measure their quality of life and depression levels. Results showed significant differences in depression and quality of life between each group. The oldest people had the lowest levels of depression and higher levels of well-being. It’s important to note that more research is needed in larger populations to confirm these results and to clarify the reasons for these outcomes.



A [2017 study](#) suggests that men and women may experience aging with MS differently. Canadian researchers surveyed 743 people with MS older than 55 who have been living with MS for more than 20 years (577 were women and 166 were men). Participants were asked to rate their health and answer questions about other factors that might influence how they cope with

living with MS. Older men with MS had a lower perception of their health, coped less well with setbacks, had lower participation in household activities (such as housework and home/car maintenance), participated less in social activities outside of the home and had a poorer diet. Older women reported higher levels of anxiety, whereas older men reported higher levels of depression. These results suggest that men cope less well with aging with MS. The researchers propose this may be due to the differences in the traditional roles of men and women. Although women were just as likely as men to retire early due to MS, older women continued to participate in household work and social opportunities more often than older men; these activities help to reduce the impact of depression on perceived health and quality of life. Subjects with higher levels of depression had a lower perception of their health, regardless of gender (stressing the importance of treating this symptom).

MS is a disease that most often affects young adults and progresses over time. The symptoms it causes and when they flare up vary not only between people but also throughout one's lifetime. There is evidence of reduced disease activity as individuals with MS age and people get better at coping with the disease (particularly women). Many factors, in addition to normal aging, contribute to an individual's rate of disease progression (for example, comorbid health conditions).

Strategies for coping with the MS over time may depend on a person's level of disability, but many are universal. It's especially important for people with the disease to maintain their health by exercising and eating a healthy diet. People with MS should also work with a comprehensive medical team which includes a primary care doctor and a neurologist who can manage MS and any other health conditions that may exist.



Is Menopause a Turning Point for Women with MS?

Menopause is a natural part of aging that occurs when the ovaries stop producing hormones called estrogens. As estrogen levels drop, monthly menstrual periods stop. Menopause is a slow process that usually occurs in stages.

[Perimenopause](#) typically begins several years before menopause when there is a gradual reduction in the

production of estrogen. Toward the end of perimenopause estrogen reduction accelerates, causing menopausal symptoms. A woman is said to be menopausal when she has not had a period for 12 consecutive months. This typically occurs between the ages of 45 and 60, however it can occur earlier, due to surgical removal of the ovaries or other medical reasons. A [2018 study](#) found that women with MS start menopause at the same age as healthy women. [Post-menopause](#) refers to the years after menopause, when a woman's estrogen levels remain at a constant low level. Menopausal symptoms ease for most women at this time, however the [health risks](#) related to estrogen loss increase.



MS is three times more common in women than in men and is more prevalent in women of childbearing age than in any other age group. Although significantly more women than men have MS, men progress at a faster rate than women until about age 45 or 50 (the average age of menopause for most women). A [2013 study](#) shows the rates of disease progression between the sexes are parallel after the age of 50. This suggests that menopause in women with MS may contribute to disease progression.

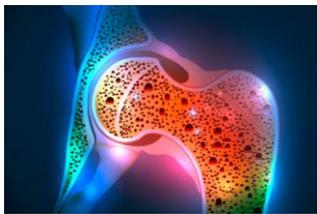


Several other studies have looked at the effect of menopause on MS disease progression in women. Italian researchers recently published results from an [observational study](#) suggesting menopause may be a turning point to a more progressive phase of MS. They found relapse rate to be reduced after menopause, however also state this effect could reflect the shift to the progressive phase in subjects with long-standing disease. Results also suggest cigarette smoking may speed up disability progression in women with MS after menopause. [Researchers](#) in Portugal followed 37 women with MS before and after they went through the change. Results showed relapse rates were reduced within five years following menopause and disability progression continued at a similar rate, compared to the premenopausal period.



Women are born with a defined number of eggs in their ovaries which decreases over time. Each egg lives inside a follicle (a fluid-filled sac) that contains cells to support egg maturation and produce hormones, for example [anti-Mullerian hormone](#) (AMH). AMH levels typically lower over the course of an adult woman's lifetime and are a direct indicator of the number of follicles (or eggs) in her ovaries, or her fertility. [Researchers](#) at UCSF analyzed AMH levels in plasma samples from 412 women with MS and 180 healthy controls collected over a period of 10 years. They found lower AMH levels (ovarian decline) to be associated with greater disability and gray matter loss in women with MS after adjusting for chronological age, disease duration, and BMI.

A [recent study](#) presented at the [ACTRIMS Forum 2020](#) (Americas Committee for Treatment and Research in Multiple Sclerosis) found that women with MS who have never given birth and those who began menopause prematurely (before age 45) tend to develop progressive forms of the disease earlier. The study team analyzed data from 134 women and 68 men with progressive MS, with a group of postmenopausal women without MS serving as controls. Results showed the higher the number of viable pregnancies (those that ended with a birth), the older the age at onset of progressive MS. The transition from relapsing remitting MS (RRMS) to secondary progressive MS (SPMS) was faster in women with early menopause than in subjects who began menopause at what's considered a normal age. Among women who developed SPMS after going through menopause, progression from RRMS was faster in those with premature menopause than in those who did not go into early menopause. It's important to note that more research involving larger numbers of subjects is needed to confirm and better understand the factors contributing to these results.



[Hormone replacement therapy](#) (HRT) involves taking small doses of estrogen and progesterone to relieve menopausal symptoms. HRT has the added benefit of helping to maintain bone density and reduce the risk of osteoporosis and bone fractures. There is evidence HRT also helps to improve MS symptoms. One [small study](#) from 1992 surveyed 19 postmenopausal women about changes in their MS symptoms during their menstrual cycle, menopause, and while using HRT. Results showed 54 percent experienced a worsening of MS symptoms with menopause and 75 percent of those taking HRT felt it improved their symptoms. More recently, a [2016 study](#) found postmenopausal women with MS who went on HRT reported better physical function than those that didn't. However, it's important to keep in mind that HRT increases the risk of certain serious conditions, including heart disease, stroke, blood clots, and breast cancer. Women should discuss these risks and other treatment options with their doctors.

Every woman experiences menopause, and MS, differently. There is evidence that the hormone changes caused by menopause may increase symptom severity and disability progression in MS. They also suggest that HRT may improve symptoms that worsen

during the menopause. More research is needed to provide clarity on how menopause affects the course of MS, as well as into the benefits of hormone-based therapies for women living with the disease before any determination can be made as to whether their benefits outweigh the risks. The fundamental tenet of the Accelerated Cure Project's mission is to facilitate research efforts such as these. It is our hope that, through research, diagnosis, treatment outcomes and quality of life will be improved for all people living with MS until a cure is found.



July 2020 Research Spotlight

EVENTS



A New Podcast Series for People with MS

EMD Serono, in collaboration with Accelerated Cure Project, has released the first two 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.

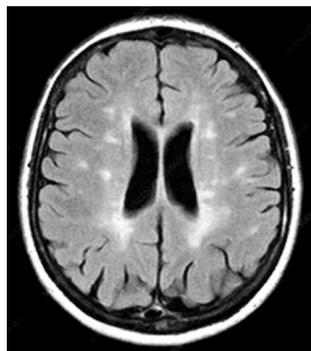
[Episode 1](#) features three unique perspectives on preconception planning for women with MS: Dr. Lori Travis, a neurologist who specializes in treating patients with MS; Dr. Erkan Buyuk, a reproductive endocrinologist, and Ms. Shannon Green, a pregnant woman living with MS.

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.

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



**Your health data
has power!**

An invitation to help us learn more about aging with MS

Please read on for an invitation from Cherie Binns, iConquerMS Research Committee co-chair, for network members to participate in a brief (5-minute) [survey](#) related to aging with MS and access to disease modifying therapies and clinical trials. All are invited to [participate!](#) If you are not already a member, please consider [joining iConquerMS](#). Your health data has power!

Hello, fellow members of iConquerMS.

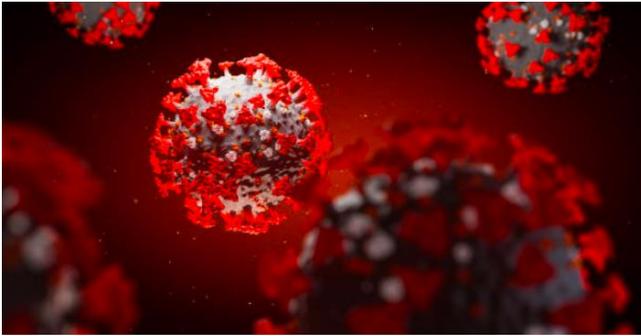
For those of you who have done the REAL MS surveys, you know that there is always an option in those surveys to put forth suggestions about research topics that matter to you. One of those areas of concern that has emerged over the past 3-4 years has been aging with MS.

Some individuals have suggested there may be a bias toward those of us who have MS and are a certain age or older. To gather accurate information and move forward in an appropriate manner, we are inviting everyone, regardless of age, to answer a [few questions](#) about the care you receive and your input on that care. Some of us believe this has the potential to open a whole new aspect of thought and care for all as we aim to gracefully age with a chronic illness.

Thank you!

Cherie C. Binns RN MSCN

Co-Chair of Research Committee (and PwMS)



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!



UsAgainstAlzheimer's

What Matters Most: Caregiving Challenges

Study Purpose:

Living with MS takes a toll on families due to both the intensity of care and long disease progression. This study will help shed light on how caregivers feel about interactions with healthcare providers. Are they included in the healthcare conversation? Are their needs brought up and addressed? We're conducting this survey in partnership with an organization that supports families coping with dementia. We'll use what we learn to better inform care practices and to improve healthcare provider education.

This Study Involves:

This study involves completing an anonymous survey. **Are you a person living with MS? Please forward this email to your caregiver(s) and invite them to take this important survey. Are you a caregiver? Please click the link below to participate.**

Study Contact Information:

If you're interested in participating in this study, you can access a survey [here](#). Thank you for helping us make life better for all caregivers and their loved ones with MS!