

# June 2020 Newsletter



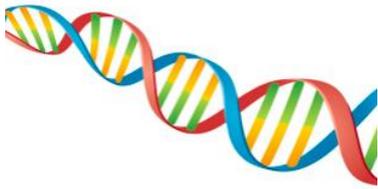
## Aging Gracefully With MS

According to a [recent study](#), approximately 90% of people with MS now in their twenties may live into their seventies and a quarter of people currently living with MS are mature adults over 65 years old. As a result, more individuals with MS face coping with normal age-related changes in their health and life while having to manage symptoms and disability related to the disease.



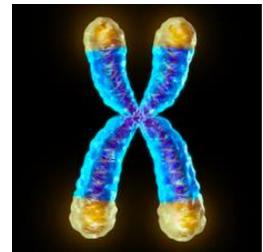
Differentiating between the effects of MS and age-related changes can be difficult, since many of its symptoms, including fatigue, pain, depression, cognitive changes, visual disturbances, difficulties going to the bathroom and with mobility, are common in normal aging. The risk of developing other health conditions (called comorbidities) also increases as a person gets older, whether they have MS or not. Common examples of comorbidities include heart disease, diabetes, and arthritis. The potential impact of comorbidities for people with MS is discussed in our [July 2019 newsletter](#). For the best outcome, individuals with MS and their healthcare providers must be vigilant and ensure that all comorbidities are appropriately treated in the course of comprehensive care.

According to the [somatic mutation theory of aging](#), how a person ages is determined by genetics. The body's cells are continually reproducing throughout an individual's lifetime. Each time a cell divides, there is a chance that some of the genes will be copied incorrectly (called a mutation). In addition, exposures to toxins, such as the chemicals in cigarette smoke, may cause mutations. The body can correct or destroy some, but not all of these abnormalities. As a person ages, the mutated cells eventually copy themselves and accumulate and this may cause problems in the body's functioning.



The information in DNA (or genetic code) is stored in four chemical [bases](#) (adenine, guanine, cytosine and thymine), which pair together to form DNA's ladder-like structure. [Telomeres](#) are sections of DNA that protect the ends of chromosomes by forming a cap, much like the plastic tip on shoelaces. They consist of the same short sequence of bases repeated over and over again. Telomeres [shorten](#) in the process of aging in cells. When cells divide, their DNA is replicated and each time this occurs the chromosomes are shortened by approximately 25 to 200 bases. However, because the ends are protected by telomeres, the only part of the chromosome that is lost is the telomere, and the central DNA is left undamaged. When the telomere becomes too short, the chromosome can no longer be replicated (and the cell dies).

[Research](#) shows the shortening of telomeres is associated with normal aging and related diseases. The rate of erosion is determined by genetics as well as the cumulative effect of other factors throughout an individual's life. For example, [oxidative stress](#) is one of the factors that contributes to the loss of base pairs when a cell divides. The amount of oxidative stress in the body is thought to be affected by lifestyle factors such as diet, smoking, and stress.



[Chinese researchers](#) looked at oxidative stress and its effect on telomere length in 59 subjects with MS compared to an equal number of control subjects (study participants without MS). The MS subjects were divided into three groups (benign, secondary progressive, and primary progressive MS). They found higher levels of biomarkers for oxidative stress in MS subjects compared to controls. Mean telomere length was significantly shorter in the primary progressive MS group, whereas no shortening was found between controls and the other MS subjects. These data suggest oxidative stress and telomere shortening are associated with the most severe stage of MS. Shortened telomere

length has also been associated with [cardiovascular disease](#), [Alzheimer's Disease](#), and other [autoimmune diseases](#), such as lupus and rheumatoid arthritis.



Chronological  
Age

It's important to note there are two types of aging – chronological aging and biological aging. An individual's [chronological age](#) is the amount of time that has passed from their birth to a given date (the primary way most people define their age). [Biological age](#), on the other hand, is more than just a measure of time passed. It is an indication of how the aging process has impacted the body (how old a person seems). Biological age takes into consideration other factors like genetics, lifestyle, nutrition, as well as health conditions an individual may have. These two ages may be different in any given individual. Chronological age always increases at a set rate as time passes. However, lifestyle choices can either increase or decrease a person's biological age. One [study](#) looked at a group of people, all of whom were 38 years old. Results showed their biological ages ranged from 28 to 61. Many factors contributed to this variability, such as genetics and habits (for example, whether or not an individual exercised, ate a healthy diet, or smoked). The distinction between the two types of aging is relevant in MS. A [recent study](#) looked at whether biological aging (as measured by telomere length) is associated with clinical disability and brain volume loss in people with MS. Data suggest shorter telomere length is associated with disability independent of chronological age, suggesting that biological aging may contribute to MS disease progression.



Biological  
Age

A number of factors have been shown to help individuals with MS age gracefully. [Canadian researchers](#) studied this subject from the perspectives of 683 older people living with the disease. Results show social connections, such as relationships with family, friends, and even pets, as well as volunteerism are the most commonly reported positive influence, followed by a good attitude and outlook. Lifestyle choices and habits (healthy eating, exercise, adequate sleep, weight management) are also important, as well as having access to high quality health care. In addition, data show spirituality and religion, independence, and finances play a part in aging gracefully with MS.





Selecting the right MS therapy depends on careful consideration of many factors. Many of the DMTs carry significant [health risks](#), some of which are common and easy to manage, while others occur less frequently and may be more serious. In addition to health risks, there is also emotional and financial liability to consider. According to a recent [study](#) conducted by the National MS Society, the high cost of DMTs and the process required for insurance approvals often worsens MS symptoms and causes emotional distress for people living with MS. These added burdens may not be necessary if, after a certain age, treatment with these medications doesn't improve health and quality of life.



To assess the clinical severity of MS among the older people with MS as well as the effect of DMTs on this population, [researchers](#) at Brigham and Women's Hospital in Boston recently identified 195 participants in the [CLIMB](#) study (Comprehensive Longitudinal Investigations in MS) who were 65 or older and had more than 5 clinical visits after that age. The research team reviewed clinical data from these participants including comorbidities, DMT use, adverse drug reactions, disability scores, and MRI results. Results showed older study participants with MS had fewer relapses. They also found a large proportion of participants were untreated. For participants who were taking treatment, the adverse drug reaction rate was lower among those who were taking the newer [oral DMTs](#) and [infusion therapies](#) than among those being treated with first-generation therapies ([interferon beta](#) and [glatiramer acetate](#)). Most side effects were mild, very few were considered severe, and none led to fatalities. The most common type was injection-related symptoms. This study suggests that while DMTs may have side effects, their use is safe in old age.

[Researchers](#) at the National Institutes of Health analyzed data from 38 clinical trials that assessed the efficacy of DMTs on disability progression in more than 28,000 people living with MS. Results suggest the effectiveness of DMTs significantly decreases with advancing age. Data shows treatment with these medications is most beneficial during the early stages of MS, and, after age 53, there is no benefit to receiving DMT for the "average" MS patient. Having said this, it is important to note this study does not suggest that all people with MS who are older than 53 should be untreated. This is a decision that should be made on an individual basis in consultation with one's healthcare providers.



# #safe

Whether and when people with longer standing MS should safely discontinue DMTs are challenging questions that require further study in clinical trials. Currently available data are mostly from database studies or smaller reviews. Investigators at the Cleveland Clinic conducted an [observational study](#), the results of which suggest discontinuing DMTs may be safe for most older people with MS. The research team looked at data from 600 participants with MS that were more than 60 years old, 178 of whom stopped DMT. Most participants stopped treatment due to age, side effects, lack of benefit, stable or secondary progressive disease, other health conditions, or cost. Most participants who stopped DMT remained off of their medication (only 10 percent restarted) and only one clinical relapse occurred. The top reasons for re-initiating treatment were patient/provider preference, changes on magnetic resonance imaging (MRI), clinical progression, or clinical trial participation. On the other hand, at the 2019 [CMSC](#) annual meeting (Consortium of Multiple Sclerosis Centers), [investigators](#) at the University of Washington presented two cases in which individuals over the age of 60 experienced unexpected disease activity after discontinuing DMT.



Historically, MS clinical trials have had age restrictions that have limited the participation of people with MS over the age of 55 (resulting in missing important data). Two ongoing studies may help shed more light on the benefit and risk of using DMTs in this age group. [DISCOMS](#) (Discontinuation of DMTs in MS) plans to enroll 260 participants with MS age 55 and older at 19 sites across the United States by February 2022. Half of the participants will stay on their current MS medication and the other half will discontinue their medication. Assessments will be performed to measure participants' quality of life, symptoms, cognitive status, and disease activity on MRI. The [STOP-I-SEP](#) clinical trial (DMT Withdrawal in Inactive Secondary Progressive MS Patients Older Than 50 Years) is currently underway in France with an estimated completion date of January 2026. As the name implies, this study is focused on learning more about stopping DMTs in older SPMS participants with stable MS. Specifically, investigators are looking at disability progression, the number of relapses participants may have, disease activity on MRI, as well as quality of life, and economic impacts.

There is evidence that the risk-benefit ratio of DMTs shifts with aging. More research is needed that includes older individuals with MS in order to carefully and systematically answer the questions of whether or not it is safe to stop a DMT at a certain age, and if so, in what category of people. In addition, further study is necessary to shed light on the other aspects of an individual's regimen that may need to be modified to optimize outcomes when their medications change, such as diet, exercise, smoking habits, as well as tending to their emotional and spiritual needs. The core of ACP's mission is to facilitate research efforts such as these, which have the potential to improve the health and quality of life for people living with MS throughout their lifetime.



## June 2020 Research Spotlight

## EVENTS



## A New Podcast Series for People with MS

EMD Serono, in collaboration with Accelerated Cure Project, has released the first of a 5-part educational podcast series, hosted by Jon Strum, called "Uncovering Sex in MS: A

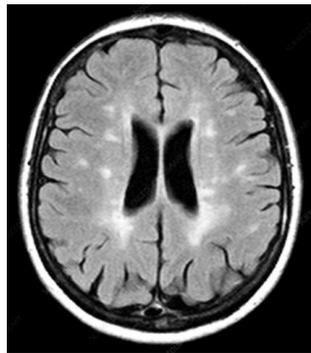
Dialogue About Sex, Parenthood and Hormones.” The topics covered in the podcast series were developed based on input from the [iConquerMS](#) community – another example of how iConquerMS members are driving and shaping MS research and care!

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. Stay tuned for future episodes!

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## 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](mailto:info@iconquerms.org). Thank you for your help and your input!

The iConquerMS Team

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## **What kind of psychological support would you like for living with MS?**

Please read on for an invitation from investigators at the University of Reading to participate in one of their studies.

Psychological and medical literature suggests that people with MS are more prone to mental health problems which highlights the need for such services to be made available

for this population. There are different types of support available to people with MS, however not all are accessible or suitable to match the varying needs of people living with the disease.

Over the next 18 months our research aims to develop a psychological intervention that is tailored for people with MS. We are inviting you to help us in this endeavor by completing a survey. We are asking individuals living with MS about their experiences of accessing support (positive and negative), and their opinions about what kind of support would be useful. We will use this information to design a psychological intervention that will reflect the views of the MS community.

To read more about this research and take part in the survey, please go to the [University of Reading website](#) and click the 'start' button at the bottom of the page. Or you can go directly to the survey by clicking [here](#).

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**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.

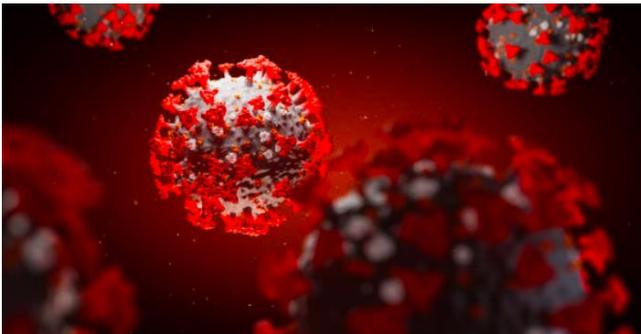
Some individuals have suggested there may be a bias toward those of us who have MS and are a certain age or older. To gather accurate information and move forward in an appropriate manner, we are inviting everyone, regardless of age, to answer a [few questions](#) about the care you receive and your 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)

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### **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!

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**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 caregiving affects one's health and quality of life. We've partnered with a sister organization supporting families coping with Alzheimer's disease on a survey about the challenges and concerns of providing care to a loved one with MS. We will use what we learn to create new materials to educate caregivers about best practices, and resources for caregiving and self-care.

**This Study Involves:**

This study involves completing up to two anonymous surveys. We'll use these data to better inform care practices and health care provider education. Let us know your biggest challenges, what resources or services you use or wish you had. What advice would you share with other caregivers?

**Study Contact Information:**

If you're interested in participating in this study, you can access the first survey on caregiving challenges [here](#) and the second one on relationships with healthcare providers [here](#). Thank you for helping us make life better for all caregivers and their loved ones with MS!