

Aging With Multiple Sclerosis



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INFOCORNER



What is NARCOMS?

NARCOMS is a registry for people who have multiple sclerosis (MS). Registry participants complete two surveys each year to provide information about themselves and their experience living with MS. Data from these surveys are used in research studies and to help further our understanding of MS. Participation in the registry is voluntary, and responders' identity and privacy are carefully secured.



What is the Goal of NARCOMS?

The NARCOMS Global MS Patient Registry helps to facilitate research about multiple sclerosis in North America and around the world. Collaboration between MS centers of excellence throughout the world helps to increase knowledge, improve clinical care, and enhance the quality of life for persons with MS.



How Private Is My Information?

We will keep the information that you provide us private and confidential by storing your data in a secure database. All information will be used for research purposes only. We do not share any personally identifying information with any person or research institution. We follow all Federal (HIPAA) laws regarding confidentiality.



Not Yet a NARCOMS Participant?

Please contact us at www.NARCOMS.org to enroll online, or call toll free at 1-800-253-7884.



Tell Us Your Thoughts!

Have an idea? We would love to hear from you!
Send us your questions, comments, and suggestions.

Call: 1-800-253-7884 (toll-free U.S.)

Email: MSRegistry@narcoms.org

Online: www.narcoms.org/contact-us

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For more information on the CMSC visit

www.mscares.org.

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DIRECTOR'S LETTER

Dear NARCOMS Now Readers:

You asked, and we listened! In our most recent feedback survey, many of you expressed interest in learning more about aging with MS. In this issue, we focused on the current research targeting the effects of aging on people with MS.



Robert Fox, MD

Medical professionals everywhere are seeing their patients live longer — whether they have MS or not. For people with MS, this change can be a result of many factors. Some of these factors include new and improved treatments for MS, healthier lifestyle choices, and overall improved healthcare. Although there is still much to learn about the effects of aging on people with MS, this issue of NARCOMS Now focuses on what we currently know.

In this issue, the Feature Focus section highlights current research studies including the DISCO-MS trial and the CLIMB study. These studies focus on learning how MS changes over time and the impact of aging on participants. The Feature Focus also gives insight about the influence that age may have on the need for DMTs, the immune system, hormones, and overall health. The MS News section provides useful tips for people aging with MS, as well as important information about cognitive issues, diet, and lifestyle choices. The Snapshot offers a breakdown of the NARCOMS registry participants by their age and gender.

We hope that this issue is of great interest to you, the readers of NARCOMS Now, and we thank you for your continued participation in the NARCOMS registry! Your involvement in this registry is critical in advancing our knowledge of MS.

Sincerely,

Robert Fox, MD

Managing Director, NARCOMS



Aging With Multiple Sclerosis

“Age is an issue of mind over matter. If you don’t mind, it doesn’t matter.”

—Samuel Clemens (Mark Twain)

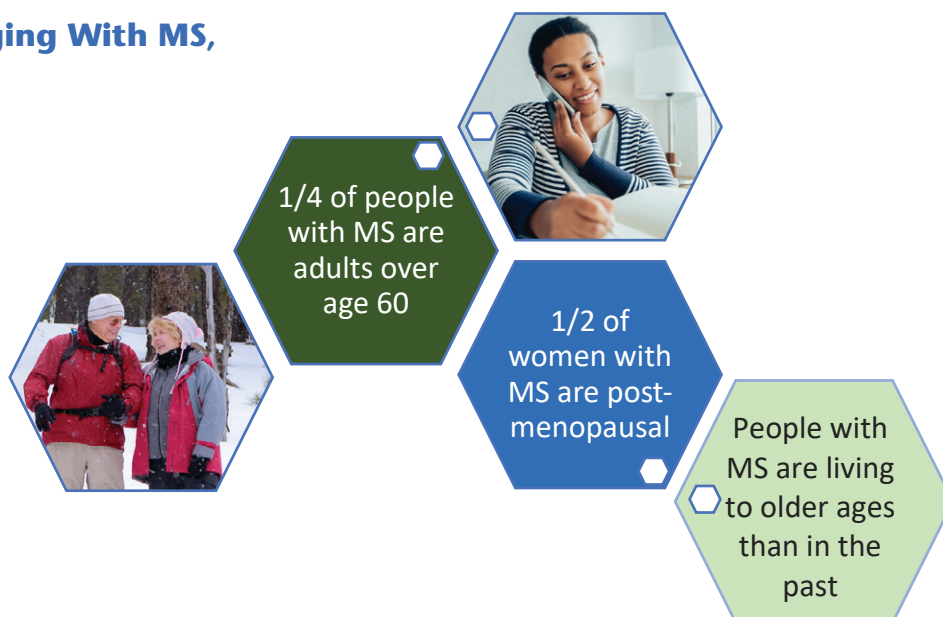
We often think of multiple sclerosis (MS) as a condition that affects mainly young adults. However, the average age of the MS population has shifted over time. One in four Americans with MS are now over age 60 years (**Figure 1**). “Over the past few decades we are seeing less of the devastating effects of MS that were once considered unavoidable,” said North Carolina-based nurse practitioner Marie Moore, FNP-C. “People with MS are living longer, with higher quality of life. Whereas office visits used to revolve around coping with disabilities, we

now spend more time discussing healthy lifestyle factors.”

What Do We Know About Older Adults with MS?

Over the past few decades, people with MS are living longer and staying more active in their later years. This may be due to the use of disease-modifying therapies (DMTs) and improved overall healthcare. NARCOMS data offer a glimpse into the aging MS population. Among 8,004 people who responded to a 2015 NARCOMS survey, the average age was 62

Figure 1. Aging With MS, at a Glance



years for people with secondary progressive MS (SPMS) and 56 years for those with relapsing remitting MS (RRMS) (**Figure 2**). Most respondents were women: 74% of responders with SPMS and 84% with RRMS were women. At the time of the survey, most respondents who had RRMS said they were still taking a DMT, while about half of those with SPMS were taking a DMT.

“We don’t know enough about how MS affect people in their 50s, 60s, and beyond,” explained MS neuroscientist Michelle Ploughman, PT, PhD. “Registries like NARCOMS can be very valuable. We also need more studies that focus specifically on how MS affects people as they age.”

DMTs: Continue or Stop?

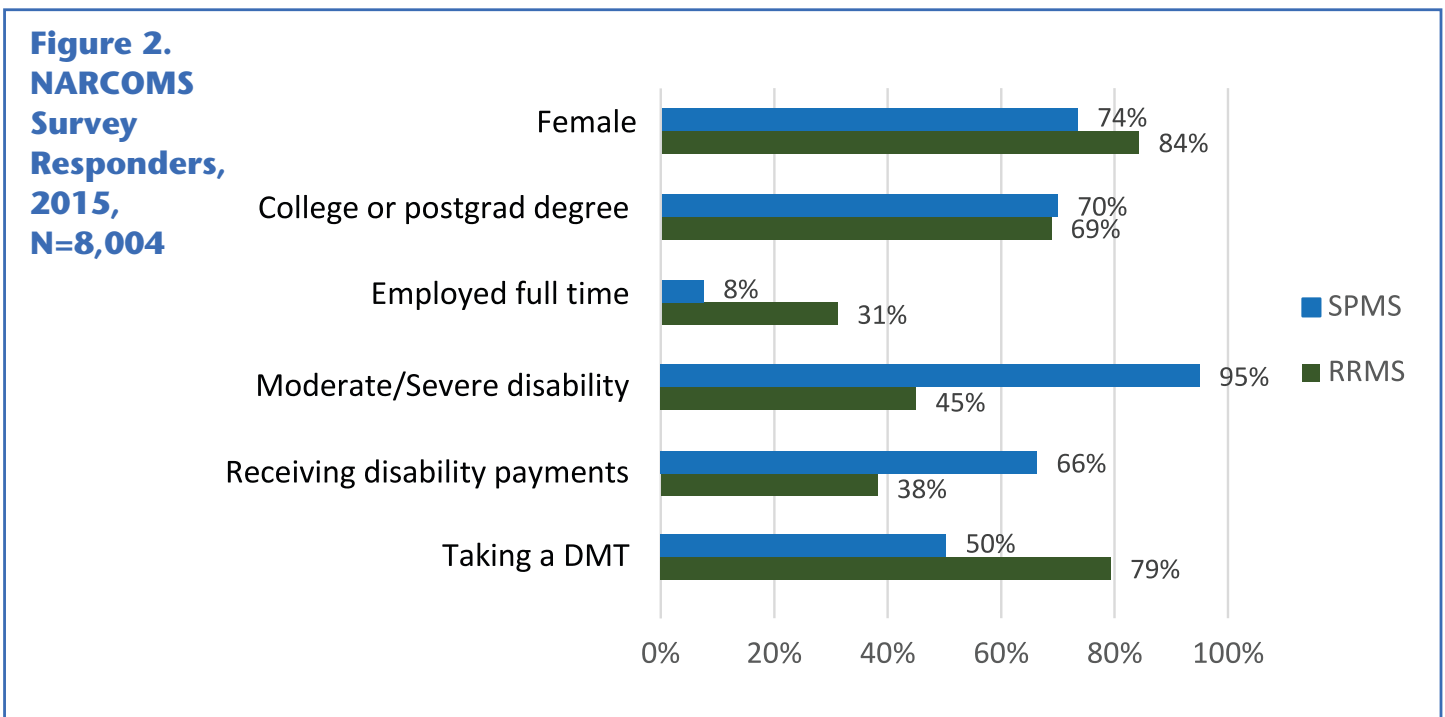
Whether people with MS should continue DMT when they reach a certain age, or after they transition to progressive MS, remains an important question. Some MS healthcare

providers suggest stopping DMT if a person is over age 55 years and has:

- 1) MS disability that prevents walking
- 2) No MS relapses or no new MRI changes for several years

If a person is using a higher efficacy agent for MS, the safety risks may start to outweigh the benefits at some point. In these cases, the person may be advised by their MS healthcare providers to discontinue treatment or switch to a DMT with a more favorable safety profile.

Research studies are under way to help inform these decisions for people with MS and their healthcare providers. One clinical trial is DISCO-MS, which enrolled people with MS over age 55 years who had worsening MS but no new MRI or relapse activity for 5 years or more. Participants were randomly assigned to either continue their DMT or stop their DMT and then followed for 18-24 months. This trial



will be completed in 2023 and will compare results between people who continued to take DMT and those who stopped.

Impact of Aging on the Immune System and Brain

What happens to our bodies as we age has long fascinated scientists. As cells age they undergo senescence, meaning they start to lose their powers to divide and grow. Telomeres, protective caps on the ends of chromosomes in each cell, start to become shorter as a person ages (see image). Senescence affects the immune system in several ways:

- White blood cells have shorter telomere lengths, which may affect their function in the immune system;
- Senescence of the brain cells leads to atrophy (shrinkage) of the brain;
- Age-related illnesses (such as cardiovascular diseases) increase.

Brain atrophy occurs in all people as part of normal aging. This often happens at a faster



Telomeres are the tips of the chromosomes (X shapes in the image above). Telomeres are longer in a younger person (green X), but they begin to break away with age. This biological process is linked with some of the changes that occur with aging.

rate in people with MS. Increased brain aging and atrophy occurs in people with either relapsing or progressive MS. In older people with MS, brain atrophy can be a cause of disability progression and cognitive problems.

Brain volume is used increasingly as an outcome measure in clinical trials. However, it's not realistic to keep track of brain volume changes in an individual person. This is because many factors can affect brain volume from one MRI scan to the next. If a person is dehydrated, or has used anti-inflammatory agents, brain measurements may appear smaller. Inflammation or swelling can give the appearance of increased brain volume.

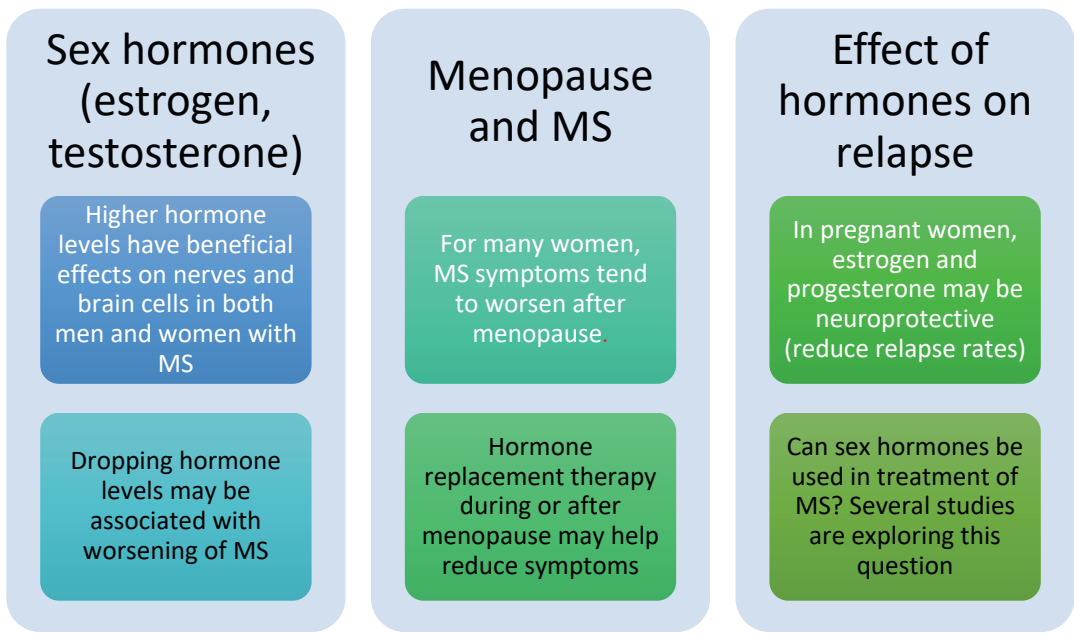
Hormonal Changes With Aging

Age-related hormonal changes can affect both men and women with MS (**Figure 3**). Higher levels of female hormones like estrogen and progesterone seem to protect against MS relapses, particularly during pregnancy. As a woman ages, levels of these hormones drop. For many women, MS seems to worsen after menopause.

An ongoing study called CLIMB is looking at how MS changes over time. In this study, men with MS had significantly lower levels of testosterone, compared with men without MS. Research shows that low testosterone levels are associated with worse disability and more cognitive decline in men.

Both male and female hormones are being investigated as possible treatments for MS, Ms. Moore said. "Hormone treatments can have risks," she noted, "and we don't yet know how replacing them affects MS over the long term."

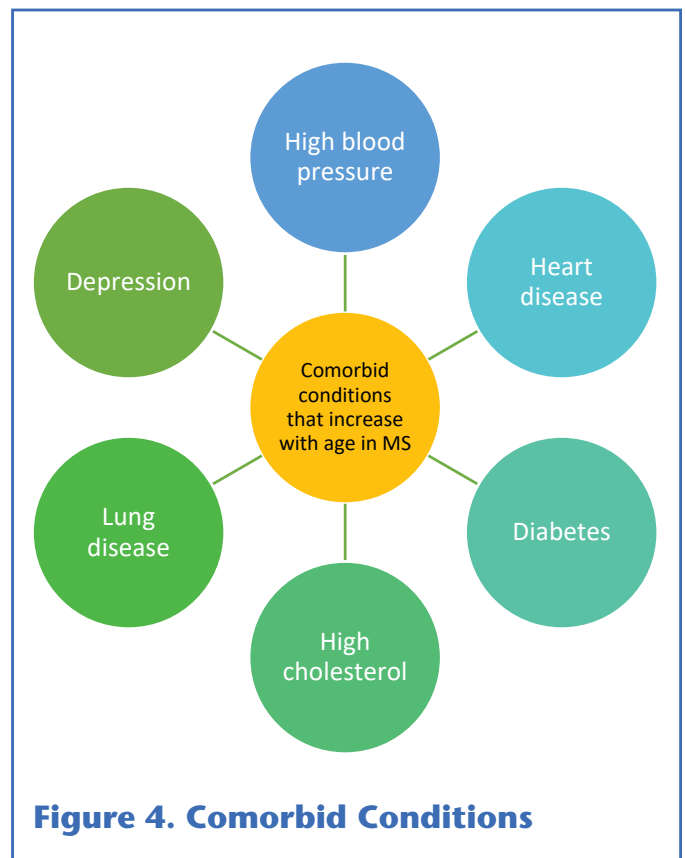
Figure 3. Hormonal Changes and Aging



Keeping Up With Health In Aging

For everyone, with or without MS, there is a risk of other health problems complicating MS as we age. Research by NARCOMS Scientific Director Ruth Ann Marrie, MD, PhD, has shown that having other health problems (“comorbid” conditions) can complicate the management of MS and lower quality of life for people with MS. Some of these conditions are listed in **Figure 4**.

Many of these conditions are treatable or even preventable. Regular exercise, improved diet, avoiding smoking, and managing other risk factors can reduce the chance of comorbid conditions. “For many people, the challenge of treating MS takes priority over caring for other parts of their health,” Ms. Moore observed. She encourages her patients to keep up with preventive health care, such as vaccinations and screenings. Another goal is to find a regular exercise program that fits one’s lifestyle and abilities.



Adjustment to Aging with MS

As people transition through life stages, priorities change. This is true regardless of whether they have a chronic disease or are

“The findings support the concept that women aging with MS are more resilient [and] have greater confidence in their ability to cope with challenges.”

— Michele Ploughman, PT, PhD

healthy (Figure 5). Attitude can make a difference in how a person adapts to the changes of aging. Studies have shown that staying involved in social activities seems to help balance the impact of disability from MS.

Are men and women different in how they age with MS? Dr. Ploughman and her colleagues at Memorial University in Newfoundland conducted a survey of 743 Canadians (166 men and 577 women) who were age 55 or older and had MS for at least 20 years. The study found that older women were just

as likely as men to retire early due to MS. However, these women tended to participate in household work and social opportunities more often than older men. This appeared to help women with MS better overcome the challenges of aging with a chronic health condition. “For people who are aging with MS, it should be a priority to stay active, independent, and involved in a social network or community,” Dr. Ploughman stressed.

Conclusion

People are living to older ages with MS, even well into their eighties (see “Octogenarians” article, page 11). This speaks to improvements in healthcare and more knowledge about the effects of the disease. The NARCOMS registry is an important way to learn more about how MS affects people as they age. Your participation in the NARCOMS surveys is crucial to gaining insight that may help others with this condition.

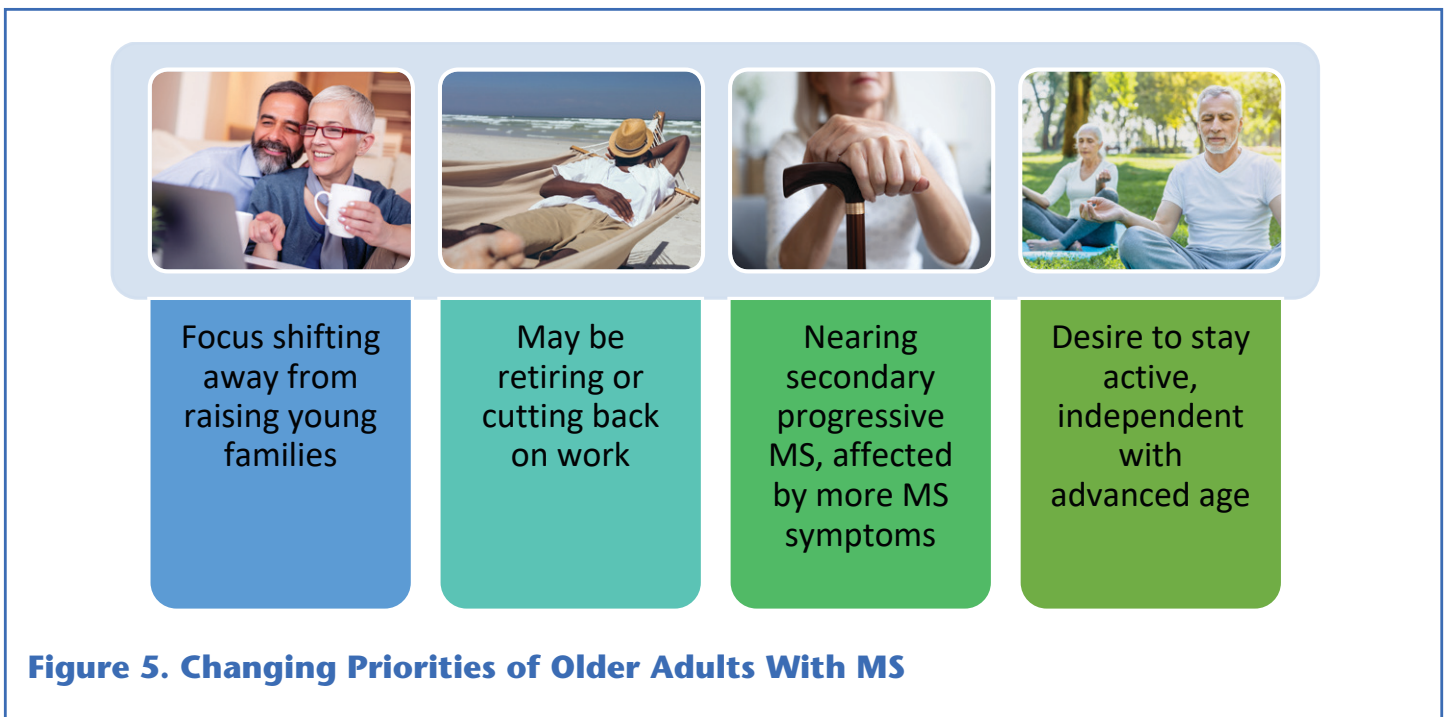


Figure 5. Changing Priorities of Older Adults With MS



SNAPSHOT

WHAT WE CAN LEARN FROM NARCOMS SURVEYS

Aging Breakdown for NARCOMS Participants

As we live longer researchers are trying to learn more about the effects of aging on those with Multiple Sclerosis (MS).

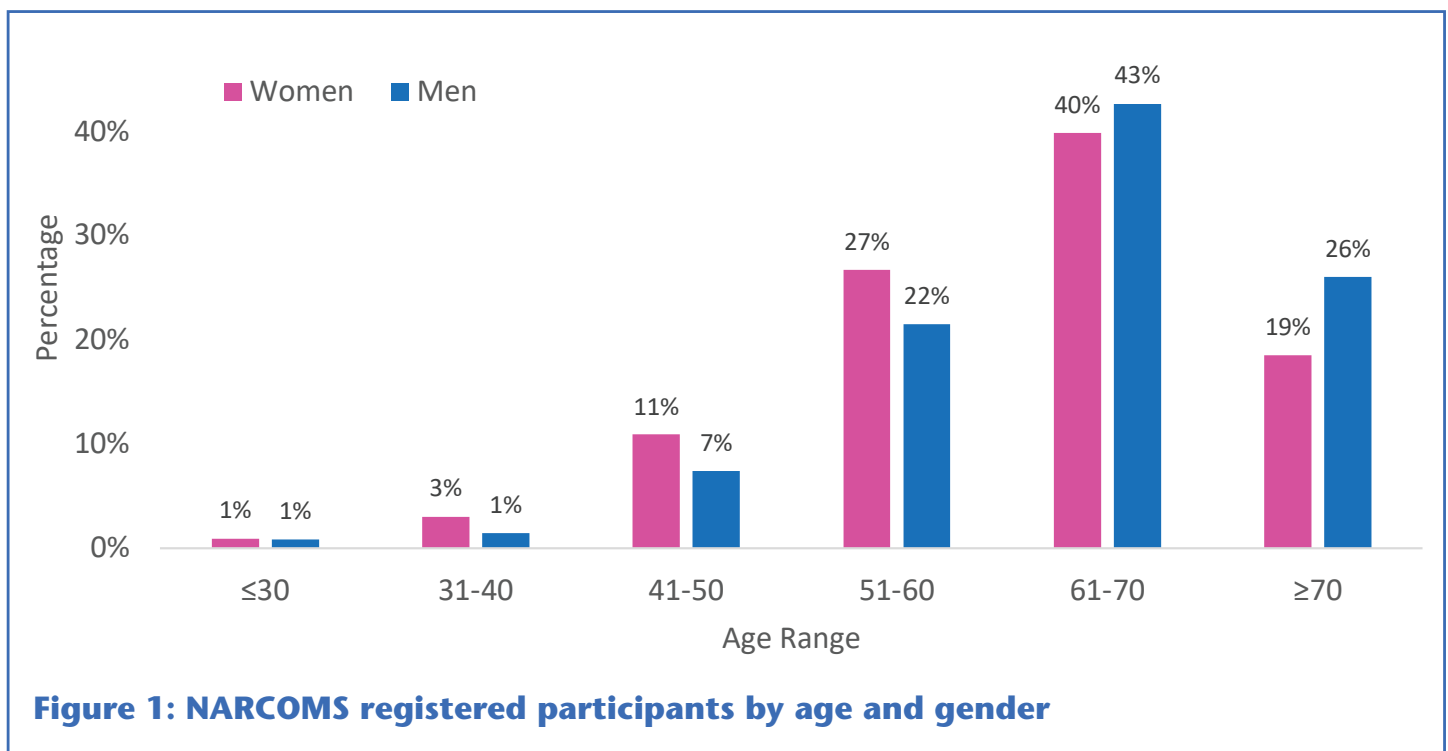
With improvements to healthcare and technology, we are all living longer. This trend is also true for people who live with MS. We are fortunate that many of you continue to participate in the Registry as you age. In fact, about 86% of NARCOMS participants are 51 or older. **Figure 1** breaks down registry contributors based on their age and gender.

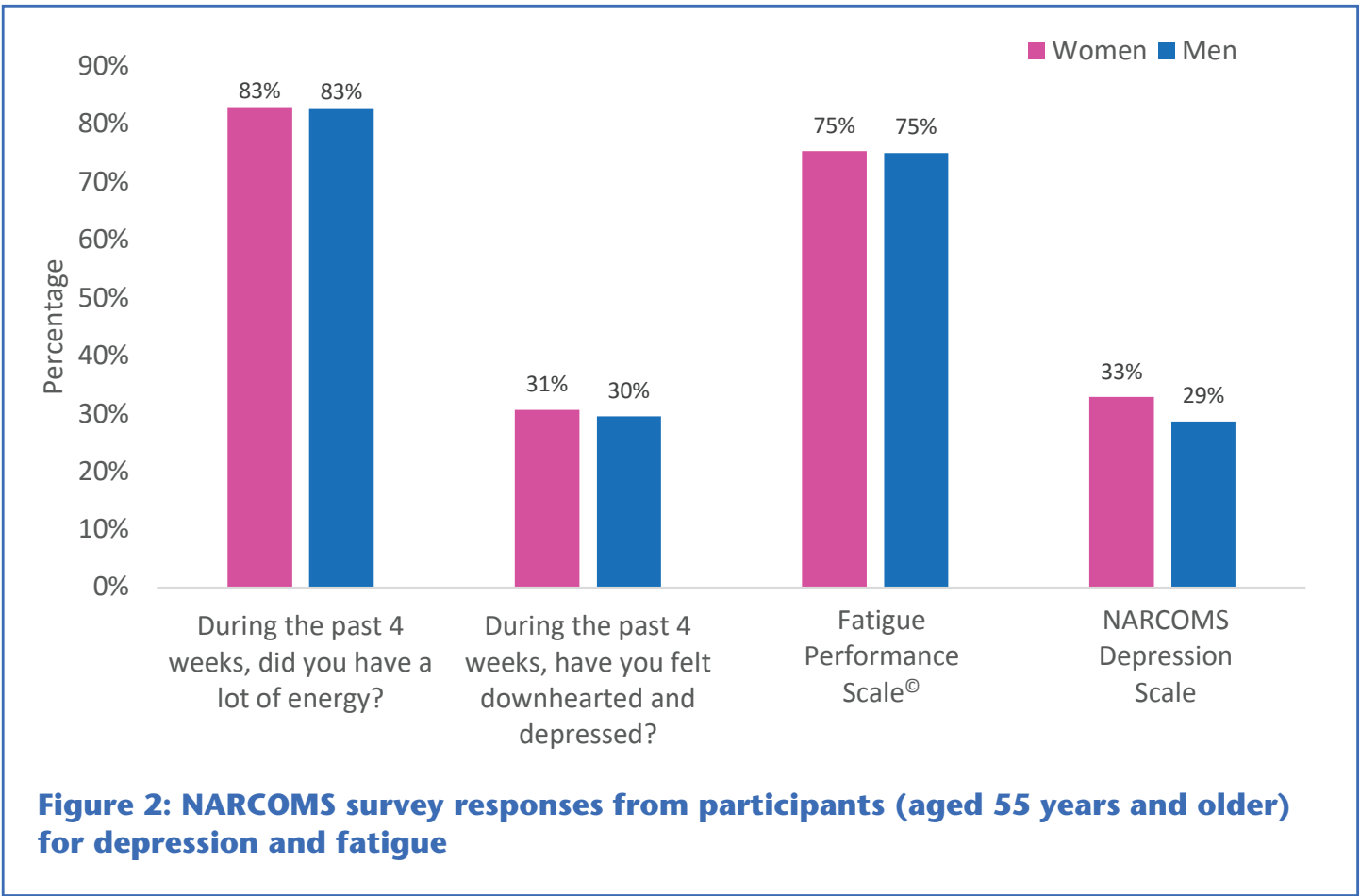
Michelle Ploughman and her colleagues recently published a study of 740 people with MS aged 55 or older. They wanted to know if men and women reported differences in

health and resilience, as they got older. She found that men reported more symptoms of depression and women reported increased anxiety symptoms¹. We wanted to compare Dr. Ploughman's findings with NARCOMS participants to see if they were similar.

To see how NARCOMS Participants compared we used depression and fatigue questions from the spring 2019 survey. We analyzed responses from our participants who are 55 and older; then checked the differences between women and men.

Figure 2 shows the responses we received. The pink bar represents answers for women while the blue represents answers for men. From the





RAND-12 we used the questions:

- “During the past 4 weeks did you have a lot of energy?”
- “During the past 4 weeks, have you felt downhearted and depressed?”

We combined the answers of “some of the time,” a little of the time,” and “none of the time” to show low, little, or no energy. For both men (n=869) and women (n=3288), 83% of NARCOMS participants 55 or over reported they experienced some fatigue. Feelings of depression were represented by the answers, “some of the time,” “most of the time,” and “all of the time.” About a third of men (30%, n=309) and women (31%, n=1214) reported at least some feelings of depression.

We used the Fatigue Performance Scale[®] and NARCOMS Depression Scale. We combined the answers of “mild,” “moderate,” “severe,” or “total fatigue disability” to determine fatigue. Three-quarters of both women and men stated that fatigue has caused some change to their lives. About a third of men (29%) and women (33%) reported that they had “mild,” moderate,” “severe,” or “total depression”.

1. Ploughman, M, Collins, K, Wallack, EM, et al. Women’s and Men’s Differing Experiences of Health, Lifestyle, and Aging with Multiple Sclerosis. *International Journal of MS Care*, 2017; 19:4, 165-171.

Fatigue Performance Scale, Copyright Registration Number/ Date: TXu000743629/1996-04-04; assigned to DeltaQuest Foundation, Inc., effective October 1, 2005. US copyright law governs terms of use.



Study of Octogenarians With MS Reveals Key Factors for “Aging in Place”

Many people with multiple sclerosis (MS) are living to older ages. A growing number of people with MS are “octogenarians” (between ages 80 and 89). A group of Canadian researchers sought to learn what factors help MS octogenarians to age in place. Aging in place means staying in one’s home or community, instead of living in a nursing home or similar institution.

To discover the secrets for successful aging with MS, the Health, Lifestyle, and Aging with MS Canadian Consortium compared a group of 23 MS octogenarians with 61 people with MS who were 1 to 2 decades younger (aged 60–70 years; the “young-old” group). They were also matched against a database of over 1 million Canadian octogenarians who did not have MS.

Five key elements were found to be part of successful aging among the oldest people with MS (see graphic, this page). The researchers had expected to find that octogenarians with MS had milder disease and less disability, compared to the younger group with MS. This was not the case. However, the older group did report higher levels of social support and financial security, and lower levels of fatigue and stress.

5 KEYS TO SUCCESSFUL AGING WITH MS

1) SOCIAL SUPPORT

The #1 factor was remaining socially connected within families and communities so to receive assistance as needed. Some of this group were married or living with a partner.

2) FINANCIAL SECURITY

Financial stability (which is related to social support) is important for aging in place with a chronic disease like MS.

3) POSITIVE ATTITUDE

Octogenarians with MS had low levels of depression and anxiety and high levels of resilience. The age 80–89 group had lower levels of stress and fatigue compared with the young-old (age 60–70) group of people with MS.

4) LIFESTYLE

Healthy lifestyle, especially exercise, was a key factor for aging in place with MS. 78% of the MS octogenarians said they walk 4 or more times each week (compared with 58% of non-MS octogenarians).

5) PARTICIPATION IN LIFE ROLES

Working longer, or remaining active in household, leisure, and out-of-home activities is important. MS octogenarians were just as active as the MS group aged 60–70.

Source: Downer et al. *Canadian Journal on Aging*. 2020;39:107–116.

“The cognitive profile of our sample [slower processing speed] is clearly compatible with MS-related cognitive impairment...This is quite distinct from the typical cognitive profile of Alzheimer’s disease, characterized by an early and prominent impairment of episodic memory.”

The MS octogenarians had more disability than other Canadians the same age. Most required assistance with some activities of daily living. Still, those with MS who lived to their 80s maintained moderate levels of physical activity and a high degree of household, leisure, and participation in activities outside the home.

The 5 elements “take on high priority among the oldest old living with MS,” the study authors stated. These factors could be important targets for younger people with MS who plan to age in place.

Downer MB, Wallack EM, Ploughman M, et al. Octogenarians with multiple sclerosis: lessons for aging in place. Can J Aging. 2020;39:107-116.

Study Shows Diet and Lifestyle Might Affect Brain Atrophy and Lesions in MS

Does a better diet affect disease progression in multiple sclerosis (MS), or doesn’t it? This question has been the source of much interest and debate in the field of MS. A recent study doesn’t fully resolve the debate. However, it does suggest that poor diet and lifestyle choices may be associated with greater brain atrophy (brain tissue loss) in people with MS and even in those without MS.

The study, by researchers from the University at Buffalo, New York, compared MRI images over a 5-year period among 175 people with MS and 42 people without MS (matched for age and gender). The participants’ health was ranked using the Healthy Heart Score, which factors in age, smoking history, weight (body mass index), diet, exercise levels, and alcohol consumption.

Lower (worse) Healthy Heart scores were more likely to be associated with greater reductions in brain volume after 5 years, regardless of



how long the person had MS. Low scores in the diet-only component were associated with higher MS lesion volumes after 5 years.

As a person ages, brain volume decreases in everyone, although it tends to occur faster in people with MS. Among the healthy control subjects, lower Healthy Heart scores were associated with greater loss of whole brain volume and brain volume in certain brain regions. This degree of loss was less than that observed in people with MS.

“Lifestyle-based modifications may still provide a beneficial effect on reducing brain atrophy” in people with MS, the authors concluded.

Jakimovski D, Weinstock-Guttman B, Gandhi S, et al. Dietary and lifestyle factors in multiple sclerosis progression: results from a 5-year longitudinal MRI study. J Neurol. 2019;266(4):866-875.

Cognitive Problems are Common in Older People With MS, But May Be Amenable to Treatment

Cognitive impairment is common among people with multiple sclerosis (MS). When a person ages, it can be difficult to know whether changes in brain function are due to the disease, to aging, or a combination. A research group from Italy studied 1,040 adults with MS (111 were age 55 years or over). Study participants completed a number of neuropsychiatric tests used to measure cognition in MS.

Rates of cognitive impairment were found to increase steadily with age. Cognitive impairment was found in 46% of the 35–44 age group, 74% of the 55–64 age group, and 92% of the group aged 65 years or older.



These appear much higher than rates usually reported in MS, but the authors note that most other studies do not include people in older age brackets.

Impaired processing speed (taking longer to complete a mental task) was the most common cognitive problem, affecting about two-thirds of older people with MS (age 55+). Other cognitive functions affected included verbal learning and executive function. The researchers did not think that dementia from causes such as Alzheimer’s disease was part of the problem, because the patterns of impairment were more typical of MS and not consistent with Alzheimer’s. The presence of depression or fatigue did not seem to influence whether a person had cognitive difficulties.

The types of cognitive impairment that occur in people with MS often respond well to treatment such as cognitive rehabilitation, so they should not be viewed in the same way as other age-related dementias.

Branco M, Ruano L, Portaccio E, et al. Aging with multiple sclerosis: prevalence and profile of cognitive impairment. Neurol Sci. 2020;41(1):243.



MS MESSENGER

WHAT TO EXPECT ON THE NEXT NARCOMS SURVEY

What to Expect on the Next NARCOMS Survey

The NARCOMS Spring Update 2020 Survey will be coming your way in April. We are going to be revisiting the Health Utilities Index[®] (HUI) which measures quality of life. We had a lot of positive feedback about the HUI. Now that we have included the HUI in the past couple of spring surveys, we can start to look at how your answers on the HUI change over time.

You will also be seeing the Multiple Sclerosis Impact Scale[®] (MSIS-29). It is cleverly named for the 29 questions associated with the scale. This set of questions will ask you how MS impacts your daily life. You will be asked to focus on the previous two weeks of your life. As always there are no right or wrong answers. Please choose answers that BEST represent what is happening to you.

You will notice that we are including a new

topic as well. We are going to be asking about the use or non-use of vaccinations. There is a lot of information about vaccinations available from the internet, caregivers, medical providers, family, friends and many of other places. We want to know about your experiences.

We hope to be able to share all of our findings with you in future issues of the *NARCOMS Now*. If there is a topic you would like to learn more about, please let us know. We always love hearing your ideas and questions.

Please let us know if we need to update your contact information. You can do that by calling (800) 253-7884 or emailing MSregistry@narcoms.org.

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Questions from participants

Where can I find information about research studies in my area?

The first place to check is with your own medical caregiver. Clinicians often know of studies that are available. Let them know you are interested in participating. You can also check with any hospitals or research institutions that are near you. Medical schools often have many studies available. You are sometimes able to register yourself with them and if there is an opportunity for you to participate in a study, they will reach out to you. The National Institutes of Health also has a website, www.clinicaltrials.gov, where you can check based on location, disease or condition, and recruitment status. Occasionally the NARCOMS Registry will alert you about studies for which you may qualify. Remember, you are never required to participate in any research study. Studies are strictly voluntary.

Disclaimer: This was prepared in response to questions received by NARCOMS participants and does not reflect and medical or treatment guidance. For any questions of concerns you should speak with your doctor.

Play WORDSEARCH

Find the following hidden words relating to aging.

APPRECIATED
EXPERIENCED
GRANDPARENT
RETIREMENT

SENIORITY
DEVELOPED
FREEDOM
LOVED

SAGE
TRAVEL
EVOLVED
GOLDEN

MATURE
SENIOR
WISE

Q Q E C E Y J G J I B V M A T
 U N G C C X D E V O L D O P R
 H U L O D E P O L E V E D P A
 H R N W L F M E J R C F E R V
 Y G R A N D P A R E N T E E E
 O T J E M V E P U I R A R C L
 G K I J S G R N V E E A F I R
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NARCOMS NOW

BE PART OF NARCOMS—HELP TO ADVANCE RESEARCH IN MS

Whether you were recently diagnosed with multiple sclerosis (MS) or have lived with it for years, your personal history with the disease helps contribute to improving the lives of others with MS.

Participation in the NARCOMS registry allows you to be part of the process. The data provided by participants gives researchers a clearer picture of how a condition like MS impacts the lives of those affected.

Participation in NARCOMS is confidential—your information is kept secure and completely private. If you have MS and are not yet participating in NARCOMS, or have been out of touch for a while, we would love to hear from you! Contact us at 1-800-253-7884 (toll-free U.S.) or via email at MSRegistry@narcoms.org.



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