

MS EMPOWERMENT SERIES

SHARED DECISION MAKING IN MULTIPLE SCLEROSIS



MULTIPLE SCLEROSIS IN MEN

How can men with MS find the support they need?

What is the role of hormones like testosterone?



An educational series for people with multiple sclerosis (MS) developed in partnership with the International Organization of MS Nurses (IOMSN).

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Hello, and welcome!

Multiple sclerosis (MS) occurs less commonly in men than it does in women. Because of this, men with MS may feel overlooked. There are some differences in how the disease starts and progresses in men. Some of these may be related to sex chromosomes or hormones.

Compared to women with MS, men often have different coping styles. It is important to provide information that addresses men's questions about MS and supports their needs.

The MS Empowerment Series, provided through the International Organization of MS Nurses (IOMSN), is designed to help foster communication between people with MS and MS nurse specialists. As a neurology nurse working in MS care and research for over 30 years, it is my privilege to be a part of this service for the MS community.



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Developed by Delaware Media Group in partnership with the International Organization of MS Nurses (IOMSN)

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MULTIPLE SCLEROSIS IN MEN

Science, social factors, and support needs

About one-quarter of all cases of multiple sclerosis (MS) occur in men. Because of this imbalance among the sexes, many men with MS report that they feel overlooked or misunderstood. "When I got the diagnosis of MS, I remember saying to my doctor, 'Why did I get a woman's disease?'" recalls Mike S., who was diagnosed with MS in his mid-twenties. "A lot of the information I saw about MS seemed to be aimed at women, or showed pictures of young or middle-aged women. I didn't know any other men with MS that I could relate to—especially young men."

Mike's experience is not uncommon, says Dorothea (Dottie) Pfohl, an MS nurse specialist who practiced and coordinated research efforts in MS for several decades at the University of Pennsylvania. "MS is a very individual condition. We need to be able to target education and support services for that person. And we need to acknowledge that many men with MS have different coping practices and needs, compared to women with this disease."

Does MS Differ for Men?

There are several differences in MS between men and women. Riley Bove, MD, an expert on hormonal and gender issues in MS, explains that the symptoms and disease course often differ

between men and women. In men, MS may worsen more rapidly. Men are more likely than women to have a primary progressive course starting out, Dr. Bove says. Research suggests that men with MS tend to have more incomplete recovery following relapses. "Overall, some men may have a slightly worse disease course. But we also must keep in mind that treatment of MS has improved greatly in the last few decades," Dr. Bove stresses. "More aggressive forms of MS often respond very well to the newer treatments that we have. Some of them are designed for people with more severe MS."

Hormones: The "T" Effect

In men and women, sex hormones are thought to influence how MS plays out over a person's lifetime. Testosterone is the primary sex hormone in men.

About Testosterone:

- Studies have shown that males with MS have lower testosterone levels, compared to males of the same age without MS. "We don't know if 'low T' is a factor that may actually contribute to the onset of MS," Dr. Bove commented.
- Testosterone levels decline in all men as they age, but some question whether this age-related decline could increase the risk of MS in men. "It's also possible that the reverse is true, and that these lower testosterone levels are a result of having a chronic disease," Dr. Bove says.

Men vs Women

Differences in MS Characteristics

Men with MS

Overall prevalence not on the increase

May have worse outcomes

More primary progressive onset

Faster progression

More lesions in cerebellum

More atrophy in gray matter

Women with MS

Higher prevalence than men **3:1**

Overall prevalence on the increase

Earlier onset

More frequent relapses

More inflammatory lesions

Pregnancy: estrogen may have a beneficial effect

- In lab and animal research, raising testosterone levels seems to reduce inflammatory cells and shift the immune system toward an anti-inflammatory pattern. Does this mean that treating men with testosterone supplements can have an effect on the MS disease course? This question has been studied for many years, and several new studies are under way.

Studying How Testosterone Affects MS in Men

From a large MS study based at Harvard Medical School called CLIMB, Dr. Bove and her colleagues selected a group of 96 men ranging in age from 18 to 65. All of them had early or relapsing MS (disease duration 10 years or less). Blood testosterone levels were measured, using a cutoff of 280 ng/dL to define hypogonadism (meaning, not producing enough testosterone).

- 39% of the men had below-normal or borderline-low testosterone levels (low T)
- Hypogonadism was seen in all the age categories studied
- Men with low T were more likely to have increased MS disability
- Men with low T were also more likely to have signs of cognitive decline when tested

Does MS result in low T in some men? Or, could low T have a role in causing MS? Is it a combination of these two? “We don’t know the answer to this,” Dr. Bove says. In the study report, she and her co-authors stated, “It’s possi-

ble that other factors—such as even remote use of glucocorticoids [steroids] beyond 30 days from blood draw, or MS comorbidities such as depression—suppress gonadal activity to some extent.” (Source: Bove R, et al. Low testosterone is associated with disability in men with multiple sclerosis. See Resources, page 15.)

Testosterone Treatment in Men With Low T, Without MS

For men who have evidence of low testosterone or “low T” due to aging or other health issues, taking a testosterone supplement or having testosterone injections can have some beneficial effects.

The Testosterone Trials were a group of studies in older men (age 65 plus) who did not have MS (see Resources). The trials began in 2009 and were completed in 2018 at 12 U.S. research centers, funded by the National Institute on Aging and other federal organizations. Participants included 788 men with low testosterone caused by aging, along with related symptoms (sexual problems, fatigue, muscle weakness, impaired memory and cognition). The mean age was 72. Many of the men were overweight or obese, which also contributes to low testosterone levels. The Testosterone Trials studied the safety and efficacy of testosterone therapy on several medical conditions, including anemia, bone density, and cardiovascular health. Benefits of treatment included:

- improved libido (sex drive) and sexual function
- increased muscle strength
- increased bone density in older men

Testosterone Treatment in Men With MS

Does boosting testosterone have MS-related benefits in men? So far, this concept has been studied in only one small pilot trial. In this study of 10 men with relapsing MS treated with 100 mg testosterone gel for 12 months, the treatment did not decrease the number of new brain lesions. However, the results suggested that testosterone should be explored further for potential neuroprotective effects.

A larger trial, TOTEM RRMS, is now under way in France to test the neuroprotective effects of testosterone treatment in a group of 40 men with MS who have low T.

- All participants will receive natalizumab (Tysabri) to control their MS.
- Half of the men will receive testosterone shots (1,000 mg/4 mL) spread out over the course of the 66 weeks. The other half will receive a placebo shot.
- The researchers will use measures of brain atrophy and other advanced MRI techniques to see if the testosterone treatment may have a protective effect on brain health. The trial is set for completion in 2023.

Should all men with MS take testosterone? If a man's testosterone levels are already in the normal range, taking supplements will not necessarily have health benefits, Dr. Bove advises. There have been concerns that testosterone replacement could worsen pre-existing prostate cancer in some men or pose other health risks, such as blood clots. More recent studies are reassuring that these risks are low, she says. For now, testosterone supplementation should be considered for men with MS as it would be for the general population: for men with low T for age, who have specific indications, such as sexual dysfunction. (Source: Qaseem A, et al. Testosterone treatment in adult men with age-related low testosterone: A Clinical Guideline from the American College of Physicians. See Resources.)

Helping Men Cope with MS

Coping with a diagnosis of MS is difficult for anyone, but men often face certain challenges based on societal values. Qualities often associ-



Answers to Questions from Men with MS

Q: How will MS affect my sexual function?

A: MS can affect men's sexual function. Difficulty getting an erection and decreased libido or interest in sex are some of the most common problems. Decreased sensation or difficulty ejaculating may also occur. Many problems with sexual function are treatable. Treatment starts by looking into the underlying causes: is the problem due to loss of nerve sensation, or related partly to fatigue or emotional issues? It may seem embarrassing to talk about these issues with a healthcare provider such as an MS nurse. Remember that these professionals are used to discussing these problems and have access to information and treatment options.

Q: Should I be on a “stronger” MS therapy?

A: Men with MS may hear a lot about why their course of MS can be severe, but this is a very individual matter. Not all men with MS have severe cases. The disease-modifying therapy (DMT) must be selected for the individual's needs. However, scientific evidence shows that the sooner a person starts on an effective, approved DMT, the better it will preserve their function and prevent progression of the disease.

Q: Will MS affect my ability to father a child?

A: MS itself does not seem to reduce fertility. Studies have shown that MS does not affect sperm counts or sperm health. It can affect libido due to its effect on mood, sleep, and energy—all of which are treatable. Some drugs used to treat MS may affect fertility or sperm health in men.

Men who take teriflunomide (Aubagio) are advised to discontinue the drug prior to fathering a child, due to the possibility of birth defects. A chemotherapy drug called mitoxantrone is very rarely used for MS treatment today, but it can have a temporary or permanent effect on sperm and may cause infertility in men.

Q: Can my MS be passed along to my children?

A: MS is a complex genetic disease. MS risk is linked to a number of genes, as are heart disease or diabetes. Having some of these genes does not mean that one's children will necessarily be affected. In fact, only about 3% to 10% of children who have a father or mother with MS are at risk of developing MS. Other risk factors, such as body weight and smoking, can be controlled.

Q: Do I need to tell my employer that I have MS?

A: You are not required by law to report your MS. When, how much, and whom you tell is your own decision. The Americans With Disabilities Act (ADA) can help you understand your rights in the workplace. The National Multiple Sclerosis Society website has information about MS and the ADA under Living Well with MS/Employment/Disclosure Decisions.

Q: How can I find support that fits my own needs?

A: Start with your MS nurse or MS healthcare professional. Ask for resources and support groups that fit your needs, or seek out professionals who treat more men with MS. The NMSS offers peer counseling to help you find support from someone with similar concerns. (See Resources.)

ated with “maleness”—such as strength, independence, and not showing emotion—can be especially difficult when a man has MS. Gender roles in many societies cast the man as the protector, bread winner, and “heavy lifter” for more physical tasks. While not all families follow this role breakdown, many men have had this message ingrained since their birth. When a man develops MS or another chronic health



“There is a need to listen to the voices of men and ensure that their voices are clearly heard so health care professionals can be responsive and sensitive to the needs of their clients. There is a need to educate men about support groups and destigmatize the decision to seek support. . .recognizing that support groups may also need to be tailored so that men feel able to attend.”

— DOMINIC UPTON, PhD
International Journal of MS Care,
2015;17:9-12.

condition, it becomes challenging or even impossible to meet these expectations.

The toned and muscular male bodies bombarding us from advertisements and movies add to the pressures felt by men with MS. “MS does not prevent men from achieving physical fitness,” Dottie Pfohl says, “but they should not try to measure this against some ideal image—in fact, none of us should.” It is also hard for some men with MS to admit they need assistive devices or tools to help them function with daily living. “This is where support groups designed especially for men with MS are so helpful,” she adds. “The participants have many shared concerns, and they learn so much from each other.”

For men with MS who are seeking support, it is important to try to find services that will address their unique concerns. Men tend to be reluctant to ask for help. Research shows that men also seek healthcare services less often than women. A summary of the support needs of men with MS published in *International Journal of MS Care* showed:

- Men with MS need additional help believing in their ability to control their MS
- Men with MS may experience less anxiety than women, but are more likely to suffer from depression, especially over the long term. These conditions are treatable, but treatment should be tailored for that individual.

- Support groups mostly comprised of women might not reflect men's' lives or concerns.

When seeking sources of support, men with MS should look for solutions that fit their own needs.

"I often counsel my male patients that there is more to being a citizen, a partner, and a father than running a race or tossing around a football," Dr. Bove stresses. "Even if their mobility is limited, their engagement and support are invaluable to the people in their lives."

Resources

Join a Local Support Group

National MS Society (NMSS.org)

1-800-344-4867

<https://www.nationalmssociety.org/Resources-Support/Find-Support/Join-a-Local-Support-Group>

When Men Get MS

Article in NMSS "Momentum" magazine

<https://momentummagazineonline.com/men-get-ms/>

One-on-One Peer Counseling

NMSS Peer Counseling Program

800-344-4867

<https://www.nationalmssociety.org/Resources-Support/Find-Support>

Disclosure of Disability in the Workplace

The ADA: Your Employment Rights as an Individual With a Disability

U.S. Equal Employment Opportunity Commission (EEOC)

<https://www.eeoc.gov/publications/ada-your-employment-rights-individual-disability>

What Are the Support Needs of Men With Multiple Sclerosis, and Are They Being Met?

International Journal of MS Care, Jan-Feb 2015. (Free article)

<https://pubmed.ncbi.nlm.nih.gov/25741222/>

Testosterone Treatment in Adult Men With Age-Related Low Testosterone: A Clinical Guideline From the American College of Physicians

Annals of Internal Medicine, January 21, 2020. (Free article)

<https://www.acpjournals.org/doi/10.7326/M19-0882>

Low Testosterone is Associated With Disability in Men With Multiple Sclerosis

Mult Scler. 2014 Oct;20(12):1584-1592. (Free article)

<https://pubmed.ncbi.nlm.nih.gov/24710799/>

Lessons from the Testosterone Trials

Endocr Rev. 2018 Jun; 39(3): 369-386.

(Free article)

<https://pubmed.ncbi.nlm.nih.gov/29522088/>



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