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MS PERSPECTIVES™

The Premier Publication for Multiple Sclerosis Patients and Care Partners

The Art of Living Fully With MS



PATIENT SPOTLIGHT

Yosemite Slim

By Sue Lawrence-Reeder



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Bolded terms throughout this publication are defined in the glossary on the back cover.

Disclaimer: The goal of this publication is to provide people living with multiple sclerosis with the latest information about the disease and its treatment. The information provided in MS Perspectives™ is not a substitute for the advice of your health care professional. Please consult a qualified health care professional for individualized care and information.

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UPDATES IN MS RESEARCH

Scientific progress continues to shape the future of multiple sclerosis (MS) care. It is important to stay informed about emerging therapies, innovative research, and advances that may improve daily life for people living with MS. These updates highlight developments that could impact treatment decisions, symptom management, and overall quality of life.



NEW TOOLS FOR MANAGING FOOT DROP IN MS

Foot drop, a common symptom in MS, can make walking more difficult and increase the risk of falls. Two new tools are helping people move more confidently. The Cionic Neural Sleeve™ is a US Food and Drug Administration (FDA)–cleared wearable device that uses functional electrical stimulation (FES) to activate the muscles that lift the foot. Worn on the lower leg and designed for use at home, it is controlled through an app that allows for personalized settings. Early users report improved stability and a more natural walking pattern.

Another option is Cadense adaptive sneakers, which use a specially designed sole with

“variable friction” technology to support foot clearance and balance. These slip-on shoes adjust to your walking pattern and are comfortable for everyday wear.

The Cionic device requires a prescription and may be covered by some insurance plans. Cadense adaptive sneakers are available for purchase without a prescription and are currently self-pay. A mobility specialist, such as a physical therapist, can help determine if these tools are a good fit. Talk to your health care team about whether they may be right for you. To learn more about each device, visit cionic.com/neuralsleeve and cadense.com.

BTK INHIBITORS: A NEW DIRECTION IN MS TREATMENT



Bruton’s tyrosine kinase (BTK) inhibitors are a new class of therapies being studied for MS. These treatments work by

blocking BTK, an enzyme found in immune cells like B cells and microglia. By doing so, they may help reduce inflammation in the brain and spinal cord and slow MS **progression**.

Several BTK inhibitors are in clinical studies for MS. Tolebrutinib is among those furthest along in development. Like other drugs in this class, it is designed to reach the brain and spinal cord, where it may help target drivers of MS progression. Recently, at the 2024 annual

meeting of the European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS), it was announced that a pivotal clinical trial of tolebrutinib met its primary objective. In the study, tolebrutinib slowed disease progression compared with placebo in people living with a form of MS known as non-relapsing secondary progressive MS (nrSPMS).

Tolebrutinib is still being studied and is not yet approved. Based on encouraging results from the pivotal clinical trial, the FDA recently granted it Breakthrough Therapy designation for nrSPMS. A decision on potential approval is expected in 2025.

Your health care team can provide you with information on BTK inhibitors and how they may shape the future of MS care.

FEATURE ARTICLE

Your MS Care, Your Way

Navigating Treatment and Support Across the MS Spectrum

Living with multiple sclerosis (MS) is a journey that looks different for everyone. Whether you are newly diagnosed, noticing changes in your condition, or have been living with MS for years, it's natural to have questions. This article explores how treatment and care can be tailored to meet your needs across the MS spectrum and offers guidance for both individuals with MS and those who support them.

UNDERSTANDING THE MS SPECTRUM

MS is a disease of the central nervous system, affecting nerves in the brain, spinal cord, and eyes. Traditionally, it has been described in terms of relapsing and progressive types. However, it is now understood as one disease state in which both **relapses** and **progression** occur along a spectrum (Figure 1).

Figure 1. MS Looks Different for Everyone, but It's One Disease

MS SPECTRUM

**MORE FREQUENT
RELAPSES;
LESS PROGRESSION**

**FEWER RELAPSES;
MORE NOTICEABLE
PROGRESSION**

At any point, a person's MS may be **active** or not active, and it may be progressing or not progressing. The goal of **disease-modifying therapy (DMT)** is to achieve **stable disease**, where there are no relapses or new inflammation on magnetic resonance imaging (MRI). Available DMTs may also slow disability accumulation, mostly from relapses that have not completely resolved.

Viewing MS as a spectrum helps explain why each person's experience is unique and why the disease can continue to change over time. This understanding highlights the importance of open and ongoing communication with your care team, so subtle changes can be addressed, treatment can be adjusted when needed, and care decisions can reflect your individual needs and goals.

DIFFERENT PHASES, DIFFERENT NEEDS

Each phase of life with MS brings its own questions, challenges, and care needs.

Newly Diagnosed

A new diagnosis can feel overwhelming. Learning how MS behaves and how a DMT may help reduce disease activity or slow progression can give you a sense of control. It is also a good time to build a trusted care team and consider your long-term goals.

Signs of Progression

If you begin experiencing new or gradual changes in function, even without relapses, talk with your care team. This may be a sign of progression, and your treatment plan may need to be adjusted to support your changing needs.

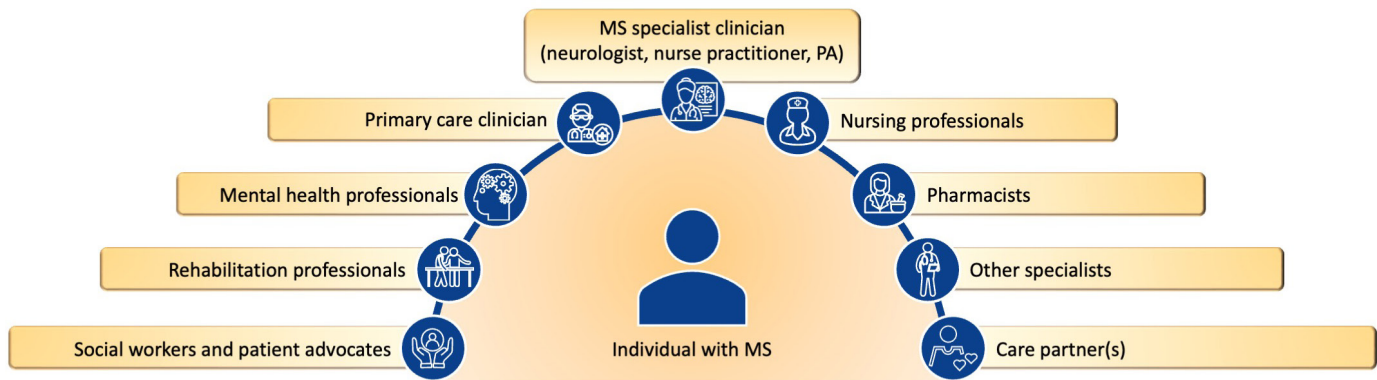
Aging With MS

As you age, managing other health concerns and protecting your quality of life become even more important. In addition, the balance between the benefits and risks of your DMT may shift as your MS, immune system, and general health change. Your care plan should evolve with your goals, priorities, and overall health.

YOUR MS CARE TEAM: WHO DOES WHAT?

MS is best managed with a team approach (Figure 2). Your care is typically led by one or more MS specialists, such as neurologists, nurse practitioners, or PAs (physician associates), who guide treatment and monitor disease activity. MS nurses are also key partners for medication questions, side effects, or symptom tracking. Your primary care clinician manages general health conditions. Pharmacists can help with medication access and safety. Rehabilitation specialists, such as physical, occupational, and speech therapists, can help with strength, movement, fatigue, communication, and cognition. Mental health professionals provide therapy for issues

Figure 2. Who's on Your MS Care Team?



such as depression and anxiety. Social workers and MS navigators help with insurance, housing, equipment, and community resources, while patient advocates support communication and help you speak up for your needs. Other specialists who may be involved depending on your specific needs include urologists, pain specialists, and ophthalmologists.

Care partners, such as a spouse, family member, or close friend, often help with appointments, daily routines, and emotional support. Knowing who to turn to and when helps you and your care partner get the support you need more quickly.

COMPREHENSIVE MS CARE: MORE THAN JUST MEDICATION

There are many types of DMTs, offering options to suit different needs and preferences. These treatments are a central part of MS care, but they are just one piece of the puzzle. A full care plan should also support your physical, mental, and emotional well-being.

Symptom management is important. Fatigue, pain, spasticity (stiff or tight muscles),

and bladder issues often occur with MS.

Treatments for symptoms may include rehabilitation therapy, assistive devices, and symptom-specific medications. Emotional health matters too. Depression and anxiety are common but treatable. A mental health professional or support group can help you take the first step toward feeling better.

Healthy habits can help you feel better now and may protect long-term brain health. Regular physical activity, balanced nutrition, good sleep, and avoiding tobacco help support your body and brain. Staying mentally and socially active, managing stress, and following your treatment plan all help protect your **brain reserve** and slow disease progression.

THE POWER OF SHARED DECISIONS

Choosing or changing treatment can feel overwhelming. Shared decision-making means you and your care team work together to review options, consider your values, and choose a plan that fits your life. Be open about what you hope to achieve and what worries you. Are you trying to stay active at work, manage symptoms, or keep up with

family life? Your goals can help shape your care in meaningful ways.

FINAL THOUGHTS

MS is a lifelong condition, but with the right tools, knowledge, and support, people with MS can lead full, active lives. No matter where you are on your journey, your voice matters, your choices matter, and help is always available.

Questions to Ask Your Care Team About MS Treatment

- What are my treatment options, and how do they work?
- What are the goals of this treatment?
- How often is the treatment given, and how is it taken?
- What kinds of side effects should I expect in the short and long term?
- How could this treatment affect my daily life, work, or travel?
- How will we know if my treatment is working?
- If this treatment doesn't work well for me, what other options would we consider?
- Are there any resources to help with the cost of the medication if I am unable to afford it?
- What else can I do to support my health beyond medication?
- Who should I call if I have a question or concern between appointments?

Preparing for Your Appointment

- Bring a written list of your questions.
- Bring someone with you—such as a family member or friend—to listen and provide support.



PATIENTSPOTLIGHT

REINVENTION, RESILIENCE, AND THE ART OF LIVING FULLY

At nearly 74, Sue L-R's journey with multiple sclerosis (MS) is a testament to adaptability, courage, and the power of personal reinvention. Diagnosed at age 30 after nearly 5 years of unexplained symptoms, Sue recalls feeling a surprising sense of relief. "It was the unknown that was so frightening," she says. "Once I knew which demon I was facing, I set out to learn as much as I could about MS and begin to prepare myself for what could be an unpredictable future."

Her career path reflects that same resilience. Over the past 4 decades of living with MS, Sue has reinvented herself several times. She began in the medical field, transitioned into electronics engineering, moved into video production, and now embraces her creative side as a stained glass artist. When vision changes from optic neuritis made electronics work impossible, she looked for a new direction. A chance opportunity led to the launch of her own video production company, which has been going strong for 24 years. Today, she runs Mainely Creatives (mainelycreatives.com), a stained glass art studio in Monmouth, Maine, where she continues to find joy in hands-on artistry.

Living with MS hasn't been without challenges. Sue has experienced periods of severe disability, including difficulty walking, driving,

feeding herself, and seeing clearly. Yet her determination has never wavered.

"Limitations are just a challenge to find a different way to accomplish a task."

During times of recuperation, she turns her focus to learning new skills and nurturing her creativity. She often practices her drawing and painting, talents she gratefully attributes to her mother.

"Limitations," she says, "are just a challenge to find a different way to accomplish a task."

To those newly diagnosed or struggling with the changes MS brings, Sue offers perspective grounded in experience.

"Acceptance of the diagnosis doesn't have to mean the worst outcome is in store," she advises. "The best advice I could give a newly diagnosed individual is to practice affirmative communication with their body and to remain positive." She has learned to

handle setbacks or difficult days as "timeouts," and she encourages others to find balance between action and rest. "It is critical to give our bodies the time they need to rest but just as critical to dig deep within our spirits to

stay active and engaged in life."

Sue credits humor as her superpower and continues to live each day with purpose, joy, and laughter. "Despite having MS, I'm all the better for it," she says.



"The best advice I could give a newly diagnosed individual is to practice affirmative communication with their body and to remain positive."

ASK THE MS EXPERT



Q Why does the weather have such an impact on people with MS?

-Anonymous

AMBER PESKIN, APRN, CNS, MSCN

ANSWER Heat and cold extremes slow the speed of impulses along demyelinated nerves, causing a temporary increase in neurological symptoms. More than 60% of people with MS experience temperature sensitivity. Heat exposure through weather, a shower, exercise, or fever may cause fatigue, weakness, blurred vision, numbness/tingling, or brain fog. Extreme outdoor cold may cause pain, stiffness, or muscle spasms. The symptoms return to baseline after cooling down or warming up. Temperature extremes or changes do not cause new lesions or disease **progression**. It is important for those with MS to learn how temperatures affect function and take protective measures. Staying hydrated, taking breaks, and using cooling devices, such as vests, fans, or towels, may help to manage heat sensitivity symptoms. Layering clothes and other winter accessories can help to combat the cold. Most importantly, listen to your body and know your limits in any temperature extreme.



Q Do you think there will ever be a cure for MS?

-David A.

CARRIE M. HERSH, DO, MSC, FAAN

ANSWER Yes, I believe a cure for MS is achievable. Medical science continues to advance rapidly. Researchers are gaining deeper insights into the causes of MS, including growing evidence linking MS to Epstein-Barr virus (EBV). Studies are underway that explore how the virus might lead to the immune system attacking the

nervous system. By targeting EBV, researchers hope to develop therapies that could prevent the onset of MS. Further, the National Multiple Sclerosis Society is leading a global initiative through its “Pathways to Cures” roadmap, which focuses on 3 strategic goals: (1) stopping disease activity and symptoms, (2) repairing damage and restoring lost function, and (3) ultimately ending MS by preventing new cases. Global leaders and key stakeholders support a wide range of research, from basic science to clinical trials, and all of these are crucial for accelerating progress toward a cure.



Q What is the difference between biosimilar and generic drugs, and do they work the same as the brand name versions?

-John G.

JENELLE HALL MONTGOMERY, PHARM.D, BCACP, CPP

ANSWER New alternatives to some MS **disease-modifying therapies** are becoming available, giving patients more choices. While both biosimilars and generic medications are designed to provide cost-effective alternatives to brand name drugs, there is a distinction between them. Generic drugs are identical copies of brand name drugs, with the same active ingredients. Biosimilars, on the other hand, are not identical but are highly similar to US FDA-approved drugs, known as reference products. To be approved, biosimilars must show they work the same way as their reference product, with no meaningful differences in safety or effectiveness.

As of now, biosimilars for MS are not widely used in clinical practice. The first FDA-approved biosimilar for MS is Tyruko® (natalizumab-sztn), which is based on Tysabri® (natalizumab).

MS RESOURCES

MS News, Education, and Community

Can Do Multiple Sclerosis

<https://cando-ms.org/>

MS TeamWorks

<https://msteamworks.com/>

MS Views & News

<https://msviewsandnews.org/>

Multiple Sclerosis Association of America

<https://mymsaa.org/>

Multiple Sclerosis Centers of Excellence

<https://www.va.gov/ms/>

Multiple Sclerosis International Federation

<https://www.msif.org/>

Multiple Sclerosis Foundation

<https://msfocus.org/>

National Multiple Sclerosis Society

<https://www.nationalmssociety.org/>

The Consortium of Multiple Sclerosis Centers, Patient Resources

<https://www.msca.org/patient-resources/>



Must Haves on Your Watchlist

Handpicked by the MS Perspectives Contributing Editors

Caregiving, a PBS series premiering June 24, 2025

<https://www.pbs.org/show/caregiving/>

Change, Not Charity: The Americans with Disabilities Act, aired on PBS March 25, 2025

<https://www.pbs.org/wgbh/americanexperience/films/change-not-charity-americans-disabilities-act/>

Glossary

ACTIVE DISEASE: Ongoing disease activity in MS, which may include clinical relapses or new lesions seen on a magnetic resonance imaging (MRI) scan, even when no symptoms are present.

BRAIN RESERVE: The brain's ability to adapt and compensate for damage. Preserving it helps maintain function longer.

DISEASE-MODIFYING THERAPIES (DMTs): Medicines that can reduce the occurrence of new relapses and new areas of damage that can be seen on MRI. They may also slow disability progression. They do not improve symptoms or fix injury that has already occurred.

PROGRESSION: A gradual worsening of symptoms over time, such as changes in mobility, thinking, or daily function.

RELAPSE: Also known as an exacerbation or flare up, referring to the occurrence of new neurological symptoms that last a minimum of 24 hours and occur in the absence of heat exposure, fever, infection, illness, or other stressor.

STABLE DISEASE: A state with no active relapses, new MRI activity, or disease progression.

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