Newly Diagnosed with MS:

Your Early Steps Checklist

This checklist is designed to help you stay organized and feel more confident in the first weeks and months after your MS diagnosis. Take things one step at a time — there's no need to do everything at once. Your path, your pace, and your needs are unique to you.

Remember: What you read here may not exactly match your experience. Your journey will be shaped by your body, your circumstances, your support system, and your care team.

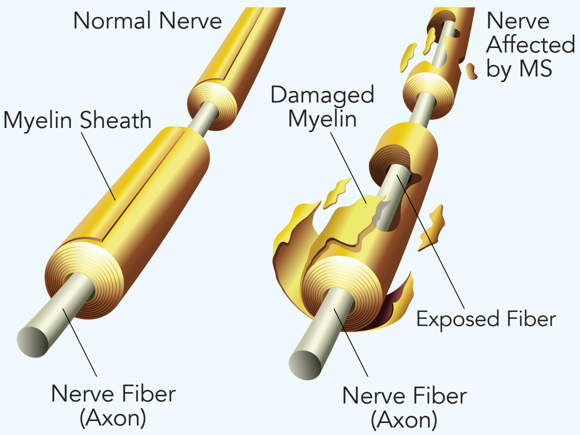
In the First Few Days

- ☐ Take a deep breath — it's okay to feel overwhelmed.
- ☐ Write down your initial questions and emotions.
- ☐ Ask your healthcare provider for a copy of your diagnosis information (MRI results, notes, or reports).
- ☐ Identify your main point of contact in your care team (neurologist, nurse, or primary care provider).
- ☐ If it feels right for you, you might choose to share your diagnosis with someone you trust. Support can be helpful, but it's also okay if you're not ready or don't have someone in that role yet — you don't have to face this alone, and support can come from many places. Share your diagnosis with a trusted person who can support you.

Learning About MS

☐ Read or watch brief, trusted resources (e.g., **MSAA's Roadmap for the Newly Diagnosed** and the **MSAA Video Library**), as well as **publications** such as ***About MS***.

- **Multiple sclerosis (MS)** is a disease of the central nervous system (CNS). The CNS consists of the brain, optic nerves, and spinal cord. With MS, areas of the CNS become inflamed, damaging the protective covering (known as "myelin") that surrounds and insulates the nerves (known as "axons"). In addition to the myelin, over time, the axons and nerve cells (neurons) within the CNS may also become damaged. MS is thought to be an autoimmune disease, where the body's own white blood cells, known as lymphocytes, become misdirected and attack the body's own myelin.



Demyelination

☐ Learn about common **MS symptoms** — and remember that everyone's experience is different.

☐ Learn about new **medical terms** or ask your doctor about these terms later.

☐ Avoid taking in too much information too quickly, and focus on small pieces a little at a time from reputable sources.

☐ Consult reliable, patient-friendly resources to learn more about disease-modifying , along with other treatment options (e.g., **MSAA's Ultimate MS Treatment Guide**).

Managing Emotions

☐ Recognize that feelings like fear, anger, or sadness are normal.

☐ Ask your doctor about support (counseling, peer groups).

☐ Try simple coping tools: breathing exercises, mindfulness, journaling.

☐ Connect with others who have MS — online or local support groups (e.g., **My MSAA Community online forum**).

Daily Living & Self-Care

☐ Prioritize rest — fatigue is common and real, so listen to your body.

☐ Focus on a balanced diet and staying hydrated.

☐ Stay active in ways that feel comfortable (stretching, light exercise).

☐ Make small adjustments at home or work to reduce stress and conserve energy.

Before Your First Neurologist/MS Specialist Appointment

☐ Gather your medical history, list of current medications, and any past symptoms.

☐ Keep track of symptoms — note what you feel, even if you are questioning if it's related to MS.

☐ Write down your questions and concerns to share with your provider and prioritize your questions. Less important questions may need to be discussed at future visits.

Sample questions:

- What type of MS do I have?
- What are disease-modifying therapies?
- What treatment options are available?
- How do these medications work, and what are their risks and benefits?
- How can I manage my current symptoms (e.g., fatigue, numbness, spasticity, vision changes)?
- How will I know if my MS is progressing?
- How often should I see you for follow-up visits?
- What should I do if I think I'm having a relapse?
- Who can I contact between visits if I have questions or if my symptoms worsen?
- What lifestyle habits (diet, exercise, sleep) can help?
- Are there local MS support groups or resources you recommend?

☐ If possible, bring someone with you to your first appointment.

☐ Ask about resources or staff members who can guide you between visits.

Building Your Support Network

☐ Identify key people on your care team (neurologist, MS nurse, physical therapist, social worker, counselor).

☐ Save emergency and appointment contact numbers in your phone.

☐ Ask your provider about helplines, patient navigators, or case management services.

☐ Explore local community or advocacy groups for additional support.

MSAA's Free Programs and Services

National Toll-Free Helpline & online chat

Cooling products

Equipment Distribution Program

Award-winning educational publications

Educational programs

Shared-management tools

Peer-to-peer online forum

Art Showcase

Acknowledgement

This publication is made possible through the generous support of Novartis.

A heartfelt thanks to Andrea Griffin and Susan Wells Courtney for their thoughtful guidance and valuable suggestions in the development of this checklist.

Written by:
Yahaira Rivera, M.B.Ed. (MSAA) in collaboration with Kate Durak (MSAA),
Alexis Kline, MPH (MSAA) and Paula Hardeman, DMSc, MPAS, PA-C
(Department of Neurology, UT Southwestern Medical Center)

Toll-Free Helpline: (800) 532-7667
Website: mymsaa.org • Email Questions: MSquestions@mymsaa.org

Stay Connected with MSAA: