

Multiple Sclerosis (MS) Treatment Journey: Key Barriers and Opportunities

In May 2025, Novartis brought together MS patients, advocates, and medical experts to discuss critical gaps in MS care to optimize patient-provider collaboration.

These are the challenges they identified and recommended actions.

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Communication Breakdowns

Patients and providers often miss key information due to appointment time limits and lack of open dialogue about symptoms.

“We [patients and providers] may be speaking a different language and not realize it.”

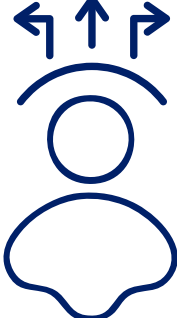
– Jacquelyn Bainbridge, PharmD, FCCP, MSCS, FAES, Professor and Vice Chair Skaggs School of Pharmacy and Pharmaceutical Sciences and Department of Neurology, Anschutz Medical Campus, University of Colorado



2

Informed Decision Making

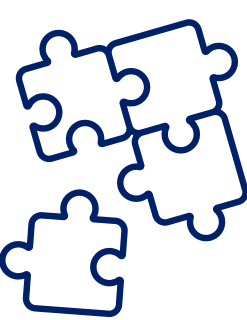
Patients and care partners feel left out of treatment decisions and there can be a lack of shared decision-making, missing aspects of patients’ needs.



“When you are first diagnosed, you don't know the questions to ask. My doctor didn't even tell me about the gamut of [treatment] options available... [Providers] have to consider their lifestyle and their background. Are they scared of needles? Do they have stomach issues? You need to think about the whole person.”

– Ashley Ratcliff Lundy, Patient Advocate

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Recognizing Personal and Cultural Factors

Personal and cultural backgrounds (identity, employment, community, language, health literacy levels, etc.) shape treatment needs and communication. Providers may overlook changing patient circumstances that may impact their care.

“Patients’ backgrounds change constantly. I've been unemployed, employed, now I work a job that I have limited amount of personal time off. Some of us will change DMTs and it may not be because of efficacy.”

– Stephanie Buxhoeveden, PhD, MSN, FNP-BC, MSCN, Researcher and Patient Advocate

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Managing Disease Progression

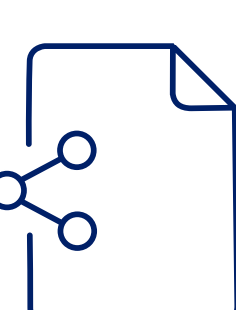
MS progression guidance is evolving, and patients and providers are still working to understand how symptoms relate to disease progression versus typical aging.



“We also need to remember that life is progressive, the aging process can present with disabilities that resemble MS progression. Importantly, lifestyle interventions, along with the use of appropriate, effective therapies, can influence the course of progression.”

– Augusto Miravalle, MD, FAAN, Chief, Division of Multiple Sclerosis and Neuroimmunology, Joseph and Florence Manaster Professor of Neurology, Rush University Medical Center

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Resource Accessibility

MS patients need educational tools in varied formats—cognitive fatigue and information overload can complicate treatment decision making.

“Not everyone is going to read a PowerPoint or listen to a podcast.”

– Luis Guerra, Person Living with MS (PwMS) and Patient Advocate

Recommended actions and tips for people living with MS, and their care partners, and providers



Patients & Care Partners

Things to keep in mind:

- **Track your symptom activity** to find patterns and triggers, improving management discussions with your doctor. **Write down questions** ahead of time and bring them to appointments or send them in advance.
- **Actively share** treatment preferences, goals, and concerns with providers during and between appointments.
- Recognize that providers are human. If expectations aren't being met, **communicate openly** about your concerns or ask for what you need to feel heard and supported.
- Work with providers to **monitor your own personal MS progression** and understand the latest progression updates on and guidance from professional organizations.
- Understand which type of **educational resources** are best for your learning style and request/seek out that format.



Health Care Team

Things to keep in mind:

- **Be transparent** with patients on the time allotted for open conversation during appointments.
- Prioritize **clear, two-way communication** to ensure patients fully understand treatment options.
- Actively consider patients' individual needs, backgrounds, preferences, and circumstances when discussing treatment options, to **meet patients where they are**.
- Support patients tracking their disease progression utilizing personal benchmarks and continue **diligently following progression updates** and guidance from professional organizations.
- Share MS educational resources that are provided in multiple languages, formats, and reading levels to **meet diverse learning needs**.



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