



Stopping Disease-modifying Therapies for Multiple Sclerosis

The AAN is the world's largest association of neurologists and neuroscience professionals and is dedicated to promoting the highest quality patient-centered neurologic care. Neurologists are doctors who identify and treat diseases of the brain and nervous system.

Experts from the AAN carefully reviewed the available scientific studies on use of disease-modifying therapy, or DMT, for treating multiple sclerosis, or MS. The following information is a summary of the evidence from those studies and other key information.

Overview

In MS, the immune system attacks the brain and spinal cord. This damages nerves and the tissue that covers and protects nerve fibers. Damage to this protective tissue changes how the nerves deliver signals from the brain and spinal cord.

Using a DMT can be better than letting MS run its course without treatment. This is because MS usually gets worse over time.

However, all medicines have possible risks. For this reason, some people whose MS is stable may think about stopping their DMT use. There is very little evidence to show the benefits or risks of stopping DMT use.

Before deciding to start or stop DMT use, be sure to discuss your decision with your clinician. This will help you think about both the benefits and the risks of your choice.

Types of Multiple Sclerosis

Relapsing

Relapsing-remitting MS (RRMS)

- Most Common MS Type
- Relapses—New or Worsening Symptoms
- Remission—Stable Between Relapses

Progressive

Secondary Progressive MS (SPMS)

- Started as RRMS
- Now Slowly, Steadily Getting Worse
- Some Relapses But Less Often

Primary Progressive MS (PPMS)

- Gradual Worsening from the Beginning
- Usually No Relapses

Clinically Isolated Syndrome (CIS)

CIS may become MS

- One or More Symptoms That Are Like MS Symptoms
- Symptoms Last 24 Hours or Longer
- At Higher Risk of MS
- Amount of Risk Depends on Clinical Exam and MRI Results

Treatment for Multiple Sclerosis

Disease-Modifying Therapies

Disease-modifying therapies (DMTs) for MS help slow the disease process to help keep your condition stable.

Lesions

DMTs lessen the number of new lesions that form or keep existing lesions from getting larger. These are abnormal spots on the brain or spinal cord.

Relapses

DMTs lessen the number of relapses that happen.

Symptom Management

DMTs are not prescribed to treat MS symptoms.

Dizziness, Fatigue, Pain

- Dizziness
- Feeling lightheaded
- Chronic pain
- Tiredness and lack of energy

Emotional Problems

- Depression, or a state of sadness that can last a short or long time
- Anxiety, or a state of fear that can last a short or long time

Vision

- Blurred vision
- Pain with eye movement

Thinking and Memory

- Trouble learning and remembering new information
- Trouble organizing and problem solving

Muscle/Movement

- Spasticity, or muscle tightness that makes it hard to move normally
- Weakness
- Numbness or tingling

Bladder/Bowel Problems

- Difficulty emptying bladder
- Difficulty moving or emptying bowels

Choosing Whether to Stop DMT Use

If you have been using DMT to treat your MS, your disease may be stable. It is not clear what causes a break in disease activity in some people. But experts think it may be the result of DMT use. Right now, no blood tests can check whether a person's DMT is working.

Often, people who use DMT for MS want to stop the therapy if they have no signs of disease activity. If you have relapsing-remitting multiple sclerosis (RRMS) and are thinking of stopping DMT use, be sure to talk with your clinician about the following things:

- How regularly you should have follow-up clinic visits
- How often you should review your decision to stop DMT use
- The side effects of your DMT and how those affect your decision to start or stop use

For progressive forms of MS, moderate evidence shows two DMTs can help slow the worsening of disability:

- Ocrelizumab for primary progressive multiple sclerosis (PPMS)
- Mitoxantrone for worsening RRMS and for secondary progressive multiple sclerosis (SPMS)

Be aware that these medicines have side effects, and some are serious.

- Ocrelizumab can weaken the immune system, which can lead to serious infections. One is a serious brain infection called progressive multifocal leukoencephalopathy, or PML. Also, if you have had hepatitis B infection, it could become active again from use of this DMT.
- Mitoxantrone is linked to heart problems, damage to certain sex organs, and bone marrow cancer. These side effects are serious and happen often. For this reason, this medicine should be used only if you and your clinician decide it would help more than harm you.

For information on the AAN's levels of evidence, see the Key to Evidence Levels at the end of this sheet.

For people with SPMS, relapses tend to be linked with a faster increase in disability. These relapses tend to happen more in people with SPMS younger than 55 years and earlier in the disease course.

If you have SPMS and are thinking of stopping your DMT use, talk with your clinician about your risk of a future relapse. Be sure to discuss how the following things may affect your decision:

- Age
- Time since MS diagnosis
- History of relapse
- MRI results

Regardless of your MS type, stopping DMT use is risky. You may have an increase in disease activity, including new or worse symptoms.

To read the full guideline, visit [AAN.com/guidelines](https://www.aan.com/guidelines).

This practice guideline was endorsed by the Consortium of Multiple Sclerosis Centers, the Multiple Sclerosis Association of America, and the National Multiple Sclerosis Society.

Key to Evidence Levels

After the experts review all of the published research studies, they describe the strength of the evidence supporting each recommendation:

Strong evidence = Future studies very unlikely to change the conclusion

Moderate evidence = Future studies unlikely to change the conclusion

Low evidence = Future studies likely to change the conclusion

Very low evidence = Future studies very likely to change the conclusion

This statement is provided as an educational service of the American Academy of Neurology. It is based on an assessment of current scientific and clinical information. It is not intended to include all possible proper methods of care for a particular neurologic problem or all legitimate criteria for choosing to use a specific procedure. Neither is it intended to exclude any reasonable alternative methodologies. The AAN recognizes that specific patient care decisions are the prerogative of the patient and the physician caring for the patient, based on all of the circumstances involved.

The AAN develops these summaries as educational tools for neurologists, patients, family members, caregivers, and the public. You may download and retain a single copy for your personal use. Please contact guidelines@aan.com to learn about options for sharing this content beyond your personal use.

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