

Getting to Know Neuromyelitis Optica Spectrum Disorder (NMOSD)



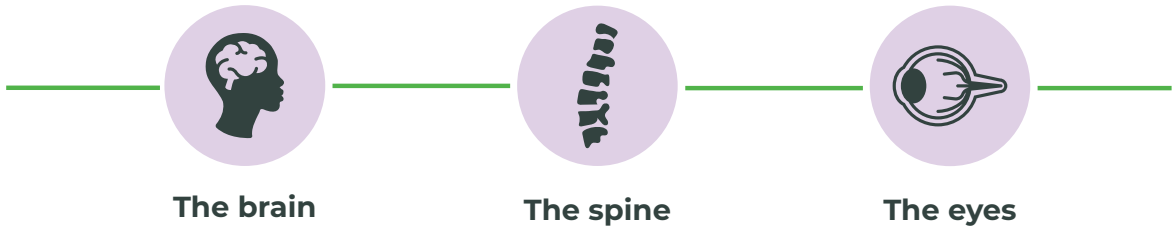
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What is NMOSD?

Neuromyelitis optica spectrum disorder, or NMOSD, is a **rare, chronic autoimmune disorder** that affects the central nervous system.

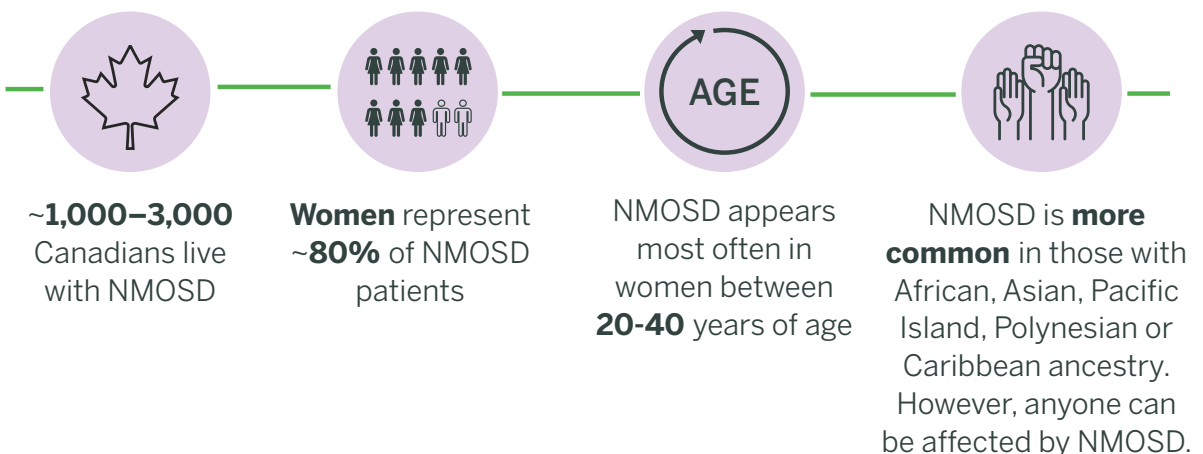
The central nervous system includes:



In NMOSD, the immune system attacks healthy organs of the central nervous system, which cause the first symptoms of the disorder to appear. NMOSD is a relapsing disease, meaning attacks continue over time. These attacks can be weeks, months, or even years apart, and they result in chronic inflammation of the spinal cord (transverse myelitis) and/or the nerves of the eyes (optic neuritis).





➤ **NMOSD shares a lot of symptoms with another autoimmune disease—multiple sclerosis, also known as MS. Unlike MS symptoms, NMOSD symptoms do not get worse between attacks, but NMOSD attacks are more severe.**

Who is affected by NMOSD?



What are the symptoms of NMOSD?

Although the symptoms of an NMOSD attack can vary from person to person, they often fall into the following categories:

OPTIC NEURITIS	TRANSVERSE MYELITIS	AREA POSTREMA SYNDROME	OTHER SYSTEMS OR IMPACTS
 <p>Inflammation of the optic (eye) nerves</p>	 <p>Inflammation of the spinal cord</p>	 <p>Lesions in the brain stem</p>	
SYMPTOMS			
<ul style="list-style-type: none"> • Eye pain • Blurry vision • Partial vision loss or blindness • Trouble seeing in low light • Trouble seeing colours • Appearance of flickering lights • Light sensitivity 	<ul style="list-style-type: none"> • Neck, limb, or back pain • Sensitivity to cold, touch, and heat • Muscle spasms • Weakness in arms or legs • Tightening in the abdominal area • Squeezing or crushing sensation across the torso • Paralysis • Bowel or bladder dysfunction • Numbness • Tingling in the legs, torso, or arms 	<ul style="list-style-type: none"> • Uncontrollable episodes of hiccups, nausea, or vomiting 	<ul style="list-style-type: none"> • Excessive itchiness • Loss of muscle coordination • Difficulty with speech • Fatigue and dizziness • Difficulty regulating body temperature • Tremors or seizures • Headache • Brain fog • Anxiety and/or depression • Sexual dysfunction • Worsening of pain intensity • Weaker contractions of the stomach muscles



Please contact your neurology team or visit the emergency room if you experience any new or worsening symptoms.

What are the long-term effects of NMOSD?

We already learned that NMOSD is a relapsing disease, meaning that symptoms can go away, and then suddenly reappear. But there are other things you should know about NMOSD relapses or attacks:

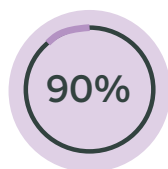
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Attacks are unpredictable. They can happen weeks, months, or years apart.



There are no specific triggers that can set off an attack.



While there is a **90% chance** of relapse after the first NMOSD attack, effective long-term management through treatment can help prevent attacks or at least make them less severe.

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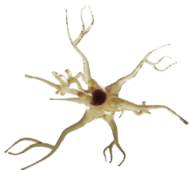


NMOSD attacks require **immediate medical attention** to help decrease symptom severity and reduce the risk of permanent disability. Therefore, discussions with your doctor about ongoing symptom monitoring is critical to long-term NMOSD management.

How does NMOSD effect the immune system?

Your immune system is designed to help protect you from harmful disease. In NMOSD, your immune system malfunctions and starts attacking healthy organs of the central nervous system. With time, these attacks cause damage to the nerves in your eyes, cells in your spinal cord, and/or certain parts of your brain.

These are the key players in your body that take part in NMOSD:



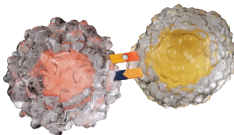
Astrocyte

An **astrocyte** is a type of cell that helps nerves work properly.



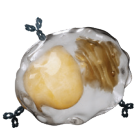
AQP4

Aquaporin-4 (**AQP4**) is a protein found on the surface of astrocyte cells.



T cell B cell

T cells and **B cells** are types of white blood cells that recognize invaders—like bacteria or viruses—in the body and send signals to the immune system to attack the invader.



Plasma cell



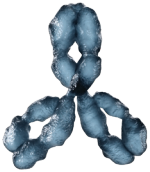
Antibody

Plasma cells make **antibodies** to protect our bodies against disease.

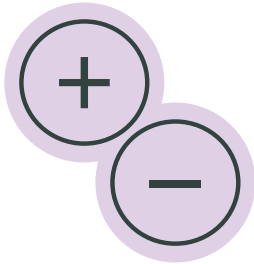
In NMOSD, T cells think that the AQP4 proteins are invaders and they signal plasma cells to create harmful antibodies against the AQP4 proteins. The harmful antibodies attack the AQP4 proteins, which damages the astrocytes and causes inflammation in the spine, eyes, and brain.

How is NMOSD diagnosed?

Early diagnosis of NMOSD is important to limit ongoing disease activity, improve recovery, and prevent permanent disability due to reoccurring symptoms. One of the best ways to test for NMOSD is through specific blood tests to see if your immune system makes harmful NMOSD-specific antibodies.

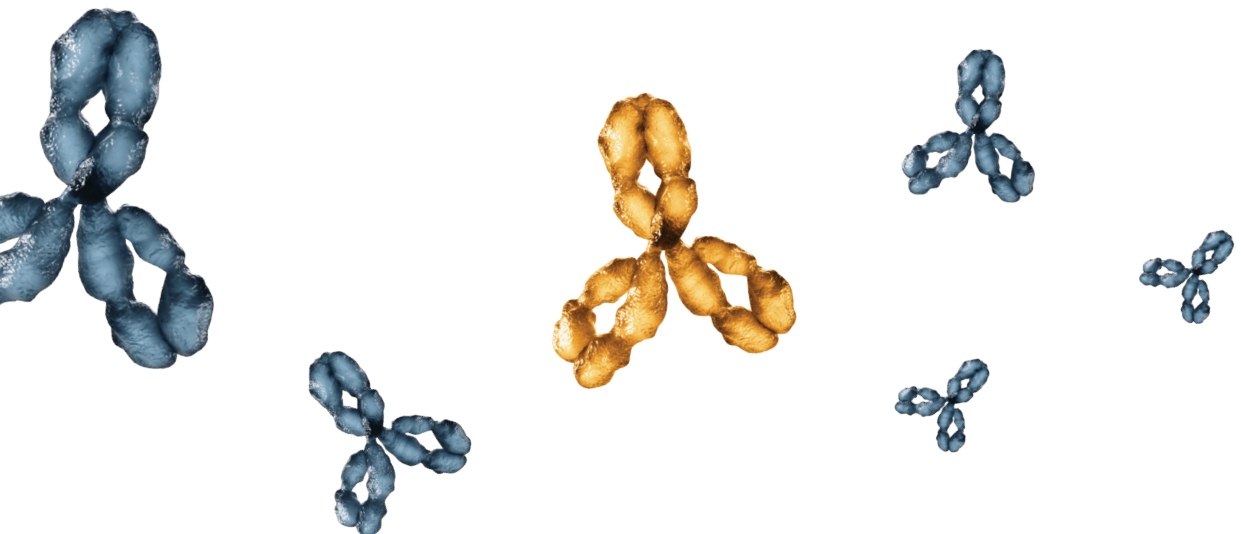


Knowing your NMOSD antibody serotype is vital in figuring out what type of NMOSD you have, which can help your doctor determine the best disease management plan for you.



70-80% of people living with NMOSD test positive for harmful antibodies to AQP4, their serotype is ***AQP4 seropositive***.

10-20% of people living with NMOSD test negative for antibodies working against AQP4, their serotype is ***AQP4 seronegative***.



Why is self-advocacy important in NMOSD?

While there is no cure for NMOSD, the symptoms of NMOSD can be managed through a combination of different approaches.



Knowledge is power

Learning more about how damage is caused to your body by NMOSD may help you better understand your disease. Ask your neurologist to explain more about the progression of NMOSD and what you can do to limit its impacts.



Discuss your options

Talk to your neurology team about the possibility of NMOSD relapses and the best long-term management plan for you.

Come prepared for talks with your neurology team

It's important to establish open communication with your neurology team to ensure that all your health concerns are being addressed. These tips can help you have a productive conversation with your healthcare team at your next appointment:



Track any new or existing symptoms including when they started, how long they lasted, and if they are getting better or worse.



Document your ongoing challenges with NMOSD.



Advocate for yourself. Make sure to share your concerns with your neurology team, no matter how small or big they are.

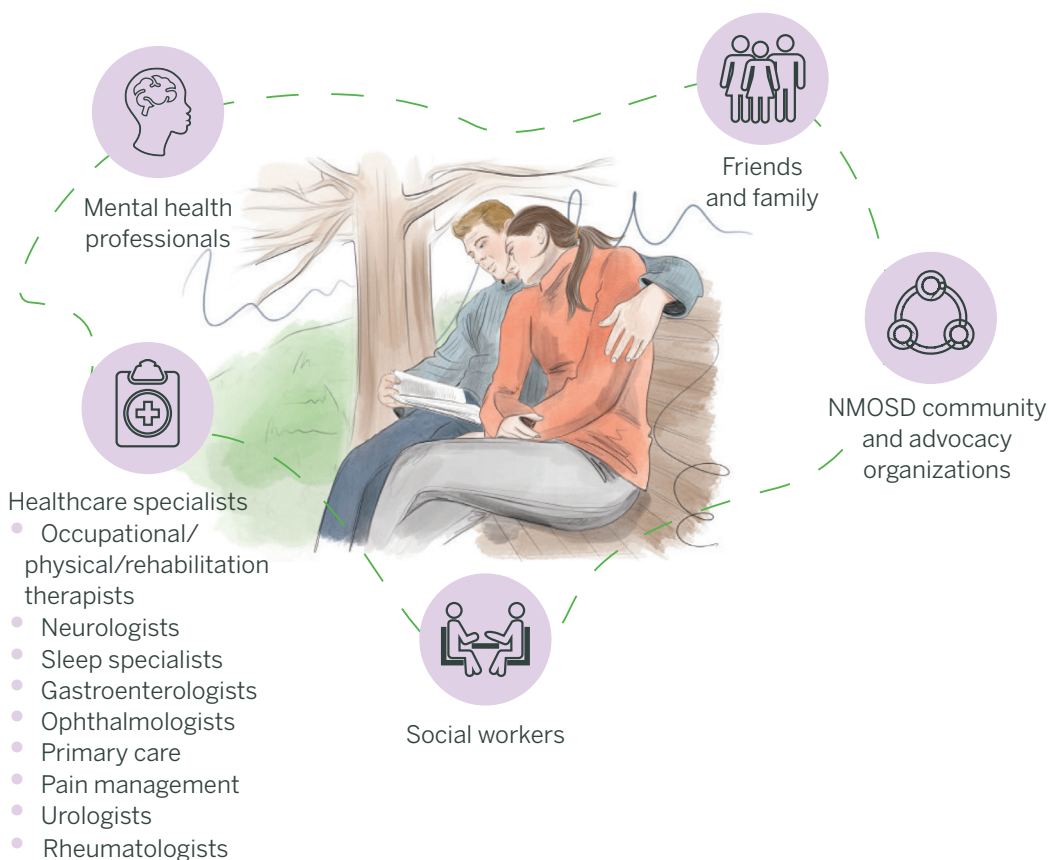


Have questions for your neurology team or want to jot down some information during an appointment? See the end of the brochure for a space to take notes.

Who can support me on my journey with NMOSD?

It is important to know that you are not alone and that there are various resources available to help you manage the impact NMOSD has on your overall wellbeing.

Your NMOSD network



Want to learn more?

There are many resources available to help you understand NMOSD. Here are some great places to start:



The Sumaira Foundation is a foundation that has made it their mission to generate global awareness of NMOSD, build supportive communities for patients and caregivers, and increase research and patient advocacy concerning NMOSD.*



The Guthy Jackson Foundation is a foundation that is dedicated to making medical breakthroughs for those living with NMOSD through research, technology, and collaboration.*

MS Canada

MS Canada (<https://mscanada.ca/>) connects people living with multiple sclerosis and allied diseases like NMOSD to the information and support programs they need for their journeys.*



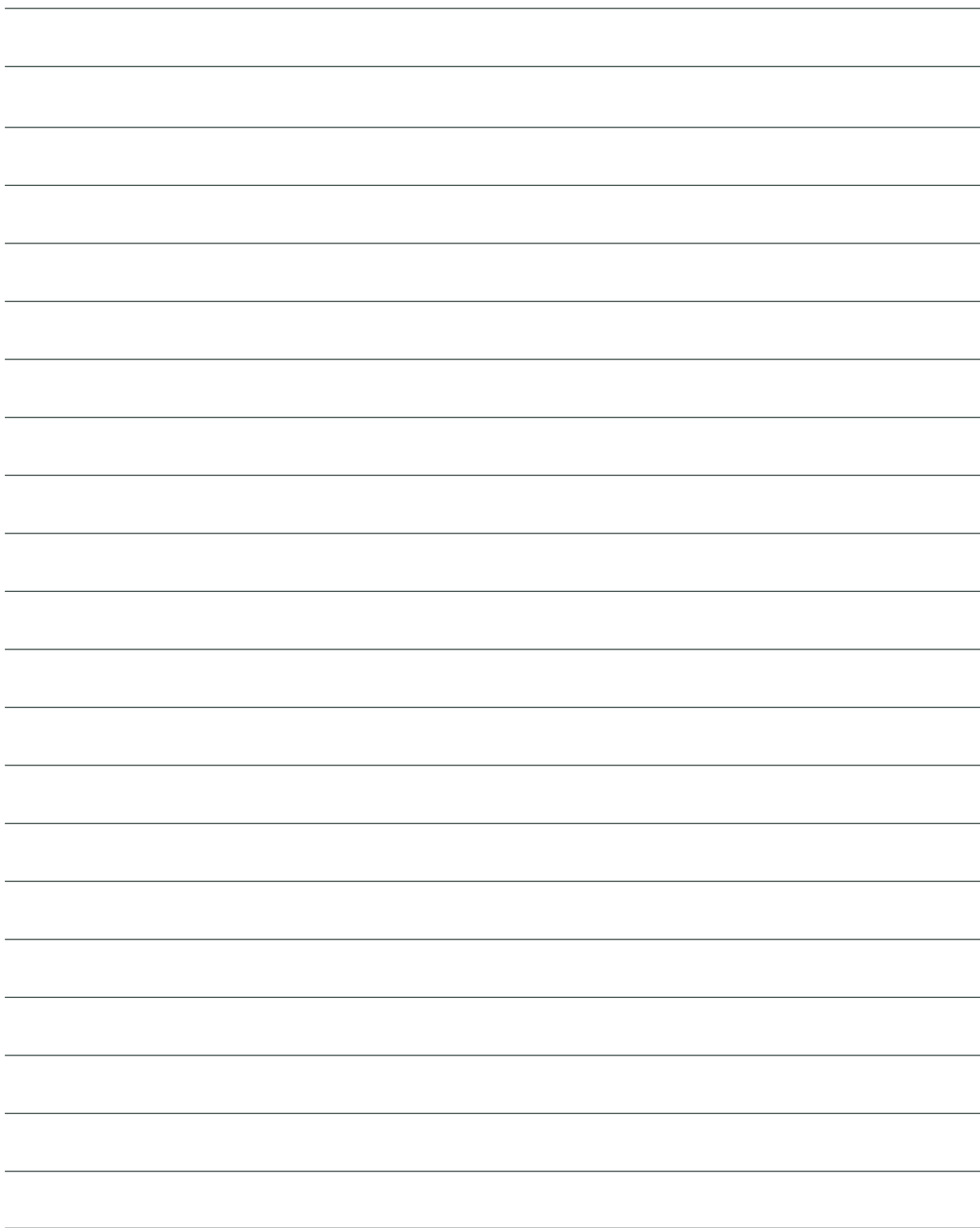
The Canadian Organization for Rare Disorders (<https://www.raredisorders.ca>) is a national network for organizations representing all those with rare disorders, providing a strong common voice to advocate for health policy and a healthcare system that works for those with rare disorders.*

* Horizon is not responsible for the content of this website.

Notes

Use this section to record information from your healthcare professional and/or take any other notes you might find useful later.

This image shows a single sheet of white paper with horizontal blue ruling lines. The lines are evenly spaced and run across the width of the page. There are approximately 20 lines visible. The paper has a slightly textured appearance and is set against a dark background.



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