

KNOW MORE ABOUT

NEUROMYELITIS OPTICA SPECTRUM DISORDER (NMOSD)

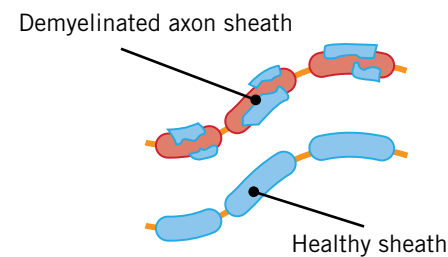
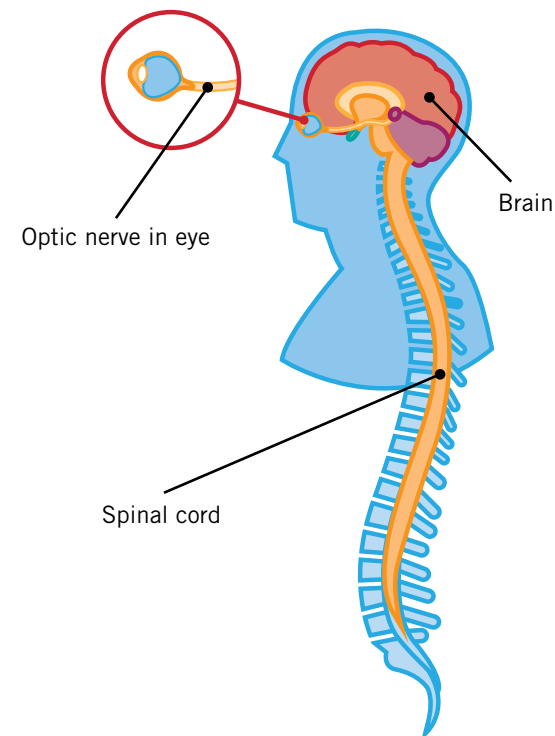


ALEXION®

KNOW ABOUT NMOSD

NMOSD IS A RARE, CHRONIC DISORDER THAT OCCURS WHEN YOUR IMMUNE SYSTEM ATTACKS THE CELLS IN YOUR CENTRAL NERVOUS SYSTEM

The central nervous system



- It is a demyelinating condition, meaning it damages the protective myelin sheath around nerve fibres.



- NMOSD may be confused for multiple sclerosis (MS), another neurological disease, but it is a different disorder with different characteristics and effects.



- Attacks may be separated by periods of remission; however, they can also be very debilitating and lead to permanent disability, like blindness or paralysis.

NMOSD is defined by attacks (**relapses**) of swelling and damage to the optic nerve (**optic neuritis**) and spinal cord (**transverse myelitis**).

“ I’ve lost so much to this condition.
I don’t know what the next relapse will do to me. ”

— Patient living with NMOSD

KNOW THE IMPACT OF NMOSD ATTACKS

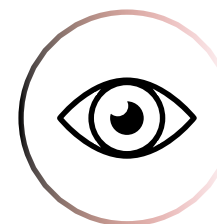
+90% OF PATIENTS EXPERIENCE REOCCURRING ATTACKS WITHIN 5 YEARS.

60% OF PATIENTS HAVE A RELAPSE WITHIN A YEAR OF THEIR FIRST ATTACK.

90% OF PATIENTS HAVE A RELAPSE WITHIN 3 YEARS OF THEIR FIRST ATTACK.

Attacks can result in permanent disability with **devastating consequences**, like blindness, paralysis, and death.

ALTHOUGH THE SYMPTOMS OF AN NMOSD ATTACK MAY VARY FROM PERSON TO PERSON, THEY OFTEN FALL INTO THE FOLLOWING CATEGORIES:



OPTIC NEURITIS

- Eye pain
- Blurred vision
- Loss of colour vision
- Blindness



TRANSVERSE MYELITIS

- Paralysis
- Sensory loss
- Limb weakness
- Bladder dysfunction
- Bowel dysfunction



OTHER SYMPTOMS

- Frequent nausea and vomiting
- Constant hiccups

NMOSD attacks are unpredictable and often severe and recurring.

KNOW THE CAUSE OF NMOSD

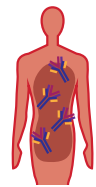
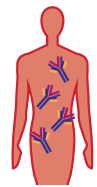
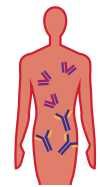
Normally, your immune system targets and attacks **invading** organisms, like bacteria and viruses:



Antigens invade	Antibodies form	Antibodies remove invading antigens
1. When foreign invaders (antigens) are detected in the body, an immune response is triggered.	2. One of the main immune responses is the production of proteins called antibodies , which help fight off the antigens.	3. Antibodies are made with specific binding sites that only bind with certain antigens. They ignore the good (healthy) cells and only attack the bad ones.

The **complement system** is another part of the immune system that helps (complements) the immune system to detect, destroy, and remove invaders and/or damaged cells.

In NMOSD, the immune system mistakes normal tissues of the central nervous system as foreign:



Immune system makes antibodies against itself	Autoantibodies target AQP4	Inflammatory damage and neuron death
1. The immune system attacks these tissues, making autoantibodies —immune proteins that mistakenly target a person's own tissues or organs—that hurt otherwise healthy parts of the central nervous system.	2. Through the complement system, these autoantibodies often target tissues in the central nervous system that are rich in a water channel protein called aquaporin-4 (AQP4) .	3. The initial attack targets the nerves of the eyes and other parts of the central nervous system, which include the brain and spinal cord.

AUTOANTIBODIES TO AQP4 CAN BE USED TO DIAGNOSE NMOSD

Autoantibodies for AQP4 can be found in the blood of people with NMOSD and can be used to diagnose and monitor the disease.

- ~73% of people with NMOSD have AQP4 autoantibodies present.

Ask your doctor about your antibody status.

KNOW MORE ABOUT NMOSD

WHO IS AFFECTED?



1–10 per 100,000 people have NMOSD.



Up to 10x more common in women than in men.



The average age of onset is around 40 years old.



NMOSD is not believed to be hereditary.

LIVING WITH NMOSD

Living with NMOSD can be challenging for you and those you love. Here are some steps you can take to help yourself:



- Exercise (like yoga) can help with maintaining and restoring flexibility, movement, and strength.
- Talk to your healthcare provider about an appropriate level and form of physical exercise.



- Talk to your healthcare provider about things you can do to manage bladder or bowel problems.



- Try to get a decent night's sleep and take rests to reduce fatigue.



- Family education is also recommended to help your loved ones understand your challenges with living with NMOSD.



- Plan out tasks so they are easier to perform. Consider things like menu planning and spreading out your chores.



- Talk to your doctor about working with an occupational or physical therapist to help you address your NMOSD symptoms.



- The stress of NMOSD can take a toll on your mental health. Talking to a mental health professional may help.



- See the resources at the end of this brochure to learn more about support groups.

Consult your doctor or a neurologist to learn about treatment options for NMOSD.

KNOW WHERE TO GO FOR MORE INFORMATION

CANADIAN RESOURCES WITH DIRECT SUPPORT FOR PATIENTS WITH NMOSD:

Multiple Sclerosis Society of Canada

The Multiple Sclerosis Society of Canada provides information, support and advocacy to people affected by MS, and funds research to find the cause and cure for the disease. The MS Society of Canada also provides information and support to people affected by NMOSD:

mssociety.ca

Canadian Organization for Rare Disorders (CORD)

A national network for organizations representing all those with rare disorders. CORD provides a strong common voice to support health policy and a healthcare system that works for those with rare disorders such as NMOSD:

raredisorders.ca

FOR MORE INFORMATION ON NMOSD:

The Guthy-Jackson Charitable Foundation

An organization dedicated to funding research and providing resources for patients with NMOSD.

Access information about NMOSD, patient resources, FAQs, and support groups:

guthyjacksonfoundation.org