CONDITION

Neuromyelitis optica spectrum disorder

Neuromyelitis optica spectrum disorder is an immune condition that causes attacks of inflammation in the optic nerves, spinal cord, or brain.

WHAT IT IS
Immune condition causing attacks in optic nerves and spinal cord

BODY SYSTEM
Nervous system

MAIN SYMPTOMS
Vision loss, limb weakness, numbness, persistent vomiting or hiccups

WHAT CAUSES IT
Immune attack, often involving aquaporin-4 antibodies

HOW IT IS DIAGNOSED
AQP4-IgG blood testing, MRI, and clinical attack pattern

MAIN TREATMENT
Attack treatment plus long-term immune therapy to prevent relapses

CAN IT BE CURED?
No - treatment can reduce relapses

IS IT AN EMERGENCY?
Sometimes - sudden vision loss, weakness, or breathing trouble

LONG-TERM OUTLOOK
Relapses can cause disability, but preventive treatment improves outlook

Overview

Neuromyelitis optica spectrum disorder, or NMOSD, is a long-term condition in which the immune system mistakenly attacks parts of the nervous system. It most often affects the optic nerves, which connect the eyes to the brain, and the spinal cord. It can also affect areas of the brain that control vomiting, hiccups, sleep, and other automatic functions.

Inflammation usually happens in episodes called attacks or relapses. An attack may cause sudden vision loss, weakness, numbness, bladder problems, or persistent vomiting. Symptoms often develop over hours or days.

Many people with NMOSD have an immune protein called aquaporin-4 immunoglobulin G, shortened to AQP4-IgG. This antibody targets cells that help support the brain, spinal cord, and optic nerves.

NMOSD is different from multiple sclerosis, even though the symptoms and MRI findings can overlap. It is also different from myelin oligodendrocyte glycoprotein antibody-associated disease, known as MOGAD. Telling these conditions apart matters because their long-term treatments are not the same.

There is no cure at present. However, prompt treatment of attacks and ongoing immune treatment can lower the chance of further relapses.

Symptoms

NMOSD symptoms depend on which part of the nervous system is inflamed. A person may have one type of attack or several symptoms at the same time.

Optic neuritis is inflammation of the optic nerve. It may cause blurred or darkened vision, reduced colour vision, or loss of sight in one or both eyes. Eye movement can be painful. Vision loss may be severe, although recovery differs from person to person.

Transverse myelitis is inflammation across part of the spinal cord. Symptoms may include:

Inflammation in the area postrema, a small region in the lower brainstem, can cause nausea, repeated vomiting, or hiccups that do not settle. These symptoms may appear without stomach pain, diarrhoea, or another clear digestive cause.

Other brain or brainstem attacks can cause double vision, facial numbness, problems with balance or swallowing, unusual sleepiness, or confusion. These symptoms have many possible causes, so testing is needed rather than assuming they are due to NMOSD.

Symptoms may improve after an attack, but recovery can be incomplete. Lasting problems are more likely after severe or repeated attacks.

- Weakness or paralysis in the arms or legs
- Numbness, tingling, burning pain, or tight band-like sensations
- Muscle stiffness or spasms
- Loss of bladder or bowel control
- Sexual difficulties
- Breathing problems if the upper spinal cord is affected

Causes and risk factors

NMOSD is caused by an abnormal immune response. It is not an infection and cannot spread

from one person to another.

In AQP4-IgG-positive NMOSD, antibodies bind to aquaporin-4, a water-channel protein found on support cells called astrocytes. This activates other parts of the immune system and causes inflammation and tissue injury.

Some people with a typical NMOSD pattern do not have detectable AQP4-IgG. This group needs careful assessment because other conditions can cause similar attacks. Testing may identify MOG-IgG, which usually points to MOGAD rather than NMOSD.

NMOSD can begin at different ages and affects people of all ethnic backgrounds. AQP4-IgG-positive NMOSD is more common in women. It may occur alongside another autoimmune condition, such as lupus, Sjögren syndrome, autoimmune thyroid conditions, or myasthenia gravis.

NMOSD is not usually inherited in a simple way. Having an affected relative does not mean that you will develop it. Researchers think a mixture of immune, genetic, and environmental factors may contribute, but there is usually no single identifiable trigger.

Diagnosis

No symptom or MRI finding should be interpreted alone. Diagnosis is based on the pattern of attacks, neurological examination, blood testing, and imaging.

A blood test for AQP4-IgG is central to diagnosis. A laboratory method called a cell-based assay is preferred because it is more accurate than older testing methods. A positive result, together with a compatible attack, strongly supports NMOSD.

If AQP4-IgG is not found, testing for MOG-IgG may help identify MOGAD. Occasionally, repeat antibody testing is considered when suspicion remains high, especially if the original sample was taken after immune treatment.

MRI scans may include the brain, optic nerves, and spinal cord. They show areas of inflammation and help distinguish NMOSD from multiple sclerosis, compression of the spinal cord, stroke, infection, and other causes. NMOSD spinal cord inflammation often covers a long section, but shorter areas can occur.

A lumbar puncture may be used to examine the fluid surrounding the brain and spinal cord. It can support the assessment and help exclude infection or multiple sclerosis, but it does not confirm NMOSD by itself.

Eye tests may measure visual sharpness, colour vision, and the thickness of nerve layers at the back of the eye. These tests can document injury and provide a baseline for follow-up.

Treatment and management

Treatment has two main goals: limiting damage during an attack and preventing future attacks.

A suspected attack usually needs urgent specialist assessment. High-dose corticosteroids like prednisone or hydrocortisone are commonly used to reduce inflammation. If an attack is severe or does not respond adequately, plasma exchange may be started. This procedure removes blood plasma containing harmful antibodies and replaces it with another fluid. Some centres use a related procedure called immunoadsorption. Intravenous immunoglobulin may be considered in selected situations.

Long-term immune treatment is usually recommended for AQP4-IgG-positive NMOSD because further attacks can cause permanent disability. Available approaches target antibody-producing B cells, the inflammatory signal interleukin-6, or complement proteins involved in immune injury. Other immune-suppressing medicines are also used.

The choice of treatment is influenced by antibody results, previous attacks, other health conditions, infection risk, pregnancy plans, access, and personal preferences. Some treatments require vaccines or infection screening before they begin. Regular blood tests or other monitoring may be needed.

Medicines used for multiple sclerosis do not automatically treat NMOSD. Some may be ineffective or could increase disease activity, which is one reason an accurate diagnosis is important.

Rehabilitation can help with recovery and day-to-day function. This may include physiotherapy, occupational therapy, mobility support, bladder care, pain management, treatment for muscle spasms, and low-vision services.

Long-term immune treatment should not be stopped or delayed without specialist guidance. A planned change is especially important before pregnancy, surgery, or vaccination.

Medicines commonly used for this include eculizumab . Which one suits you, if any, is a decision for you and your doctor.

Complications

An NMOSD attack can injure the optic nerves or spinal cord. Possible lasting effects include reduced vision, difficulty walking, weakness, numbness, chronic nerve pain, muscle spasms, and bladder or bowel problems.

High spinal cord or brainstem inflammation can affect breathing or swallowing. Severe vomiting can lead to dehydration and changes in body salts.

Repeated attacks may increase disability because NMOSD usually causes damage during relapses rather than through steady worsening between attacks. Preventing attacks is therefore a major part of care.

Long-term immune treatments can increase the risk of certain infections. The type of risk differs between treatments. Monitoring, vaccination planning, and early assessment of infection symptoms help manage this risk.

Living with uncertain relapses or lasting disability can also affect sleep, mood, work, relationships, and independence. Psychological support and practical rehabilitation are valid parts of NMOSD care.

Prevention

There is no known way to prevent NMOSD from first developing. It is not caused by something you ate or by a lack of exercise, and it is not usually preventable through lifestyle changes.

Once NMOSD is diagnosed, long-term immune treatment can reduce the risk of another attack. It cannot guarantee that a relapse will never happen.

Keeping follow-up appointments, taking treatment as agreed, completing recommended monitoring, and having a written plan for new neurological symptoms can support early care. Avoid stopping immune treatment suddenly unless the clinical team managing your NMOSD advises it.

General measures such as not smoking, regular activity within your abilities, balanced nutrition, and appropriate vaccinations support overall health. They do not replace relapse-prevention treatment.

Living with it and what to expect

NMOSD often follows a relapsing course, particularly when AQP4-IgG is present. This means there are attacks separated by periods of stability. The timing and severity of future attacks cannot be predicted for an individual.

Recovery continues for weeks or months after some attacks. Rehabilitation may improve strength, mobility, vision-related skills, and independence, although not every symptom disappears. Between attacks, many people are neurologically stable rather than gradually worsening.

Some people have lasting fatigue, pain, stiffness, bladder symptoms, or reduced vision.

Mobility aids, home or workplace changes, and low-vision technology can make daily activities safer and easier. Using these supports does not mean recovery has stopped.

Follow-up generally focuses on preventing relapses, checking treatment safety, managing lasting symptoms, and reviewing any new neurological changes. MRI and eye testing may be repeated when clinically useful, but routine scans do not replace reporting new symptoms.

Pregnancy is possible for many people with NMOSD, but treatment and relapse planning are important before conception. Some medicines need to be changed, while stopping effective treatment may also carry risk. Planning should involve the NMOSD specialist and pregnancy care team.

Modern preventive treatments have improved the outlook. Even so, experiences differ. Some people remain independent with few lasting symptoms, while others need ongoing help because of vision loss, weakness, or repeated attacks.

When to get medical help

New neurological symptoms may represent an attack, and early treatment can matter.

Seek emergency medical care for:

Contact your NMOSD team or seek same-day medical assessment for new eye pain, blurred vision, spreading numbness, increasing muscle weakness, or repeated unexplained vomiting or hiccups. Persistent vomiting also needs prompt attention because it can cause dehydration.

Fever, severe headache, a stiff neck, unusual confusion, or a rapidly worsening illness needs urgent assessment if you take immune-suppressing treatment.

Routine follow-up is the right place to discuss stable pain, fatigue, spasms, bladder symptoms, rehabilitation needs, treatment monitoring, vaccinations, or pregnancy planning.

- Sudden or rapidly worsening loss of vision
- New weakness, paralysis, or inability to walk
- Difficulty breathing, swallowing, or staying awake
- Sudden loss of bladder or bowel control with weakness or numbness
- Severe symptoms after starting treatment, such as breathing difficulty or facial swelling

Common questions

Is NMOSD the same as multiple sclerosis?

No. Both can inflame the optic nerves, brain, and spinal cord, but they involve different immune processes and often have different MRI and antibody findings. Their treatments also differ.

Can NMOSD go away on its own?

Symptoms from an individual attack may improve, especially with prompt treatment. The underlying tendency to relapse usually remains, particularly in AQP4-IgG-positive NMOSD. Long-term treatment is often used to reduce that risk.

Will I lose my sight or need a wheelchair?

Not everyone develops severe disability. The outcome is shaped by the location and severity of attacks, recovery, and whether further attacks can be prevented. Early attack treatment, preventive therapy, and rehabilitation may improve the outlook.

What does an AQP4-positive result mean?

It means the blood test found antibodies against aquaporin-4. In someone with a compatible neurological attack, this strongly supports NMOSD and helps guide long-term treatment.

Can stress, food, or exercise trigger a relapse?

There is no proven diet or exercise pattern that prevents NMOSD attacks. Stress can worsen fatigue, pain, or other existing symptoms without necessarily causing new inflammation. New loss of vision, weakness, or numbness should still be assessed.

Can I have children if I have NMOSD?

Many people with NMOSD can become pregnant. Planning is important because relapse risk and medication safety must both be considered before pregnancy, after delivery, and during breastfeeding.

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