CONDITION

Opthalmoneuromyelitis

Opthalmoneuromyelitis is an autoimmune condition that mainly inflames the optic nerves and spinal cord.

WHAT IT IS
Autoimmune inflammation of the optic nerves and spinal cord

BODY SYSTEM
Nervous system

MAIN SYMPTOMS
Vision loss, eye pain, weakness, numbness

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

HOW IT IS DIAGNOSED
AQP4 antibody testing, MRI, and clinical criteria

MAIN TREATMENT
Steroids for attacks and immune-suppressing relapse prevention

CAN IT BE CURED?
No - treatment reduces future attacks

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

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

Overview

Opthalmoneuromyelitis is an uncommon name for a condition now usually called neuromyelitis optica spectrum disorder , or NMOSD . It is also called optic neuromyelitis or, less often, Devic syndrome.

NMOSD causes inflammation in the nervous system. It most often affects the optic nerves, which carry visual information from the eyes to the brain, and the spinal cord. It can also affect parts of the brain that control vomiting, hiccups, sleep, alertness, breathing, or swallowing.

The inflammation happens when the immune system mistakenly attacks healthy cells. Many people with NMOSD have an antibody called aquaporin-4 immunoglobulin G , shortened to AQP4-IgG . Aquaporin-4 is a water-channel protein found on supporting brain and spinal cord cells called astrocytes.

NMOSD usually causes distinct attacks, also called relapses. Symptoms may improve between attacks, but each attack can leave lasting changes in vision, movement, sensation, bladder function, or other abilities. Prompt treatment of attacks and long-term relapse prevention are therefore important.

NMOSD is not the same as multiple sclerosis. The conditions may cause similar symptoms, but their tests, expected course, and treatment are different.

Symptoms

Symptoms often develop over hours or days. Their severity and duration differ between people and between attacks.

Optic neuritis is inflammation of an optic nerve. It may affect one or both eyes and can cause:

Myelitis is inflammation of the spinal cord. Symptoms may include:

Some people develop inflammation in the area postrema , a small part of the lower brainstem. This can cause repeated vomiting, nausea, or hiccups that do not have a clear digestive cause.

Inflammation elsewhere in the brainstem or brain may cause double vision, facial numbness, severe sleepiness, confusion, seizures, swallowing problems, or breathing difficulty. These symptoms are less common but can be serious.

- Blurred, dim, or lost vision
- Pain in or behind the eye, sometimes worse with eye movement
- Colours appearing faded
- Missing areas in the field of vision
- Weakness or paralysis in the arms or legs
- Numbness, tingling, burning, or unusual sensitivity
- Tight or painful muscle spasms
- A band-like feeling around the chest or abdomen
- Problems walking or keeping balance
- Loss of bladder or bowel control
- Difficulty passing urine
- Sexual difficulties

Causes and risk factors

NMOSD is caused by abnormal immune activity. In most people who test positive for AQP4-IgG, the antibody helps trigger inflammation and injury around aquaporin-4.

Why this immune response begins is not fully understood. An infection may sometimes occur before an attack, but NMOSD is not an infection and cannot spread from person to person.

The condition is not usually inherited directly. Having a relative with an autoimmune condition may reflect shared susceptibility, but this does not mean children will develop NMOSD.

NMOSD can occur at different ages. AQP4-positive NMOSD affects women more often than men. It can occur in people of any ethnic background.

Some people also have another autoimmune condition, such as lupus, Sjögren syndrome, autoimmune thyroid disease, or myasthenia gravis.

A person with similar symptoms may instead have myelin oligodendrocyte glycoprotein antibody-associated disease , known as MOGAD. MOGAD is now considered a separate condition and may require a different long-term treatment plan.

Diagnosis

There is no single test that confirms every case. Diagnosis combines the pattern of symptoms, examination findings, antibody tests, and magnetic resonance imaging, or MRI.

Blood is usually tested for AQP4-IgG. A laboratory method called a cell-based assay is preferred because it is more accurate than some older testing methods. A positive result, together with a typical neurological attack, strongly supports NMOSD.

If AQP4-IgG is not found, testing for MOG antibodies may help distinguish MOGAD from NMOSD. Negative antibody tests do not automatically rule out NMOSD, but the diagnostic criteria are stricter when AQP4-IgG is absent.

MRI scans can show inflammation in the optic nerves, spinal cord, brainstem, or brain. Spinal cord inflammation in NMOSD often extends across several spinal segments, although this pattern is not present in every attack.

A lumbar puncture may be used to examine the fluid around the brain and spinal cord. This test can support the diagnosis and help rule out infection or multiple sclerosis, but it does not confirm NMOSD by itself.

Blood tests may also look for infections, vitamin deficiencies, or other autoimmune conditions that can cause similar symptoms.

Treatment and management

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

An acute attack is usually treated promptly with high-dose corticosteroids like prednisone or hydrocortisone given into a vein. Corticosteroids reduce inflammation; they are different from muscle-building steroids.

If symptoms are severe or do not respond well enough, plasma exchange may be considered. During plasma exchange, blood passes through a machine that removes plasma containing antibodies and replaces it with another fluid. Some centres use intravenous immunoglobulin in selected circumstances.

Long-term treatment reduces the chance of further attacks. The choice depends on AQP4 antibody status, previous attacks, other health conditions, pregnancy plans, infection risk, access, and local approvals.

Options may include targeted biologic medicines such as eculizumab, inebilizumab, or satralizumab for eligible people with AQP4-positive NMOSD. Other immune-suppressing medicines, including rituximab, azathioprine, or mycophenolate, are also used in some settings.

These treatments affect the immune system in different ways. They require monitoring for infections and other side effects. Some medicines require specific vaccinations or infection precautions. Complement-blocking medicines such as eculizumab carry a serious risk of meningococcal infection, so vaccination and a clear safety plan are essential.

Rehabilitation can address remaining symptoms. It may include physiotherapy, occupational therapy, vision rehabilitation, bladder care, pain treatment, mobility aids, and support for fatigue or emotional health.

Medicines should not be stopped suddenly without guidance. Loss of treatment protection can increase the chance of another attack.

Complications

An attack can leave lasting damage even when inflammation has settled. Possible complications include reduced vision, weakness, difficulty walking, numbness, nerve pain, muscle stiffness, and bladder or bowel problems.

Severe spinal cord or brainstem inflammation can affect breathing or swallowing. Reduced mobility may increase the risk of falls, pressure injuries, blood clots, and loss of bone strength.

Repeated vomiting can cause dehydration and abnormal levels of body salts. Persistent

hiccups can interfere with sleep, eating, and recovery.

Treatment can also cause complications. Immune-suppressing medicines may increase infection risk, alter blood counts, or affect the liver and other organs. Regular blood tests and planned reviews help identify problems early.

Living with uncertainty about relapses may contribute to anxiety, low mood, or social isolation. These effects deserve attention alongside physical symptoms.

Prevention

There is no established way to prevent NMOSD from first developing. It is not caused by something you ate, a lack of exercise, or ordinary contact with another person.

After diagnosis, long-term immune treatment can reduce the risk of further attacks. Taking treatment as planned and attending monitoring appointments are important parts of relapse prevention.

Vaccinations may help prevent infections that could become more serious during immune-suppressing treatment. The timing of vaccines may need to be coordinated with treatment. Live vaccines may not be suitable with some medicines.

General measures such as not smoking, staying active within your abilities, protecting bone health, and managing blood pressure support overall health. They do not replace NMOSD-specific treatment.

Living with it and what to expect

NMOSD often follows a relapsing course. An attack may last days or weeks, followed by partial or substantial recovery over weeks to months. Some symptoms can remain permanent.

Unlike multiple sclerosis, NMOSD usually causes disability mainly through attacks rather than gradual worsening between attacks. Avoiding new attacks is therefore a central part of long-term care. No treatment removes the risk completely.

Some people return to work, education, driving, exercise, and family responsibilities with few adjustments. Others need mobility aids, visual support, changes at work, or regular help with daily activities. The course cannot be predicted precisely from one attack.

Fatigue, pain, muscle spasms, bladder symptoms, and reduced vision may continue even when MRI scans show no new inflammation. Rehabilitation and symptom-focused treatment can improve daily function, although they cannot reverse every injury.

Regular follow-up usually includes discussion of new symptoms, treatment side effects, infections, vaccinations, pregnancy plans, and practical needs. Blood tests or other monitoring may be required for long-term medicines.

Pregnancy planning is particularly important because NMOSD activity and medication safety must both be considered. Treatment should not be stopped solely because pregnancy is being considered without first making a specialist plan.

When to get medical help

Seek emergency medical care for:

Contact your neurological team urgently for new eye pain, blurred or faded vision, spreading numbness, increasing muscle weakness, persistent hiccups, or repeated unexplained vomiting. An NMOSD attack can start with symptoms that seem mild, and early assessment matters.

Fever, severe headache, stiff neck, a new rash, or marked illness while taking an immune-suppressing medicine also needs prompt assessment. If you use a complement-blocking medicine, follow its specific emergency plan for possible meningococcal infection.

Routine appointments are appropriate for stable fatigue, longstanding pain, rehabilitation needs, medication monitoring, or questions about work, travel, vaccines, and pregnancy planning.

- New or rapidly worsening loss of vision
- New weakness, paralysis, or inability to walk
- Difficulty breathing, swallowing, or staying awake
- Severe confusion, collapse, or a seizure
- Sudden loss of bladder control with weakness or numbness

Common questions

Is opthalmoneuromyelitis the same as multiple sclerosis?

No. NMOSD and multiple sclerosis can both affect the optic nerves and spinal cord, but they involve different immune processes. MRI patterns and antibody tests help distinguish them. Some multiple sclerosis medicines are not effective for NMOSD and may be unsuitable, making an accurate diagnosis important.

Will my eyesight come back after optic neuritis?

Vision may improve as inflammation settles, especially with prompt treatment. Recovery can be partial or substantial, but severe attacks may leave permanent sight loss. Vision rehabilitation can help you use remaining vision and adapt daily activities.

What does AQP4-positive mean?

It means a blood test found antibodies against aquaporin-4. This supports an NMOSD diagnosis when symptoms fit and helps guide long-term treatment. A negative result does not by itself rule out NMOSD.

Is NMOSD contagious or inherited?

It is not contagious. You cannot catch it through touch, air, food, sex, or shared belongings. It is not usually inherited in a simple pattern, although autoimmune susceptibility can sometimes occur in families.

Can I exercise with NMOSD?

Many people can exercise safely at a level matched to their strength, balance, vision, and fatigue. Physiotherapy can help develop an adapted plan. Some people notice that heat temporarily worsens older neurological symptoms; this does not always mean a new attack.

Can NMOSD affect pregnancy?

Pregnancy and the months after birth can affect relapse risk, and some treatments are not suitable around conception, pregnancy, or breastfeeding. Planning ahead allows treatment changes to be timed safely while maintaining as much relapse protection as possible.

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