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Neurology Care 7 days a Week. Because Your Brain Matters.

Neuromyelitis Optica Spectrum Disorder (NMOSD)

Patient education guide · Demyelinating & Autoimmune · Madison Neurology LLC

What is it?

NMOSD is an autoimmune disease in which the immune system — usually via antibodies against the aquaporin-4 water channel — attacks the optic nerves and spinal cord, causing attacks of vision loss and paralysis. It is distinct from MS and treated differently; preventing attacks is the central goal because disability in NMOSD accumulates attack by attack.

How does it happen?

Most patients have a detectable antibody against aquaporin-4 (AQP4), which targets a protein on support cells in the optic nerves, spinal cord, and specific brain regions. What triggers the autoimmunity is unknown. NMOSD sometimes accompanies other autoimmune diseases such as lupus or Sjögren's.

Common symptoms

- Optic neuritis: severe vision loss in one or both eyes
- Transverse myelitis: weakness or paralysis of legs (± arms), numbness, bladder/bowel dysfunction
- Area postrema attacks: intractable nausea, vomiting, or hiccups
- Severe neuropathic pain and painful tonic spasms
- Attacks can be devastating but recovery between them may be substantial

How is it diagnosed?

Blood testing for AQP4 antibodies is central (highly specific); MOG antibody testing evaluates antibody-negative cases. MRI shows long spinal cord lesions and characteristic optic nerve involvement distinct from MS patterns. Spinal fluid helps differentiate from MS.

How is it treated?

Acute attacks are treated urgently with high-dose steroids and, if response is incomplete, plasma exchange — speed matters for preserving vision and movement. Attack prevention has been revolutionized by targeted therapies: eculizumab, ravulizumab, satralizumab, and inebilizumab are approved specifically for NMOSD and reduce relapse risk by 70-90%+; rituximab and other immunosuppressants are alternatives. Note: some standard MS drugs can worsen NMOSD, which is why accurate diagnosis is critical.

What does the future hold?

Untreated, NMOSD causes accumulating disability with each attack; with modern preventive therapy, most patients stop having attacks altogether. Recovery from individual attacks varies. Lifelong preventive treatment and prompt attack response plans (knowing to seek immediate care for new symptoms) protect vision and mobility.

Questions patients commonly ask

Q: How is this different from MS?

A: Different antibody target, different MRI pattern, different treatment — some MS drugs make NMOSD worse. NMOSD attacks tend to be more severe but the disease does not usually smolder progressively the way MS can.

Q: If I feel fine between attacks, why take ongoing treatment?

A: Disability in NMOSD comes from attacks; prevention is everything. Modern preventives reduce attack risk dramatically.

Q: Will my vision come back after optic neuritis?

A: Recovery varies — prompt steroid and plasma exchange treatment improves the odds; prevention ensures it doesn't happen again.

National support groups & resources

- **Guthy-Jackson Charitable Foundation (NMOSD/MOGAD)** — guthyjacksonfoundation.org
- **National Multiple Sclerosis Society** — nationalmssociety.org — 1-800-344-4867
- **National Organization for Rare Disorders** — rarediseases.org — 1-800-999-6673

(Organization contact details were current at the time of compilation; please verify online.)

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