

## MAKE THE MOST OF YOUR NEXT DOCTOR'S APPOINTMENT

Whether you are seeking a definitive diagnosis of neuromyelitis optica spectrum disorder (NMOSD) or have questions about treatment options, this list can help you get ready to have a conversation with your doctor.



### CREATE A LIST OF YOUR SYMPTOMS AND KEEP TRACK OF CHANGES

NMOSD symptoms can often seem unrelated, so it's important your doctor has a full picture of your condition. An **NMOSD symptoms checklist** can help you understand and record new or worsening symptoms.

#### **COLLECT YOUR MEDICAL RECORDS**

Your medical history and any previous test results can help your doctor determine the best course of action.



### **CONTINUE YOUR RESEARCH**

It is important to have your own understanding of NMOSD. Exploring the information provided on **NMOSDWontStopMe.com** and completing additional online research using credible sources can help you make informed choices and be aware of new symptoms.

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#### **ASSESS YOUR TREATMENT PLAN**

It may be overwhelming to try and understand the different treatment options. After learning about your options, talk with your doctor about what treatment plan works best for your lifestyle.



#### HAVE AN OPEN DIALOGUE

As you learn more about your disease, you should always feel empowered to share new information and update your doctor on new or worsening symptoms. In a survey of people living with NMOSD and their care partners, those who are "extremely comfortable" discussing other treatment options with their doctor are almost three times as satisfied with their care and almost twice as likely to have more good days than bad days.<sup>1</sup>

# WHAT TO ASK

Make the most out of your time with your doctor. These conversation starters can serve as a helpful guide for appointments.

- 1. Are my symptoms permanent or will they go away at some point?
- 2. Why does someone else I know with NMOSD have different symptoms than me?
- 3. What should I do if I develop new or worsening symptoms?
- 4. Are there factors that may trigger an NMOSD attack?
- 5. How can you tell if my treatment plan is working to manage NMOSD?
- 6. What lifestyle modifications should I make to help manage my disease?

Write any additional questions here: \_\_\_\_

# **NMOSD TERMS TO KNOW**

NMOSD is a complex disease and can feel challenging to understand. Familiarizing yourself with these common terms can help facilitate your discussion.

**Autoimmune disease:** A type of disease in which the body's immune system mistakenly attacks healthy cells, causing chronic inflammation and symptoms. The exact cause of these diseases is not always known.<sup>2</sup>

**B cells:** In a healthy immune system, B cells create antibodies that help protect the body from viruses and bacteria that cause illnesses like the common cold. In NMOSD, certain B cells mistakenly create AQP4 antibodies that target the central nervous system and can lead to NMOSD attacks.<sup>3</sup>

**Aquaporin-4 (AQP4):** A common protein that helps water enter and leave cells. AQP4 is targeted by the autoimmune system in about 80% of cases of NMOSD, which are referred to as AQP4 antibody positive (AQP4-IgG+) NMOSD.<sup>2,4</sup>

**Attack:** Also known as a relapse or flare, an NMOSD attack occurs when inflammation results in an acute increase in symptoms and severity.<sup>2</sup>

Transverse myelitis: Inflammation of the spinal cord, which can cause impaired mobility.<sup>2</sup>

**Optic neuritis:** Inflammation of the optic nerve (the nerve at the back of the eye) that can cause pain and vision problems.<sup>2</sup>

References: 1. Horizon Therapeutics plc. NMOSD Community Satisfaction Survey. *NMOSD Won't Stop Me. 2023*. 2. The Sumaira Foundation. What to KNOW about NMO. Accessed January 19, 2023. https://www.sumairafoundation.org/wp-content/uploads/2022/12/FLYER\_SumairaNMO\_121422-3-1.pdf 3. Bennett JL, O'Connor KC, Bar-Or A, et al. B lymphocytes in neuromyelitis optica. *Neurol Neuroimmunol Neuroinflamm*. 2015;2(3):e104. doi:10.1212/NXI.0000000000000104 4. Hamid SHM, Whittam D, Mutch K, et al. What proportion of AQP4-IgG-negative NMO spectrum disorder patients are MOG-IgG positive? A cross sectional study of 132 patients. *J Neurol*. 2017;264:2088-2094. doi:10.1007/s00415-017-8596-7

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