

# Navigating NMOSD starts with knowledge

Having neuromyelitis optica spectrum disorder (NMOSD) is out of your control, but finding the answers that you or your caregiver needs to help manage it is not. This discussion guide is designed to help you have an open and honest talk with your healthcare provider so that you can get the best care possible.



## BEFORE YOU GO

### Come prepared with questions

It's natural to have a lot of questions and concerns about NMOSD. Think about what you want to discuss, and jot down some questions before your visit. These will help you remember what you want to cover when you meet with your healthcare provider.

### Bring a family member or friend

Having someone go with you to your visit can be comforting. It also means that you will have an extra pair of ears to hear what your healthcare provider has to say.

### Take plenty of notes and get materials from your healthcare provider

There can be a lot of medical information to take in, so writing things down will help you remember the important details later. Don't be afraid to ask for more explanation if you hear unfamiliar medical terms. If you have difficulty taking notes, your healthcare provider may have more materials to give to you.



## TALK ABOUT YOUR SYMPTOMS

It's important that you be open with your healthcare provider about how NMOSD is affecting you. Be clear about what symptoms you may be having, when they began, how long they've lasted, and if they are getting worse.

**Check which symptoms below apply to you. Remember, not everyone experiences all of the symptoms of NMOSD:**

- |                                                                               |                                                           |
|-------------------------------------------------------------------------------|-----------------------------------------------------------|
| <input type="checkbox"/> Blurry vision                                        | <input type="checkbox"/> Persistent nausea                |
| <input type="checkbox"/> Partial/complete blindness                           | <input type="checkbox"/> Uncontrollable vomiting          |
| <input type="checkbox"/> Weakness and/or paralysis in my legs or arms         | <input type="checkbox"/> Persistent hiccups               |
| <input type="checkbox"/> Painful spasms                                       | <input type="checkbox"/> Bladder and/or bowel dysfunction |
| <input type="checkbox"/> Numbness and/or loss of sensation throughout my body | <input type="checkbox"/> Sleep problems                   |
|                                                                               | <input type="checkbox"/> Other: _____                     |



## TALK ABOUT YOUR GOALS

Lowering the chance of having a relapse is likely your #1 goal—and your healthcare provider's. But it's important to talk about any other goals that you may have for living with NMOSD.

**Check which goals below apply to you, and then share them with your healthcare provider:**

- ☐ Lowering my chance of having a relapse
- ☐ Finding a treatment that minimizes the impact on my immune system
- ☐ Improving my symptoms
- ☐ Being able to function at work and/or at home
- ☐ Finding a dosing schedule that won't disrupt my life too much
- ☐ Minimizing side effects that impact my day-to-day life
- ☐ Other goal(s): \_\_\_\_\_



## TALK ABOUT HOW YOU CAN BEST MANAGE NMOSD

NMOSD is a chronic disease that causes relapses, which can put you at risk for increased disability. Speak with your healthcare provider right away about a long-term treatment plan. If you are being treated for NMOSD and have new and/or worsening symptoms, your disease may not be fully under control. Or, if your disease is under control, perhaps you are experiencing chronic infections or other side effects from your treatment. Don't be afraid to speak up and ask questions.

Your healthcare provider can talk to you about all of your options to best manage NMOSD in the long run and to prevent further disability. Here are some questions to get the treatment conversation started:

### Conversation starters

- What's my risk of a relapse?
- How can I help reduce my risk of a relapse?
- How do I know if my treatment is working?
- What's causing the damage in my body, and can I stop it?
- What are some options for treating NMOSD?

**Interested in learning more about an important cause of damage in NMOSD?**

Visit [nmosd.com](https://nmosd.com) to discover more information.



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