

ZEROing In: A Guide for Talking About NMOSD and ULTOMIRIS With Your Neurologist



Navigating a conversation about Neuromyelitis Optica Spectrum Disorder (NMOSD) with your neurologist can feel overwhelming, but being prepared can make a difference. This guide offers things to reflect on your experience with NMOSD and provides questions to help ensure your discussion is as productive and informative as possible, so that you can feel more in control of your journey.

If you don't yet have a trusted neurologist to work with, you can visit <https://ultomiris.com/nmosd/find-nmosd-specialists> to find a local NMOSD specialist who can support you in navigating your condition.

Understanding NMOSD and Relapses

Questions to ask your neurologist:

- Could you explain how NMOSD affects my central nervous system, including the brain, spinal cord, and optic nerves?
- What are the common symptoms of NMOSD, and how do those relate to an NMOSD relapse?
- What are the warning signs of a potential relapse, and how can I recognize them early?
- What role does a relapse play in NMOSD? What does it mean for my symptoms and day-to-day life?

What to think about or bring up:

- Mention any recent or worsening symptoms you've experienced, such as fatigue, vision changes, or muscle weakness.
- If applicable, share details about how symptoms are affecting your daily life (eg, work, mobility, relationships).

INDICATION

What is ULTOMIRIS?

ULTOMIRIS is a prescription medicine used to treat adults with a disease called Neuromyelitis Optica Spectrum Disorder (NMOSD) who are anti-aquaporin 4 (AQP4) antibody positive. It is not known if ULTOMIRIS is safe and effective for the treatment of NMOSD in children.

IMPORTANT SAFETY INFORMATION

What is the most important information I should know about ULTOMIRIS?

ULTOMIRIS is a medicine that affects your immune system and may lower the ability of your immune system to fight infections.

Please see additional **Important Safety Information** throughout and full [Prescribing Information](#) and [Medication Guide](#) for ULTOMIRIS, including Boxed WARNING regarding serious meningococcal infections.

Discovering ULTOMIRIS as a Treatment Option and What to Expect



In the clinical trial, ULTOMIRIS reduced the risk of relapse by 98.6% compared to placebo.

The trial included 58 people treated with ULTOMIRIS and 47 people on placebo.

Placebo is an inactive substance or treatment that looks the same as, and is given in the same way as, the investigational medication being studied. As there are FDA-approved therapies available, the placebo group data were collected as part of a previously conducted trial.

Learn more about the clinical trial here: <https://ultomiris.com/nmosd/how-ultomiris-may-help>

Questions to ask your neurologist:

- Are there test(s) required for AQP4+ or NMOSD diagnosis?
- What should the goal of treatment be in NMOSD?
- What is ULTOMIRIS, and how well does it work for people living with NMOSD?
- How does ULTOMIRIS work, and what makes it different from other options?
- What is the dosing schedule for ULTOMIRIS, and how is it administered?
- What can I expect once I've started on ULTOMIRIS?
- ULTOMIRIS requires a meningococcal vaccination before getting started. Can you explain to me why that is?
- What are the potential side effects, and how are they typically managed?
- Will I need to adjust any existing medications or treatments before starting ULTOMIRIS?
- How can I monitor my response to treatment and track progress over time?
- Does the manufacturer offer financial support, or can they help with navigating the insurance process?

What to think about or bring up:

- If you're currently undergoing treatment, share your experience. Reflect on if you had relapses, big or small, since starting the treatment. Consider whether you've had any infections (like a UTI) or other issues that required a visit to a doctor or hospital. **Be sure to share this information with your neurologist as they may not be fully up to date on visits you might have had to the hospital or to see another provider.**
- If you are not yet on treatment, be clear about what your treatment priorities are (eg, reducing relapse risk).
- Alexion, the manufacturer of ULTOMIRIS, can offer financial assistance and additional support services to help you throughout your treatment journey. Be sure to ask your neurologist for more information about how to get connected to resources.

IMPORTANT SAFETY INFORMATION (Cont'd)

- **ULTOMIRIS increases your chance of getting serious meningococcal infections that may quickly become life-threatening or cause death if not recognized and treated early.**
 1. You must complete or update meningococcal vaccine(s) at least 2 weeks before your first dose of ULTOMIRIS.

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Wrapping Up + Knowing What's Next



Questions to ask your neurologist:

- How should I be monitoring my progress on my treatment plan?
- Are there any support services from the manufacturer of my medication that can help throughout my treatment journey?
- Are there patient support groups or online communities you recommend?
- Can you provide educational resources to help me and my family better understand NMOSD?

What to think about or bring up:

- Connect with programs like Alexion's OneSource™, which offers patient education, support, and resources for those on specific treatments. Be sure to raise this with your provider, so they can get you connected with someone from the OneSource team.
- Alexion can also connect you with another person living with NMOSD who has experience on ULTOMIRIS for a 1:1 conversation. If you'd like to get connected with someone, fill out a form at nmosdpeerconnects.com, and someone will be in touch with you shortly.

Remember, your neurologist is there to be your partner in managing NMOSD. Bring this guide to your next appointment to help leave with the clarity on how to move forward.

If you have further concerns, don't hesitate to reach out to Alexion's patient support program, OneSource by calling **1-888-765-4747** or emailing **OneSource@Alexion.com**



Ready to talk with a neurologist and have a conversation about ULTOMIRIS?

Visit ultomiris.com to find an NMOSD specialist local to you.

IMPORTANT SAFETY INFORMATION (Cont'd)

2. If you have not completed your meningococcal vaccines and ULTOMIRIS must be started right away, you should receive the required vaccine(s) as soon as possible.
3. If you have not been vaccinated and ULTOMIRIS must be started right away, you should also receive antibiotics for as long as your healthcare provider tells you.
4. If you had a meningococcal vaccine in the past, you might need additional vaccines before starting ULTOMIRIS. Your healthcare provider will decide if you need additional meningococcal vaccines.
5. Meningococcal vaccines do not prevent all meningococcal infections. **Call your healthcare provider or get emergency medical care right away if you get any of these signs and symptoms of a meningococcal infection:** fever, fever with high heart rate, headache and fever, confusion, muscle aches with flu-like symptoms, fever and a rash, headache with nausea or vomiting, headache with a stiff neck or stiff back, or eyes sensitive to light.

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Your healthcare provider will give you a Patient Safety Card about the risk of serious meningococcal infection. Carry it with you at all times during treatment and for 8 months after your last ULTOMIRIS dose. Your risk of meningococcal infection may continue for several months after your last dose of ULTOMIRIS. It is important to show this card to any healthcare provider who treats you. This will help them diagnose and treat you quickly.

ULTOMIRIS is only available through a program called the ULTOMIRIS and SOLIRIS Risk Evaluation and Mitigation Strategy (REMS). Before you can receive ULTOMIRIS, your healthcare provider must: enroll in the REMS program; counsel you about the risk of serious meningococcal infections; give you information about the signs and symptoms of serious meningococcal infection; make sure that you are vaccinated against serious infections caused by meningococcal bacteria, and that you receive antibiotics if you need to start ULTOMIRIS right away and are not up to date on your vaccines; give you a **Patient Safety Card** about your risk of meningococcal infection.

ULTOMIRIS may also increase the risk of other types of serious infections, including *Streptococcus pneumoniae*, *Haemophilus influenzae*, and *Neisseria gonorrhoeae*. Certain people may be at risk of serious infections with gonorrhea.



Who should not receive ULTOMIRIS?

Do not receive ULTOMIRIS if you have a serious meningococcal infection when you are starting ULTOMIRIS.

Before you receive ULTOMIRIS, tell your healthcare provider about all of your medical conditions, including if you:

- have an infection or fever
- are pregnant or plan to become pregnant. It is not known if ULTOMIRIS will harm your unborn baby.
 - Pregnancy Registry: There is a registry for pregnant women who take ULTOMIRIS to check the health of the pregnant mother and her baby. If you are pregnant or become pregnant while taking ULTOMIRIS, talk to your healthcare provider about how you can join this registry or you may contact the registry at 1-833-793-0563 or www.UltomirisPregnancyStudy.com to enroll.
- are breastfeeding or plan to breastfeed. It is not known if ULTOMIRIS passes into your breast milk. You should not breastfeed during treatment and for 8 months after your final dose of ULTOMIRIS.

Tell your healthcare provider about all the vaccines you receive and medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements which could affect your treatment.

What are the possible side effects of ULTOMIRIS?

ULTOMIRIS can cause serious side effects including infusion-related reactions. Symptoms of an infusion-related reaction with ULTOMIRIS may include lower back pain, stomach (abdominal) pain, muscle spasms, changes in blood pressure, tiredness, feeling faint, shaking chills (rigors), discomfort in your arms or legs, or bad taste. Stop treatment of ULTOMIRIS and tell your healthcare provider right away if you develop these symptoms, or any other symptoms during your ULTOMIRIS infusion that may mean you are having a serious infusion-related reaction, including: chest pain, trouble breathing or shortness of breath, swelling of your face, tongue, or throat, and feel faint or pass out.

The most common side effects of ULTOMIRIS in people with NMOSD are COVID-19 infection, headache, back pain, urinary tract infection, and joint pain (arthralgia).

Tell your healthcare provider about any side effect that bothers you or that does not go away. These are not all the possible side effects of ULTOMIRIS. For more information, ask your healthcare provider or pharmacist. Call your healthcare provider right away if you miss an ULTOMIRIS infusion or for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

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