

INFUSION GUIDE FOR NMO AND NMOSD

by National Infusion Center Association

with contributions from The Sumaira Foundation, Dr. Michael Levy, MD, PhD,
and The National Organization for Rare Disorders (NORD)



Neuromyelitis optica (NMO), Devic's disease, or neuromyelitis optica spectrum disorder (NMOSD) are different names for the same condition. **NMO is a rare autoimmune disease that causes inflammation of the optic nerves and spinal cord in the central nervous system (CNS).**

The disease manifests through relapses (also referred to as *attacks* or *exacerbations*). The most common relapses include **optic neuritis** (*inflammation of the optic nerve causing vision loss*), **myelitis** (*inflammation of the spinal cord causing potential paralysis and mobility issues*) or **area postrema syndrome** (*inflammation of a small area in the brain that causes nausea, vomiting, and hiccups*).

Immunosuppressive therapies, administered through **infusions**, are one of several treatment options for NMOSD. In some cases, such infusions can slow the progression of disease and reduce the risk of relapses.

If you have never had an infusion, the process may seem overwhelming or scary. The following information is designed to help ease your mind and prepare you for your infusion

HOW DO INFUSIONS WORK?



As opposed to taking medication by mouth, infused medicines are administered through a small tube that is placed in your hand or arm. Completing an infusion treatment can take anywhere from 2 - 6 hours, depending on the medication. The medication is very slowly administered directly into your bloodstream. Sometimes, you need to stay at the infusion center for a brief period of monitoring after the infusion is complete to ensure there are no adverse reactions or side effects.

ARE INFUSIONS JUST FOR CANCER?

Infusions may remind you of chemotherapy treatments for cancer, but they are also frequently used for other conditions and diseases, including rheumatoid arthritis, Crohn's and colitis, lupus, migraines, and chronic pain to name a few.

WHERE CAN I GET MY INFUSION?



There are a variety of sites of care where you can receive your infusion:

- Many healthcare providers have an infusion suite as part of their practice
- Free-standing infusion centers
- Hospital outpatient departments

It is important to choose a center that is familiar with your medicine's protocol and knows how to handle any adverse reactions the medicine could cause. Use **NICA's Infusion Center Locator** (locator.infusioncenter.org) to find a site of care near you.



DO ALL PEOPLE LIVING WITH NMOSD NEED INFUSIONS?

No, there are medications to treat NMOSD that are administered by mouth, injection, and infusion. Medications such as azathioprine, methotrexate, mycophenolate, rituximab, Soliris, and Uplizna are used to allow the reduction of steroids. All of these treatments increase the risk of serious infections. With an additional treatment option expected to be released in 2020 (*satralizumab by Roche*), it is extremely important to work with your healthcare provider to determine the best treatment plan for you.

ARE INFUSIONS PAINFUL OR UNCOMFORTABLE?

Getting an infusion can come with some discomfort, but typically infusions are not painful. Some infusion offices allow you to bring a family member or friend with you to your infusion. Infusion centers often provide snacks, blankets, and wifi to make your infusions as comfortable as possible. Depending on which infused medication you receive, you could be given medicines by mouth prior to your infusion to decrease the side effects of your infusion. It is important that you report any symptoms or side effects to your healthcare provider.

HOW DO I PAY FOR INFUSIONS?



Biologics can be expensive. When choosing an insurance plan, it is very important to select a plan with a deductible, out-of-pocket maximum, and infusion copay that you can afford. Some pharmaceutical companies offer copay cards that assist with the cost of your medication until your deductible is met. Ask your healthcare provider about available assistance programs for your medication.

The National Organization for Rare Disorders (NORD) offers RareCare®, a program that provides medication and financial assistance with insurance premiums and copays, diagnostic testing assistance, and travel assistance for clinical trials or consultation with disease specialists. To learn more about NORD's program for NMOSD, call 203-202-8833 or email NMOSD@rarediseases.org.

HOW LONG UNTIL MY SYMPTOMS IMPROVE?



Medications that treat NMOSD are preventive – they reduce relapses and can delay disability. They do not treat or reduce existing symptoms. It is important to discuss your treatment plan with your healthcare provider, so you know what to expect. It is important that you do not stop your treatment without talking to your healthcare provider.

This guide covers the basics of infusions for patients with NMOSD. Always ask your healthcare provider any questions you may have about your disease, treatment plan, or any other general questions. Infusions, when coupled with a comprehensive treatment plan, can be an integral part of managing your disease. NICA has more infusion resources, such as how to prepare for your infusion, located at

infusioncenter.org/education

The National Infusion Center Association aims to improve access to office-administered intravenous and injectable medications through advocacy, education, and resource development.

The Sumaira Foundation for NMO is an organization dedicated to generating global awareness of neuromyelitis optica spectrum disorder (NMOSD), fundraising to help find a cure, and creating a community of support for patients + their caregivers.

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The National Organization for Rare Disorders (NORD) is a nonprofit patient advocacy organization fighting to improve the lives of patients with rare diseases for over three decades through providing services and direct support to the rare community and leading innovation in policy and research.