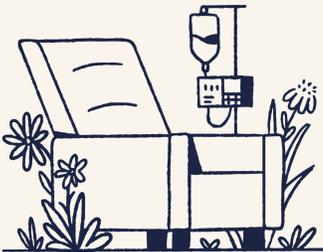


INFUSION GUIDE FOR NMOSD

Neuromyelitis optica spectrum disorder (NMOSD) and Devic's disease are different names for the same condition. NMO is an autoimmune disease that causes inflammation in different locations in the central nervous system. The disease manifests itself through relapses (also called exacerbations or attacks) and the most common relapses are of optic neuritis (inflammation of the optic nerve), myelitis (inflammation of the spinal cord) or syndrome of the area postrema (inflammation of a small area in the brain that causes nausea, vomiting and hiccups). Biologics, administered through infusions, are one of several treatment options for NMOSD. In some cases, infusions of a biologic can slow the progression of disease and reduce the risk of relapses. If you have never had an infusion, the process may seem daunting or scary. The following information is designed to help ease your mind.

HOW DO INFUSIONS WORK?



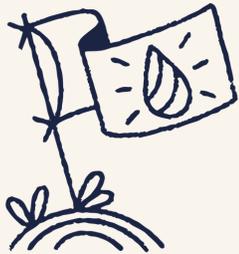
As opposed to taking medication by mouth, infused medicines are administered through a small tube that is placed in your hand or arm. Completing an infusion treatment usually takes a couple hours because the medicine is very slowly put directly into your bloodstream. Sometimes you need to stay at the infusion center for a brief period after the infusion is complete to be monitored for 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, like Rheumatoid Arthritis, Crohn's and Colitis, migraines, iron deficiency, and chronic pain to name a few.

WHERE CAN I GET MY INFUSION?



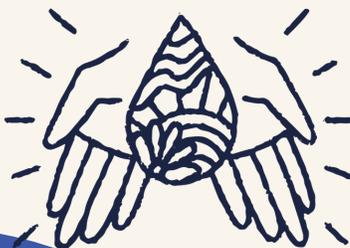
Your infusion does not have to be completed in a hospital; there are now several sites of care. Many healthcare providers have an infusion suite as part of their practice. Free-standing infusion centers and hospital outpatient departments also offer infusion services. It is important to choose a center that knows your medicine's protocol and knows how to handle any reactions the medicine could cause. Use the IAF Infusion Center Locator (patientaccess.org) to find a site of care near you.

DO ALL PEOPLE LIVING WITH NMOSD NEED INFUSIONS?



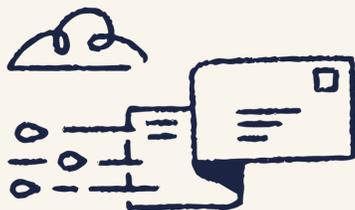
No, there are medications to treat NMOSD that are administered by mouth, injection and infusion. Drugs such as Prednisone, Azathioprine, Methotrexate, Mycophenolate and Rituximab are used to allow reduction of steroids. All of these treatments increase the risk of serious infections. With three additional treatment options now available to the NMOSD community (eculizumab by Alexion, satralizumab by Roche and inebilizumab by Horizon Therapeutics), 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 them to their infusion. Infusion centers often provide snacks, blankets, wifi, and IV warming (where your medication is heated to body temperature) to make your infusions as comfortable as possible. Depending on which infused medication you take, you could be given medicines by mouth prior to your infusion to lessen 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 very expensive. When choosing insurance, it is very important to select a plan with a deductible, out of pocket max, and infusion copay that you can afford. Some pharmaceutical companies offer copay cards that can assist with the cost of your medication until your deductible is met. Ask your healthcare provider about assistance programs for your medication. The National Organization for Rare Disorders (NORD) offers RareCare, a program providing 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, 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 patient access to office-administered intravenous and injectable medications through advocacy, education, and resource development.

The Sumaira Foundation is a 501(c)(3) organization dedicated to generating global awareness of NMOSD* and MOG-AD*, fundraising to support research to find a cure, and creating a community of support for patients + their caregivers.

Michael Levy, MD, PhD, is a neurologist with 12 years of clinical and research expertise in rare neuroimmunological disorders.

The National Organization of Rare Diseases (NORD) is a patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them, and is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.