Back-to-School Kit
Neuromyelitis Optica Spectrum Disorder (NMOSD)

Below is a brief summary of the disorder affecting your student. While the presentation of symptoms may vary, this overview provides general information on the onset and impacts of the disorder. We hope this information is helpful and assists you in supporting your student as they navigate the education system while also managing their condition.

What is neuromyelitis optica spectrum disorder, and who gets it?

Neuromyelitis optica spectrum disorder (NMOSD), also called Devic's Disease after Eugène Devic who first described the disorder, is an inflammatory disorder that affects the brain, optic nerves, and spinal cord. NMOSD can affect people of any age, affecting children as young as two years and adults as old as 90 years, but is most commonly diagnosed in adults between the ages of 20 and 40. It is more prevalent in women than men and disproportionately affects those of African descent.

What are the initial symptoms of NMOSD, and what are the chronic symptoms those with the disorder often manage long-term?

For most rare neuroimmune disorders like NMOSD, there is an initial onset where the body attacks itself. The aftereffects of attacks can lead to life-altering long-term symptoms that the person with the condition will need to manage. If the condition is monophasic, which means it only results in one attack at the onset, the child will only need to manage the symptoms from the damage of that single attack. If the condition is recurrent, the child will have continual attacks unless an effective treatment option is found.

NMOSD is most often diagnosed when a person is found to have a certain amount of the Aquaporin 4 (AQP4) antibody in their blood via a blood test. In autoimmune diseases like NMOSD, the immune system mistakenly makes antibodies against normal proteins like AQP4, a protein acts as a channel that helps control the flow of water in the nervous system, which damages astrocytes and causes inflammation, disrupting signals between the eye and the brain, in the brain itself, and between the brain and different parts of the body, causing a variety of health issues. NMOSD is usually recurrent.

The initial attack of this rare neuroimmune disorder can include any of the following issues. Additionally, if the child does not respond well to treatment or is left untreated, the damage caused can lead to the attack being a lifelong chronic symptom. Symptoms of this rare neuroimmune disorder include the following:

- **Optic neuritis**: inflammation in the optic nerve, which connects the back of your eye to your brain and sends signals that allow you to see, which results in vision loss in one or both eyes
- **Acute myelitis**: inflammation in the brain and/or spinal cord that can result in seizures, changes in behavior, mood, or thinking, and paralysis in affected parts of the body
- **Area postrema syndrome**: episodes of otherwise unexplained hiccups or nausea and vomiting lasting greater than two days
- **Acute brainstem syndrome**: inflammation in the back or bottom of the brain that often causes double vision or issues with balance and coordination, which can lead to walking difficulty
- **Symptomatic narcolepsy or acute diencephalic clinical syndrome with MRI findings**: the inflammation of the diencephalon, a part of the brain that controls various hormones, causing changes in sleep, eating, menstrual cycles, and other hormonal fluctuations

- **Symptomatic cerebral syndrome with MRI findings**: inflammation in the outer layer of the brain that often causes seizures, changes in thinking or behavior, and confusion

Some people may still be diagnosed with NMOSD even without testing positive for AQP4 antibody if they have two of the core characteristics mentioned above, with at least one of them being optic neuritis, acute myelitis with longitudinal extensive transverse myelitis (LETM), or area postrema syndrome, and meet special MRI criteria.

What are common accommodations students with NMOSD might need to access education?

The accommodations necessary for children with NMOSD can vary depending on the severity of its impact on the child, but the following are accommodations more frequently requested by those with NMOSD:

- Longer exam periods (cognitive dysfunction may slow function)
- Ability to sit and rest when needed (there may be some mobility issues present)
- Different ways of receiving material (may need visual, audible, tactile information)
- Preferential seating (may need the ability to sit close to the teacher to keep focus)
- Schedule adjustments (may need leniency on when assignments are due, particularly because of routine immunosuppressive therapies which may cause the child to miss some school)
- Ability to have access to restroom freely (may have loss of bladder control)

What does short-term treatment look like for those with NMOSD?

It's important for those with NMOSD to start treatment right away after diagnosis. Once diagnosed, the most common treatments are:

- **Intravenous steroids (methylprednisolone)**: usually the first-line therapy and is typically given for 3-5 days when symptoms causing a loss of function are present. People then usually take a decreasing amount of oral steroids over a few months to lower the risk of another attack. Most respond very well to steroids.

- **Plasmapheresis (Plasma Exchange or PLEX)**: often started in people with severe weakness or who do not recover function after steroids, but may also be started initially for those with more severe symptoms. PLEX is a process that involves the removal and return of some of a person's blood to remove harmful antibodies, including those against Aquaporin-4, also known as AQP-4.

- **Intravenous Immunoglobulin therapy (IVIG)**: sometimes considered in certain circumstances instead of the standard intravenous steroids and/or PLEX. IVIG is an intravenous infusion of antibodies taken from thousands of healthy people. These extra antibodies overwhelm the immune system and prevent it from attacking healthy proteins such as AQP-4.

Additionally, attacks in NMOSD have a recurrence of over 90%, and for this reason, most people are placed on long-term immunosuppressive therapies. By suppressing the immune system, antibodies are prevented from attacking normal proteins in patients with NMOSD.

What does the long-term management of NMOSD look like?

As a teacher, it's important to be aware of how NMOSD impacts students and to support their needs effectively.

For students on long-term NMOSD medication, maintaining good hygiene practices, such as regular hand-washing and wearing masks around those with contagious illnesses, is important. Immunosuppressive medications can increase the risk of infections, particularly in the respiratory and urinary systems, which may cause additional health problems if they occur frequently.

For students returning to school, it's important for families to address ongoing needs like special accommodations and support for physical challenges. Long-term management for families involves coordinating with medical professionals, acquiring necessary equipment, and reintegrating into school or community activities. Understanding the emotional impact of NMOSD on children and families is important as families will need to adapt to a new way of life post-hospitalization.

Those with NMOSD may experience long-term issues such as visual issues, muscle weakness, and bladder or bowel challenges. Children with NMOSD might face depression or anxiety, which need to be monitored and addressed with appropriate support. A combination of education, therapy, and ongoing support helps both the child with NMOSD and their loved ones navigate the physical and emotional impacts of NMOSD.

Is NMOSD genetic or contagious?

Currently, NMOSD is not thought to be caused by any genetic or hereditary condition. It is also not thought to be contagious, nor are any of the rare neuroimmune disorders we represent.

How can people cope with an NMOSD diagnosis?

Adapting to a “new normal” is difficult, and every person with NMOSD copes differently. Some have found it easier to cope after learning more about NMOSD from their doctors and getting a better understanding of how NMOSD will affect their lives. However, some parents may choose not to keep their child informed on some of the difficult aspects of having the condition due to the age and innocence of the child. We recommend speaking with the parents of the child to determine how much the child knows about their own condition.

Learn More

SRNA
wearesrna.org

Back-to-School Kit Teacher's Guide
srna.ngo/bts-tg

More information on NMOSD
srna.ngo/nmosd