Back-to-School Kit Optic Neuritis (ON)

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 optic neuritis, and who gets it?

Optic neuritis, or ON, is an inflammatory demyelinating condition of the central nervous system that damages the optic nerve, leading to vision problems like eye pain, color vision loss, or other issues. The optic nerve connects the back of your eye to your brain and sends signals that allow you to see. In ON, the immune system mistakenly attacks the myelin, the protective coating of the optic nerve. Inflammation occurs when the immune system treats specific parts of the body as foreign or like a virus it needs to fight off. This inflammation disrupts the signals between the eye and the brain, causing visual issues.

ON affects three times as many women as men, and it typically occurs between ages 20 and 45. Caucasians, especially those of northern European descent, have an eightfold higher likelihood of developing ON compared to Black and Asian individuals.

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

For most rare neuroimmune disorders like ON, 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.

In the acute (early) stages of ON, most people experience vision loss in one eye, although both eyes may be affected. ON often starts with reduced vision and color perception, accompanied by pain behind the eye that worsens with eye movement. Vision loss can range from mild blurring to complete darkness. Other signs include a variety of visual field issues, with central blind spots being most common, as well as light flashes, and abnormal response of the pupil to bright light. This attack can lead to lifelong chronic symptoms of headaches, visual impairment, and sensitivity.

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

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

- Different ways of receiving material (may need different forms of visual information, such as large print text, or a substitution for audible or tactile information disbursement)
- Preferential seating (may need the ability to sit close to the teacher/whiteboard due to visual impairment. If blind in the right eye, they should not be sat on the far left side of the classroom, and vice versa)
- Different ways of putting down information learned (may not be able to see and thus may be unable to write. Orating answers or using a digital device to transmit answers can be substituted)

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

Intravenous corticosteroids are the most common treatment for ON. Corticosteroids can shorten recovery time, but do not impact how much vision someone will regain. Severe cases of optic neuritis may be treated with plasmapheresis (plasma exchange or



PLEX). This is a process that involves the removal and return of some of a person's blood to remove harmful antibodies.

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

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

For students returning to school, it's important for families to address ongoing needs like special accommodations. 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 ON on children and families is important as families will need to adapt to a new way of life post-hospitalization.

Those with ON may experience long-term issues such as visual issues. Children with ON 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 ON and their loved ones navigate the physical and emotional impacts of ON.

Is ON genetic or contagious?

Currently, ON 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 ON diagnosis?

Adapting to a "new normal" is difficult, and every person with ON copes differently. Some have found it easier to cope after learning more about ON from their doctors and getting a better understanding of how ON 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 ON srna.ngo/on