Back-to-School Kit
Transverse Myelitis (TM)

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 transverse myelitis, and who gets it?

Transverse myelitis, or TM, refers to inflammation of the spinal cord. This type of inflammation occurs when the immune system treats specific parts of the body as foreign or like a virus or bacteria that it needs to fight off. This inflammation can damage the protective layer around the nerves of the spinal cord called myelin and can also damage the nerves directly.
Damage to the nerves of the spinal cord can interfere with these messages getting to and from different parts of the body. This can result in weakness and changes in how things feel. The inflammation can also lead to autonomic dysfunction, which causes problems with the part of the nervous system that controls involuntary activities, such as heart rate, breathing, and digestion.

TM is rare, with about 1,400 new cases per year in the U.S. TM is more likely to affect people between the ages of 10-19 and 30-39, although TM can happen at any age. About 25% of cases are in children.

What are the initial symptoms of TM, 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.

The initial onset of TM can happen over hours to days. Those with TM often have muscle weakness or paralysis that gets worse in a short amount of time. The spinal cord reaches from the bottom of the brain to the bottom of the back, and symptoms from TM depend on what part of the spinal cord has inflammation or damage. If the inflammation is lower in the spinal cord, only the legs become paralyzed or weak. If the inflammation is higher up in the spinal cord, it may affect both the arms and legs. In most people, sensations like vibration, temperature, and pain can change depending on where the spinal cord inflammation has occurred. Many people with TM also experience a painful or tight band-like feeling around their abdomen and back. Spinal cord inflammation can also make someone unable to control their bladder and/or bowels (incontinence) or affect their ability to feel their bladder and/or bowels normally.

The initial attack of this rare neuroimmune disorder can include any of the above issues—but, considering how sudden the onset of TM is, the damage caused can often lead to the attack being a lifelong chronic symptom. TM tends to be monophasic.

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

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

- Ability to sit and rest when needed (there may be some mobility issues present)
- Ability to have access to restroom freely (may have loss of bladder control)
- Physically accessible classrooms (weakness may prevent easy access to the classroom)
- Accessible workstations (may need space for mobility aids, or different space than peers)

- Alternatives to writing by hand (may have issues with holding a pencil and needs a different method of inputting answers)
- Adaptive tech that allows for writing (may use alternative methods such as computers to convey data and complete tests and homework)

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

It's important to start treatment right away after diagnosis. Once diagnosed, the most common treatments to treat the attack include the following:

- **Intravenous steroids (methylprednisolone)**: usually the first-line therapy

- **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.

- **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.

- **Cyclophosphamide**: only used if there is continued progression after intravenous steroids and PLEX.

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

As a teacher, it's important to be aware of how TM 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 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 TM on children and families is important as families will need to adapt to a new way of life post-hospitalization.

Those with TM may experience long-term issues such as pain, muscle weakness, and bladder or bowel challenges. Children with TM 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 TM and their loved ones navigate the physical and emotional impacts of TM.

Is TM genetic or contagious?

Currently, TM 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 advocate for.

How can people cope with a TM diagnosis?

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

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wearesrna.org

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

More information on TM
srna.ngo/tm

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