

TRANSVERSE MYELITIS

What is it?

Transverse Myelitis (TM) is a neurological disorder caused by inflammation across both sides of one segment of the spinal cord. During an inflammatory response the myelin or protective fatty coating on nerve cells is damaged or destroyed. This inflammation of the spinal cord interrupts the communication between nerve fibers in the spinal cord and the rest of the body, affecting sensation and nerve signaling below the injury. Symptoms include pain, sensory problems, weakness in the legs and possibly the arms, and bladder and bowel problems. The symptoms may develop suddenly over a period of hours or over days to weeks. There is no difference between genders. It can affect people of all ages but there is an increase in diagnosis between the ages of 10-19.

Researchers believe it is the body's immune response, not the infection itself, that causes the inflammatory response. This indicates an auto-immune reaction where the body attacks its own tissue rather than the infection. Research has made connections to the damage of spinal nerves following a viral or bacterial infection, especially those associated with a rash. According to the *National Institute of Neurologic Disorders and Stroke*, infectious agents suspected of causing TM include Varicella zoster (the virus that causes chickenpox and shingles), Herpes simplex, Cytomegalovirus, Epstein-Barr, Influenza, Echovirus, Human Immunodeficiency virus (HIV), Hepatitis A, and Rubella. In some cases, bacterial infections like a middle ear infection and bacterial pneumonia have also been linked.

What are the symptoms?

Symptoms can start slowly and progressively worsen over hours or days. Damage depends on the affected area of the spinal cord. Most cases involve damage at the thoracic level affecting bowel, bladder and legs. Back pain, muscle weakness and tingling sensations can progress to urinary retention, loss of bowel control and even paralysis.

- Pain as primary presenting symptoms
- Sharp, shooting sensation down the leg
- Numbness, tingling
- Difficulty voiding
- Constipation
- Coldness or burning
- Sensitivity to touch
- Temperature sensitivity
- Muscle spasms
- Headache
- Fever
- Loss of appetite

What is the treatment?

There is no current cure for TM. Treatments aim to alleviate symptoms and reduce spinal cord inflammation. Initial treatment with intravenous steroid therapy, plasma exchange and if needed pulse dose intravenous cyclophosphamide, as well as intensive physical, and occupational therapy. Nerve pain management and emotional support are also part of treatment and recovery. Recovery usually begins 2-12 weeks after the initial onset of symptoms but may take up to 2 years. About 1/3 of cases experience a full recovery while another 1/3 experience deficits with walking, sensory dysfunction and bowel and bladder control. The remaining 1/3 do not recover and their activities of daily living are extremely limited.



Kennedy Krieger Institute

The Specialized Health Needs Interagency Collaboration (SHNIC) program is a collaborative partnership between the Kennedy Krieger Institute and the Maryland State Department of Education.

Suggested school accommodations

Students will require support when they return to school due to the changes of their motor functions and the necessary and ongoing therapies for the student to be comfortable. Supporting students with this condition in the school require educators and parents/guardian to work as a team. Some accommodations to consider for a 504/IEP could include:

- PT/OT evaluations
- Modified or flexible school day
- Plan for absences and make-up work
- Preferential classroom seating (to see board easier, exit class without disturbances)
- Modified or limited homework
- Unlimited bathroom pass
- Elevator access if needed
- Temperature regulations
- Assistive technology
- Close classroom locations
- Note taker or computer
- Extra adult support if needed
- Emotional support to student
- Plan classes around fatigue
- Allow to participate in activities and gym per student's symptoms
- Safety concerns
- Staff education/training as appropriate
- Emergency Evacuation Plan (EEP)

Specific health issues for Individualized Healthcare Plan

- Diagnosis including age and child specific characteristics
- Current medication list including PRN medications
- Orders for catheterization including times and supplies needed
- Orders for temperature regulations if applicable
- Baseline skin assessment, including protocols for splints, orthotics and braces
- Nutrition orders and/or supplements required
- Plan for monitoring fatigue and/or rest break or area
- Educate school personnel about nature of disease
- Communicate with school staff, parents/guardian, and provider any changes or concerns about the disease
- Emergency Care Plan(s) (ECP) related to medical needs in the school setting and staff education/training as appropriate for each

Resources & Manuals

Transverse Myelitis Association

<http://myelitis.org>

National Institute of Neurological Disorders and Stroke

<https://www.ninds.nih.gov/Disorders/All-Disorders/Transverse-Myelitis-Information-Page>

Boston Children's Hospital- Acute Transverse Myelitis

<http://www.childrenshospital.org/conditions-and-treatments/conditions/acute-transverse-myelitis/overview>