Transverse Myelitis

Transverse myelitis (TM) is a neurological disorder caused by inflammation across one segment of the spinal cord. The term *myelitis* refers to inflammation of the spinal cord; *transverse* simply describes the position of the inflammation, across the width of the spinal cord. Attacks of inflammation can damage or destroy myelin, the fatty insulating substance that covers nerve cell fibers. This damage causes nervous system scars that interrupt communications between the nerves in the spinal cord and the rest of the body.

Symptoms of TM include a loss of spinal cord function over several hours to several weeks. What usually begins as a sudden onset of lower back pain, muscle weakness, or abnormal sensations in the toes and feet can rapidly progress to more severe symptoms, including paralysis, urinary retention, and loss of bowel control.

Some people recover from TM with minor or no residual problems, others suffer permanent impairments that affect their ability to perform ordinary tasks of daily living.

Demyelination usually occurs at the thoracic level, causing problems with leg movement and bowel and bladder control, which require signals from the lower segments of the spinal cord.

Transverse myelitis occurs in adults and children, in both genders, and in all races. No familial predisposition is apparent. The peak number of new cases per year appears to occur between 10 and 19 years and 30 and 39 years. About 1,400 new cases of transverse myelitis are diagnosed annually in the United States, and approximately 33,000 Americans have some type of disability resulting from TM.

The exact causes of transverse myelitis are not known. The inflammation that damages the spinal cord may result from viral infections, abnormal immune reactions, or insufficient blood flow through the blood vessels located in the spinal cord. Transverse myelitis also may occur as a complication of syphilis, measles, Lyme disease, and some vaccinations, including those for chickenpox and rabies.

Viral Theory

Transverse myelitis often develops following viral infections due to varicella zoster (the virus that causes chickenpox and shingles), herpes simplex, cytomegalovirus, Epstein-Barr, influenza, echovirus, human immunodeficiency virus (HIV), hepatitis A, or rubella. Bacterial skin infections, middle-ear infections and bacterial pneumonia have also been associated with the condition.

In post-infectious cases of TM, it is believed that the immune system, which normally protects the body from foreign organisms, mistakenly attacks the body's own tissue, causing inflammation and, in some cases, damage to myelin within the spinal cord.

Transverse myelitis may be either *acute* (developing over hours to several days) or *subacute* (developing over 1 to 2 weeks). Four classic features of transverse myelitis emerge: (1) weakness of the legs and arms, (2) pain, (3) sensory alteration, and (4) bowel and bladder dysfunction. Most patients will experience weakness of varying degrees in their legs; some also experience it in their arms. Progression of the disease over several weeks often leads to full paralysis of the legs, requiring the use of a wheelchair.

Pain is the primary symptom of transverse in about half of all patients. The pain may be localized in the lower back or may consist of sharp, shooting sensations that radiate down the legs or arms or around the torso. Up to 80 percent of those with transverse myelitis report areas of heightened sensitivity to touch, such that clothing or a light touch with a finger causes significant discomfort or pain (a condition called *allodynia*). Many also experience heightened sensitivity to changes in temperature or to extreme heat or cold.

Physicians diagnose transverse myelitis by taking a medical history and performing a thorough neurological examination.

Treatment

As with many disorders of the spinal cord, no effective cure currently exists for people with transverse myelitis. Treatments are designed to manage and alleviate symptoms and largely depend upon the severity of neurological involvement. Therapy generally begins when the patient first experiences symptoms. Physicians often prescribe corticosteroid therapy during the first few weeks of illness to decrease inflammation.

Following initial therapy, the most critical part of treatment for TM consists of keeping the patient's body functioning while hoping for either complete or partial spontaneous recovery of the nervous system. This may sometimes require placing the patient on a respirator.

Patients with acute symptoms, such as paralysis, are most often treated in a hospital or in a rehabilitation facility where a specialized medical team can prevent or treat problems that afflict paralyzed patients. Later, if patients begin to recover limb control, physical therapy begins to help improve muscle strength, coordination, and range of motion.

Prognosis

Recovery from transverse myelitis usually begins within 2 to 12 weeks of the onset of symptoms and may continue for up to 2 years. However, if there is no improvement within the first 3 to 6 months, significant recovery is unlikely. About one-third of people affected with transverse myelitis experience good or full recovery from their symptoms. Another one-third show fair recovery and are left with deficits such as spastic gait, sensory dysfunction, and prominent urinary urgency or incontinence. The remaining one-third show no recovery at all, using wheelchairs, perhaps with marked dependence on others for basic functions of daily living.

The National Institute of Neurological Disorders and Stroke (NINDS) supports research to clarify the role of the immune system in TM and other autoimmune diseases or disorders. Other work focuses on strategies to repair demyelinated spinal cords including approaches using cell transplantation. The ultimate goals of these studies are to encourage the same regeneration in humans and to restore function to paralyzed patients.

Source: National Institute of Neurological Disorders and Stroke (NINDS), Transverse Myelitis Association

The above excerpt is from the Christopher & Dana Reeve Foundation Paralysis Resource Center website.
https://www.christopherreeve.org/living-with-paralysis/health/causes-of-paralysis/transverse-myelitis

Websites

Johns Hopkins Transverse Myelitis Center
http://www.hopkinsmedicine.org/neurology_neurosurgery/specialty_areas/transverse_myelitis/
Johns Hopkins Hospital
Pathology 627
600 North Wolfe Street
Baltimore, MD 21287
Phone: 410-502-7099, option 1
This Center is the first in the world dedicated to the diagnosis, clinical management, and research of transverse myelitis. A team of neurologists, rehabilitation specialists, neuropsychiatrists, neurosurgeons, neuro-ophthalmologists, therapists, and other scientists provide a comprehensive diagnostic evaluation of transverse myelitis and maximize treatment, recovery and function in patients.

Cody Unser First Step Foundation
https://www.facebook.com/codysfirststep/
P.O. Box 56696
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Phone: 505-792-9551

The Cody Unser First Step Foundation is a not-for-profit corporation raising research funds to fight paralysis and to build awareness of transverse myelitis. Named for Cody Unser, who was diagnosed with TM at age 12.

Siegel Rare Neuroimmune Association (SRNA) (formerly Transverse Myelitis Association)
https://wearesrna.org/
1787 Sutter Parkway
Powell, OH 43065-8806
Phone: 1-855-380-3330
Email: info@myelitis.org
The SRNA is an advocacy organization for people with transverse myelitis and other neuro-immunologic disorders of the central nervous system. The organization provides news and information, facilitates support and networking; functions as a clearinghouse for articles and research literature about the TM diagnosis; and investigates and supports research and innovative treatment efforts.

> **SRNA: Smart Patients**
> https://www.smartpatients.com/partners/transverse-myelitis-association
> This page offers an online community.

American Academy of Neurology: Evidence-based Guidelines on Transverse Myelitis
http://journals.lww.com/neurotodayonline/Fulltext/2011/12150/AAN_Releases_First_Evidence_based_Guidelines_on.2.aspx
AAN has issued an evidence-based guideline for the clinical evaluation and treatment of transverse myelitis.

Brain and Spine Foundation: Transverse Myelitis
http://www.brainandspine.org.uk/our-publications/booklets/transverse-myelitis/
This booklet provides information on causes, treatment, and prognosis. It can be downloaded as a PDF.

Evidence-based guideline: Clinical evaluation and treatment of transverse myelitis: Report of the Therapeutics and Technology Assessment Subcommittee of the American Academy of Neurology
https://www.neurology.org/doi/10.1212/WNL.0b013e31823dc535
T.F. Scott, E.M. Frohman, J. De Seze, et al. *Neurology* Dec. 2011 pages 2128-2134.

Merck Manual Home Health Handbook: Acute Transverse Myelitis
http://www.merckmanuals.com/home/brain_spinal_cord_and_nerve_disorders/spinal_cord_disorders/acute_transverse_myelitis.html
This page offers information on TM for patients and caregivers.

National Institute on Neurological Disorders and Stroke (NINDS): Transverse Myelitis Information Page
https://www.ninds.nih.gov/Disorders/All-Disorders/Transverse-Myelitis-Information-Page

NINDS: Transverse Myelitis Fact Sheet
https://www.ninds.nih.gov/health-information/disorders/transverse-myelitis?search-term=transverse%20myelitis

National Organization for Rare Disorders (NORD): Transverse Myelitis
https://rarediseases.org/rare-diseases/transverse-myelitis/

Clinical Trials

The first Phase I clinical trial using Q-cells for those with transverse myelitis was announced in Oct. 2018.

FAQ developed for the community:
https://wearesrna.org/clinical-studies-and-trials/upcoming-phase-i-human-clinical-trial-using-q-cells-in-transverse-myelitis/

Press release:
https://www.utsouthwestern.edu/newsroom/articles/year-2018/reversing-paralysis.html

Neuromyelitis Optica (NMO) Resources

Guthy-Jackson Charitable Foundation
http://www.guthyjacksonfoundation.org
Beverly Hills, CA
Phone: 310-620-3074
Email: info@guthyjacksonfoundation.org
The Foundation is dedicated to funding basic science research to prevent, treat and cure Neuromyelitis Optica (NMO) Spectrum Disease Neuromyelitis Optica (NMO)--a disease syndrome of the central nervous system that affects the optic nerves and spinal cord.

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