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 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.

Q: What causes Transverse Myelitis?

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. Nerve cells in the spinal cord are damaged, and this interrupts the signals between spinal nerves and the rest of the body, which can cause issues such as loss of sensation and/or movement and bladder/bowel control.

Q: Are there different types of Transverse Myelitis?

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 weaknesses 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.

Classifications of Transverse Myelitis Based on Severity and Spread

- **Partial (or incomplete) Transverse Myelitis:** Patchy inflammation affecting part of the spinal cords width, often resulting in asymmetrical symptoms.
- **Complete Transverse Myelitis:** Severe inflammation spanning the full width of the cord, leading to complete dysfunction below the lesion.
- **Longitudinally Extensive Transverse Myelitis (LETM):** Lesions extending over three or more vertebral segments.
- **Gray Matter-Centric Transverse Myelitis:** Effects the center and or front of the spinal cord (common in acute flaccid myelitis).

Q: How is it diagnosed?

Physicians diagnose transverse myelitis by taking a medical history and performing a thorough neurological examination. Doctors will look for abnormal inflammation of the spinal cord and spinal cord symptoms which develop over a few days. An MRI of the spine and brain may also be used to help with the diagnosis.

Q: What are the symptoms/side effects of TM?

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. Other side effects may include bladder and bowel management issues and sexual dysfunction.

Q: How is it treated?

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.

Q: Are there any clinical trials for Transverse Myelitis?

There are clinical trials for Transverse Myelitis looking into symptom management, targeted therapies, and gene therapies. Generally, https://clinicaltrials.gov/ is a good source of information for new and completed trials.

Q. How is Transverse Myelitis managed long term?

Long term management of TM will include managing secondary conditions including bladder management, bowel management, skin care to prevent pressure injuries, management of sexual dysfunction. Issues with pain and spasticity will also need to be addressed.

Q. Are there any advances in diagnosing and treating Transverse Myelitis?

Recently, diagnosis of TM now focuses more on identifying the underlying causes, such as MOG antibody disease (MOGAD), or neuromyelitis optica spectrum disorder (NMOSD), to guide specialized treatments.

Following diagnosis, newer rehabilitation technologies such as wearable exoskeletons are being used as for gait re-education and to prevent muscle atrophy. Research is also exploring neuroprotective agents to repair spinal cord damage and immunomodulatory drugs for cases resistant to first-line therapies.

Sources: National Institute of Neurological Disorders and Stroke (NINDS), Siegel Rare Neuroimmune Association, National Institute of Health, Cleveland Clinic, OHSU Brain Institute

Need to talk to someone?
Our Information Specialists are available to answer your questions.
Call toll-free 1-800-539-7309 Mon-Fri, 7 am-8 pm EST.
Or schedule a call or ask a question online at
https://www.ChristopherReeve.org/Ask.

Resources for Transverse Myelitis:

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 effort.

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_Evi dence_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.

Cody Unser First Step Foundation
https://www.facebook.com/codysfirststep/
P.O. Box 56696
Albuquerque, NM 87187
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.

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.

Johns Hopkins Transverse Myelitis Center
https://www.hopkinsmedicine.org/neurology-neurosurgery/specialty-areas/myelitismyelopathy
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 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.

Merck Manual Home Health Handbook: Acute Transverse Myelitis
https://www.merckmanuals.com/home/brain-spinal-cord-and-nerve-disorders/spinalcord-disorders/acute-transverse-myelitis?query=transverse%20myelitis
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?searchterm=transverse%20myelitis

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

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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