



The following excerpt has been taken from the Christopher & Dana Reeve Foundation Paralysis Resource Center website.

http://www.paralysis.org/site/c.erJMJUOxFmH/b.1293649/k.FFDD/Transverse_Myelitis.htm

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

Websites:

The **Johns Hopkins Hospital Department of Neurology** has established a clinical center for non-surgical causes of spinal cord dysfunction, including myelopathy and transverse myelitis. Experts are available in neurology, urology, rheumatology, orthopedic surgery, neuroradiology, rehabilitation medicine and physical and occupational therapy. The goal is to provide a comprehensive diagnostic evaluation and maximize recovery and function.

<http://www.hopkinsneuro.org/tm/>

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 12 when diagnosed with TM.

www.codysfirststep.org

Transverse Myelitis Association Features news and information for the TM community, 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.

www.myelitis.org

They sponsor an online discussion list for those with TM who wish to communicate with one another. www.myelitis.org/tmic/

Transverse Myelitis Association's Equipment Swap Forum

<http://www.myelitis.org/forum/viewforum.php?f=62>

for exchanging or giving away equipment for free.

National Institute on Neurological Disorders and Stroke (NINDS) offers a detailed fact sheet on TM.

www.ninds.nih.gov/health_and_medical/disorders/transversemyelitis_doc.htm

Local Transverse Myelitis Support Groups lets you locate a local TM Support Group by clicking on an area via the TM web site page for support group listings.

<http://www.myelitis.org/support.htm>

Transverse Myelitis Internet Club provides a forum for people to communicate with others about Transverse Myelitis, including discussion group, bulletin board, and additional resources.

<http://www.myelitis.org/tmic/>

Transverse Myelitis Network: online forum

<http://transversemyelitis.ning.com/>

Transverse Myelitis: A Guide for Patients and Carers provides information on causes, treatment, and prognosis in booklet format, downloadable from here:

http://www.brainandspine.org.uk/information/publications/brain_and_spine_booklets/transverse_myelitis/index.html

Merck Manual: Acute Transverse Myelitis.

<http://www.merck.com/mrksearch/SearchServlet?HeaderImage=&HeaderImageAlt=&q=transverse%20myelitis>

Offers information on TM for patients, caregivers, and healthcare providers.

The following books and videos are available for free loan from the PRC library. For more information, please see www.paralysis.org and click the Lending Library tab.

Books

- Holcombe, Marjorie B. **The Will to Walk: Journey of Recovery from Paralysis**. Precious Sounds, 2010.
- James N. Parker, M.D. and Philip M. Parker, PH.D, Editors. **Transverse Myelitis: A Revised and Updated Directory for the Internet Age**. San Diego, CA: ICON Group Publications, 2002.
- Rucker, Allen. **The Best Seat in the House: How I Woke Up One Tuesday and Was Paralyzed for Life**. New York: HarperCollins, 2007.
Rucker is a TV writer and author who became paraplegic at the T10 level from TM at the age of 51.

- Tabak, Herb. **No Whining: Craig Hospital Spinal Cord Injury Rehab: Reaching New Heights**. Lincoln, Neb. : iUniverse, 2006.

Videos

Cody: The First Step. New York, NY: Cinema Guild, 2009. DVD 69 minutes.
Documentary on Cody Unser who was diagnosed at age 12 with TM and founded the Cody Unser First Step Foundation.

The information contained in this message is presented for the purpose of educating and informing you about paralysis and its effects. Nothing contained in this message should be construed nor is intended to be used for medical diagnosis or treatment. It should not be used in place of the advice of your physician or other qualified health care provider. Should you have any health care related questions, please call or see your physician or other qualified health care provider promptly. Always consult with your physician or other qualified health care provider before embarking on a new treatment, diet or fitness program. You should never disregard medical advice or delay in seeking it because of something you have read in this message.