

National Institute of Neurological Disorders and Stroke

Transverse Myelitis Fact Sheet

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What is transverse myelitis?

Transverse myelitis is a neurological disorder caused by inflammation across both sides of one level, or segment, of the spinal cord. The term *myelitis* refers to inflammation of the spinal cord; *transverse* simply describes the position of the inflammation, that is, 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 transverse myelitis 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. Although some patients recover from transverse myelitis with minor or no residual problems, others suffer permanent impairments that affect their ability to perform ordinary tasks of daily living. Most patients will have only one episode of transverse myelitis; a small percentage may have a recurrence.

The segment of the spinal cord at which the damage occurs determines which parts of the body are affected. Nerves in the cervical (neck) region control signals to the neck, arms, hands, and muscles of breathing (the diaphragm). Nerves in the thoracic (upper back) region relay signals to the torso and some parts of the arms. Nerves at the lumbar (mid-back) level control signals to the hips and legs. Finally, sacral nerves, located within the lowest segment of the spinal cord, relay signals to the groin, toes, and some parts of the legs. Damage at one segment will affect function at that segment and segments below it. In patients with transverse myelitis, 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.

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Who gets transverse myelitis?

Transverse myelitis occurs in adults and children, in both genders, and in all races. No familial predisposition is apparent. A peak in incidence rates (the number of new cases per year) appears to occur between 10 and 19 years and 30 and 39 years. Although only a few studies have examined incidence rates, it is estimated that about 1,400 new cases of transverse myelitis are diagnosed each year in the United States, and approximately 33,000 Americans have some type of disability resulting from the disorder.

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What causes transverse myelitis?

Researchers are uncertain of the exact causes of transverse myelitis. The inflammation that causes such extensive damage to nerve fibers of 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. Cases in which a cause cannot be identified are called *idiopathic*.

Transverse myelitis often develops following viral infections. Infectious agents suspected of causing transverse myelitis 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. Bacterial skin infections, middle-ear infections (*otitis media*), and *Mycoplasma pneumoniae* (bacterial pneumonia) have also been associated with the condition.

In post-infectious cases of transverse myelitis, immune system mechanisms, rather than active viral or bacterial infections, appear to play an important role in causing damage to spinal nerves. Although researchers have not yet identified the precise mechanisms of spinal cord injury in these cases, stimulation of the immune system in response to infection indicates that an autoimmune reaction may be responsible. In autoimmune diseases, 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.

Because some affected individuals also have autoimmune diseases such as systemic lupus erythematosus, Sjogren's syndrome, and sarcoidosis, some scientists suggest that transverse myelitis may also be an autoimmune disorder. In addition, some cancers may trigger an abnormal immune response that may lead to transverse myelitis.

An acute, rapidly progressing form of transverse myelitis sometimes signals the first attack of multiple sclerosis (MS), however, studies indicate that most people who develop transverse myelitis do not go on to develop MS. Patients with transverse myelitis should nonetheless be screened for MS because patients with this diagnosis will require different treatments.

Some cases of transverse myelitis result from spinal arteriovenous malformations (abnormalities that alter normal patterns of blood flow) or vascular diseases such as atherosclerosis that cause *ischemia*, a reduction in normal levels of oxygen in spinal cord tissues. Ischemia can result from bleeding (*hemorrhage*) within the spinal cord, blood vessel blockage or narrowing, or other less common factors. Blood vessels bring oxygen and nutrients to spinal cord tissues and remove metabolic waste products. When these vessels become narrowed or blocked, they cannot deliver sufficient amounts of

oxygen-laden blood to spinal cord tissues. When a specific region of the spinal cord becomes starved of oxygen, or ischemic, nerve cells and fibers may begin to deteriorate relatively quickly. This damage may cause widespread inflammation, sometimes leading to transverse myelitis. Most people who develop the condition as a result of vascular disease are past the age of 50, have cardiac disease, or have recently undergone a chest or abdominal operation.

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What are the symptoms of transverse myelitis?

Transverse myelitis may be either *acute* (developing over hours to several days) or *subacute* (developing over 1 to 2 weeks). Initial symptoms usually include localized lower back pain, sudden *paresthesias* (abnormal sensations such as burning, tickling, pricking, or tingling) in the legs, sensory loss, and *paraparesis* (partial paralysis of the legs). Paraparesis often progresses to *paraplegia* (paralysis of the legs and lower part of the trunk). Urinary bladder and bowel dysfunction is common. Many patients also report experiencing muscle spasms, a general feeling of discomfort, headache, fever, and loss of appetite. Depending on which segment of the spinal cord is involved, some patients may experience respiratory problems as well.

From this wide array of symptoms, 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. Initially, people with transverse myelitis may notice that they are stumbling or dragging one foot or that their legs seem heavier than normal. Coordination of hand and arm movements, as well as arm and hand strength may also be compromised. Progression of the disease over several weeks often leads to full paralysis of the legs, requiring the patient to use a wheelchair.

Pain is the primary presenting symptom of transverse myelitis in approximately one-third to one-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.

Patients who experience sensory disturbances often use terms such as *numbness*, *tingling*, *coldness*, or *burning* to describe their symptoms. 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.

Bladder and bowel problems may involve increased frequency of the urge to urinate or have bowel movements, incontinence, difficulty voiding, the sensation of incomplete evacuation, and constipation. Over the course of the disease, the majority of people with transverse myelitis will experience one or several of these symptoms.

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How is transverse myelitis diagnosed?

Physicians diagnose transverse myelitis by taking a medical history and performing a thorough neurological examination. Because it is often difficult to distinguish between a patient with an idiopathic form of transverse myelitis and one who has an underlying condition, physicians must first eliminate potentially treatable causes of the condition. If

When a spinal cord injury is suspected, physicians seek first to rule out *lesions* (damaged or abnormally functioning areas) that could cause spinal cord compression. Such potential lesions include tumors, herniated or slipped discs, *stenosis* (narrowing of the canal that holds the spinal cord), and abscesses. To rule out such lesions and check for inflammation of the spinal cord, patients often undergo *magnetic resonance imaging* (MRI), a procedure that provides a picture of the brain and spinal cord. Physicians also may perform *myelography*, which involves injecting a dye into the sac that surrounds the spinal cord. The patient is then tilted up and down to let the dye flow around and outline the spinal cord while X-rays are taken.

Blood tests may be performed to rule out various disorders such as systemic lupus erythematosus, HIV infection, and vitamin B12 deficiency. In some patients with transverse myelitis, the cerebrospinal fluid that bathes the spinal cord and brain contains more protein than usual and an increased number of leukocytes (white blood cells), indicating possible infection. A spinal tap may be performed to obtain fluid to study these factors.

If none of these tests suggests a specific cause, the patient is presumed to have idiopathic transverse myelitis.

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How is transverse myelitis 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. Although no clinical trials have investigated whether corticosteroids alter the course of transverse myelitis, these drugs often are prescribed to reduce immune system activity because of the suspected autoimmune mechanisms involved in the disorder. Corticosteroid medications that might be prescribed may include methylprednisone or dexamethasone. General analgesia will likely be prescribed for any pain the patient may have. And bedrest is often recommended during the initial days and weeks after onset of the disorder.

Following initial therapy, the most critical part of the treatment for this disorder 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. Often, even before recovery begins, caregivers may be instructed to move patients' limbs manually to help keep the muscles flexible and strong, and to reduce the likelihood of pressure sores developing in immobilized areas. Later, if patients begin to recover limb control, physical therapy begins to help improve muscle strength, coordination, and range of motion.

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What therapies are available to help patients left with permanent physical disabilities?

Many forms of long-term rehabilitative therapy are available for people who have

permanent disabilities resulting from transverse myelitis. Medical social workers, often affiliated with local hospitals or outpatient clinics, are the best sources for information about treatment programs and other resources that exist in a community. Rehabilitative therapy teaches people strategies for carrying out activities in new ways in order to overcome, circumvent, or compensate for permanent disabilities. Rehabilitation as yet cannot reverse the physical damage resulting from transverse myelitis or other forms of spinal cord injury. But it can help people, even those with severe paralysis, become as functionally independent as possible and thereby attain the best possible quality of life.

Commonly experienced permanent neurological deficits resulting from transverse myelitis include severe weakness, *spasticity* (painful muscle stiffness or contractions), or paralysis; incontinence; and chronic pain. Such deficits can substantially interfere with a person's ability to carry out everyday activities such as bathing, dressing, and performing household tasks.

People living with permanent disability may feel a range of emotions, from fear and sadness to frustration and anger. Such feelings are natural responses, but they can sometimes jeopardize health and potential for functional recovery. Those with permanent disabilities frequently experience clinical depression. Fortunately, depression is treatable, due to the development of a wide range of medications that can be used with psychotherapeutic treatment.

Today, most rehabilitation programs attempt to address the emotional dimensions along with the physical problems resulting from permanent disability. Patients typically consult with a range of rehabilitation specialists, who may include physiatrists (physicians specializing in physical medicine and rehabilitation), physical therapists, occupational therapists, vocational therapists, and mental health care professionals.

Physical Therapy: Physiatrists and physical therapists treat disabilities that result from motor and sensory impairments. Their aim is to help patients increase their strength and endurance, improve coordination, reduce spasticity and muscle wasting in paralyzed limbs, and regain greater control over bladder and bowel function through various exercises. Physiatrists and physical therapists teach paralyzed patients techniques for using assistive devices such as wheelchairs, canes, or braces as effectively as possible. Paralyzed patients also learn ways to avoid developing painful pressure sores on immobilized parts of the body, which may lead to increased pain or systemic infection. In addition, physiatrists and physical therapists are involved in pain management. A wide variety of drugs now exist that can alleviate the pain that results from spinal cord injuries such as those caused by transverse myelitis. These include nonsteroidal anti-inflammatory drugs such as ibuprofen or naproxen; antidepressant drugs such as amitriptyline (tricyclic) and sertraline (a selective serotonin reuptake inhibitor); and anticonvulsant drugs such as phenytoin and gabapentine.

Occupational Therapy: Occupational therapists help patients learn new ways of performing meaningful, self-directed, goal-oriented, everyday tasks (*occupations*) such as bathing, dressing, preparing a meal, house cleaning, engaging in arts and crafts, or gardening. They teach people how to develop compensatory strategies, how to make changes in their homes to improve safety (such as installing grab bars in bathrooms), how to change obstacles in their environment that interfere with normal activity, and how to use assistive devices.

Vocational Therapy: In addition to acquainting people with their rights as defined under the Americans with Disabilities Act of 1990 and helping people develop and promote work skills, vocational therapists identify potential employers, assist in job searches, and act as mediators between employees and employers to secure reasonable workplace accommodations.

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What is the 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; they regain the ability to walk normally and experience minimal urinary or bowel effects and paresthesias. Another one-third show only fair recovery and are left with significant deficits such as spastic gait, sensory dysfunction, and prominent urinary urgency or incontinence. The remaining one-third show no recovery at all, remaining wheelchair-bound or bedridden with marked dependence on others for basic functions of daily living. Unfortunately, making predictions about individual cases is difficult. However, research has shown that a rapid onset of symptoms generally results in poorer recovery outcomes.

The majority of people with this disorder experience only one episode although in rare cases recurrent or relapsing transverse myelitis does occur. Some patients recover completely, then experience a relapse. Others begin to recover, then suffer worsening of symptoms before recovery continues. In all cases of relapse, physicians will likely investigate possible underlying causes such as MS or systemic lupus erythematosus since most people who experience relapse have an underlying disorder.

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What research is being done?

Within the Federal Government, the National Institute of Neurological Disorders and Stroke (NINDS), one of the National Institutes of Health (NIH), has primary responsibility for conducting and supporting research on spinal cord disorders and demyelinating diseases such as transverse myelitis. The NINDS conducts research in its laboratories at the NIH and also supports studies through grants to major medical institutions across the country.

NINDS researchers seek to clarify the role of the immune system in the pathogenesis of demyelination in autoimmune diseases or disorders. Other work focuses on strategies to repair demyelinated spinal cords including approaches using cell transplantation. The knowledge gained from such research should lead to a greater knowledge of the mechanisms responsible for demyelination in transverse myelitis and may ultimately provide a means to prevent and treat this disorder.

The NINDS also funds researchers who are using animal models of spinal cord injury to study strategies for replacement or regeneration of spinal cord nerve cells. The ultimate goals of these studies are to encourage the same regeneration in humans and to restore function to paralyzed patients. Scientists are also developing neural prostheses to help patients with spinal cord damage compensate for lost function. These sophisticated electrical and mechanical devices connect with the nervous system to supplement or replace lost motor and sensory function. Neural prostheses for spinal cord injured patients are being tested in humans.

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Where can I get more information?

For more information on neurological disorders or research programs funded by the National Institute of Neurological Disorders and Stroke, contact the Institute's Brain Resources and Information Network (BRAIN) at:

BRAIN
P.O. Box 5801
Bethesda, MD 20824
(800) 352-9424
<http://www.ninds.nih.gov>

Information also is available from the following organizations:

Transverse Myelitis Association

1787 Sutter Parkway
Powell, OH 43065-8806
info@myelitis.org
<http://www.myelitis.org>
Tel: 614-766-1806

American Chronic Pain Association (ACPA)

P.O. Box 850
Rocklin, CA 95677-0850
ACPA@pacbell.net
<http://www.theacpa.org>
Tel: 916-632-0922 800-533-3231
Fax: 916-632-3208

**Miami Project to Cure Paralysis/
Buoniconti Fund**

P.O. Box 016960
R-48
Miami, FL 33101-6960
mpinfo@miamiproject.med.miami.edu
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Tel: 305-243-6001 800-STANDUP (782-6387)
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4200 Forbes Boulevard
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Lanham, MD 20706-4829
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"Transverse Myelitis Fact Sheet," NINDS.

NIH Publication No. 01-4841

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Last updated February 14, 2007

