



About Tethered Cord Syndrome

Tethered Cord Syndrome (TCS) is a rare neurological disorder in which the spinal cord becomes abnormally attached to surrounding tissues or structures within the spinal column. This attachment restricts the natural movement of the spinal cord as a person grows or experiences physical stress. Normally, the spinal cord floats freely within the spinal canal, surrounded by cerebrospinal fluid that cushions and allows it to move slightly with the body's movements. However, in TCS, the tethering causes the spinal cord to be pulled and stretched, leading to abnormal tension.

Over time, this increased tension can cause nerve damage, affecting the function of the legs, bladder, bowel, and other systems controlled by the spinal cord. This condition can be congenital (present at birth), often associated with neural tube defects like spina bifida, or a thickened or fatty filum terminale, but can also develop in individuals without a history of neural tube conditions. Alternatively, it can be acquired later in life due to spinal injury, surgery, or scar tissue buildup. TCS is often linked to connective tissue disorders such as Ehlers-Danlos Syndrome (EDS) that can lead to hyperelasticity and weakness of the tissues, increasing the likelihood of tethering due to abnormal tissue formation or laxity. The severity and timing of symptoms can vary widely, with some individuals experiencing mild discomfort or no symptoms at all, while others may face debilitating neurological complications that progress over time. As the spinal cord stretches, the damage can worsen, and if left untreated, it can lead to permanent disability.

TCS is considered rare, with an estimated occurrence of about 1 in 4,000 children. Symptoms may not emerge until later in childhood or even adulthood, and the condition may go undiagnosed for years. Early diagnosis and surgical intervention are key to preventing long-term neurological damage.

Causes

TCS may be congenital (present at birth) or acquired later in life.

- In congenital cases, it's often related to spina bifida or abnormalities in spinal cord development, such as a thickened filum terminale or fatty masses (lipomas).
- Acquired tethering may occur after spinal cord injury, surgery, or scar tissue formation.

Some individuals with tethered cord may not experience symptoms until childhood, adolescence, or even adulthood, particularly during growth spurts, pregnancy, or spinal degeneration.

Symptoms

Symptoms vary depending on the age of onset, severity, and individual differences, but they often include:

- Lower back pain or stiffness
- Leg weakness, numbness, or abnormal walking patterns
- Paresthesia (numbness, tingling)
- Foot conditions (e.g., toe walking, foot drop, clubfoot)
- Scoliosis
- Asymmetrical symptom distribution, with one side of the body often being more affected than the other
- Bowel or bladder control problems
- Skin changes over the lower spine (dimples, fatty lumps, unusual birthmarks)

In young children, symptoms may first appear as a regression in toilet training or subtle gait issues. In adults, tethering can cause increasing pain or neurological deficits over time.



Diagnosis

Tethered cord syndrome is a clinical diagnosis based on a combination of neurological symptoms, physical exam findings, and imaging results that suggest the spinal cord is abnormally anchored, or tethered, limiting its normal movement. The typical workup may include:

- A thorough history and neurological exam
- A physical exam to identify skeletal conditions or neurocutaneous signs
- MRI imaging, to identify abnormalities such as a low-lying conus medullaris, thickened filum terminale, or fatty masses
- In some cases, the spinal cord may appear normal on imaging, a condition known as occult tethered cord syndrome

Treatment

The main treatment for TCS is surgery to release the tethered cord, known as a tethered cord release.

- Early surgery can prevent permanent nerve damage, especially in children.
- Retethering—when scar tissue causes symptoms to return—is a known risk, especially during growth. This is often treated with repeat tethered cord release or more advanced procedures when needed.
- In complex or recurrent cases, more advanced procedures like spinal column shortening or nerve root sectioning may be required.
- Some patients require continued care after surgery such as pain management, physical therapy, bowel and bladder management, and mobility assistance.



Prognosis

With timely intervention, many patients experience stabilization or improvement in symptoms. Delays in diagnosis or treatment can lead to permanent nerve damage or disability.

Medically Reviewed and Updated 1 August 2025

References

American Association of Neurological Surgeons, 2024.

<https://www.aans.org/patients/conditions-treatments/tethered-spinal-cord-syndrome/>

Barrow Neurological Institute, 2020.

<https://www.barrowneuro.org/condition/tethered-spinal-cord/>

Boston Children's Hospital, 2025.

<https://www.childrenshospital.org/conditions/tethered-spinal-cord>

Children's Hospital of Philadelphia, 2025.

<https://www.chop.edu/conditions-diseases/tethered-spinal-cord-syndrome>

Cleveland Clinic, 2023.

<https://my.clevelandclinic.org/health/diseases/24672-tethered-spinal-cord>

New York-Presbyterian, 2025.

<https://www.nyp.org/ochspine/tethered-spinal-cord>