Tethered Spinal Cord

What Is Tethered Spinal Cord?
Tethered spinal cord occurs when the spinal cord becomes attached (or tethered) to tissues surrounding it. When tethered spinal cord occurs, the spine isn’t free to move normally. As a result, the spinal cord is pulled or stretched, which interferes with its blood supply and may cause nerve damage.

What Causes Tethered Spinal Cord?
Tethered spinal cord is often linked to spina bifida. More than 40 percent of children who have spina bifida will need surgery to untether the spinal cord during their lifetimes. In most of those cases, the spinal cord is tethered to the tough membrane called the dura, which covers the spinal cord.

Other causes of tethered cord syndrome include:

- Dermal sinus tract (a rare congenital disability).
- Diastematomyelia (a split spinal cord).
- Lipoma (a benign, fatty growth).
- Previously treated tumor.
- Thickened/tight filum terminale (a delicate, threadlike tissue near the tailbone).
- Scoliosis (spinal deformity).
- A history of spine trauma or spine injury.
- Previous spinal cord surgery.

Tethered Spinal Cord Symptoms and Effects
Sometimes children who have tethered spinal cord don’t develop symptoms and therefore don’t require treatment.
The first signs of tethered spinal cord might be visible on the lower back. Visible symptoms might include:

- A spot of discolored skin.
- A wound or lesion.
- A patch of hair.
- A deep dimple.
- A fatty tumor.

The most common tethered cord symptoms are:

- Trouble walking or standing.
- Leg or back pain.
- Changes in bladder and bowel function.
- Increased spasms or stiffness (also known as spasticity).
- Scoliosis that gets worse over time.

Tethered Spinal Cord Diagnosis and Treatment

If you think your child has a tethered spinal cord, the following tests might help diagnose the condition and its severity.

- CT scan.
- MRI.
- Ultrasound (usually used only for infants).
- Urological testing.
- X-rays.

A neurosurgeon reviews all the test results and your child's signs and symptoms before deciding if tethered spinal cord release surgery would be beneficial for your child. Although medicines can't treat tethered spinal cord itself, they sometimes help to ease pain or reduce muscle stiffness (spasticity) linked to the condition.

What is Tethered Spinal Cord Release?

Tethered spinal cord release is a fairly routine surgical procedure used to treat a tethered cord. There are two types of tethered spinal cord release surgery. In the simplest and most common form, a neurosurgeon makes a small opening in the back of the spine, below the end of the spinal cord, to cut the filum terminale, which is a band of tissue at the end of the spinal cord. This is a short procedure with very low risks.

The more complex form of surgery is for patients who have previously had surgery to repair open spina bifida or
other complex malformations, such as a lipoma or a split cord malformation. During the procedure, a neurosurgeon opens up the back and the spinal column to gently cut away the spinal cord from the scarred tissue it’s attached to, which allows the spinal cord to move freely. This is done using microsurgical techniques, but carries a slightly higher risk of complications.

If a child has tethered cord syndrome and doesn’t have the operation, their spinal cord could stretch even further, leading to more damage. Although tethered spinal cord surgery prevents symptoms from getting worse, it may not reverse the damage that has already happened. In some cases, children who have the procedure experience improvement of pain, weakness, numbness or tingling after surgery. However, the amount of lost muscle and bladder function that they recover varies for each individual.

Preparing for Surgery

You can help make sure your child has the best possible surgery outcome by understanding what to expect before, during and after tethered spinal cord release at Gillette Children’s Specialty Healthcare.

- A week before the surgery, we will contact you.
  We will gather a health history, including details about medicines (name, dose, frequency), pharmacy and primary care doctor. We will discuss what to expect on the day of surgery and during the hospital stay, and let you know what you’ll need when your child leaves the hospital.

- Maintain a healthy diet and regular activity.
  Overall health can affect how well and how quickly your child recovers from tethered spinal cord release. In general, kids should maintain regular levels of activity leading up to surgery. Before and after the surgery, make sure your child eats enough food with iron, calcium and vitamins C and D. Fresh colorful fruits and vegetables, dairy food, and other products with added iron and calcium offer great ways to get these nutrients.

- Tell us about latex allergies.
  Gillette is a latex-free facility. However, we still want to know if your child has a latex allergy or has ever had a severe reaction to latex.

- Manage stress.
  Sometimes fears, behavior or expectations related to upcoming surgery can cause stress for families. Contact your child’s primary health care provider or Gillette Child and Family Services for support. We can also help with resources that might reduce anxiety for your child and family. Our Child Life Specialists can provide emotional support and distractions, such as toys and movies in the waiting area before surgery begins. Child life specialists can also meet with your child’s siblings to address their feelings and concerns.

Knowing what to expect can help everyone feel more prepared. We’ll take time to clarify short- and long-term expectations for outcomes following tethered spinal cord release.

During Your Hospital Stay
**Arrival:**

The perianesthesia staff welcomes you when you arrive. We weigh your child and ask them to change into a hospital gown. We also check temperature, pulse and blood pressure. A Child Life Specialist helps your child feel more at ease with toys, crafts or movies.

**Surgery Preparation**

Next, you and your child meet with the surgery team, which includes:

- Pediatric neurosurgeon
- Nurse anesthetist
- Anesthesiologist
- Nurses

This is a chance for you to raise any questions or concerns. The anesthesiologist discusses how anesthesia and pain medicine are used during surgery. You can talk about your child’s experiences with pain and request medicine or other techniques to help them relax.

**Surgery**

1. The neurosurgeon makes a cut (incision) on your child’s back.
2. The neurosurgeon cuts (releases) the source of the tethering, such as the threadlike filum at the end of the spinal cord, lipoma or scar tissue.
3. Sometimes the neurosurgeon removes a small portion of the bony vertebrae (laminae) for better exposure, or to decompress the spinal cord.
4. The neurosurgeon opens the thin layer of matter (dura) covering the spinal cord and gently cuts the spinal cord away from the scarred attachments to the surrounding tissues.
5. The procedure lasts two to four hours.

**After Surgery**

Although each child’s experience is different, a typical hospital stay after a tethered cord release lasts four to seven days. If your child has the procedure, they will likely be hospitalized in the Neurosciences Unit. Here, they rest flat in bed for 24 to 72 hours after surgery. The duration of bed rest depends on what caused the tethering, the age of your child, and other factors. A pediatric neurosurgeon decides how long your child needs to stay in bed. A neurosurgery team member visits your child every day during hospitalization, making recommendations and checking the incision. Before your child returns home, we make sure they:
• Have adequate pain management with oral medicines.
• Can eat and drink well.
• Can get up and out of bed easily.
• Can use the restroom (pass stool and urine) without difficulty.

Your child’s care team includes a pediatric neurosurgeon, pediatric nurse practitioners, physician assistants, and registered nurses. Physical therapists evaluate some children to assess and monitor their strength and ability to move safely.

Rehabilitation and Recovery

Every child heals differently, and outcomes depend on the neurologic condition of your child before surgery. Kids usually return to normal activities within a few weeks. Your child will likely have an appointment with a neurosurgery provider two weeks after discharge from the hospital, to check the incision. Six weeks after surgery, a neurosurgeon or advance practice provider will evaluate your child’s progress. The pediatric neurosurgery team generally sees kids regularly throughout childhood and adolescence to watch for any return of tethered cord symptoms.
Integrated Care

If your child has tethered spinal cord, you’ll find care and support in a family-centered environment at Gillette Children's Specialty Healthcare. Our leading pediatric neurologists and neurosurgeons will work closely with you to create a custom treatment plan for surgical and rehabilitative care.

It’s possible your child will continue to experience pain, weakness, difficulty walking or other medical issues after surgery to untether the spine. Our multidisciplinary team of specialists offers services to make sure they have everything they need to feel comfortable, confident and cared for.

Your child or family member might receive care from specialists in one of the following areas:

- **Neurology.**
- **Neurosurgery.**
- **Pediatric Rehabilitation Medicine.**
- **Gastroenterology.**
- **Occupational therapy.**
- **Physical therapy.**
- **Radiology and imaging.**
- **Rehabilitation therapies.**
- **Urology.**

Make An Appointment 551-290-8707

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