

Let's Talk About...

Tethered cord syndrome

Tethered cord syndrome is a condition where the spinal cord is restricted and can't grow longer as your child grows. It can occur alone or in children who have spina bifida. Learn more about tethered cord syndrome, the signs, and treatment below.

What causes tethered cord syndrome?

Tethered cord syndrome usually happens because the spinal cord doesn't separate from the skin of the back while a baby is developing before birth. When a baby is born with spina bifida, some of the spinal cord sits at the bottom of their back instead of stretching up the spine the way it should.

What are the symptoms of tethered cord syndrome?

Symptoms of tethered cord syndrome can appear at any time, but mostly happen during your child's growth spurts. They include:

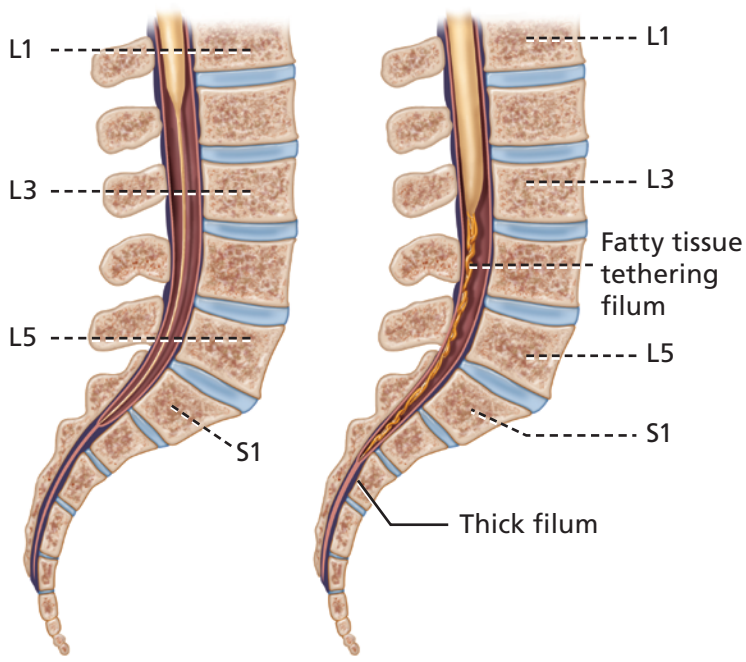
- Leg and foot weakness and tighter leg and foot muscles
- Trouble walking or using legs and feet
- Slower movements
- Deformed joints
- Back pain usually caused by activity
- Not being potty-trained by 6 years old or having lots of accidents after being potty-trained
- Urinary tract infections
- Urgently feeling the need to urinate
- Scoliosis (curved spine)



How is tethered cord syndrome diagnosed?

Your child will have many tests when they are young to diagnose tethered cord syndrome or watch it over time:

- **Neurological physical exam:** A neurosurgeon will see how the nerves and reflexes are working.
- **Manual muscle test (MMT):** An MMT measures lower body strength. Your child may need this test every 3–6 months depending on their symptoms. Healthcare providers will compare each test to the last one to see how your child is doing.
- **Magnetic resonance imaging (MRI):** An MRI uses a magnet and radio signals to create a 3D image of the inside of the body. It doesn't hurt, but it is very noisy. Healthcare providers will do an MRI of the spine and sometimes the head. If your child has a second MRI, the provider will compare it with the first test.



- **Spine x-rays:** These photos help healthcare providers notice the spine curving early.
- **Urodynamic test:** This test shows how well the bladder empties and fills. It also measures the bladder pressure and how well the bladder sphincters (small valves that control urine flow) work.

What happens when my child has untethering surgery?

During surgery, the surgeon gently releases the spinal cord from abnormal fat, scar tissue, or the filum terminale, the ligament that normally secures the spinal cord to the base of the spine. This allows the spinal cord to move freely.

Healthcare providers do not recommend treating tethered cord syndrome until a child shows symptoms. When they grow older, the spine lengthens, the spinal cord stretches, and the symptoms appear.

How do I take care of my child after untethering surgery?

- Make sure your child lies flat for 24 hours or more after surgery and is rolled from side to side often. They should move slowly at first to prevent cerebrospinal fluid (CSF) from leaking from the surgery site.
- Give your child pain medicine as their healthcare provider recommends. Your child will probably only need ibuprofen or acetaminophen after 3–4 days.
- Help your child resume activity slowly after surgery. They may exercise while sitting or lying down at first and then move to active exercise in a few days. Most children are walking or returning to normal activity 3–4 days after surgery.
- Watch your child’s bladder function. A healthcare provider will put a catheter in the bladder during surgery and continue using it 1 or 2 days after surgery. This will help urine leave the bladder. If your child urinated on their own before surgery, this will be their goal when the catheter is removed. However, if your child can’t completely empty their bladder after surgery, they may need an intermittent catheterization program. Sometimes your child will leave the hospital continuing to catheterize until bladder function fully returns.
- Help your child with bowel management. The healthcare provider will probably give your child a laxative or suppository for 1–2 days after surgery. Once the bowel is cleaned out, your child can resume their regular bowel management program.
- Keep the surgical opening clean and dry to prevent infection. Since it is so low on your child’s back, it’s important to ensure no urine or poop gets in the incision. If your child wears a diaper, they may need a dressing over the opening to protect it until it heals.

When can my child leave the hospital?

Your child can leave the hospital about 2–5 days after surgery, depending on which tissue was involved (fat, thickened filum terminale, or scar tissue). They should be able to resume full activity, including school, within 4 weeks after surgery.

Schedule a follow-up visit with the neurosurgeon so they can check your child’s wound and repeat neurological testing. The new tests will be compared to tests done before the surgery. Urodynamic (bladder function) testing happens 3–6 months after surgery.

What are possible problems after surgery?

The most common problem after untethering surgery is infection. Prevent this by keeping the surgical opening clean and dry. Other problems include:

- **Shunt malfunction:** About 10–15% of children with a shunt to treat hydrocephalus have shunt malfunction after tethered cord surgery. This can happen up to 6 months after the untethering surgery, but the greatest risk is in the first month. Check your child closely for signs that their shunt is not working properly.
- **Retethering:** Even after surgery, the spinal cord can tether (bind together) at any time, called retethering. After surgery, continue to check your child’s progress and notice any problems. If your child needs surgery for retethering, they are at greater risk for losing nerve function in the legs, feet, bowel, or bladder. Your child’s neurosurgeon will watch them closely and recommend surgery only when absolutely necessary.

What can I expect after my child’s untethering surgery?

Each child improves differently after untethering surgery. You will probably not notice changes for 6 weeks—6 months after surgery, but neurological, bladder, pain, and spine function can improve significantly. No matter how your child’s body improves, neurologic function should not get worse unless the cord begins to retether.

Rarely, muscle or bladder function will become worse for a while after surgery and then get better. Most children who get worse and then better will eventually return to their original level of muscle or bladder function. Many improve even more.

Notes

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