Let's Talk About...

Tethered Cord Syndrome

What is tethered cord syndrome?

Tethered means to "restrict" or "bind." A "Tethered cord" is a spinal cord that is bound down or restricted. The tethered spinal cord cannot move freely as the child bends and moves about. This stretches the small blood vessels that nourish the spinal cord and results in less blood flow to the spinal cord and nerves.

Tethered cord can occur alone or with spina bifida. Doctors do not recommend treatment until the child shows some symptoms. As the child grows, the spine lengthens, the spinal cord stretches, and the symptoms appear.

What are the symptoms of tethered cord?

Symptoms of tethered cord syndrome can appear at any time, but are mostly seen during growth periods.

Loss of nerve function

One of the first signs of tethered cord is more weakness in the legs and feet and tighter leg and feet muscles. Your child may have a hard time walking or using his legs and feet. Also, it takes more energy to move. The child's movements are slower and decreased. Tight muscles can also cause joints to become deformed. This can make it harder for orthopedic surgery, such as heel cord lengthening and ankle and foot surgeries, to be effective.

There may be other reasons for changes in walking or in the use of the legs and feet. These may include improperly fitted shoes or braces, a dislocated hip, or weight gain. It's a good idea to identify and correct these first to see if they are the cause of walking problems. If walking problems continue to get worse, then the problems may be due to tethered cord. It is essential to recognize these problems early, have regular muscle tests, and have test results reviewed by the physical therapist and neurosurgeon.

Pain

Back pain caused by a tethered spinal cord usually occurs with activity and improves with rest. The pain tends to become worse until your child has surgery. However, not all children with tethered cord have back pain. Not all children with back pain have tethered cord syndrome.

Changes in bladder function

A common sign of tethered cord syndrome is a change in bladder function. Symptoms may include not being able to potty train by 6 years of age, stop being potty trained for a while (incontinence), urinary tract infections (one in boys, or more than one in girls), or suddenly and urgently needing to urinate. If a child has a catheterization program and is able to stay dry, a change may mean they have some leakage. The urologist or neurosurgeon may order urodynamic testing to see if the problem is caused by a tethered cord.

Scoliosis

Scoliosis (crooked spine) is common and has several different causes. If your doctor cannot find another cause, the scoliosis may be caused by a tethered cord. Surgery to untether the cord should be done before the curve becomes so severe that it interferes with function and movement. If the scoliosis does not get better after surgery, the child may need spinal fusion surgery. This is not very common.

How does the doctor check for tethered cord syndrome?

Your child will receive these studies early in their life. This is to diagnose the tethered cord or watch it over time:

- **Neurological physical exam**: Your child may have a neurologic examination from a neurosurgeon. This is to see how the nerves and reflexes are working.
- **Manual Muscle Test (MMT)**: Your child may receive an MMT examination. This measures lower body strength. Your child may receive this type of examination every 3 to 6 months depending on your child's symptoms. Each exam is compared to the previous exam to see how your child is doing.
- **MRI**: This special exam 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. Your child will receive an MRI of the spine and sometimes the head. If your child receives a second MRI test, the doctor will compare it with the first test.
- **Spine X-rays**: These help detect early curvature of the spine.
- **Urodynamic test**: This test shows how well the bladder empties and fills. This test also measures the pressure in the bladder and the function of the bladder sphincters (small valves that control urine flow).

What kind of surgery is available?

Surgery gently releases the spinal cord from abnormal fat, scar tissue, or the ligament which normally secures the end of the spinal cord to the base of the spine (the filum terminale). This allows the spinal cord to move freely.

What care will my child need after surgery?

Activity and positioning

Your child will stay in a flat position for 24 hours or longer after surgery and be rolled from side to side frequently. Your child should resume activity slowly after surgery. This is to prevent cerebrospinal fluid leaking from the surgery site.

Pain control and rest

Pain control is an important part of care after surgery. After the first day or two, pain medicine can usually be given by mouth. By day 3 or 4, your child will probably only need Tylenol® or ibuprofen for pain control.

Your child should resume activity slowly after surgery. He may have some physical therapy using passive exercise (exercising while lying or sitting down) and active exercise (exercising while upright and moving). Most children are out of bed walking or returned to normal activity 3 to 4 days after surgery.

Bladder management

Bladder management is important both before and after surgery. A catheter will be placed in the bladder through the urethra during surgery and left in place for a day or two after surgery. This will help urine leave the bladder. If your child used clean intermittent catheterization before surgery, he can resume this after the catheter comes out. If your child has always been able to empty his bladder on his own, this will resume once the catheter is removed also.

Bowel management

Bowel management is also important. Your doctor will probably give your child a laxative or suppository for 1 to 2 days after surgery. Once the bowel is cleaned out, your child can resume his regular bowel management program.

When can my child leave the hospital?

Your child will be discharged about 2 to 5 days after surgery, depending on which tissue was involved (fat, thickened filum terminale, or scar tissue). He should be able to resume full activity, including school, within four weeks after surgery. You need to make a follow-up visit with the neurosurgeon. When you visit the surgeon, he will check your child's wound and repeat neurological testing. The new tests will be compared to tests done before the surgery. Urodynamic testing (a test that measures the function of the bladder) is repeated 3 to 6 months after surgery.

What are possible complications after surgery?

- **Children with hydrocephalus and a shunt**: About 10–15% of children who have a shunt, have shunt malfunction after tethered cord surgery. This can happen up to 6 months after the untethering surgery. The greatest risk is in the first month. Check your child closely for signs and symptoms that the shunt is not working properly.
- **Retethering**: Even after surgery, tethering can come back at any time. This is called "retethering." After surgery, continue to check your child's progress and identify any problem symptoms. If your child needs surgery for retethering, there is a greater risk of losing nerve function. This may affect the legs, feet, or bowel and bladder function. Your neurosurgeon will follow your child closely and recommend surgery only when absolutely necessary.

What kind of improvement can I expect after my child's surgery?

Improvement in body functions after surgery is different for each child. But neurological, bladder, pain, and spine function can improve significantly. You probably will not see improvement for 6 weeks to 6 months after surgery, though. Regardless of the outcome, neurologic function should not get worse, unless the cord begins to retether. In rare cases, muscle or bladder function will become worse for a while after surgery, and then get better. Most children who get worse then better will eventually return to their original level of muscle or bladder function and many improve even more.