Tethered Cord Syndrome

BIRTH DEFECT RESEARCH FOR CHILDREN

What is Tethered Cord Syndrome?

The word “tethered” means “to fasten or confine.” Tethered Cord Syndrome is a condition where the spinal cord is abnormally attached within the bony spine causing stretching and tugging that can be painful and lead to disability.

Tethered Cord Syndrome

Normally, the spinal cord moves freely through fluid within the spine from the base of the brain down to the lower back. Soon after conception, special cells join to create a tube that will form the baby's spinal cord. The surface layer of the embryo, called the ectoderm, moves below the skin and is surrounded by connective tissue, called dura, that becomes the spinal covering and bone. If the ectoderm and the dura do not join properly or completely, the spinal cord can become "tethered." When a child with tethered cord bends or stretches, the tension on the spinal cord can lead to permanent damage to muscles and nerves that control legs, feet, bowel and bladder.

What are symptoms of Tethered Cord Syndrome?

Children will complain of pain or show signs of discomfort. There are three types of symptoms that suggest Tethered Cord Syndrome:

Skin on lower part of back
- Fatty mass
- Hairy patch or discoloration
- Skin tags
- Dimples

Bowel or Bladder problems
- Changes in bowel control
- Incomplete emptying of the bladder
- Frequent urinary tract infections
- Changes in bladder pressure (seen on tests called urodynamics)
- Difficulty toilet training younger children

Orthopedic problems
- Persistent back pain
- Increasing curvature of the spine (scoliosis)
- Loss of sensation in the legs or feet
- Unequal changes in the size of the legs or feet
- Stumbling or changes in walking
- Weakness in the legs or feet

What causes Tethered Cord Syndrome?

Tethered Cord Syndrome is usually caused by an error in normal fetal development, resulting in conditions like dermal sinus tract, diastematomyelia (split spinal cord), lipoma, tumor, spina bifida, or a tight filium terminale. Folate supplements for women in childbearing years can reduce the rate of problems like spina bifida, but many causes of tethered cord syndrome seem unaffected by folate.

Is Tethered Cord Syndrome inherited?

There is no evidence that Tethered Cord Syndrome is inherited.

Are there any conditions associated with Tethered Cord Syndrome?

Many children with spina bifida also have tethered spinal cords.

How is Tethered Cord Syndrome diagnosed?

MRI (Magnetic Resonance Imaging) that shows a detailed 3-dimensional picture of the spine and spinal column can detect Tethered Spinal Cord. During infancy, an ultrasound may be able to detect a Tethered Spinal Cord as well.

How is Tethered Cord Syndrome treated?

Treatment depends on the severity of the symptoms. In more severe cases, the spinal cord can be surgically released from the spine. Operation time can range from four to six hours depending on how much tethering has occurred. If the child has reached adult height with minimal symptoms, doctors may suggest only careful observation. It is very important to have a sense of whether the symptoms are improving, declining, or staying the same. This is often the deciding factor in decisions

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about surgery.

How often does Tethered Cord Syndrome occur?

The exact incidence of Tethered Cord Syndrome is unknown because it often goes undetected.

What is the prognosis for children who suffer from Tethered Cord Syndrome?

The goal of surgery is to prevent further deterioration and tethering. Most children tolerate the surgery well. Back pain usually gets better but bladder control may not improve. There is a 50% percent chance of sensation and motor problems returning to normal after surgery. Ninety percent of children who suffer from Tethered Cord Syndrome will develop irreversible neurological problems if they are not treated.

Fact Sheet by:

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