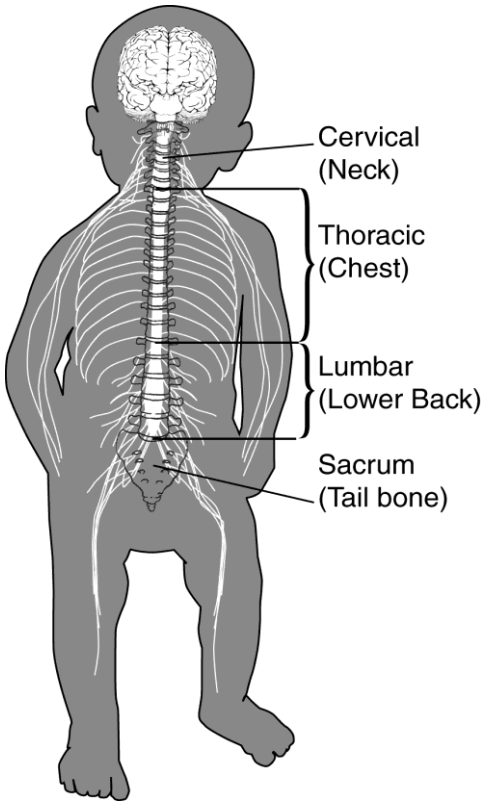
Tethered spinal cord

What is the spinal cord?

The spinal cord is made up of nerve cells and fibers. It is shaped like a long tube and runs down the center of the back. It acts like a giant relay station that allows nerve impulses to travel back and forth from the brain to the body and back again.

Spinal cord and vertebrae



A healthy spinal cord:

- Has 33 bones called vertebrae around it. They form the bony spine and protect the spinal cord from injury.
- Connects the brain with every part of the body.
- Has 31 pairs of spinal nerves.

What is a tethered spinal cord?

A tethered spinal cord happens when the lower part of the spinal cord attaches to the meninges (the membrane around the cord).

- This keeps the cord from being able to move freely.
- As a child grows and moves around, the spinal cord gets stretched and pulled. This can cause problems with pain and movement.

What causes it?

A tethered spinal cord often happens with spina bifida.

- Spina bifida is an opening in the spine. This problem develops before birth, so a baby is born with it.
- Children with spina bifida often have some tethering but may not need treatment unless they have symptoms.

Other causes can include:

- Injury or infection to the spine
- Spinal surgery
- A tumor on the spine

What are the possible symptoms?

Symptoms depend on how severe the tethered cord is. A child may have 1 or more of these:

- A lesion, dimple or patch of hair on the lower back
- Changes in the growth of the spine or feet
- Foot deformities, such as clubfoot or hammer toes

In case of an urgent concern or emergency, call 911 or go to the nearest emergency department right away.

- Pain or weakness in the legs or back
- A numb or tingling feeling in the legs
- Trouble walking that worsens over time or with activity that improves with rest
- An increase in side-to-side curve of the spine (scoliosis)
- Changes in bladder and bowel control (also known as incontinence)

Symptoms can appear in babies or children or later in life. The time when symptoms appear depends on how severe they are and how they progress.

What tests could my child have?

Your child may have any of these:

- X-rays
- Ultrasound of spinal cord to show how the spinal cord moves in its membrane (meninges)
- CT scans
- MRI scans
- Muscle tests to check for movement, feeling and strength
- Tests to check the kidneys and bladder

What is the treatment?

Early surgery can sometimes help prevent new symptoms and damage to the spinal cord.

- If your child's legs and back were weak before surgery, physical therapy (PT) can sometimes improve muscle strength or movement.
- Some children may need more surgeries as they grow.
- Routine follow-up is important to check healing and to make sure re-tethering does not happen.

If your child has surgery, they will need to stay in the hospital for 2 to 5 days. This will give them time to rest, heal and get medicines after surgery.

What are the possible complications?

Symptoms can get worse over time. Damage to the spinal cord can happen if surgery is not done when advised by your child's doctor.

Other problems may be linked to surgery. Your child's doctor will talk with you about the risks, benefits and complications of surgery for your child.

When should I call the doctor?

After your child has surgery, call the doctor **right away** if your child has:

- Signs of infection at the surgery site, such as:
  - Drainage or a bad smell.
  - Increased redness, warmth or tenderness.
- Fever (temperature of 100.4°F or higher)
- Any problems or symptoms that return or get worse after surgery, such as:
  - Weakness, numbness or tingling feelings in the legs or feet.
  - Changes in bladder or bowel control.
  - Trouble walking or moving
- Pain not helped by pain medicine

Also call the doctor if you have any questions or concerns about how your child looks or feels.

What follow-up does my child need?

Call your child's doctor to schedule a follow-up visit to make sure your child is healing after surgery. Keep all of your child's appointments for any tests or doctor's visits that they advise.

This teaching sheet contains general information only. Talk with your child's doctor or a member of your child's healthcare team about specific care of your child.

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