

# FACTSHEET



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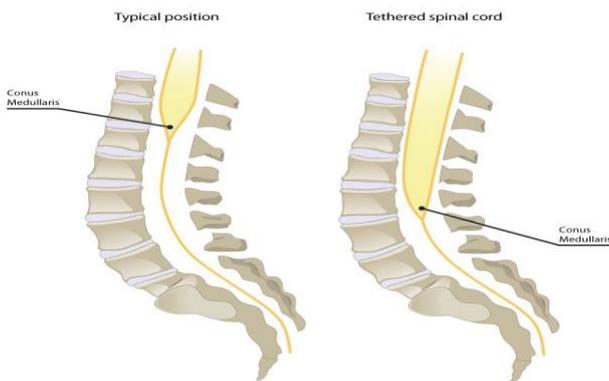
## Tethered cord syndrome

A tethered spinal cord does not move. It is pulled tight, whereas normally the spinal cord hangs loose in the spinal canal.

### What is tethered cord syndrome?

'Tethered' means tied, and 'cord' refers to the 'spinal cord'. Tethered cord syndrome describes when a child's spinal cord has not developed normally during pregnancy. The spinal cord is 'tied' or 'fixed' to the lower end of the spinal column, instead of being free to move up and down (see Figure 1)

Figure 1 – Typical and Tethered spinal cords



Signs of a tethered cord include skin observations such as a hairy tuft, sacral dimple or a fatty mass on the back. A spinal ultrasound will often be ordered to help diagnose a tethered cord. If a tethered cord is found, imaging with an MRI is usually done to gain more detailed information about the spinal cord.

Many children do not have symptoms at the time of diagnosis. Symptoms can happen at any stage in life but are more likely to occur during periods of rapid growth. This is when the spinal cord is stretched. We do not know why some children develop symptoms and signs of tethering, while others don't.

Stretching of a tethered spinal cord can cause damage to the spinal cord and interfere with its blood supply. Symptoms that may suggest this has happened include:

- Pain (back pain or pain radiating into the legs)
- Sensory changes
- Motor changes such as:
  - progressive weakness
  - changes in the shape of the feet
  - progressive scoliosis
  - loss of bowel and bladder control.

### How is tethered cord syndrome treated?

Tethered cord syndrome is a common condition and is treatable with cord detethering surgery.

Your child will need close monitoring including regular medical reviews and assessments by your physiotherapist (manual muscle testing). Your child may also need regular kidney ultrasounds. Ultrasounds can pick up symptoms early and give treatment so that further permanent damage is prevented. The longer that symptoms are not treated, the less your child's chance of full recovery from any deterioration.

The decision to do surgery to detether the cord is based on clinical judgment. Your neurosurgeon may choose to perform elective de-tethering surgery (before symptoms

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arise) or choose to wait. The timing of surgery will be determined by the age and weight of your child, the MRI findings and your child's symptoms.

### **What are the complications of surgery?**

Risks of surgery are low, but can include:

- Infection
- Bleeding
- Damage to the spinal cord - this could result in worsening muscle, bladder, bowel and sexual function.
- Cerebrospinal fluid (CSF) leak.

### **Is repeat detethering necessary?**

Most children need only one detethering procedure. A small number of children (10-20%) need repeat cord detethering surgery.