

# What is Tethered Spinal Cord Syndrome?

Information for parents and carers



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## What is Tethered Spinal Cord Syndrome?

A tethered spinal cord is a neurological condition whereby the spinal cord is attached to the tissue around the spinal canal. This results in the spinal cord not being able to move freely as the child grows. A tethered spinal cord is pulled tight at the end and this can reduce blood flow and affect functioning of the nerves and the distal part of the spinal cord in the spinal canal. If left untreated it can lead to progressive spinal cord/ nerve damage. Tethered spinal cord syndrome is diagnosed when the tethered cord is accompanied by symptoms such as sensory issues, muscle weakness, pain or incontinence. Tethered spinal cord can be seen in children born with closed spina bifida (i.e. spinal lipomas) but can also occur in a small group of children with myelomeningocele (open spina bifida). Babies are often born with a tethered spine due to a problem with the development of the spine. However rarely tethered spinal cord can also occur after birth due to damage to the spine or from scar tissue after spinal surgery.

## Symptoms of Tethered Spinal Cord Syndrome

Sometimes the presence of a tethered spinal cord can result in a physical display on the child's back such as a bump, discolouration or a hairy patch. There may also be unusual anatomy of the genitals or anus which can also lead to bowel or bladder problems. Other symptoms include, back and leg pain, muscle weakness or numbness in the legs/feet and problems standing or walking.

## Diagnosis of Tethered Spinal Cord Syndrome

It is likely your baby/child will need an MRI scan of the spine and ultrasound scan (USS) of the bladder and kidneys. The scans along with clinical examination will help the neurosurgical doctors to diagnose whether there is tethering of the spinal cord. The neurosurgical team will also take in to account your child's symptoms and any medical history they have. There may also be a need for urine, stool (poo) and blood samples to be collected. All of this information enables the doctors to reach a diagnosis and therefore a treatment plan.

## Treatment of Tethered Spinal Cord Syndrome

The neurosurgical team will discuss the treatment options with you based on your child's diagnostic test results and their symptoms. It may be that your child needs to go for surgery to have the spinal cord untethered. The aim of surgery is to release the spinal cord and attempt to prevent any future damage to the nerves. The surgery involves making a cut on your child's back in order to get to the affected area of the spine, the surgeon will then begin the untethering, which can take some time depending on the complexity of the tethering. This is usually done with close monitoring of the nerves and spinal cord at the time of surgery to reduce the risk of complications. Once this has been completed the area around the spinal cord will be closed and the wound will be closed.

## What are the risks of surgery?

Like all operations, surgery for untethering carries a risk of complications. Most of these complications are uncommon, but they can be serious. There are always risks associated with having a general anaesthetic and the anaesthetist will discuss these with you. There is also a risk of infection, blood clots and leakage of cerebral spinal fluid (CSF), which is the fluid that flows around your brain and spinal cord. There is also a risk that there could be damage to the nerves. All of these risks will be explained to you by the neurosurgeon and you will have an opportunity to ask any questions you may have.

## What happens after surgery?

Your child may need to go to the High Dependency Unit (HDU) post-op so they can be monitored closely, have adequate analgesia and ensure they are recovering from their surgery well. Otherwise they will be brought back to ward L52 post-surgery. It is likely that your child may need to stay on flat bed rest for a few days following the surgery to reduce the risk of cerebral spinal fluid (CSF) leak. Your child may be on some fluids until they are able to eat and drink normally. They may also be given some antibiotics and pain relief. They will be on continuous monitoring so the nursing staff can keep an eye on your child's heart rate and oxygen levels. Your child will have to stay in hospital for at least a few days post-surgery. They will be reviewed daily by the neurosurgical team and once they feel they are well enough to be discharged, you will be able to go home.

## Useful numbers

**Ward L52** - 0113 392 7552

**Ward L47** - (PICU) 0113 392 7447

**Ward L48** - (HDU) 0113 392 7448

## References

<https://www.aans.org/Patients/Neurosurgical-Conditions-and-Treatments/Tethered-Spinal-Cord-Syndrome>

<https://www.childrenshospital.org/conditions-and-treatments/conditions/t/tethered-spinal-cord/treatments>

<https://www.spinabifidaassociation.org/resource/spinal-cord-tethering/>

<https://www.hcahealthcare.co.uk/our-services/treatments/untethering-of-the-spinal-cord>

[https://www.nhs.uk/conditions/chiari-malformation/Documents/Patient Information for Tethered Cord 2008%5B1%5D.pdf](https://www.nhs.uk/conditions/chiari-malformation/Documents/Patient%20Information%20for%20Tethered%20Cord%202008%5B1%5D.pdf)



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