

## Neuroscience Unit

# Tethered Spinal Cord

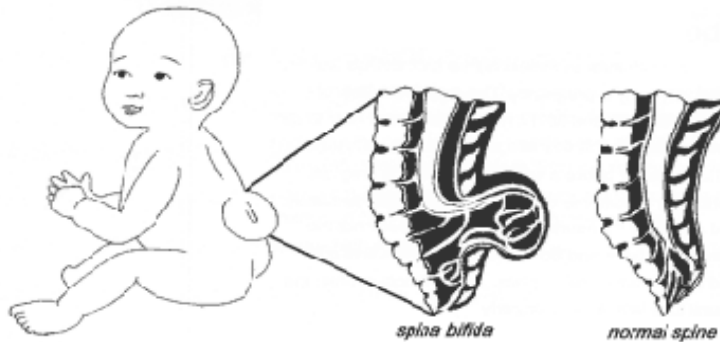
### Information for parents and carers

#### Introduction

This guide aims to provide information for parents and children about tethered spinal cord. Further information is always available about specific care from the nursing and medical staff.

#### What is a tethered spinal cord?

Tethered spinal cord describes the condition where the bottom end of the spinal cord is fixed, resulting in neurological problems in the function of the legs, bladder or bowel. It may also be associated with limited movement of the back, and back pain.



Source: CDC, *Preventing Neural Tube Birth Defects: A Prevention Model and Resource Guide*.

Tethered spinal cord commonly occurs with spina bifida. This is a condition that involves the incomplete formation of one or more bones (vertebrae) in the back, and malformation of the spinal cord and its nerves. As a consequence of this, there is a gap at the lower end of the backbone and there is a risk of damage to the spinal cord.

Tethered spinal cord is a developmental condition and is associated with overlying skin lesions; these include:

- Myelomeningoceles- These are cysts comprising of tissue, cerebrospinal fluid, spinal nerves and spinal cord)
- Lipomas- fatty lumps.

#### Occurrence

In the first four weeks of pregnancy the embryonic cells form the *neural tube* – this eventually develops into the brain and spinal cord. It is at this early stage of foetal development that the conditions leading to the tethering of the spinal cord occur.

During foetal development, the spinal cord runs all the way down the inside the bones of the spine to the tail bone. By the time of birth, this has "shortened" to normal level just above the small of the back. It is only the nerves to the legs, bladder and bowel that sit in a bag of spinal fluid toward the tail bone. A tethered cord can affect spinal nerves and cause function to deteriorate.

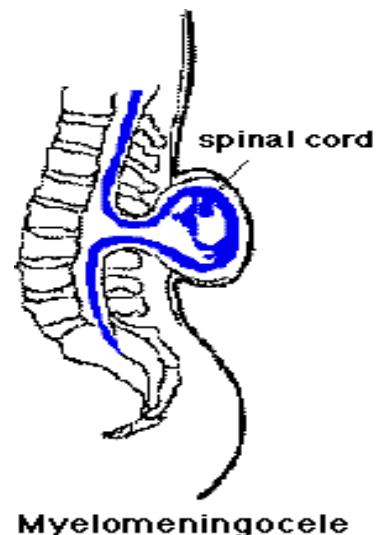
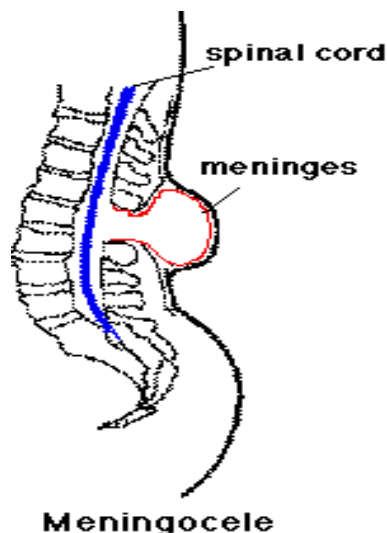
Not all children need an operation. Tethered spinal cord will often be seen on the scans of children with a myelomeningocele, but it is treated only when the child's condition deteriorates. A child's natural growth spurts at certain ages can be an aggravating factor in tethered spinal cord.

### Diagnostic signs and symptoms

- Skin "marker" in the form of a lump, dimple or tuft of hair
- Lower limb anomalies – weakness, deformity, unusual walking style (gait)
- Pain or "pins and needles" in the legs, back and neck
- Progressive scoliosis (curvature of the spine)
- Urinary problems – bed wetting, failure to potty train, recurrent urinary tract infections, stress incontinence

### Diagnostic investigations

- Full neurological examination by a doctor
- Urological studies – these examine how well the bladder empties and whether there is any back flow of urine to the kidneys
- Magnetic Resonance Imaging (MRI scan) – these scans produce high quality pictures of various parts of the body without using X-rays. A magnetic field and radio waves measure the magnetic properties of all body tissues.



### Surgical treatment.

When a child has clinical signs of tethered spinal cord or has a deteriorating condition, surgery is an option. The aim of surgery is to prevent further deterioration in the child's condition. If the child is experiencing any loss of function, this may be restored, but not in all cases. The operation aims to

release the spinal cord tether. In most patients, this is possible, but if there is any risk of causing neurological damage the surgeon will stop the procedure. It is possible for tethering to recur, especially during further growth spurts. Children are therefore reassessed at regular intervals following surgery.

### ***Post-operative care.***

#### **Pain relief**

It is essential that your child is kept as comfortable as possible and they will return to the ward with a 'drip' of pain killing medication. Patient-controlled analgesia (PCA) pumps are used with older children, this allows them to give themselves a dose of the drug whenever they need it by pressing a button. For younger children Nurse-controlled analgesia (NCA) will be used, this is where your child's nurse will be able to give them extra doses of pain killers as required.

The nurses will regularly check the comfort of your child and if necessary additional pain killers can be given, normally Paracetamol (Calpol) and/or Ibuprofen.

#### **Positioning**

Children are usually kept flat in bed for 5 days following surgery to avoid pressure on the back wound and to minimise the risk of cerebrospinal fluid (CSF) leakage. Your child will be aided to move their position every couple of hours to reduce potential problems associated with immobility. After 5 days, the physiotherapists and nurses will assist your child with standing and walking.

#### **Wound care**

Children will usually have a dressing over the wound site, which is removed after a couple of days. Stitches are usually dissolvable, but feel free to discuss this with the nurses and doctors. If the stitches are not dissolvable, your child will need to return to the ward a week after discharge to have them removed.

Should a CSF leak occur from the wound site, a firmer "pressure" dressing is applied to stop the leak. On rare occasions, return to theatre for re-stitching of the wound is needed to seal the leak and reduce the risk of infection.

#### **Eating and Drinking**

During and after surgery your child will have a 'drip' of fluids running to ensure they do not get dehydrated. As soon as your child feels up to eating and drinking normally, they may do so and the 'drip' will be taken down.

Some children do feel sick, this is a common side effect of the pain killing drug and having the anaesthetic. If this problem persists then drugs can be given to make them feel better.

#### **Toileting**

Children usually return to the ward with a urinary catheter in place (this is inserted whilst they are asleep). This will stay in place for a couple of days, to drain urine while they are on bed rest. If intermittent catheterisation is a part of your child's everyday routine then this should continue whilst in hospital.

It is not uncommon for children to get constipated as a result of changes in their diet, mobility and usual routines. The nurses will monitor your child's bowel actions and gentle laxatives may be used if necessary.

## Leisure and Schooling

The ward has a play specialist and a school teacher who will provide activities appropriate to your child's age and educational needs.

You are welcome to stay with your child during the hospital admission. The nurses will arrange a bed for you, either with your child or in McDonald House that is located within the hospital site. You should prepare to be in hospital for approximately a week; though it may be a little longer than this.

## Discharge advice

- ❖ Your child will usually not require pain relief to take home. However, occasionally paracetamol may be given for mild discomfort.
- ❖ Stitches are usually dissolvable, therefore they will not need to be removed and will dissolve in approximately 2-3 weeks. Non-dissolvable stitches will need to be removed approximately 1 week following discharge, please feel free to discuss this further with the nurse or doctors.
- ❖ Most children resume their normal activities within two weeks of surgery. However, it can take up to six months for them to return to their usual routines
- ❖ It is recommended that your child returns to school four weeks after discharge
- ❖ Swimming may be resumed after one month, and other sporting activities after three months
- ❖ We follow you and your child up in outpatients four to six weeks after discharge, and often ask you to return to the ward before this to allow staff to check your child's wound.

**Please report any leak of fluid from the back wound to the ward immediately. Any redness or swelling that develops should be reported promptly, too. It may be necessary to take a course of antibiotics in case of infection.**

The nurses on the Neurosurgical ward will be available for telephone advice.

Neurosurgical ward telephone numbers:

**0151 282 4492**

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The information contained within this leaflet is based on evidence where available and the consensus opinion of the consultant neurosurgeons working with this NHS Trust. This leaflet only gives general information. You must always discuss the individual treatment of your child with the appropriate member of staff. Do not rely on this leaflet alone for information about your child's treatment. This information can be made available in other languages and formats if requested.

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