

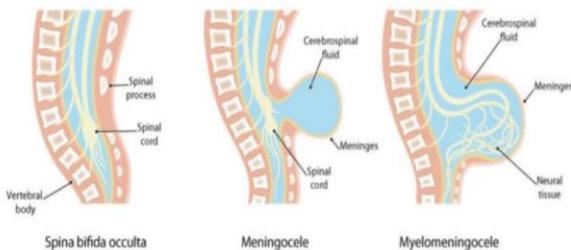
FACTSHEET



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Spina Bifida: Spinal Cord Surgeries and Complications

Spina Bifida describes a group of spinal abnormalities resulting in the incomplete development of the spinal cord, the bones of spinal column (vertebrae) and overlying skin. In the most severe form (myelomeningocele), the spinal cord nerves and meninges bulge through an opening in the spine to form a sac outside of the baby's back. Surgery is performed to correct this defect.



What surgery will my baby with Spina Bifida need?

In Spina Bifida (meningocele and myelomeningocele), there is a spinal defect where nerves, tissue and the sac covering are exposed. When they are exposed, they are at risk of infection and additional trauma. The aim of surgery is to put the spinal cord back into the spinal canal, close the defect and overlying skin to prevent infection and protect them from trauma. In an 'open' lesion (no skin covering), this is usually done within the first few days of life.

If the lesion is covered by skin, the surgery may be done at a later date, taking into consideration the baby's age, weight and general condition. This will be discussed with the neurosurgeon on a case by case basis.

What are the complications of surgery?

Potential complications around the time of surgery include infection, bleeding, difficulty with wound healing, cerebrospinal fluid (CSF) leak and damage to the spinal cord.

Long term complications include tethered cord syndrome.

What is Tethered Spinal Cord Syndrome?

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

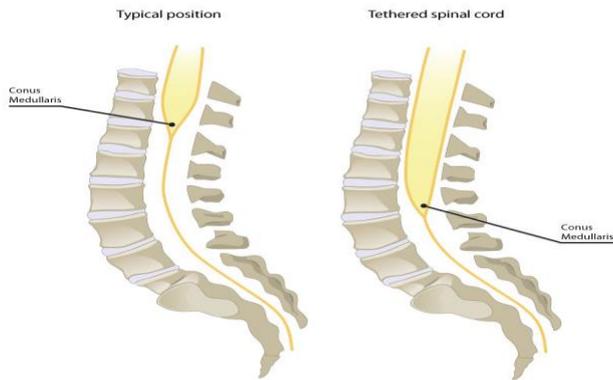
For people living with Spina Bifida, their spinal cord at birth is usually low-lying or tethered. This is a result of how their nerves and spinal cord developed during pregnancy. This does not usually require surgery unless your child is symptomatic.

20-50% of children with myelomeningocele may develop tethered cord syndrome (with symptoms) after their initial surgery. This is because scar tissue will form around it which can cause the spinal cord to fasten to immovable structures instead of being free to move up and down.

During periods of growth especially, the spinal cord can become stretched. This stretching damages the spinal cord and can interfere with the blood supply to the spinal cord. The result can be progressive neurological, urological, or orthopaedic deterioration that leads to loss of regular function.

Symptoms that may suggest this has happened include:

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



Can anything be done to prevent tethering?

Many methods have been tried to prevent or reduce tethering, but none have been as successful as surgery.

Your child will need close monitoring including regular medical reviews and assessments by the physiotherapist (manual muscle testing). Your child will also require regular bladder and kidney ultrasounds. Ultrasounds can pick up symptoms early so that we may provide treatment to prevent further deterioration.

Most people living with Spina Bifida will show some tethering on an MRI (radiological tethering). The decision to perform surgery to operate on a tethered cord again is based on symptoms and requires clinical judgment. After reviewing the studies, the neurosurgeon will consider the patient's symptoms in combination with the results of tests. Untethering surgery aims to prevent further deterioration. The longer that symptoms remain untreated, the less the chance of your child's full recovery from any deterioration.

What are the complications of untethering?

Risks of surgery are low, but can include infection, bleeding, damage to the spinal cord and CSF leak. There is also a risk that the spinal cord can become tethered again even after untethering surgery.

Hydrocephalus and shunt problems

People living with Spina Bifida and a shunt for hydrocephalus may need to have their shunt function checked first as that may be the cause of functional or neurological changes. A CT scan of the brain may be done to check for this.

Please refer to the [Hydrocephalus fact sheet](#) for more information.

What about fetal surgery?

Fetal surgery in Australia is currently only being performed at the Mater Hospital in Brisbane. It involves opening the mother's abdomen and uterus and closing the abnormal defect over the baby's spinal cord while the baby is in utero. It does not restore lost neurological function but may prevent progressive loss from occurring. The MOMS trial showed that children with Spina Bifida may be more likely to walk independently and less likely to require a shunt after fetal surgery compared with traditional repair after birth, but there were also higher risks of maternal and infant complications.

Major risks of fetal surgery include:

- Infection
- Blood loss
- Prematurity delivery & related complications including brain haemorrhage, organ immaturity and death

Please discuss with your doctor if you have any questions about fetal surgery and to determine if you meet the criteria.