

FACTSHEET



This fact sheet is for education purposes only. Please consult with your doctor or other health professionals to make sure this information is right for your child. If you would like to provide feedback on this fact sheet, please visit: www.schn.health.nsw.gov.au/parents-and-carers/fact-sheets/feedback-form.

What is Spina Bifida?

Spina Bifida comes from a latin term which means “split spine”.

Spina Bifida describes a group of spinal abnormalities that occurs in the first four weeks of a pregnancy. In this time the baby’s developing spine (neural tube) fails to close properly. Spina Bifida is the incomplete development of:

- The spinal cord
- The bones forming the spinal column (vertebrae)
- The 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 on the outside of the baby’s back.

Hydrocephalus (too much fluid in the brain) and Arnold Chiari Malformation (abnormal development of the brain) are often associated with Spina Bifida. Spina Bifida can occur anywhere along the length of the spine and affects each child differently.

Each child will have an individualised treatment plan developed by the Spina Bifida team, in partnership with their family.

What causes Spina Bifida?

There is no single cause for Spina Bifida. It is thought to be due to both genetic and environmental factors and occurs very early in a pregnancy (before the 4th week).

Genetic

The genetic factors are not well understood. In 95% of cases there is no family history, but people with a close relative (parent, sibling) with Spina Bifida are 5 to 10 times more likely to have a baby born with Spina Bifida.

Genetic testing and counselling, specific to your family circumstances may be something you wish to discuss with your doctor.

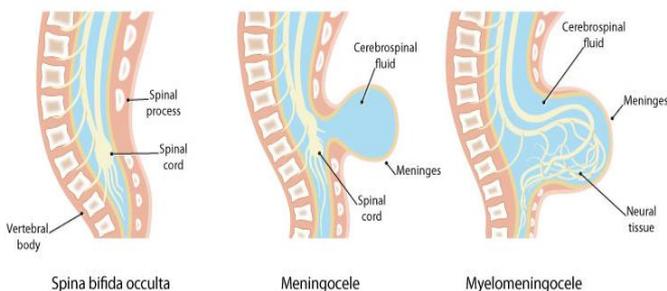
Environmental

There is a link between Spina Bifida and the intake of folate (folic acid) in the diet before and during pregnancy. Wheat flour is now fortified with folic acid in Australia. Folic acid is a B vitamin (B11) that comes from foods like:

- Leafy green vegetables.
- Citrus fruits, liver
- Legumes.

Folic acid is important for a healthy growing baby. Women planning to have a baby should take folic acid supplements. About 70% of cases are reduced by taking folic acid supplements.

- For the general population, the recommended dose is 0.5mg a day.
- For women with a family history of Spina Bifida (or neural tube defects) 5mg per day is recommended.



This supplement should be started at least one month before becoming pregnant. This should continue for at least the first three months of the pregnancy.

How is Spina Bifida diagnosed?

The diagnosis of Spina Bifida can be made from ultrasounds and blood screening tests between the 16th and 18th weeks of pregnancy. Once the diagnosis is made, families are often referred to the Spina Bifida Service at their local children's hospital for information and counselling.

How does Spina Bifida affect individuals?

Depending on their individual abilities, children living with Spina Bifida may need varying degrees of assistance to achieve goals throughout their lives.

The main areas impacted are:

- Lower limb weakness
- Altered skin sensation
- Bladder and bowel continence
- Hydrocephalus
- Learning.

Additional fact sheets are available about each of these areas of Spina bifida on the SCHN website.

Lower limb weakness

A child may have difficulty mobilising and might need mobility aids, such as orthoses, crutches or a wheelchair.

Altered skin sensation

A child with Spina Bifida may have a change to or loss of sensation to areas of their skin. Therefore attention and care will be needed to be taken to avoid damage or injury, and to maintain healthy skin.

Bladder and bowel control

Normal bladder and bowel control may not be possible. Damage to the nerves that control these functions may mean the bladder is affected and can not empty properly. Catheters may be needed to help empty the bladder, to prevent urinary tract infections and kidney damage. Bowel continence is achieved through diet and regular toileting. In many cases medication may be needed. The goal of bladder and bowel management is to achieve social continence. Continence issues are supported by nursing and medical advice.

Hydrocephalus

Some children living with Spina Bifida also have a condition called hydrocephalus. An Arnold Chiari malformation is often associated with Spina Bifida and leads to a build-up of fluid in the brain (hydrocephalus). To treat this, a shunt may be needed to drain the fluid into the abdomen where it is reabsorbed by the body. Hydrocephalus may also lead to other conditions such as seizures and problems with eyesight.

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

Learning

People living with Spina Bifida associated Hydrocephalus and Arnold Chiari Malformation may have difficulty learning. Difficulties may be in the areas of:

- organising
- planning
- initiating
- problem solving and
- dealing with new tasks.

The Spina Bifida Service will support learning strategies to manage these difficulties.

Initial management of a newborn

- Newborn babies are usually transferred, shortly after birth to a children's hospital Neonatal Intensive Care Unit (NICU) for assessment.
- Surgical closure of the lesion on the baby's back is recommended in the first 48-72 hours to reduce the chance of infection and further damage to the spinal cord.
- Treatment for Hydrocephalus may include an operation to insert a shunt which will drain excess fluid from the brain to another part of the body. Please refer to the [Hydrocephalus fact](#) sheet for further information.
- While in the hospital, baseline tests for kidney and bladder function will be conducted, as well as an assessment with physiotherapy.

Ongoing follow up

- Recovery from surgery varies, but is generally about 3 to 4 weeks and hospitalisation is usually needed.
- Follow up appointments are 6 weeks after discharge, then every three months for the first two years and then on a regular basis according to need throughout childhood.
- Multidisciplinary services at a Spina Bifida Service include medical, surgical, nursing, physiotherapy, occupational therapy, social work, orthotics and other specialists.
- Letters will be sent to your family's general practitioner to ensure continuity of care.

Where to find us

In NSW all three children's hospitals have a Spina Bifida Service. Your child will be referred to the one that serves your local area. To contact the Spina Bifida Service you can call the secretary on:

- **(02) 9845 2769** for The Children's Hospital at Westmead
- **(02) 9382 1595** for Sydney Children's Hospital at Randwick
- **(02) 4925 7868** for and Kaleidoscope, Hunter Children's Health Network

Further information

- Please ask for Fact Sheets from the Spina Bifida Service staff or download them for free from www.schn.health.nsw.gov.au/parents-and-carers/fact-sheets
- Watch the "Spina Bifida Animation" from the Spina Bifida Resource Network (American) at: www.thesbrn.org.
- The NSW Spina Bifida Collaborative Group website has all the presentations from the 2012 conference www.nswspinabifidacollab.org.au.

Glossary of terms

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| Arnold Chiari malformation (also Chiari II malformation) | Where the lower parts of the brain (brainstem and cerebellum) are abnormally formed and positioned. This can cause an obstruction to the normal flow of cerebrospinal fluid, leading to hydrocephalus. |
| Cerebrospinal fluid (CSF) | A clear fluid around the brain, within its ventricles, and around the spinal cord. It supports the central nervous system by maintaining a uniform pressure and supplying nutrients and chemicals. |
| Folate (also Folic acid) | A vitamin in the B group of vitamins obtained from foods such as leafy green vegetables, some fruits, berries and nuts. It is important for DNA synthesis in rapidly dividing cells. |
| Hydrocephalus | A build-up of fluid within the brain leading to enlarged ventricles, increased head circumference in babies and compression of the brain. A VP shunt may be required to drain the fluid. |
| Meninges | Membranes that cover the brain and spinal cord. |
| Meningocele | Incomplete fusion of the vertebrae, but not the spinal cord. There is a sac covered with meninges and filled with CSF. Usually no functional deficit. |
| Myelomeningocele | Failure of both the vertebrae and spinal cord to fuse posteriorly. Most common type of Spina Bifida. The sac contains nerves from the spinal cord as well as CSF and meninges. |
| Neural tube defect | Incomplete closure of the neural tube during embryonic development. The neural tube forms the spine and the brain. |
| Orthoses | Splints that maintain the legs in a good position for walking and provide support for weak muscles and joints. These are custom made for each child from specialised plastic and metal materials. Regular children's shoes can be worn with orthoses. |
| Ventricles | A system of chambers within the brain containing cerebrospinal fluid. |
| Vertebrae | Bones that form the spinal column surrounding the spinal cord. |
| Ventriculoperitoneal (VP) Shunt | A device used to relieve pressure from the brain caused by fluid accumulation. |