

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.

Care of a newborn baby with Spina Bifida

Any new birth will have its challenges for a family. Caring for a newborn baby with Spina Bifida may have more considerations. There are resources to help new parents through this early phase.

Learning about Spina Bifida and how to care for your baby will take time. Discuss your questions or concerns with the members of your child's treating team.

In hospital management of Spina Bifida

Most babies born with Spina Bifida require early medical and surgical treatment. The hospital stay is usually three-four weeks. Once you are ready to go home with your baby, the relationship with the Spina Bifida Service will continue in an outpatient capacity. During the initial hospital stay, every effort is made to ensure new parents understand the needs of their own child.

The Spina Bifida Service is a team consisting of several specialists including:

- A paediatrician
- A neurosurgeon
- Orthopaedic surgeon
- Spina surgeon
- Urologist
- Clinical nurse consultant
- Social worker
- Physiotherapist
- Orthotists
- Occupational Therapist.

The medical co-ordinator (usually a paediatric rehabilitation specialist) takes overall care of your baby and talks with all the members of the team.

Neurosurgery treatment

If necessary, closure of the Spina Bifida lesion is performed within the first two or three days of life. This operation involves:

- Protecting and preserving function of the spinal cord
- Bringing the skin together to cover the lesion.

Hydrocephalus (a build-up of fluid on the brain) may not be apparent while the Spina Bifida lesion remains open as the fluid is able to escape. Hydrocephalus may develop after the back is closed. Additional surgery may be needed to insert a shunt which will redirect the fluid from the brain. For more information see the fact sheet called "Hydrocephalus."

Physiotherapy assessment

The Physiotherapist will assess your baby to review lower limb function and musculoskeletal alignment. They will decide what treatment is required based on your child's individual needs.

Some treatment options include:

- Casting
- Splinting
- Stretches
- Stimulation of weak muscle groups
- Stimulation of normal development.

Bladder and urology treatment

During your baby's first few weeks in hospital, an initial assessment is made of kidney health and bladder function. These tests include:

- An ultrasound of the kidneys and bladder.
- Sometimes a micturating cysto-urethrogram (checks for reflux of urine back into the kidneys).

These tests help to determine whether intervention is needed for bladder management and catheters may be used to ensure the bladder is emptying completely.

Follow up arrangements

Follow up varies based on the individual needs of each child. The first medical follow up is usually six weeks after discharge from hospital. Babies grow rapidly and pass through many developmental stages in the first two years of life. Regular reviews are usually needed about every three months to six months or as required.

Physiotherapy and Occupational Therapy may be required. Sometimes it is possible to organise therapy closer to home, but most families return to the children's hospital for their therapy.

Support Groups

Every family will have different needs for support, especially during the early years. Each hospital has its own suggestions and ways to provide you with the support that you may need. Make sure you ask your Spina Bifida Service or social worker for assistance.

Remember:

There will be a lot of new information. Try and keep a list of questions to ask the doctor when you see them in the Spina Bifida Service. Read the available information and remember the Spina Bifida Service is here to support your family.

You can find further information about Spina Bifida at:

- Please ask for Fact Sheets from the Spina Bifida Service staff or download them for free from <http://www.schn.health.nsw.gov.au/parents-and-carers/fact-sheets>
- Watch the “*Spina Bifida Animation*” from the Spina Bifida Resource Network (American) youtube.com or www.thesbrn.org.