

# 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](http://www.schn.health.nsw.gov.au/parents-and-carers/fact-sheets/feedback-form).

## Hydrocephalus and Spina Bifida

Many people living with Spina Bifida also have a condition called Hydrocephalus. Hydrocephalus means “water on the brain.” Hydrocephalus occurs due to a defect at the base of the brain, known as the “Arnold Chiari (Chiari 2) malformation.” This is where parts of the brain push into the top part of the spinal canal. This blocks the normal flow of cerebrospinal fluid (CSF), forcing the fluid to cause pressure in the brain. In babies, the pressure from the fluid can cause the head size to increase. In older children and adults, the head cannot increase as the bones forming the skull have already fused.

### What are the effects of Hydrocephalus?

#### Learning

Children living with Spina Bifida with Hydrocephalus may have difficulty learning. Some of these difficulties may be in:

- Organising
- Planning
- Initiating
- Problem solving and
- Dealing with novel tasks.

These difficulties can impact all kinds of learning and development, including school work, activities at home, self-care and employment opportunities.

Some ways to support your child’s learning include:

- A structured environment with lots of repetition.
- Help in the classroom or workplace to stay on task.
- The Spina Bifida team can help with individual strategies.

#### Eyesight

Eye problems can be associated with Hydrocephalus. These might include:

- nystagmus (involuntary rapid movements of the eyes),
- optic atrophy (degeneration of the optic nerve),
- squints (cross-eyed)
- reduced eyesight.

The development of a squint can also suggest dysfunction in the shunt used to treat Hydrocephalus. Having regular eye tests is good for eyes and also to monitor pressure in your child’s head.

#### Seizures (fits)

People living with Hydrocephalus are at greater risk of having a seizure (or a fit). This can happen at any time throughout their lifetime. If fits occur regularly, it may be necessary to take medication.

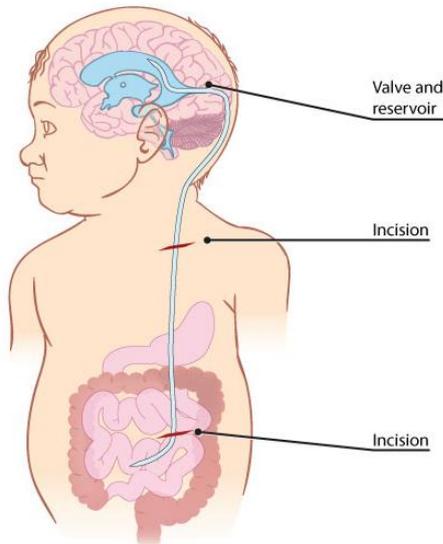
An infected ventricular peritoneal (VP) shunt can cause a seizure.

### How is Hydrocephalus treated?

The increased pressure on the brain caused by Hydrocephalus can be relieved by an operation to insert a Ventricular peritoneal (VP) shunt (common type of shunt). The shunt drains the fluid from the brain to another part of the body.

The shunt is a long, thin piece of tubing with a one way valve that takes the fluid from the ventricles in the brain, under the skin to the abdominal cavity. It is completely inside the body, but the outline of the tubing can be seen as it passes down the side of the neck, below the ear. A

long coil of tubing is normally placed in the abdomen to allow the shunt to lengthen as the person grows. The shunt does not cure Hydrocephalus, but by draining the excess fluid it can allow the head and brain to grow normally.



### What problems can occur with shunts?

A shunt won't work properly if the tubing is blocked, kinked, broken or becomes disconnected. Also if the valve stops working then the shunt won't work properly. Infection can also cause the shunt to not work properly. Shunt infection can happen at any stage, but is more common just after a new shunt has been inserted or after revision of the shunt.

Hydrocephalus is monitored in the outpatient clinic by the paediatrician, rehabilitation specialist and/or the neurosurgeon. A review of the signs and symptoms of shunt dysfunction is carried out at each clinic visit. Having a paediatrician is important for monitoring of milestones, and a good general practitioner is needed into adult life.

### The warning signs of a shunt not working or infection can include some of the following:

#### In older children:

- Headache
- Visual disturbance (blurred vision)
- Drowsiness
- Loss or decrease of consciousness
- Lethargy

#### In infants:

- Rapid head growth (in babies)
- Full, bulging or tense soft spot (fontanel) at the top of the head (present until the skull closes at about 18 months of age)

- Swelling and/or pain along the shunt, especially at the side of the neck
- Unusual irritability
- Nausea and vomiting
- Crossed eyes/sun setting eyes
- Periods when the baby stops breathing (apnoea) or drowsiness
- Difficulty drinking/swallowing/crying

#### Less common signs can include:

- Difficulty in walking and changed mobility (due to weakness, balance problems, deterioration in sensation or worsening of orthopaedic problems)
- Memory problems or significant change in intellectual functioning
- Decline in milestones
- Seizures (new or worsening or increased frequency of existing seizures)
- Back pain or worsening scoliosis
- Changes in incontinence
- Hearing sensitivities

#### Signs and symptoms of an infected shunt:

- Fever
- Neck stiffness
- Redness
- Leakage from the shunt wound area or tenderness along the tract
- Abdominal pain

**Please be aware that shunt malfunction can be life threatening. It is important to know what kind of shunt you have, symptoms of shunt malfunction and where to go for help.**

#### Remember:

There will be a lot of new information.

Try and keep a list of questions to ask the doctor when you see them.

Ask your Spina Bifida team if you have any concerns.

**You can find further information about Hydrocephalus and Spina Bifida at:**

- Queensland Education has developed a Hydrocephalus fact sheet. Download for free from: [www.sdc.qld.edu.au/Provectus/Spinal%20Disability/FTP\\_files/spinal\\_m02\\_p20\\_hydrocephalus\\_v2.pdf](http://www.sdc.qld.edu.au/Provectus/Spinal%20Disability/FTP_files/spinal_m02_p20_hydrocephalus_v2.pdf).
- Gillette Children's specialty health care has a variety of newsletter publications. Download for free from: [www.gillettechildrens.org/uploads/general/Newsletter\\_PDFs/Peds\\_Perspective - Hydrocephalus - Final.pdf](http://www.gillettechildrens.org/uploads/general/Newsletter_PDFs/Peds_Perspective_-_Hydrocephalus_-_Final.pdf).
- Hydrocephalus Association [www.hydroassoc.org](http://www.hydroassoc.org)
- Shine Charity UK have a YouTube clip "Get inside my head" which is available at: <http://www.shinecharity.org.uk>.