



# Hydrocephalus: information for families

---

Hydrocephalus occurs when either too much cerebrospinal fluid (CSF) is produced (very rare) or when it is stopped from circulating or being re-absorbed. This information sheet from Great Ormond Street Hospital (GOSH) explains about hydrocephalus, how it is treated and what to expect when your child has treatment.

CSF is a watery liquid that surrounds the brain and spinal cord, acting as a 'cushion'. It also supplies nutrients to the brain. The CSF builds up within the ventricles (cavities) of the brain resulting in increased pressure on the brain. In babies, this also causes the head to enlarge.

## What causes hydrocephalus?

The most common causes are:

- **Congenital** – This means that your child was born with hydrocephalus. Children born with spina bifida often develop hydrocephalus. This does not mean that all children with hydrocephalus also have spina bifida.
- **Prematurity** – Hydrocephalus can occur as a complication of being born too early, and when there has been bleeding in the brain.
- **Meningitis** – Hydrocephalus can occur as a complication of meningitis as the infection may cause a problem with reabsorption of CSF.
- As a complication from a **brain tumour** – this does not mean children with hydrocephalus develop brain tumours
- **Unknown** – In many cases, we do not know what caused the hydrocephalus.

## How is hydrocephalus diagnosed?

It is usually diagnosed by an increasing head circumference in infants, an ultrasound scan, a CT scan or sometimes an MRI scan.

## How is hydrocephalus treated?

If hydrocephalus is not treated, your child's head would get larger and the pressure on the brain would interfere with his or her development. In severe cases, this can result in permanent brain damage or visual problems. The aim of treatment is to reduce the pressure on the brain by draining the CSF away.

The fluid is drained away using a 'shunt', which is a long tube made of silicone. It is inserted in to the ventricles in an operation and drains the CSF away to either the abdomen or, more rarely, to the heart. The shunt contains a valve so that the fluid can only drain away from the head at the desired rate.

A different operation called a ventriculostomy may be performed instead; the aim of the operation is to drain CSF from the ventricular freely, without the need for a shunt.

Your surgeon will discuss which is best for your child.

## What happens before the operation?

You will already have received information about how to prepare your child for the operation in your admission letter.

The doctors or nurse practitioner will explain about the operation in more detail, discuss any worries you may have and gain your consent for the operation. Another doctor will also visit you to explain about the anaesthetic.

If your child has any medical problems, particularly allergies and constipation, please tell the doctors about these. Please also bring in any medicines your child is currently taking. You will be asked to give your child a bath or shower and hair wash before surgery.

## What does the operation involve?

Part of your child's hair, behind the ear, will be shaved and they will have an incision (cut) there in a horseshoe shape and a small incision on their abdomen.

Your child will have this operation under a general anaesthetic. They will be away from the ward for about one to one and a half hours. It is important that your child does not eat or drink anything for a few hours before the anaesthetic.

This is called 'fasting' or 'nil by mouth'. Fasting reduces the risk of stomach contents entering the lungs during and after the procedure. You will be informed the night before the procedure of the time that your child should be 'nil by mouth' – in other words, have nothing to eat or drink before the anaesthetic. Fasting times are provided in your admissions letter.

It is equally important to keep giving your child food and drink until those times to ensure they remain well-hydrated and get adequate nutrition. This may involve waking your child in the night to give them a drink which we recommend.

## What happens after the operation?

The nurses will observe your child closely for the first few hours and keep them comfortable with pain relief. He or she will be able to eat and drink a few hours after the surgery.

The first time a child has a shunt inserted, they will need to lie flat for 24 hours after the operation according to the surgeon's instructions.

Over the next few days, your child will be sat up gradually. The usual stay in hospital is two to three days.

To begin with, the area around the top of the shunt may be slightly raised, but as the swelling settles and your child's hair grows back you will not notice this. As your child grows, the area will become less prominent.

## Going home

Your child may have dissolvable stitches or they may have stitches that need to be removed seven days after the operation. If they need removing, this can be done by your GP, or at your local hospital. You can wash your child's hair and give them a bath the day after the stitches are removed. If the stitches are dissolvable, you can wash your child's hair five days after the operation.

## Complications of a shunt

There can be complications to having a shunt inserted, of which you should be aware. If you notice any of the following, please call the hospital for advice.

### Infection

An infection is most likely to develop in the first three months after shunt insertion. The symptoms of an infection in the shunt may include:

- Headache

- Irritability
- High temperature (over 37°C)
- Not feeding well
- Possibly vomiting
- Possibly drowsy

Please phone Koala ward for advice initially. If the shunt is infected, your child will need a course of antibiotics and the shunt removed temporarily and this will take place at GOSH.

### **A blocked shunt**

The symptoms of a blocked shunt include:

In babies

- A bulging fontanelle (soft part of the top of the head)
- Vomiting
- Crying and irritability
- Becoming sleepy (less responsive)
- Looking pale
- Increased head size

In toddlers and children

- Headache
- Vomiting
- Tiredness
- Drowsy

- Looking pale

Please phone Koala ward immediately and go to your local hospital immediately. If the shunt is not working properly, all or part of it will need to be replaced.

### **Low pressure**

The symptoms of low pressure are:

In babies

- Sunken fontanelle
- Miserable
- Pale and possibly shocked
- Sweaty
- Vomiting

In toddlers and children

- Severe headache
- Pale
- Sweaty
- Vomiting

In the majority of cases, the symptoms will disappear after lying flat for a while. If you are worried about your child, you must call Koala ward for advice immediately.

## **Further information and support**

If you have any questions, please call Koala ward on 020 7829 8826 or the Neurosurgical Nurse Practitioners on 020 7405 9200 extension 1611

SHINE can offer advice and support for parents of children with hydrocephalus. Call them on 01733 555 988 or visit their website at [www.shinecharity.org.uk](http://www.shinecharity.org.uk)