

Hydrocephalus

Information for patients, parents and guardians

You have been given this factsheet because your child has hydrocephalus (excess fluid in the brain). We hope it will answer some of the questions you may have. If there is anything you do not understand, a member of your child's healthcare team will be happy to explain further.

What is hydrocephalus?

It is a build-up of cerebrospinal fluid (CSF) in the brain.

It can occur at any age from birth to adulthood, and affects both boys and girls.

There are 3 main types of hydrocephalus:

- congenital hydrocephalus – present at birth
- acquired hydrocephalus – develops after birth
- normal pressure hydrocephalus – usually only develops in older people.

Cerebrospinal fluid (CSF) is made in the ventricles (fluid-filled areas) of the brain. It constantly circulates through the ventricles, around the spinal cord and over the surface of the brain, where it is absorbed back into the bloodstream.

If the fluid is not circulating or being absorbed properly (or, rarely, if too much fluid is being produced) then it leads to an excess amount of fluid in the system.

When this happens, the ventricles become enlarged, which puts pressure on the delicate brain tissue. There is a build-up of pressure in the head, which can lead to some of the signs and symptoms below.

Signs and symptoms of hydrocephalus

Babies:

- increasing head size
- tense bulging fontanelle (the diamond-shaped patch on the top of your baby's head)
- irritability and restlessness
- high pitched cry
- crying when held
- eyes appear to be looking down (known as sun-setting eyes)
- easily visible (distended) scalp veins
- changes in feeding.

Children:

- headache
- nausea and vomiting
- blurred or double vision
- irritability
- drowsiness
- lethargy and poor concentration
- seizures.

Diagnosis and treatment

The way we manage hydrocephalus depends on the cause.

Your child will have a computerised tomography (CT) scan or a magnetic resonance imaging (MRI) scan to confirm the diagnosis and find the cause of the hydrocephalus. A CT scan uses x-rays and an MRI scan uses magnets to take detailed pictures of the brain.

They are completely painless, but your child will need to stay still while the pictures are taken. They may need sedation or a short anaesthetic so the scan can be carried out accurately.

The neurosurgeon (a specialist doctor), will discuss the results with you and recommend the appropriate treatment.

If hydrocephalus is left untreated there can be permanent damage to the child's vision and normal development can be affected. Your child may become unwell very quickly, which will require urgent surgery.

Will my child need an operation?

Most forms of hydrocephalus require an operation to achieve a more normal flow of the CSF and relieve the pressure on the brain. This can be achieved by:

- a procedure called an ETV (endoscopic third ventriculostomy), or
- insertion of a VP (ventricular-peritoneal) shunt.

ETV

During an ETV, a surgeon makes an opening through a part of the brain called the third ventricle, using an endoscope (thin telescope). This allows the CSF to flow through to the brain's surface, where it can be absorbed, bypassing any blockage further down.

This is only suitable in for certain types of hydrocephalus and isn't usually performed on babies and young children.

The surgery takes two to three hours under general anaesthetic (medicine to make you go to sleep). After the operation your child will have a small wound on the side of their head, which will be sealed with paper stitches called steristrips.

VP shunt

A VP shunt is designed to redirect the excess CSF from the brain to another part of the body (usually

the tummy), where it will be absorbed. The shunt is completely enclosed inside the body and consists of two flexible thin tubes that are connected by a valve which controls the rate of drainage and prevents the CSF flowing back to the brain.

The tubing is coiled in the abdominal cavity to allow for growth. (Very occasionally the CSF is diverted into the heart - this is called a VA shunt).

The surgery takes two to three hours under general anaesthetic (medicine to make you go to sleep) and your child will have small wounds on their head and tummy, which will be covered with a dressing.

Before surgery

The surgeon will explain the procedure, risks and alternatives to you and you will be asked to sign a consent form.

An anaesthetist will see you and your child to discuss the anaesthetic and a blood sample will be taken.

Your child will not be allowed to eat and drink before going for surgery and must not have any food or milk for six hours before the operation. They can drink clear fluids up to two hours before the operation.

One parent can accompany your child to theatre and stay with them until they are asleep.

The ward nurses and play specialist will be available to discuss any concerns and help prepare your child for surgery.

After surgery

Your child will return to the ward having spent a short time in recovery. One parent is usually allowed into recovery once your child is awake. Your child may be sleepy for a few hours, and the nurses will observe them closely and give pain relief medicine if required.

Your child may have drip in their arm to give them fluids until they are drinking. They can start drinking when they feel able. It is best to start with clear fluids before moving onto milk or food.

Sometimes they feel a bit sick and can take a while to get back to normal eating and drinking.

They may develop a headache due to the change in pressure in their head. If so they should sit up slowly and leave moving until the next day.

Any dressings can be removed the next day. The paper stitches can be left to come off over the next week.

Your child will have to stay in hospital for at least two days. Length of stay in hospital may depend on the cause of the hydrocephalus and if any further treatment or investigation is required. In most cases shunts are intended to stay in for life, although revisions may be necessary from time to time.

After leaving hospital

- Your child should gradually return to normal activities.
- They can have paracetamol (Calpol) for pain if required, following the instructions on the bottle.
- Wash their hair gently with mild shampoo and allow the paper stitches to come off.
- Older children should avoid contact sports such as rugby and boxing for six months.
- You should inform your child's teacher of their operation.

Things to be aware of

You should look out for:

- any of the signs and symptoms of hydrocephalus as described on this factsheet
- any inflammation of the wound
- a high temperature.

These could indicate a problem with the shunt or third ventriculostomy, such as a blockage or infection, which could require further surgery.

Follow-up care

Your child will be seen by the advanced nurse practitioner or children's neurosurgery specialist nurse on the ward two weeks after surgery.

The neurosurgeons will see them in three months.

Further information

If you have any questions or concerns please speak to a member of your child's healthcare team or contact children's neurosurgery ward (G2N) on 023 8120 6692.

Useful links

NHS website: www.nhs.uk/conditions/hydrocephalus

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For help preparing for your visit, arranging an interpreter or accessing the hospital please visit **www.uhs.nhs.uk/additionalneeds**

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