

## Paediatric Neurosciences

# Information for Parents on Hydrocephalus and Shunts

This leaflet explains more about hydrocephalus and its treatment, including the benefits, risks and any alternatives and what you can expect when you come to hospital. If you have any further questions, please speak to a doctor or nurse caring for your child.

## What is hydrocephalus?

Hydrocephalus is an abnormal build-up of cerebrospinal fluid (CSF) in the ventricles (cavities) inside the brain. The ventricles are fluid-filled spaces in the brain. CSF is a clear, colourless fluid that looks like water and contains small amounts of salt, sugar and cells. CSF is constantly produced in the ventricles. It moves around the brain and spinal cord, is absorbed and then replaced by new CSF.

Some of the functions of CSF are to protect the brain and spinal cord from injury. The CSF nourishes the brain cells which helps with brain functioning and it carries away waste products from brain cells.

CSF moves around the brain and spinal cord on a specific pathway. When too much CSF gets trapped anywhere along this pathway, it can expand the ventricles and put pressure on the surrounding brain. This condition is called **hydrocephalus**.

**Communicating hydrocephalus** is the build-up of pressure from too much CSF which is not being properly absorbed.

**Non-communicating hydrocephalus** is the build-up of pressure from CSF when a blockage occurs within the brain. Some causes of non-communicating hydrocephalus may be a tumour, a blood clot or a narrowing of part of the CSF pathway found at birth. A person born with hydrocephalus is said to have “congenital hydrocephalus”. Those who develop it later in life are said to have “acquired hydrocephalus”.

## Signs of hydrocephalus

To find out if your child has hydrocephalus, the doctor will assess your child and do some tests.

Signs of hydrocephalus **in a baby**. Your baby may have some or all of the following symptoms:

- poor feeding
- vomiting (throwing up)
- sleepy (hard to wake up) or not as awake or alert as usual
- large head (your GP or health visitor can measure this)
- bulging soft spot (fontanelle) on the top of the head
- seeming irritable (cries easily or without reason)
- seizures
- very noticeable scalp veins
- slowness at reaching milestones (for example, slow to roll over, slow to sit)
- "sunset" eyes, when the eyes appear to be always looking down and they are not able to look up.

Signs of hydrocephalus **in a child**. Your child may have some or all of the following symptoms:

- headaches
- nausea and vomiting
- tired (sleeping more than usual, difficult to wake up, does not want to play as usual)
- seeming irritable
- changes in personality, behaviour or school performance
- loss of coordination
- seizures
- changes in vision.

## **Hydrocephalus is diagnosed with CT scan, MRI or ultrasound**

Hydrocephalus is often diagnosed with imaging tests. These tests include CT scan, MRI and ultrasound. These technologies give doctors different views of what is going on inside the brain. These imaging tests may reveal a blockage or a build-up of CSF. Using MRI and ultrasound, hydrocephalus is sometimes diagnosed before a child is born. Because CT scans and MRI require a person to be still while the pictures are being taken, some children need to be given sedation medicine or a light general anaesthetic to help them keep still during the tests. We also have dedicated play specialists to support and provide distraction.

## **Hydrocephalus is treated with surgery**

There are no effective medicines for hydrocephalus and most children require surgery. The goal is to lessen the pressure in the brain by providing another pathway for CSF to be drained and absorbed away from the brain. There are two types of surgery for hydrocephalus. The most common treatment is the insertion of a shunt. The shunt works by moving fluid from an area where there is too much CSF to an area where it can be absorbed into the body. Some children with non-communicating hydrocephalus can have surgery called an "endoscopic third ventriculostomy" (ETV).

## Shunt surgery

The most common treatment of hydrocephalus is the surgical placement of a shunt. A shunt is a soft, flexible tube. The top end of the shunt is placed in the ventricle fluid spaces inside the brain. This tube is attached to a valve that controls the flow of CSF through the shunt. The tube is then tunnelled below the skin to an area of the body where the fluid can be absorbed. One area is the lining of the abdominal cavity (the peritoneum). This is called a ventriculo-peritoneal shunt (VP shunt).

Less often, the shunt is connected from the brain to other parts of the body. A shunt from the brain to the lining around the lung (pleural space) inside the chest is called a ventriculo-pleural shunt. A shunt from the brain to veins draining into the heart is called a ventriculo-atrial shunt.

## There are different types of shunt tubes and valves

Your child's neurosurgeon will decide what type of shunt tube is best for your child. All shunts will only allow CSF flow in one direction. Some shunts may also have a small bubble or "reservoir" near the top that the doctor can use to take samples of CSF for testing. Sometimes a special type of shunt is needed where the pressure setting is adjustable. This is called a programmable shunt valve. This allows the surgeon to program the shunt to control how much CSF is draining. It is important to remember the pressure setting of the shunt and that the setting of this shunt can be changed by a magnet. If at any point your child requires an MRI you must make sure to inform the MRI department that s/he has a programmable shunt and what setting it is set at. After the MRI the shunt pressure setting needs to be confirmed by carrying out an x-ray. If your child requires an audiology consultation you must also inform the department prior to having an audiology assessment. It is not advised that newborn hearing checks are carried out in the community and your child will need to be referred to audiology to carry out their hearing check.

## During the shunt operation

Your child is taken to the operating theatre suite and goes to sleep under general anaesthesia so that your child will not feel any pain during the operation. An area on the head and an area on the abdomen (belly) is scrubbed with a special soap. The surgeon makes incisions (cuts) on the head and abdomen and the shunt tubing is tunnelled just below the skin. The ventricular (top) end of the shunt is passed through a small hole in the skull made by the surgeon and gently passed into the ventricle. The abdominal (bottom) end is passed through a small opening in the abdomen. The incisions are then closed using staples or stitches. The operation takes between one and two hours.

## After the shunt operation

Your child is then taken to the recovery room where s/he will wake up soon after the operation. You will be able to see your child as soon as s/he wakes up. Your child will spend about one to two hours in recovery and then will be returned to their bed on the neurosciences/surgical ward. Your child will have a head bandage on and will have a dressing on their head and another dressing on the abdomen or chest, depending on the type of shunt. The nurse will check your child often and s/he will also be checking to see how easily your child wakes up, even at night. Your child will have an intravenous (IV) line after surgery until s/he is drinking well. For some children (mainly under one year) we may give specific bed rest advice to prevent low pressure headaches.

## Pain after the operation

After the operation, your child may have pain at the operative sites and the nurse will give your child regular pain relief medicine. This should control the pain. If it does not control the pain, speak to your child's nurse. Your child may also learn other ways to control pain, such as blowing bubbles or relaxation breathing. Your child's surgeon will tell you when your child can start normal activity, such as sitting up and walking. After your child has recovered from the surgery s/he can go home.

## Going home after the operation: possible complications

Occasionally the shunt might stop working properly after you go home. Sometimes the tube can become blocked, come apart or break. Or your child may grow taller so that the tube moves out of the abdomen. Or it may become infected. If you notice any signs of hydrocephalus coming back, it is very important to contact your Neurosurgical Centre:

**Nicholls ward 020 8725 3389 or 020 8725 2098**

**Clinical Nurse Specialist in Paediatric Neurosciences on 020 8725 2649 and**

**e-mail: [stgh-tr.cns paed s neurosciences@nhs.net](mailto:stgh-tr.cns paed s neurosciences@nhs.net)**

Your child will need medical attention if you see any signs or symptoms of a shunt problem. Your child needs to be seen either on Nicholls Ward / St George's A&E or at your local hospital immediately, if you see any signs or symptoms of shunt failure. If your child's shunt is not working properly, the pressure will return to the brain.

Signs that the shunt is not working are the same as the signs of hydrocephalus, listed above. Your child may have the same signs as before their shunt was put in or there may be new signs.

## Signs of a shunt infection include the following:

- puffiness or redness of the skin around the tube and at incision (cut) sites
- a fever
- a stiff neck

- fluid coming out of the incision
- loss of appetite or not eating well
- generally feeling sick
- headache
- abdominal (tummy) pain.

## Symptoms of low pressure are:

### In babies

- Sunken Fontanelle
- Miserable
- Pale
- Sweaty
- Vomiting

### In toddlers or children

- Severe headache
- Pale
- Sweaty
- Vomiting

In the majority of these cases the symptoms will disappear after lying flat for a while.

## Stitches

Most sutures used are dissolvable, however if sutures do need to be removed we will arrange for you to come back to the ward to have them taken out. Stitches should be taken out about seven to ten days after the operation.

## Follow up after the operation

Your surgeon will need to see your child for in a follow-up clinic. The appointment may be made for you when your child leaves the hospital. If not, you will receive a letter with an appointment.

## If you have any questions

Any medical questions you may have can be answered by your neurosurgeon or nurse specialist.

Do write down any questions you may have before you meet the neurosurgeon or nurse specialist otherwise you can contact the nurse specialist via telephone or e-mail.

For any questions regarding follow up or appointments you may call your neurosurgeon's secretary. You will be provided with a shunt pack which includes information provided from the Shine charity and a front page with your child's shunt details, contact details for the Paediatric Neurosciences Clinical Nurse Specialist and Nicholls ward.

The telephone number for the clinical nurse specialist is 020 8725 2649 Monday to Friday or for out of hours please contact Nicholls Ward on 020 8725 2098/3389.

## Longer term: as your child grows to adulthood

Your child will need to be seen by their neurosurgeon yearly to ensure the shunt is working properly and that the pressure does not begin to build up again. We have a nurse-led shunt clinic which can be carried out by telephone or face to face.

Several members of a team will help and guide you as your child grows and develops. You should encourage your child to become involved in this continuing process.

Useful Links:

[www.shinecharity.org.uk](http://www.shinecharity.org.uk) Tel: 01733 555 988

This document is intended for information purposes only and should not replace advice that your relevant health professional would give you.

We will provide Shine charity resources along with your child shunt pack.

**For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit [www.stgeorges.nhs.uk](http://www.stgeorges.nhs.uk)**

## Additional services

### Patient Advice and Liaison Service (PALS)

PALS can offer you on-the-spot advice and information when you have comments or concerns about our services or the care you have received. You can visit the PALS office between 9.30am and 4.30pm, Monday to Friday in the main corridor between Grosvenor and Lanesborough wings (near the lift foyer).

**Tel:** 020 8725 2453 **Email:** [pals@stgeorges.nhs.uk](mailto:pals@stgeorges.nhs.uk)

### NHS Choices

NHS Choices provides online information and guidance on all aspects of health and healthcare, to help you make decisions about your health. **Web:** [www.nhs.uk](http://www.nhs.uk)

### NHS 111

You can call 111 when you need medical help fast but it's not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year. Calls are free from landlines and mobile phones. **Tel:** 111

### AccessAble

You can download accessibility guides for all of our services by searching 'St George's Hospital' on the AccessAble website ([www.accessable.co.uk](http://www.accessable.co.uk)). The guides are designed to ensure everyone – including those with accessibility needs – can access our hospital and community sites with confidence.

