

Hydrocephalus in Children and Young People

This leaflet provides information about hydrocephalus for our paediatric patients. If you have any further questions or concerns, please speak to the staff member in charge of your care.

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 and 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. It protects, nourishes and discards waste products from these vital organs.

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**.

A person born with hydrocephalus is said to have “congenital hydrocephalus”. Those who develop it later in life are said to have “acquired hydrocephalus”.

Communicating hydrocephalus is the build-up of pressure from too much CSF which is not being properly absorbed. For example, from an infection (such as meningitis) or a bleed in the brain.

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.

What are the signs of hydrocephalus?

Signs of hydrocephalus **in a baby**. Your baby may have some or all 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 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.

Does my child need any tests to confirm the diagnosis?

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 and the 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. If your child is found to have hydrocephalus, they will be referred to a consultant neurosurgeon at a hospital where they provide paediatric neurosurgery.

What treatments are available?

There are no effective medicines for hydrocephalus and most children require surgery. The goal is to reduce 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. A 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).

The decision on the best way of treating the hydrocephalus will be made by your consultant neurosurgeon, who will discuss this with you.

Please see our other information leaflets about the different surgeries used in the management of hydrocephalus.

What happens if my child does not get treatment?

Hydrocephalus, if left untreated, causes increased pressure inside the skull. In babies this can potentially affect their development and the ability to meet milestones. In older children, the symptoms will continue to get worse and this can be a threat to life if left untreated.

Useful sources of information

Shine UK

[Shine - Spina Bifida & Hydrocephalus](#) Tel: 01733 555 988

Harry's Hydrocephalus Awareness Trust (Harry's HAT)

[Harry's HAT | Harry's Hydrocephalus Awareness Trust](#) Tel: 07961001710

The book "Hydrocephalus, What I'd Wish I'd Known" is available via the website or ask your CNS team if they have a copy which you can have.

Hydro&Me

[Hydro & me - hydroandme](#)

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

Contact us

Clinical Nurse Specialists in Paediatric Neurosciences

(Monday to Friday 8am to 5pm)

Telephone: 020 8725 2649

E-mail: paedneurocns@stgeorges.nhs.uk

Out of hours

Nicholls ward 020 8725 3389 or 020 8725 2098

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.stgeorges.nhs.uk

Was this information helpful? Yes / No

Please let us know, contact patient.information@stgeorges.nhs.uk and include the leaflet title.

Thank you.

Additional services

Patient Advice and Liaison Service (PALS)

PALS can offer you advice and information when you have comments or concerns about our services or care. You can contact the PALS team on the advisory telephone line Monday, Tuesday, Thursday and Friday from 2pm to 5pm.

A Walk-in service is available:

Monday, Tuesday and Thursday between 10am and 4pm

Friday between 10am and 2pm.

The Walk-in and Advisory telephone services are closed on Wednesdays.

Please contact PALS in advance to check if there are any changes to opening times.

PALS is based within the hospital in the ground floor main corridor between Grosvenor and Lanesborough wings.

Tel: 020 8725 2453 **Email:** pals@stgeorges.nhs.uk

NHS UK

The NHS provides online information and guidance on all aspects of health and healthcare, to help you make decisions about your health.

Web: 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 our services by searching 'St George's Hospital' on the AccessAble website (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.

