

Information leaflet for parents/carers

# Hydrocephalus Neurosurgery



# Hydrocephalus

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## Hydrocephalus

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## Introduction

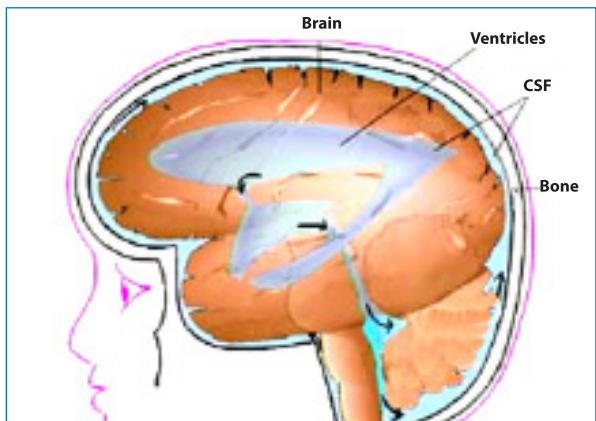
This information booklet has been designed with the help of parents for families to use. We hope it will help you to understand and share information about your child's condition. Please bring this booklet every time you visit the hospital, that way we can keep it updated with your child's treatment and management plan.

## What is hydrocephalus?

Hydrocephalus is one of the most common conditions affecting children who need to have neurosurgical treatment.

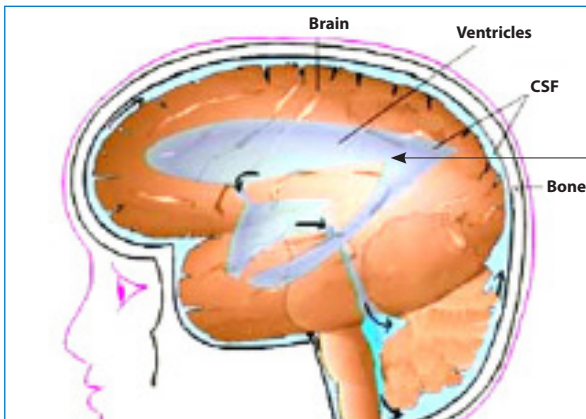
The brain and spine are surrounded by a watery fluid called cerebrospinal fluid (CSF) which acts as a "cushion". Hydrocephalus develops when either too much CSF is produced or if there is a problem which stops the CSF from circulating and being re-absorbed into the bloodstream. When someone has Hydrocephalus, CSF builds up within the ventricles or cavities of the brain and as a result there is increased pressure in the brain.

The long-term outlook for patients with Hydrocephalus has dramatically improved over recent years; however, patients with Hydrocephalus will continue to require regular neurosurgical follow up throughout their life.

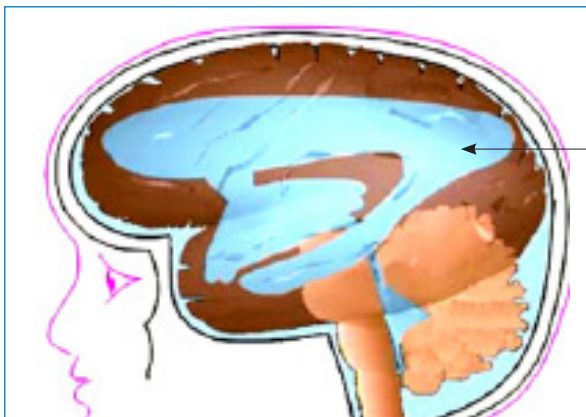


## How is hydrocephalus diagnosed?

In babies and infants the head will enlarge due to the pressure of CSF. In older children and adults the head size cannot increase because the skull is completely joined together. In this case, an ultrasound, CT or MRI scan are used to diagnose hydrocephalus.



Normal  
Ventricles



Hydrocephalus  
(enlarged  
ventricles)

## How is hydrocephalus treated?

Hydrocephalus is treated by draining away the excess CSF. This can be done using a Shunt or through an Endoscopic Third Ventriculostomy (ETV). The neurosurgeon will discuss with you which treatment option is suitable for your child. They will be happy to answer any questions you may have.

## What is a shunt?

CSF can be drained away using a shunt, which is a long tube (catheter) inserted into the ventricle, which drains the CSF away into the abdominal cavity. CSF can also be drained to other areas if the abdomen is not suitable. The shunt has a valve which controls the amount of CFS that is drained away.

During the operation a small hole will be made in your child's head and a little hair shaved from around the area. A small incision will be made to your child's abdomen. Both areas should heal over the following weeks.

- Shunts divert fluid from one compartment to another.
- In hydrocephalus, shunts commonly divert CSF from the ventricles to the abdomen (peritoneal cavity)

## **What happens before the operation?**

The neurosurgeon will explain the operation to you in detail. Your child will need a general anaesthetic for the operation and will be seen by an anaesthetist before the surgery. Please refer to the information on the ward, speak to the anaesthetist or ask your nurse if you would like any further information. Your child will be away from the ward for 1-2 hrs and will need to fast (be nil by mouth, no food) before the operation. Your child's nurse will explain the fasting details as it is important to follow these instructions.

## **What happens after the operation?**

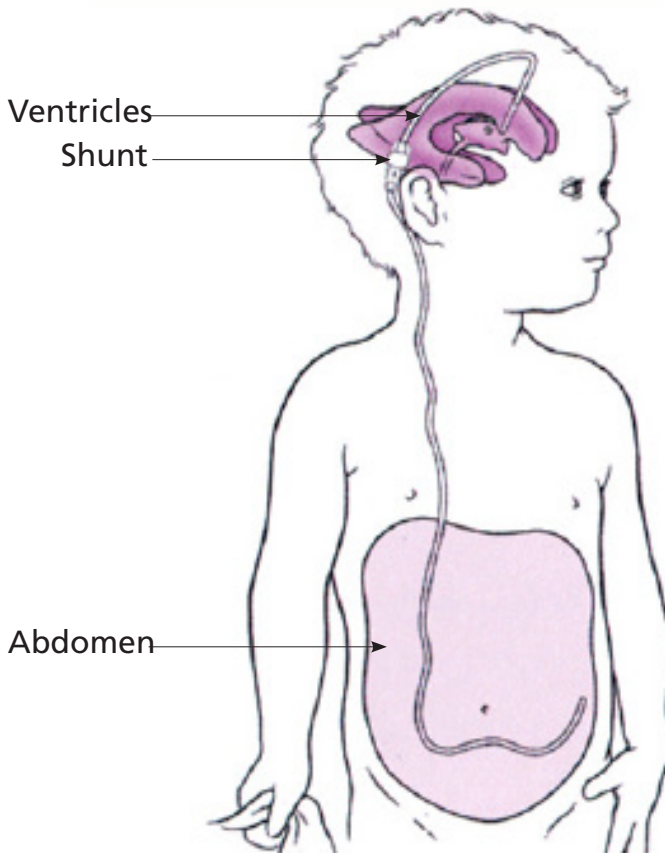
Your child will return to Ward 10 after their surgery. They will be closely monitored and given regular pain relief and anti sickness medicines to help with any discomfort. Your child may feel sleepy and complain of a sore throat, head, neck or tummy. This is normal after a general anaesthetic and shunt surgery.

The neurosurgeons review each child on the ward every morning. They are happy to answer any questions that you may have and will plan for discharge home as soon as your child is ready.

## What complications can occur with shunts?

- Shunts can become infected
- Shunts can fail or block at any time
- Some shunts may drain too much or too little CSF
- Shunts may need to be replaced

Whatever the reason may be for the shunt not working, your child's symptoms will be the same. Most children become unwell over a period of one or two days however they can become unwell very quickly, over a matter of hours.





## What are the symptoms of hydrocephalus/ blocked shunt?

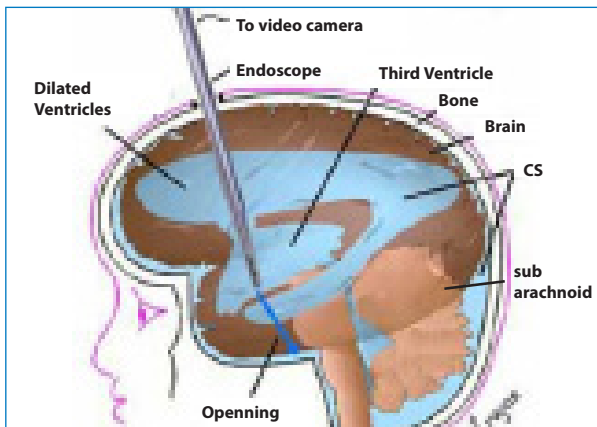
If you notice any of the following symptoms please call the hospital straight away for advice:

Signs of Infection	Signs of Blocked shunt	Signs of Low pressure
Headache	Headache	Sunken soft spot (in babies)
Irritability	Vomiting	Irritability
High temperature	Crying	Sweaty
Not feeding well	Irritability	Headache
Vomiting	Sleepy/ less drowsy responsive	
Drowsy	Sensitive to light	
Swelling or redness over shunt tract	Increased head size Bulging soft spot (in babies)	
	Confusion	
	Seizures	
	Decline in academic performance	
	Incontinence (in children who are normally continent)	
	Sunsetting - In babies when eyes look down	

## Caring for your child's wounds after shunt surgery

Care should be taken with washing and dressing. Keep wounds covered immediately after surgery, the nurses and doctors will check the wounds and remove the dressing as soon as it is safe to do so. Once the dressings are removed avoid directly washing wounds until fully healed. Unless otherwise advised you can wash your child's hair 5 days after surgery. Avoid soaking and dry the areas thoroughly after washing. Keep the areas clean and dry, report any redness, leaking or discomfort to the nurse or doctor. Your child will need to attend a review clinic on Ward 10 shortly after you are sent home where the wounds will be reviewed by one of the doctors. An appointment for the outpatient clinic later in the year will be sent through the post. Please ask a nurse if you have any questions.

## What is an Endoscopic Third Ventriculostomy (ETV)



## Endoscopic Third Ventriculostomy (ETV)

An ETV can be used to treat hydrocephalus, as an alternative to a shunt.

The neurosurgeon makes a small hole in the base of the third ventricle which allows the CSF to flow into the sub arachnoid space where it can be absorbed.

Your child will have a small hole in their head which was made for the endoscope. This should heal over the weeks following surgery. It is important to look at the wound for any leaking of fluid or any signs of infection such as itching, redness or leaking from the site. Children must not be allowed to touch the area with their fingers for the first 5 days to prevent infection and allow healing.

- CSF is diverted to relieve pressure on the brain as an alternative to a shunt
- A small hole is made of the floor of the 3rd ventricle
- This allows movement of CSF out of the ventricular system into the sub arachnoid space where is reabsorbed
- A successful ETV means a shunt will not be needed
- There is less chance of infection and further surgery

## What happens before the operation?

The neurosurgeon will explain the operation to you in detail. Your child will need a general anaesthetic for the operation and will be seen by an anaesthetist before the surgery. Please refer to the information on the ward, speak to the anaesthetist or ask your nurse if you would like any further information. Your child will be away from the ward for 1-2 hrs and will need to fast (be nil by mouth) before the operation. Your child's nurse will explain the fasting details as it is important to follow these instructions.

## What happens after the operation?

Your child will return to Ward 10 after their surgery. They will be closely monitored and given regular pain relief and anti sickness medicines to help with any discomfort. Your child may feel sleepy and complain of a sore throat or head- this is normal after a general anaesthetic and ETV. The head of your child's bed will be slightly raised to help the ETV to start working.

The neurosurgeons review each child on the ward every morning. They are happy to answer any questions that you may have and will plan for discharge home as soon as you and your child are ready.

## What complications can occur with ETVs?

- Not all types of hydrocephalus are suitable for ETV
- ETV's can block or stop working at any time.
- Most children become unwell over a period of one or two days however they can become unwell very quickly- over a matter of hours.

Whatever the reason may be for the ETV not working, your child's symptoms will be the same and further surgery will be required.

## What are the symptoms of failed ETV?

If you notice any of the following symptoms please call the hospital straight away for advice:

Signs of Infection	Signs of Blocked shunt/ Blocked ETV	Signs of Low pressure
Headache	Headache	Sunken soft spot (in babies)
Irritability	Vomiting	Miserable
High temperature	Crying	Sweaty
Not feeding well	Irritability	Headache
Vomiting	Sleepy/ less responsive/Drowsy	
Drowsy	Sensitive to light	
Redness or swelling to the wound	Increased head size Bulging soft spot (in babies)	
	Confusion	
	Seizures	
	Decline in academic performance	
	Incontinence (in children who are normally continent)	

## Caring for your child's wounds after ETV

Care should be taken with washing and dressing. Keep wounds covered immediately after surgery, the nurses and doctors will check the wound and remove the dressing as soon as it is safe to do so. Once the dressing has been removed avoid directly washing wounds until fully healed. Unless otherwise advised you can wash your child's hair 5 days after surgery. Avoid soaking and dry the areas thoroughly after washing. Keep the areas clean and dry, report any redness, ooze, leaking or discomfort to the nurse or doctor. Your child will need to attend a review clinic on Ward 10 shortly after you are sent home where the wounds will be reviewed by one of the doctors. An appointment for the outpatient clinic later in the year will be sent through the post. Please ask a nurse if you have any questions.

## ETV/Shunt Alert Card

On discharge from the ward or unit you will be given an ETV or Shunt Alert Card. This provides a singular point of reference with relevant information about your child's condition, the surgical treatment provided and outlines all the relevant contact information and escalation process were a child at risk for shunt malfunction. Please keep this with you as an alert card is very helpful when accessing emergency services.

## Outpatient clinic

Your child will be given yearly appointments at Birmingham Children's Hospital to be reviewed by one of the neurosurgical team in the main outpatients department. It is important that you attend these appointments. The neurosurgeon will want to know if you have seen any changes in your child's health or behaviour since you last visited and will be happy to talk about any concerns you have.

It is a good idea to write down any questions that you may have and bring them to clinic with you.

## GP

Your GP will be sent some correspondence after your child's appointments and will be made aware of any ongoing treatment at BCH.

## Vaccination

Your child can have the usual childhood vaccinations including whooping cough. If you have any concerns or questions please speak to the nurse specialist.

## Travel

It is safe for your child to fly once they have recovered from surgery and their hospital stay. We recommend that you take this information booklet with you in the case of a hospital admission while you are away from home. Please make sure that you have appropriate medical insurance when travelling abroad. If you need any further information please contact the nurse specialist.

## Sports/activities

Your child can take part in most sporting activities avoiding only those that involve deliberate blows to the head such as boxing and rugby. Please refer to your child consultant if you have any questions or concerns.

## Social activities

Social activities should be discussed with your child's individual consultant. This is due to the variations of underlying causes that may have caused the Hydrocephalus. Many children will not be restricted with the social activities in which they do although caution may need to be considered in protecting the shunt tubing.



## School

It is important that your child's school or nursery are aware of their condition and understand what to do if your child becomes unwell or has a problem which could be related to the shunt or ETV. An action plan should be agreed and shared with parents.

The school / school nurse can contact the specialist neurosurgery nurse at BCH for advice and information about Hydrocephalus.

ETV or Shunt's can block or stop working at any time. Most children become unwell over a period of one or two days however they can become unwell very quickly- over a matter of hours.

If a child with an ETV or shunt displays any of the symptoms of blockage, shunt or low pressure:

1. The child's parents should be contacted immediately
2. If parents are unavailable the neurosurgical unit should be contacted. Ward 10 offer 24/7 telephone advice
3. It may be necessary to consider review at the nearest A&E Department
4. Shunt/ ETV malfunction may also present over a longer period of time, for this reason any of the following should be brought to parents/ carers attention:
  - Behaviour changes
  - Decline in academic performance
  - Visual problems
  - Fatigue
  - Vomiting

It is not uncommon for children with Hydrocephalus to have some degree of learning disability and all remain at risk of re occurring medical problems possibly requiring absence from school. Information for teachers is available from Shine ([www.shinecharity.org.uk](http://www.shinecharity.org.uk)). The Hydrocephalus Association (USA) has developed 'A Teachers Guide to Hydrocephalus': this detailed booklet can be found on-line at [www.hydroassoc.org](http://www.hydroassoc.org)

**Children and young people with hydrocephalus need a shunt or ETV that is working properly at all times.**

## **What are the long term effects for my child?**

The long-term outlook for patients with Hydrocephalus varies greatly. Each child's progress and development will be different, depending upon the underlying cause and severity of Hydrocephalus. The team of professionals at BCH will support your child as they develop to their greatest potential. However your child will need to have regular neurosurgical follow up throughout their life.

## **Looking after and sharing information about your child**

We have updated our Privacy Notices in line with the data protection legislation General Data Protection Regulation (GDPR) Data Protection Act 2018. For more information about how we use your personal data please visit our website at:

<https://bwc.nhs.uk/privacy-policy>

**This page has been left blank for you to write any questions that you may wish to ask at your next clinic appointment:**

## Further support

In addition to the information you have been given the following organisations provide support for families and children with Hydrocephalus.

### **SHINE**

SHINE Charity is a large organisation that supports individuals, families and schools as they face the challenges arising from Spina bifida and Hydrocephalus (UK).

Tel: 01733 555 988

Web: [www.shinecharity.org.uk/hydrocephalus](http://www.shinecharity.org.uk/hydrocephalus)

### **Headway**

A UK charity promoting understanding of all aspects of brain injury and to provide information, support and services to people with a brain injury, their families and carers.

Freephone helpline: 0808 800 22 44

Email: [helpline@headway.org.uk](mailto:helpline@headway.org.uk)

Web: [www.headway.org.uk/hydrocephalus.aspx](http://www.headway.org.uk/hydrocephalus.aspx)

### **Brain and Spine Foundation**

A UK charity aiming to improve the quality of life for people affected by neurological disorders. They also provide information on a range of different neurological conditions.

Freephone helpline: 0808 808 1000

Email: [helpline@brainandspine.org.uk](mailto:helpline@brainandspine.org.uk)

Web: [www.brainandspine.org.uk](http://www.brainandspine.org.uk)

## Further support (cont')

### Contact a Family

A UK charity providing advice, information and support to families of disabled children, no matter what their disability or health condition. They also run a scheme called "Making Contact" where they may be able to put your family in touch with others who share a similar experience.

Freephone helpline: 0808 808 3555

Email: [info@cafamily.org.uk](mailto:info@cafamily.org.uk)

Web: [www.cafamily.org.uk](http://www.cafamily.org.uk)

# Personal Information

Name: \_\_\_\_\_

Date of Birth:\_\_\_\_\_

Hospital Number:\_\_\_\_\_

Consultant: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone Numbers:\_\_\_\_\_

GP Details: \_\_\_\_\_

Parent/Guardian:\_\_\_\_\_

1st Language:\_\_\_\_\_ Interpreter Required Y ☐ N ☐

Siblings: \_\_\_\_\_

Other Important People: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

# My Child's Surgery

Type of operation	Date	Consultant

Shunt Description	Date Inserted

Notes

# My child’s appointments

Where	When	To See

Notes



# My child’s investigations

Type	Date	Where

Notes

## How to contact us

Department of Neurosurgery  
Birmingham Children's Hospital NHS Foundation Trust  
Steelhouse Lane  
Birmingham  
B46NH  
Tel: 0121 333 9999 (Switchboard)

## For all urgent enquiries and any out of hours advice 24/7

Ward 10 (Ask for the nurse in charge)  
Tel: 0121 333 9092  
Tel: 0121 333 9093

Clinical Nurse Specialist in Neurosurgery Katie Herbert  
Monday – Friday: 08.00 to 16.00  
Mobile: 07760 216 195  
Tel: 0121 333 8232  
Email: [katie.herbert1@nhs.net](mailto:katie.herbert1@nhs.net)

For outpatient appointments  
Neurosurgical secretary  
Tel: 0121 333 8075

# Other Useful Contacts

Professional	Name	Telephone Number
Physiotherapist		
Occupational Therapist (OT)		
Play Specialist		

## Further Information

We hope this information will help you to understand about your child's condition and treatment. This information was developed using the most up to date evidence available. Further details are available upon request. If you feel you need any more information or have any further questions or concerns please speak to any of the nurses on Ward 10 or the clinical nurse specialist for neurosurgery. Contact details are listed at the beginning of the booklet.

Tel: 0121 333 8505

Email: [child.infoctr@bch.nhs.uk](mailto:child.infoctr@bch.nhs.uk)

This information has been produced by the Neurosurgery Department at Birmingham Children's Hospital.

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