

Endoscopic Third Ventriculostomy (ETV) in Children and Young People

This leaflet explains ETV surgery in children and young people in the management of hydrocephalus, including the benefits, risks, 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 an endoscopic third ventriculostomy?

An endoscopic third ventriculostomy (ETV) is sometimes an alternative to having a shunt inserted, depending on the case. It is performed by a neurosurgeon who makes a small hole in the skull, passes a small camera (endoscope) into the brain and then makes a new channel in the bottom of the third ventricle. This allows the cerebral spinal fluid (CSF) to bypass the blockage and to be reabsorbed via the normal CSF pathways.

Sometimes a small reservoir will be left under the skin, this allows the neurosurgeons to access the CSF directly and drain any excess CSF if required.

An example of a reservoir from Codman/Integra, other brands are available. Image provided courtesy of Integra LifeSciences.

Why does my child need an ETV?

And ETV is performed to manage hydrocephalus, which is a build-up of CSF within the fluid spaces in the brain. If left untreated, hydrocephalus causes increased pressure within the brain which can make your child very unwell and, if left for too long, can be a threat to life. The ETV will give the CSF a new channel to pass through and be reabsorbed.

What are the risks?

The risks for surgery will be explained to you during taking the consent for surgery. These include bleeding, infection, CSF (fluid) leak, risk of causing a stroke, epilepsy, memory problems and risk to life. With any surgery, there is always a small risk of infection. If you suspect your child has an infection, they will need to be reviewed by a doctor.

Signs / symptoms of infection include:

- Puffiness or redness of the skin around the wound site
- Fever / high temperature
- Stiff neck
- Dislike of lights (photophobia)
- Fluid coming out of the incision (this can be clear or yellow / pus-like)
- Loss of appetite or not eating well
- Feeling sick with or without vomiting
- Headache
- Generally feeling unwell.

Another risk of ETV surgery is if the channel doesn't work or gets blocked. The symptoms of this are symptoms of high pressure which you may have seen prior to the ETV surgery. If you suspect your child's ETV is not working as it should, this is an emergency and will require you to take your child to hospital for review.

Further Information on what to look out for post ETV operation will be included in your child's ETV information pack.

What do I need to watch for after ETV surgery?

Post ETV surgery, you will need to monitor the wound for any CSF leak. The chances of this happening are relatively low, however if it occurs it can be due to infection or the channel not working as expected. The option to treat this includes to 'tap' the reservoir, which involves inserting a small needle into the reservoir to drain off excess CSF. The wound can also be re-stitched or the ETV may need to be re-done or converted into a shunt. If you notice any fluid leaking, please contact the team to arrange an urgent review or attend A&E.

Are there any alternatives?

There are no effective medicines for hydrocephalus and most children require surgery. Another surgery to manage hydrocephalus is the insertion of a shunt. The surgical options will be discussed with you at the point of diagnosis.

Asking for your consent

It is important that you feel involved in decisions about your child's care. For some treatments, you will be asked to sign a consent form to say that you agree for your child to have the treatment and understand what it involves. You can withdraw your consent at any time, even if you have said 'yes' previously. If you would like more details about our consent process, please ask for a copy of our policy.

What happens during an ETV surgery?

Your child is taken to the operating theatre suite and goes to sleep under general anaesthesia so that s/he will not feel any pain during the operation. Areas on the head are scrubbed with a special soap. The surgeon makes incisions (cuts) on the head and the small camera (endoscope) is gently passed through to the ventricles (fluid sacs). The surgeon will make a new channel through the membrane at the floor of the third ventricle to create a new channel for the CSF to pass through. In some cases, the surgeon may leave a small reservoir underneath the skin to allow for direct CSF access. The incisions are then closed using staples or stitches. The operation takes between one and two hours.

What happens after ETV surgery?

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. They may have a head bandage and will have a dressing on their head. The nurses will check your child often and they 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. Your child's neurosurgeon will tell you when your child can start normal activity, such as sitting up and walking. After your child has recovered from the surgery they can go home. This is usually one to three days after surgery.

How will my child's pain be managed?

After the operation, your child may have some pain at the operative site and their nurse will give them regular pain relief medicines, usually both paracetamol and ibuprofen. We find these medications generally provide a good level of pain control for this type of surgery, however if you feel that they are in pain, then please speak to your child's nurse and additional analgesia can be considered. Your allocated nurse will be assessing pain control regularly throughout the day and night and may ask your child to score or rate their pain. We take pain management in children seriously and if you have any concerns about pain management, please speak to the neurosurgical team or allocated nurse.

What do I need to do after I take my child home?

Recovery from ETV surgery is short. Your child can go back to school after a week when they feel well and can start light activity once they feel up to it. We advise the dressings stay on for around a week and can then come off for a gentle hair wash and shower. We suggest not submerging the wounds in water until fully healed. Further wound advice can be found on the wound care leaflet.

You will need to monitor your child for signs of infection or ETV failure. More information can be found in the ETV information pack or contact the CNS team for any further information.

Will my child have a follow-up appointment?

Your child will be reviewed in clinic two to three months post ETV surgery to check the healing of the wound. After this, your child will be followed up on a yearly basis until the consultant feels that they can be discharged.

Useful sources of information

Shine UK Shine - Spina Bifida & Hydrocephalus Tel: 01733 555 988

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

<u>Harry's HAT | Harry's Hydrocephalus Awareness Trust</u> Tel: 07961 001 710 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: <u>paedneurocns@stgeorges.nhs.uk</u>

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 <u>www.stgeorges.nhs.uk</u>

Was this information helpful? Yes / No

Please let us know, contact <u>patient.information@stgeorges.nhs.uk</u> 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.



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