

Endoscopic Third Ventriculostomy (ETV)

Information for Children, Parents and Carers



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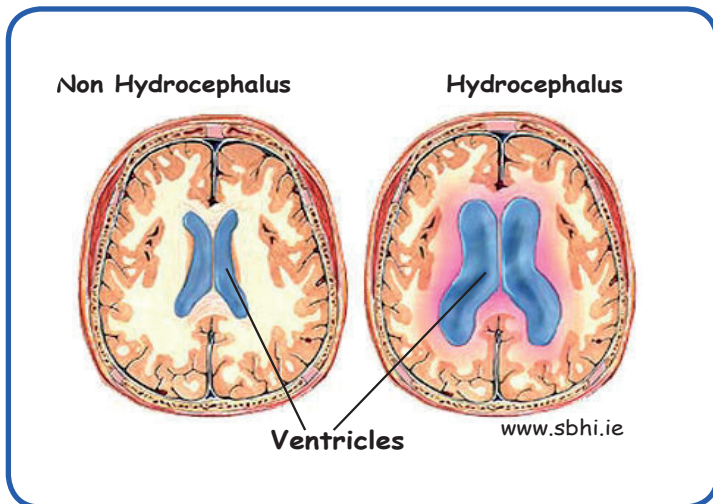
What is an endoscopic third ventriculostomy (EVT)?

Endoscopic Third Ventriculostomy (ETV) is a surgical procedure that treats a condition known as **hydrocephalus**.

What is hydrocephalus ?

Hydrocephalus is a condition caused by a build up of fluid in the brain. This fluid is called Cerebrospinal Fluid. **Cerebrospinal Fluid (CSF)** is a clear colourless fluid which surrounds your child's brain and spinal cord; it acts as protection. The fluid is constantly produced and reabsorbed.

Children with hydrocephalus usually have a failure of fluid reabsorption or a blockage to the flow of CSF. This can cause a build up of fluid which increases the pressure on their brain. If the pressure is not reduced, it will cause brain damage which will affect their development.



What is the cause of hydrocephalus?

There are many causes of hydrocephalus. However, sometimes the cause is unknown. Hydrocephalus may be present when a child is born but is not usually inherited from a parent. Most commonly it can happen as a result of the following conditions:

- Prematurity
- Spina Bifida
- Meningitis
- Tumours or Cysts
- Head injury
- Aqueduct Stenosis
- Some Syndromes

The reason your child has hydrocephalus will be explained to you by your child's doctor. Not all types of hydrocephalus are suitable for the ETV procedure. Some children with hydrocephalus will require a Ventriculoperitoneal (VP) Shunt. The doctor will do CT Scans or MRI scans to decide if your child is suitable.

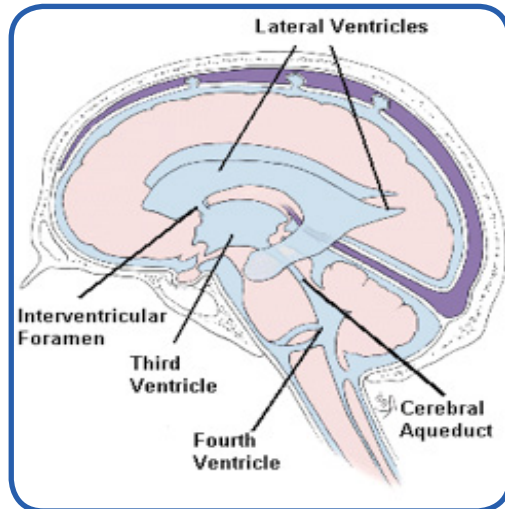


What does an ETV involve ?

ETV is an operation which is performed when your child is asleep under anaesthetic. The ETV will make a new pathway for fluid to flow. To do this, an opening (a hole) is created to bypass any blockage stopping the normal flow of fluid.

Your child's neurosurgeon will make a small hole called a burrhole in their head to allow them to look into your child's ventricles using an endoscope. An opening will be made at the bottom of their "Third Ventricle" (see picture). Once the fluid starts to flow through the hole the pressure in your child's brain will reduce.

Ventricle System of the Brain



How will I know if the ETV has been successful ?

After their operation, your child's condition will be monitored closely. We will be observing for signs that the pressure is reducing inside your child's head such as:

- Improvement in signs of hydrocephalus such as headaches and vomiting will decrease.

It will not always be obvious straight away if the ETV has been successful so your child will be followed up in out patients and may need a scan of their head.

What will happen if the ETV does not work?



If the ETV does not work, the neurosurgical team treating your child will discuss other surgical options with you. In most cases where ETV does not work these children may need a Ventriculoperitoneal (VP) Shunt. If your child needs this it will be discussed with you.

How long will my child need to stay in hospital ?

This will depend on the reason your child needed the ETV.



In most cases your child will need to come into the hospital the night before surgery. If your child recovers well following the surgery and has no other complications they may go home the following day. Your child's doctor will discuss expected length of stay with you. It is not unusual for it to take a few days for the child to recover

post ETV. Your child may need to stay in hospital for at least three days after this surgery, as it takes a while for the brain to adapt to this new fluid diversion.

If your child's ETV fails and your child needs a VP Shunt then your stay in hospital will be longer.

What to expect before and after surgery?

Before Surgery

Your child's doctors will meet with you to explain the surgery and to ask you to sign a consent form. You may also meet the anaesthetist who will explain how your child will be given medication to make sure they are asleep and pain free during their operation.

Before surgery your child may need a number of tests including blood tests, CT scan or MRI scan and Cranial Ultrasound.



During your child's stay in hospital nursing staff will monitor your child by carrying out a number of simple checks which include:

- Level of consciousness
- Blood pressure
- Temperature
- Heart rate
- Reaction of eyes to light
- How they can move their arms and legs
- Monitor if there are any changes in behaviour

Your child will need to be monitored regularly. For this, they may need to be woken from sleep.

Small babies will have their head measured before and after surgery.

On the day of surgery your child will fast for a number of hours. This means they will not be allowed to eat or drink. The nurse looking after your child will tell you how long your child will need to fast.

After Surgery

When your child first returns to the ward, they may be a bit sleepy. The nurse looking after them will monitor their recovery by carrying out some of the tests mentioned above.

Your child will have a small wound on their head. Sometimes the doctor will need to shave a bit of hair around this area during surgery. This hair will grow back in a short period of time, covering their scar.

Some children may vomit or have an upset stomach from surgery. If this happens your child may be given medication to help relieve it.



When your child returns to the ward after the operation they may have some discomfort as the pain medication given during their operation wears off. The nurse caring for your child will give them pain medication to help control any pain or discomfort.

Some children will have a small drain in their head after their operation to allow fluid drain, this may be clamped. This drain is usually removed within a day or two after their operation.

What do I need to watch out for when I go home ?

It is very important to remember when you go home that ETV is **not a cure for hydrocephalus. If the ETV fails your child will develop hydrocephalus again, even years after your child has had the ETV.**

This can happen at any time. You need to watch out for the signs of hydrocephalus. The most common signs are listed on the next page. If your child shows any of the signs mentioned and you are worried it is important to contact someone. If the symptoms are not acute please contact the neurosurgical nurse specialist or neurosurgery advanced nurse practitioner for advice.

If you are unable to get in touch with these nurses, please go to your GP. If the symptoms are acute and worrying, please bring your child to your nearest paediatric (children's) hospital.

It is important that you carry an ETV card at all times, which will be given to you before you leave the hospital.

Signs and symptoms of hydrocephalus

Baby

- Enlargement of the baby's head (getting bigger)
- The fontanelle (soft spot on top of head) may become full and hard
- Fever (high temperature)
- Vomiting or refusing feeds
- Sleepiness
- Irritability-more difficult to settle/comfort
- Downward looking eyes (cannot look upwards)
- High pitched crying
- Seizures /fits



Toddlers/older children

- Head enlargement /getting bigger
- Headache or Vomiting
- Dizziness
- Visual (eye) problems / Sensitivity to lights
- Drowsiness / sleeping alot
- Irritability / change in personality
- Loss of previous ability- for example weakness in legs or arms.
- Seizures / fits



Unfortunately, some of these signs are common to many childhood illnesses. If your child shows any of the signs mentioned and you are worried it is important to contact someone. If the symptoms are not acute please contact the neurosurgical nurse specialist or neurosurgery advanced nurse practitioner for advice. If you are unable to get in touch with these nurses, please go to your local emergency department. If the symptoms are acute and worrying, please bring your child to your nearest local paediatric (children's) hospital to check their ETV is working.

It is very important that your child carry a ETV medical alert card at all times. This will inform emergency medical staff about your child's condition. If you have not been provided with an ETV medical alert card please contact the Neurosurgical Nurse Specialist who can arrange one to be sent to you (contact details provided at front of booklet).

Will I have to do anything with my child's wound?

Usually, it will take the wound about two weeks to heal. The neurosurgery team will advise you how long to leave the wounds covered for.

Usually, the stitches are dissolvable and will be absorbed by your child's body over a short period of time. If the stitches are not dissolvable, arrangements will be made for you to bring your child to the hospital and have them removed. Every effort will be made to remove them without sedation, however there are occasions when sedation must be used.



Alternatively, if sedation does not work, your child may need to have a general anaesthetic and go to theatre to have the stitches removed at home, if you notice any redness, swelling, or discharge from your child's wound please contact your child's doctor as they may have a wound infection. If the wound becomes very raised or leaks fluid it may be a sign that the ETV has failed.

When I can bath my baby / child ?

It is ok to bath your baby / child the day after surgery if you do not wet their hair. It is important to keep the wound dry for 5-7 days, you should not wash the hair until after this time.



Can my child return to school ?

We would advise you to let your child to return to school when they appear well enough to attend. The school should also be informed about the signs and symptoms of hydrocephalus listed above.

Can I take my child on holidays ?



It is safe to travel with your child. However it is advisable to have travel insurance. It is important to carry your child's ETV medical alert card in case your child needs medical attention abroad.

What follow up will my child need ?

Once you have been discharged from hospital you will be given an appointment to come back to see your child's Advanced Nurse Practitioner (ANP) or doctor. In the first year we may need to see them more often to check on their progress but after that your child will be seen on a yearly basis. Your child may also be followed by a paediatrician to monitor their progress.

If you have any further questions contact details are on the front of this booklet

These numbers are not an emergency service. If you have urgent concerns please attend your local paediatric (children's) hospital or contact emergency service on 999 or 112.

Spina Bifida and Hydrocephalus Association www.sbhi.ie

Brainwave Irish Epilepsy Association www.epilepsy.ie

Please make sure you received a medical alert card - it must be with your child at all times.

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The information contained in this booklet is correct at time of print