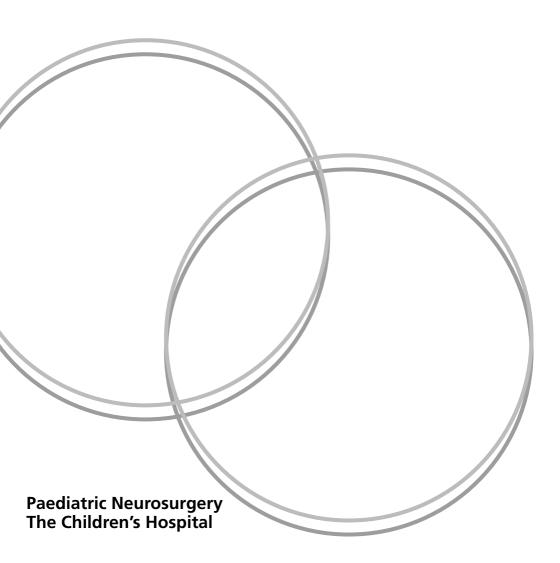


Ventriculostomy

Information for parents and carers



Why does my child need a ventriculostomy?

Every child produces a fluid called cerebrospinal fluid (CSF). Within the brain there are four chambers, called ventricles, where this fluid is produced. CSF flows in the ventricles, around the brain and around the spinal cord. It protects, nourishes and discards waste products from these vital organs.

If a blockage develops in one of the ventricles, this means the CSF cannot flow freely. When this happens, there is a build-up of CSF within the ventricles, causing them to swell and create pressure within the brain. This is called hydrocephalus.

Hydrocephalus needs to be treated to prevent symptoms becoming worse. A ventriculostomy is one way to treat hydrocephalus.

What is a ventriculostomy?

A ventriculostomy or endoscopic third ventriculostomy (ETV) is an operation to create a small channel (hole) in one of the ventricles. This will allow the CSF to flow freely again.

How is the operation carried out?

The operation is carried out under a general anaesthetic. This means your child will be unconscious and not be able to feel anything. A consultant anaesthetist (doctor who will help put your child to sleep) will talk to you and your child (if appropriate) about the anaesthetic.

What are the risks?

This is a simple and safe operation. However, as with all operations, it carries some risks. These include:

- the hole made during the operation reclosing, which would mean another operation would be required
- bleeding in the brain from the hole
- infection
- wound leak
- paralysis
- seizure
- stroke.

The surgeon will discuss the risks with you in more detail.

Benefits

If the ventriculostomy is successful the CSF can flow freely in the ventricles. This means your child doesn't have to have a VP/VA shunt inserted, which is a small plastic tube that can drain away the CSF. This lowers the risk of complications, which include infection and further blockages.

Are there any alternatives?

Your surgeon will discuss alternative options with you. They will discuss the possibility of a VP/VA shunt with you and will give you a leaflet about this if it is an option.

Anaesthetic risks

In modern anaesthesia, serious problems are uncommon. Risk cannot be removed completely, but modern equipment, training and drugs have made general anaesthesia a much safer procedure in recent years. Throughout the whole of life, a person is at least 100 times more likely to suffer serious injury or death in a road traffic accident than as a result of anaesthesia¹.

Most children recover quickly and are soon back to normal. Some children may suffer side effects like sickness or a sore throat. These usually only last a short time and there are medicines available to treat them if necessary.

The exact likelihood of complications depends on your child's medical condition and on the nature of the surgery and anaesthesia your child needs. The anaesthetist can talk to you about this in detail before the surgery.

Consent

We will ask you for your written consent (agreement) for the operation to go ahead. If there is anything you are unsure about, or if you have any questions, please ask the doctor before signing the consent form.

Fasting instructions

If your child is coming into hospital to have this procedure as a planned operation (not as an emergency procedure), please make sure that you follow the fasting (starving) instructions. These should be included with your appointment letter or would have been given at the pre-operative assessment appointment.

If this surgery is an emergency, the nurses on the ward will give you fasting instructions.

Fasting is very important before an operation. If your child has anything in their stomach whilst they are under anaesthetic, it might come back up while they are unconscious and get into their lungs.

Pregnancy statement

All girls aged 12 years and over will need to have a pregnancy test before their operation or procedure. This is in line with our hospital policy.

We need to make sure it is safe to proceed with the operation or procedure, because many treatments including anaesthetic, radiology (X-rays), surgery and some medicines carry a risk to an unborn child.

The pregnancy test is a simple urine test and the results will be available immediately. If the result is positive, we will discuss this and work out a plan to support your child.

What happens before the operation?

Your child will have been seen before the surgery by the neurosurgical team, who will have discussed this procedure with you before giving you this leaflet.

Your child may already be an inpatient on the ward before their surgery, after being admitted as an emergency. If they are not, you will be asked to bring them in to hospital at 7.30am. They need to come to Children's Theatre Direct Admissions (TDA). This is based on Robin's Ward at the Children's Hospital in Oxford.

When you arrive, a nurse or healthcare assistant will greet you and show you to the waiting area. The nurse will check your child's paperwork and put some name-bands around their wrists or ankles. They will also measure your child's temperature, heart rate and breathing rate.

Your child will then be seen before their surgery by the neurosurgical team. The doctors will take their medical history and samples of blood. This is to make sure the right type of blood is available during the surgery, if it is needed. The blood test will also be sent to check their electrolyte level (biochemistry) and for any signs of infection.

The nurse or healthcare assistant will look after you and your child until your child is in theatre. There are also play specialists available to help your child prepare for the operation and to keep your child them distracted with play activities both before and after the operation. They will also help with preparing them for their anaesthetic. There are toys and gaming devices available for all ages

The nurse and healthcare assistant will make sure you understand the routine of the day and your child's care before the operation. They can answer any questions you both may have.

If your child is unwell and this procedure needs to be carried out as an emergency, your child will already be an inpatient (so will not need to be taken to TDA). They will still need to have blood samples taken before the surgery.

In the anaesthetic room

A nurse and one parent/carer can come with your child to the anaesthetic room. Your child can also take a toy or comforter.

It may be possible to give the anaesthetic with your child sitting on your lap. Your child may either have anaesthetic gas to breathe, or an injection through a cannula (a thin plastic tube that is placed under the skin, usually on the back of the hand). Local anaesthetic cream (EMLA or Ametop, sometimes known as 'magic cream'), can be put on their hand or arm before injections so they do not hurt as much. It works well for 9 out of 10 children.

If the anaesthetic is given by gas, it will take a little while for your child to be anaesthetised. They may become restless as the gases take effect. If an injection is used, your child will normally become unconscious very quickly indeed. Some parents may find this upsetting.

Once your child is asleep you will be asked to leave quickly so that the medical staff can concentrate on looking after them. The nurse will take you back to the ward to wait for your child.

Your child will then be taken into the operating theatre to have the operation. The anaesthetist will be with them at all times.

What happens during the operation?

Before the operation has starts, some of your child's hair may have to be shaved. The surgeons will try to shave the smallest area possible and it will grow back in time, after the operation.

The surgeon will make a small horseshoe-shaped or straight incision (cut) on their scalp, approximately 2cm. They will then remove a small section of skull (smaller than a 10p coin). They will pass a long, thin tube fitted with a tiny camera in through this hole, which can pass through the ventricles. This allows them to see where to make the hole in the ventricle, which will release the fluid by creating a small channel between the ventricles allowing it to be reabsorbed as usual.

Your child will be encouraged to be as upright as possible, as the fluid passing through the hole will help to keep it open. The surgeon will explain the procedure to you before the surgery.

When they are finished, the surgeon will normally replace the bone to close the hole in the skull. The skull bone will fuse back together with rest of the skull bone over the next 6 weeks. The scalp will be stitched back together using dissolvable stitches, which will gradually fall out over the next 7-14 days.

After the operation

After the operation your child will be taken to the recovery room while they come round from the anaesthetic. You will then be collected to go with the nurse to the recovery room where you will be able to see them.

A recovery nurse will look after your child until they are ready to come back to the ward. The nurse will regularly check your child's pulse, blood pressure, temperature and wound. They will also make sure your child has adequate pain relief. The nurse will then bring you and your child back to the ward.

When your child is back on the ward, the nurses will continue to regularly check their pulse, breathing, blood pressure and temperature.

The nurse will need to look in your child's eyes with a small torch, to check that they are reacting as they should. They will also ask them a couple of questions (if they are old enough/able to answer) to check their level of consciousness.

Some children remain sleepy for a little while after their operation, while other children wake up quickly. If your child is still sleeping, it is important for the nurse to wake them up, to check they can be easily woken.

The nurse will also need to assess how much movement and sensation your child has in their limbs. Once your child begins to recover, the frequency of these checks can be reduced. We will also regularly inspect your child's wound, to check for leaking or bleeding.

Recovery from the anaesthetic

Once your child is awake from the anaesthetic they can start drinking and, if they are not sick, they can begin to eat a light diet. Often, children are given fluids through their cannula until they are able to tolerate their normal diet again.

Occasionally, the anaesthetic may leave your child feeling sick for the first 24 hours and they may vomit. The best treatment for this is rest and small, frequent amounts of fluid, toast or biscuits. We can also give medication to help with this, but it should settle with time.

The hospital experience is strange and unsettling for some children so do not be concerned if your child is more clingy, easily upset, or has disturbed sleep. Just be patient and understanding.

It is likely your child will be ready to go home around three days after the operation.

Pain assessment and pain relief

Your child's named nurse will use a pain assessment tool to help assess your child's pain score after their operation. This is a chart which helps us to gauge how much pain your child may be feeling.

You and your child will be introduced to this assessment tool either at their pre-assessment visit or on the ward before their operation. You can continue to use this assessment at home to help manage your child's pain if you wish.

Your child will be given paracetamol (either as liquid or tablets) regularly after the operation, to help keep them comfortable.

Discharge advice – Leaving hospital

Wound care and hygiene

The wound on your child's scalp may be covered by a thin dressing, but is usually left without one. The wound will need to be kept clean and dry for a minimum of 72 hours. Your child's doctor will tell you if your child's hair can be washed after this time.

Your nurse can help you wash your child's hair for the first time, to reassure you that you won't hurt them. A mild/baby shampoo can be used, but avoid soaking or rubbing the wound, as this causes the stitches to dissolve too quickly, which may result in the wound opening or not healing well.

Fresh, clean water should be used to wash and rinse their hair, as this reduces the risk of infection. It is also important to avoid using conditioner, moisturisers or body lotion around the wound area, as they can also cause the stitches to dissolve too quickly and be a risk for infection.

The stitches used to close the wound will gradually dissolve in around 7-14 days, but this can take up to 6 weeks. Your child should be discouraged from scratching the wound, as this could cause an infection. If the wound site becomes red, inflamed or painful, please see your GP or call the ward on the number given at the back of this leaflet.

The skin around the scar may feel numb. This is normal and will improve with time.

Please make sure you have enough children's paracetamol at home, ready for when your child comes home from hospital. You can give them children's paracetamol, but not more than once every 4-6 hours, with no more than 4 doses in a 24 hour period.

Please make sure you follow the correct dosage instructions for your child's age.

Follow-up care

Your child may have headaches for some time after surgery. You can give them children's paracetamol, but not more than once every 4-6 hours.

You can also give them children's ibuprofen every 6-8 hours, but only give a maximum of 4 doses in a 24 hour period. Please make sure you follow the correct dosage instructions for your child's age.

Your child's doctor will tell you when they need a follow-up appointment. The letter confirming this will come by post within 2 weeks. Please contact the hospital switchboard and ask to speak to your consultant's secretary if this does not arrive after this time.

Your child's follow-up appointment will be in Children's Outpatients, approximately 4 weeks after they have left hospital.

Getting back to normal

When your child returns to school depends on how they feel when they return home. Most children usually go back to school 1 to 2 weeks after they have come out of hospital after this operation.

They can return to sporting activities such as PE, bike riding, swimming, etc. 3-4 weeks after discharge (depending on how they feel).

Your child can go away on holiday (including flying) when they feel well enough and have had their follow-up appointment. Make sure that your travel insurance company is aware that your child has had a ventriculostomy to treat hydrocephalus.

Signs to lookout for

Failure of the ventriculostomy is most likely to occur within the first 3 months after surgery. A ventriculostomy will fail if the hole (channel) between the ventricles closes up. If this happens, your child may display the same symptoms they had before their operation.

Signs that the ventriculostomy may have closed include:

- drowsiness
- limb weakness
- confusion
- visual problems (problems with sight)
- increased headaches
- irritability
- not wishing to feed/eat or vomiting
- bulging fontanelle (in a baby)
- fever (high temperature)
- any other sign that gives you concern.

If your child has any of these symptoms you should contact the ward urgently (contact numbers are at the end of the leaflet).

How to help with your child's recovery

A healthy balanced diet is important for your child's recovery, as it gives them energy to recover and helps with wound healing.

Regular pain relief is also important, as it helps reduce any discomfort. This will help your child to keep moving, which can speed up their recovery.

How to contact us

If you have any further questions, or any worries or queries about your child once you get home, please contact us. We are available 24 hours a day, 7 days a week.

Robin's Ward

Tel: **01865 231 254/5**

Melanie's Ward

Tel: 01865 234 054/5

Neurosurgical Nurse Specialist

Tel: **01865 226 535**

To contact your child's consultant's secretary, please phone the John Radcliffe Hospital Switchboard:

Tel: **0300 303 7777**

If your child requires urgent treatment, please call 999 or go to your nearest Emergency Department.

How you can give feedback about your experience

We would like to hear about your experience with our Childrens' Services. There are different ways to feedback to us:

Online: www.ouh.nhs.uk/childrens-feedback

Email: childrens.patientexperience@ouh.nhs.uk

Or ask for a paper survey to fill in.

Further information

You may find the information on the following website helpful: **www.shinecharity.org.uk**

References

¹From the Royal College of Anaesthetists (2014) Fourth Edition

Your child's general anaesthetic. Information for parents and guardians of children.

www.rcoa.ac.uk/patientinfo

We hope that this information is useful to you and would welcome any comments about the care or information you have received.

Please bring this leaflet with you on the day of your child's operation.

If you need an interpreter or would like this information leaflet in another format, such as Easy Read, large print, Braille, audio, electronically or another language, please speak to the department where you are being seen. You will find their contact details on your appointment letter.

Making a difference across our hospitals

 $charity@ouh.nhs.uk \mid 01865\,743\,444 \mid hospital charity.co.uk$

OXFORD HOSPITALS CHARITY (REGISTERED CHARITY NUMBER 1175809)

Oxford Hospitals Charity

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