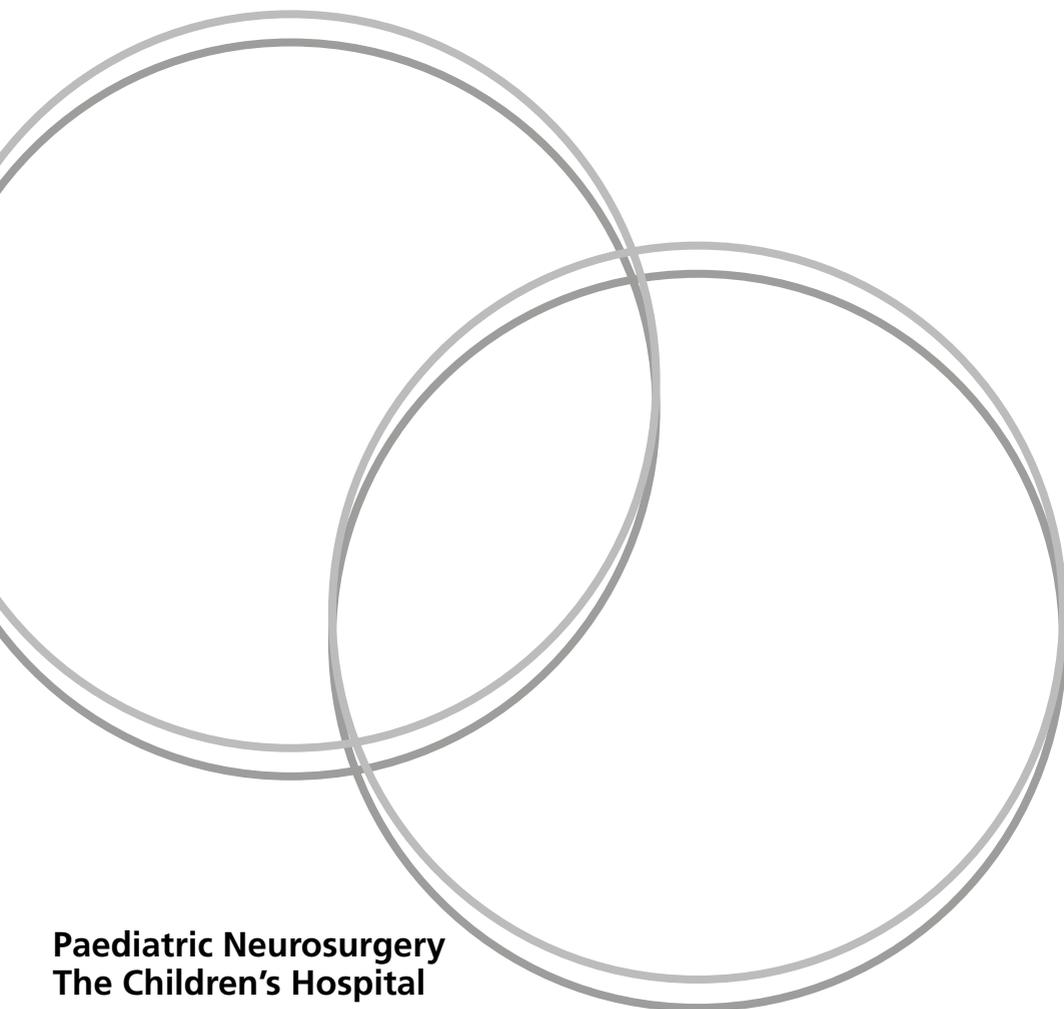




Oxford University Hospitals
NHS Foundation Trust

Foramen Magnum Decompression

Information for parents and carers



Paediatric Neurosurgery
The Children's Hospital

What is foramen magnum decompression?

Foramen magnum decompression (FMD) involves making a vertical cut at the back of the neck and head, to remove a small piece of bone from the skull and a small section of the first vertebra (first bone in the spine). This creates extra space at the base of the skull for the brain and spinal cord.

The operation will be carried out under general anaesthetic. This means your child will be unconscious and will not be able to feel anything. A consultant anaesthetist (doctor who will put your child to sleep) will talk to you and your child (if appropriate) about the anaesthetic. This will be at your child's pre-operative visit, which could be on the day of their operation or a few weeks before, depending on how urgent their surgery is.

Why does my child need an FMD?

Your child may need an FMD because they have a Chiari malformation. This is where a part of the brain (the cerebellar tonsils) is compressed at the base of the skull (the foramen magnum). This can lead to spinal cord problems in the future, such as syringomyelia (a cyst or cavity forming within the spinal cord) or scoliosis (curvature of the spine).

Some of the symptoms associated with a Chiari malformation include:

- headaches
- neck pain, especially following strenuous activities such as exercise or coughing
- vomiting
- swallowing difficulties
- impaired co-ordination (unsteady on their feet).

What are the risks?

All operations carry some risks. The risks of this operation are classed as being a low chance of happening

They include:

- bleeding from the blood vessels at the base of the skull
- wound infection
- leaking from the wound which requires re-stitching and/or a lumbar drain
- stroke
- damage to the brainstem and spinal cord.

The doctor will discuss these risks with you in more detail.

What are the benefits?

The operation aims to create more space around the base of the brain, which will help reduce the pressure within the head. This will alleviate the symptoms mentioned previously. It will also help to prevent further complications from the Chiari malformation.

Chiari malformation can be treated conservatively (without surgery) if your child has no symptoms. Your child's neurosurgeon will be able to discuss this with you 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 after their anaesthetic. Some children may suffer side effects such as sickness or a sore throat. These usually last only 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 your child's operation.

Consent

The surgeon will explain the operation to you and will confirm the risks and benefits. We will then ask you for your consent for the operation to go ahead. You will be given the chance to ask any questions you might have before we ask you to sign the consent form. If there is anything you are unsure about, or if you have any questions, please ask the surgeon before signing the consent form.

You will also see one of the anaesthetists involved in the operation. They will explain the anaesthetic process and risks to you, as well as any pain relief your child will have after the operation.

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?

You will be asked to bring your child 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 health care 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.

In the anaesthetic room

A nurse or play specialist and one parent or 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 placed on their hand or arm before the injection so they don't hurt as much. This 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 gas takes effect. If an injection is used, your child will normally become unconscious very quickly. 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 their operation. The anaesthetist will be with them at all times.

What happens during the operation?

Before the operation 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 vertical cut at the back of your child's neck and head. They will then remove a small piece of bone from base of their skull.

The cut will be closed with dissolvable stitches as well as surgical glue, to keep it watertight. Both of these will gradually disappear. The dissolvable stitches usually dissolve over 7-14 days, but can take up to 6 weeks.

The operation usually takes 2-3 hours, but your child will be away from the ward for up to 4 hours. This is to allow the anaesthetic to take effect before the operation and then give them time to come round afterwards.

After the operation

After the operation your child will be taken to the recovery room whilst 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 nurses will make regular checks of your child's pulse, temperature, blood pressure 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.

The nurse will need to look in your child's eyes with a small torch, to check they are reacting as they should. They may 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 that 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

When 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.

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 have a special infusion pump attached directly to a vein in their arm to give them pain relieving drugs. This is called a Patient Controlled Analgesia pump (PCA). Your child's nurse (or your child, if they are old enough) can press a hand-held button when they feel pain or discomfort and the pump will deliver a pre-programmed dose of painkilling drugs directly into their vein. The machine controls the amount of drugs they receive, so they cannot have too much in one go.

During the operation your child will have had a narrow tube inserted into their bladder, called a catheter. This is because a side effect of the painkiller morphine (usually used with the PCA) is not being able to pass urine, which can be uncomfortable. We can also use this to monitor the amount of urine your child is passing. The catheter will remain in place until the morphine is stopped.

Your child will have the PCA for 24-48 hours after the operation. This will be used to keep them comfortable, along with medicines that they will be given by mouth, such as paracetamol (either as liquid or tablets).

After the PCA has been stopped your child will be given regular pain relief by mouth to help keep them comfortable. If your child feels sick, or is too sleepy to swallow their medicines, they can be given through their cannula.

Recovery on the ward

The nurse will continue to carry out regular observations of your child after their operation. This allows them to make sure that your child is recovering well. The nurse will need to carry these checks out throughout the night, as well as during the day, but this frequency will decrease as your child recovers.

The surgeons will give specific instructions about how much your child can move about after the operation, but it is likely that they will need to stay in bed for 24-48 hours.

To start with, your child will need to stay resting, lying flat in bed, but they will be encouraged to turn from side to side. This can be uncomfortable, but will prevent their neck from becoming stiff and can help them to recover. If your child finds it difficult to move from side to side, the nurse will reposition them every 2-4 hours.

A physiotherapist will visit your child on the ward to give them some neck movement exercises. This will help them to regain movement in their neck after the operation.

The anaesthetic and operation itself may cause your child to have headaches, but these will get better as they recover. These can be caused by changes in pressure in the head from high to low. We can give your child pain relief to help with these.

It is likely your child will be ready to go home between 5-7 days after the operation.

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.

Discharge advice – Leaving hospital

Wound care and hygiene

Before they leave hospital, your child can have a bath or a shower. Your nurse will show you how to wash your child's hair, 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 will cause the dissolvable 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.

It is important that your child doesn't soak their head in the bath or shower, as this will also cause the stitches to dissolve too quickly.

Your child should be discouraged from scratching the wound, as this could cause an infection. If the wound becomes red, inflamed or painful please call the ward, the nurse specialist or contact your child's consultant's secretary/PA. Contact numbers are at the end of this leaflet.

Occasionally non-dissolvable stitches will be used. This will be discussed with you by your surgeon before the operation, if they think they will need to be used.

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 and ibuprofen at home, ready for when your child comes home from hospital.

Follow-up care

Your child may suffer from headaches and neck stiffness for a couple of weeks after their surgery. 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.

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.

These should help relieve any discomfort they have, especially first thing in the morning.

If your child was shown how to do gentle neck exercises in hospital by the physiotherapist, encourage them to continue with these exercises at home. They will help relieve stiffness and are good for strengthening damaged neck muscles.

Your doctor will tell when your child needs 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 child's consultant's secretary if it does not arrive after this time.

Your child's follow-up appointment will be in Children's Outpatients approximately 4-6 weeks after they have left hospital. Your child will also have a follow-up appointment with their neurosurgical consultant around 4-6 weeks after leaving hospital, to check on their recovery.

Getting back to normal

When your child returns to school depends on how they feel when they return home. Most children who have this operation return to school 2-4 weeks after they have left hospital.

Your child may feel tired for several weeks after the operation, but this is normal. Gradually increase the amount your child does until they are back to their usual level of activity.

Your child may be able to return to sporting activities such as PE, bike riding, swimming, etc. after 6-12 weeks, depending on their recovery.

Your child can go away on holiday (including flying) when they feel well enough and have had their follow-up appointments. Please make sure that your insurance company is aware that your child has had spinal surgery.

Signs to look out for

Please watch out for the following symptoms when you return home with your child:

- drowsiness
- limb weakness
- confusion
- increased headaches
- your child starting to have seizures (fits) or the frequency of their normal seizures increases
- the wound site becoming painful, red, inflamed or beginning to produce pus
- any leaking of any other fluid from the wound.

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 in 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, 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 304 7777**

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

How to 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

Ann Conroy Trust

Website: www.annconroytrust.co.uk

Tel: **0300 111 0004**

Support, education and research for people living with Chiari malformation, syringomyelia and associated conditions.

Brain and Spine Foundation

Website: www.brainandspine.org.uk

Tel: **0808 808 1000**

Helping people affected by brain and spine conditions.

NHS Choices

Website: www.nhs.uk/conditions/chiari-malformation

References

¹From the Royal College of Anaesthetists (2014) Fourth Edition Your child's general anaesthetic. Information for parents and guardians of children.

Website: 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

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OXFORD HOSPITALS CHARITY (REGISTERED CHARITY NUMBER 1175809)



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