

What You Need to Know When Your Child is Having Craniofacial Surgery



Children's Health Ireland
at Temple Street

National Paediatric Craniofacial Centre
Children's Health Ireland at Temple Street
Temple Street
Dublin 1



Main Hospital Number 01 878 4200
Craniofacial Office 01 878 4883
craniofacial@cuh.ie

Introduction

Your child is due to have surgery for a craniofacial condition in the near future. The Craniofacial Team will discuss this condition with you and when surgery will be carried out.

We understand that any admission to hospital is an anxious time for families. We have written this information book to help prepare you and your child for the next steps. Please keep this book safe, bring it with you each time you come to clinic and when you come into hospital. We hope that you will find it useful.

It is important that you read this booklet and all of the information you are given. If there is anything you don't understand we are available to discuss this in more detail with you in the Out Patient's Department (OPD) at your child's clinic appointment.

You may also find the websites below useful.

www.cuh.ie

www.craniofacial.ie

My child's diagnosis is	
My child's surgery is called	
My child's surgery will take (insert number of hours)	
My child will/will not need a blood transfusion (write in)	
My child will/will not need a CT/MRI scan (write in)	
My child will be in hospital for (insert number of days)	

Questions I want to ask at the Craniofacial Clinic

At my child's appointment we may get to meet some or all of the following (please fill in name as appropriate)

Consultant Craniofacial Surgeon	
Consultant Neurosurgeon	
Craniofacial Nurse Specialist	
Craniofacial Clinical Services Co-Ordinator	
Ear Nose and Throat (ENT) Consultant	
Ophthalmologist (Eye Specialist)	
Dentist	
Physiotherapist	
Medical Social Worker	

What is consent?

Consent is giving permission to the Craniofacial Surgeon and Neurosurgeon to perform surgery on your child and you will be asked to sign a consent form. Please read the *Giving Your Consent* included in the information pack you received.

What is a general anaesthetic?

Craniofacial surgery is performed under general anaesthetic, your child will be put asleep, a breathing tube is placed into their nose or mouth and down into their trachea (windpipe). This breathing tube is connected to a ventilator machine that assists breathing during the operation.

Risks of a general anaesthetic cannot be completely removed, but modern equipment, training and medications have made it much safer in recent years. The risks are higher if your child has any other illness, or medical condition.

Please inform a member of the Craniofacial team if your child has any medical conditions or illness.

Occasionally a very young child's medical condition is not fully known before surgery takes place.

Before your child's surgery you will meet a member of the Anaesthetic Team who is a specialist doctor who will give your child their general anaesthetic and will keep them asleep during their surgery. If you, your child or a member of your immediate family (mother, father, sibling) have had any problems following a general anaesthetic such as bleeding, sickness or other problems, please discuss this with the Anaesthetic team.

Benefits of craniofacial surgery

Your child has craniosynostosis which causes your child to have an abnormal head shape.

Some types of craniosynostosis may cause problems with eyesight, hearing or breathing. It may also cause delays in learning and physical development.

Sometimes craniosynostosis can cause a rise in pressure within the skull this is known as raised intracranial pressure (ICP), this is rare.

Children's self-esteem and psychological health can also be affected because they look different to their friends and this can cause them to feel sad or upset.

Sometimes if children feel sad or upset they may not want to join in doing fun things with their friends or family. They may find it difficult to fit in at school or at other social occasions. This may affect their overall quality of life. If this is the case for your child, please inform a member of the Craniofacial team.

The aim of surgery is to give your child a "normal" head shape. We expect that by improving the head shape so your child no longer looks different should help their overall self-esteem and psychological health. In some cases the surgery will reduce the risk of developing raised intracranial pressure.

Risks of craniofacial surgery

There are risks with any surgery. Although serious risks are rare, it is important that you are aware of them and have the opportunity to discuss them with your Craniofacial Surgeon and Neurosurgeon.

These risks include:

- 1 Bleeding
- 2 Infection
- 3 Damage to the lining of the brain or of the brain itself
- 4 Air Embolism
- 5 Death

Bleeding

Children often require a blood transfusion during craniofacial surgery, especially if they are under 2 years of age or if the surgery is quite extensive. Your child will be monitored very closely during and after the surgery for any blood loss.

If a blood transfusion is required it will be standing by. This blood is tested before surgery to ensure it is suitable for your child.

The majority of children receive their blood transfusion during surgery or in the recovery room.

If you or any member of your family have a history of bleeding issues, inform a member of the Craniofacial team

For further information please read the *Questions you may have about your child's blood transfusion* leaflet in your information pack.

Infection

The likelihood of your child developing an infection during or after surgery is very low. All children receive antibiotics during surgery and for a short time afterwards. After surgery you will be shown how to wash and care for your child's wound at home.

In very rare cases, the dissolvable plates and screws which are used to secure your child's skull bones can become inflamed. This is rarely an infection but simply the body's reaction to the plates and screws.

These plates and screws can take up to 2 years to completely dissolve; inflammation can occur at any time during this period.

In most cases this is managed with anti-inflammatory medication such as Ibuprofen and regular hair washing. On rare occasions children need the area examined and cleaned under general anaesthetic.

Damage to the lining of the brain or of the brain itself

Removing the bone of the skull can sometimes be quite difficult as the lining of the brain, known as the dura, can be 'stuck' to the bone underneath. This is particularly true in cases with raised intracranial pressure. A tear in the dura is repaired surgery. Damage to the brain is extremely rare.

Air Embolism

During the removal of the bone of the skull small blood vessels are visible. This could potentially cause air to get into the blood vessels which could travel into the blood, heart and brain.

If enough air enters it can act as an airlock and cause the blood pressure to fall. On rare occasions it can cause the blood flow to stop completely (as the heart is not able to 'pump' blood through the trapped air), this can be fatal and can cause death.

This is extremely rare.

Death

Death as a result of surgery for craniosynostosis is extremely rare. The main causes of death are bleeding and air embolism as described above.

Possible issues following craniofacial surgery

Stretching of the scar

Following surgery there will a scar along the top of your child's head, ear to ear in a wavy line. In many cases this is a thin line which is well hidden by your child's hair.

However, stretching of the scar can occur particularly when a child takes a growth spurt during puberty. A relatively straightforward procedure can be undertaken once a child is fully grown to reduce the size of the scar and make it less obvious.

Raised Intra-cranial pressure (ICP)

Raised intracranial pressure happens when the pressure inside the skull is raised. Some children with craniosynostosis develop raised ICP at some stage of their life. We do not fully understand exactly why it occurs and it is not always related to the shape or size of the skull. The risk of developing raised ICP, even many years after surgery, is approximately 5%- 10%. If raised ICP occurs the Craniofacial Surgeon and Neurosurgeon will explain the treatment with you and your child. This could involve surgery to change the shape and size of their skull shape or the insertion of a shunt to reduce the pressure.

You will receive information about the signs on raised ICP after your child's surgery.

Re-fusion of the skull bones

Approximately 5% of children who undergo surgery to correct their head shape, the new shape is not maintained and the original shape will reoccur. If this happens the Craniofacial Surgeon and Neurosurgeon will discuss the next step with you and your child. The decision to have a second surgery to correct the head shape is taken on an individual basis.

Disclosure of existing health / medical conditions

It is very important that we have details of your child's full medical history before surgery. It is very important that you inform the Craniofacial Team if there is a family history of craniofacial conditions or bleeding problems.

Sometime we may only find out about these conditions during the surgery and there is always the risk that this may affect the surgery or your child's recovery following surgery. Should this happen the craniofacial team will discuss this with you.

**Questions I want to ask the Craniofacial Team
before surgery**

Pre-operative (surgery) assessment appointment

This appointment is usually scheduled one week before your child's surgery, you will meet the Craniofacial Nurse Specialist or a member of the Craniofacial / Plastic Surgery Team.

This appointment includes a medical checkup to confirm your child is well for surgery. If your child has any medical problems including allergies please share this information at this appointment.

Please bring any prescription or over the counter medications your child takes with you. Some or all of the following investigations may be carried out:

- Blood Tests
- Clinical Photographs
- Eye exam

During this appointment, you will also meet one or both Consultants to discuss and sign a consent form giving permission for your child's surgery. Most children having craniofacial surgery come into hospital on the day of surgery.

At home before surgery

Keeping your child well

If your child is given antibiotics in the weeks before surgery this could mean their surgery is cancelled. If your child is unwell in the weeks before surgery it is very important that you contact the craniofacial nurse specialist or a member of the craniofacial team as soon as possible to discuss your child.

If possible please keep your child away from other children or adults who are unwell with colds or infections. This will reduce the chance of their operation being cancelled because they are unwell.

If your child is unwell in the days before surgery please contact a member of the Craniofacial Team as soon as possible- Telephone 01-8784200

If your child is cancelled because they are unwell they usually need at least 6 weeks to recover fully. If your child's surgery is cancelled for any reason the Craniofacial Team will advise you of a rescheduled date as soon as possible.

Vaccinations

Your child should not receive any of their vaccinations (immunisations) within 48 hours of their planned surgery. Please see www.hse.ie/eng/health/immunisation/

Letter from admissions office

It is important that you read all the information sent to you from the Admissions Office. This will include details of your child's planned date of surgery and time to arrive at the hospital. Please always arrive 15 minutes early.

Fasting times

If your child is being admitted to the hospital on the day of surgery you will be advised of the fasting times, which are the time from which your child may not have anything else to eat or drink, this includes water. Your child's surgery will be postponed or cancelled if they eat or drink after these times. If you have any questions about these times please ask the Craniofacial Nurse Specialist.

Staying with your child in hospital

We encourage and welcome parents to stay in hospital with their child, unfortunately due to limited space only 1 parent may sleep by their child's bedside overnight.

There are a limited number of parent's accommodation rooms in the hospital. You may contact the Parents Accommodation Office (01 878 4300) to request a room once your child's admission has been confirmed. However, it is not possible to book a room as priority is given to parents of critically ill children and families living outside the greater Dublin area.

The Parents Accommodation Office will contact the ward where your child is staying once they have a bed available for you.

What to bring to hospital

Medications

If your child is taking medication please bring this with you, along with a copy of their prescription and discuss with your child's nurse.

Bottles/soothers, milk, formula or special feeds

Bring your child's bottles and soothers as these can be sterilised on the ward. Your child's food will be provided by the hospital. If your child requires milk such as soy or goat's, a special feed which you get on prescription, please bring this with you. It is advisable to bring one or two feeds with you to allow for travel and admission time. If your child is breast fed, you can continue to breast feed after surgery. Please talk to the Craniofacial Nurse Specialist if this is how you plan to feed your child while they are in hospital.

Nappies, toiletries and clothes

Bring nappies and toiletries for your child. Towels will be provided for your child on their ward. Avoid bringing clothing that needs to be pulled over your child's head after surgery as this may be difficult due to dressings, drains or swelling. Bring button up or zipped clothing instead.

For older children, bring their dressing gown, socks and slippers to wear when they walk down to the Operating Theatre. Bring a favourite blanket, comforter, books, toys or DVDs and Player to help pass the time.

For your convenience, bring your child's buggy or pushchair for their stay. Please remember you are responsible for all personal belongings.

At home before coming to hospital

Please wash your child's hair the day before surgery during their bath or shower. Your child's hair will be shaved if they are under 2 years of age or if they are having a cranial vault distraction surgery.



Hospital checklist

Don't forget	Tick
Medications and Prescription	
Milk, formula, special feed, feed for travelling	
Bottles/soothers	
Nappies & toiletries	
Clothing (buttons at the front)	
Dressing gown & socks/ slippers	
Blanket/comforter	
Toys/ DVD's & Player	
Buggy/pushchair	
Wash hair and have a bath or shower the night before surgery	

On the ward before surgery

When you arrive, you will meet the nurse who will look after your child before surgery and they will ask you questions about their health since birth. Your child will be weighed and have their temperature, blood pressure and heart rate measured. Any outstanding investigations or tests will also be completed at this time. A member of the Anaesthetic Team will assess your child to see they are fit for surgery.

Your child's nurse will advise you if you may accompany your child to the Operating Theatre.

You will be advised of Fasting Times for your child that is the time from which your child may not have anything to eat or drink this includes water. Please make sure your child is wearing their dressing gown, socks and slippers on the way to the Operating Theatre to keep warm. Young children will be wrapped in a blanket.

While your child Is In surgery

You will be given an approximate length of time your child's surgery is expected to last. We advise that while your child is in surgery that you take time to have something to eat and get some fresh air outside of the hospital or rest in Parents Accommodation. Please make sure that contact telephone numbers are given to the nurses on the ward before you leave and your mobile phone is fully charged. You will not receive any phone calls when your child is in surgery as everyone there has a job to do to look after your child while they are asleep.

Contact information

Craniofacial Clinical Nurse Specialist
email:craniofacialCNS@cuh.ie
01-8784200 Bleep 771

Craniofacial Clinical Co-Ordinator
email:craniofacialco-ordinator@cuh.ie
01-8784441 or 0876256857

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