

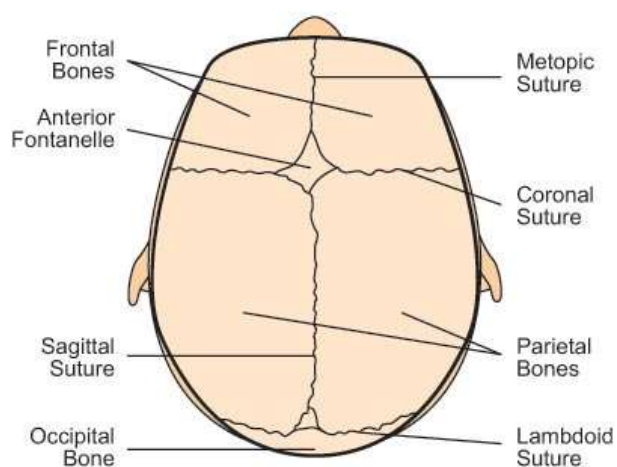


Total calvarial remodelling: information for families

Total calvarial remodelling is used to correct an abnormal head shape. It also enlarges the space within the skull to allow the brain to grow and develop. This information sheet from Great Ormond Street Hospital (GOSH) explains about the operation total calvarial remodelling and how to prepare your child for surgery as well as what to expect in hospital afterwards.

The skull is made up of several 'plates' of bone which, when we are born, are not tightly joined together. The seams where the plates join are called 'sutures'.

Normal Skull of the Newborn



As we grow older, the sutures gradually fuse (stick) together, usually after all head growth has finished. When a child has craniosynostosis, the sutures fuse before birth. It can affect one suture or several.

When one or more sutures fuse too soon, the space inside the skull cannot expand as a child grows. This can put pressure on the brain (intracranial pressure) which can have significant

long term effects. Total calvarial remodelling can be performed at any time after one year of age.

Getting ready for the operation

Pre-admission clinic

Preparing for a planned operation, test or procedure before coming in to hospital avoids delays and reduces the risk of cancellation. The results of any tests and investigations are available in plenty of time and can also be re-checked if they are not within the normal range. Your child may need various blood tests before the operation – this depends on your child's medical condition and the nature of the surgery that is planned.

The doctors and/or nurses will meet you and your child to take down their medical history and any other information needed before your child is admitted to hospital. The nurses will explain about any care your child will need before and after the operation. If your child has any medical problems, particularly allergies, please tell the doctors about these. Please also bring in any medicines your child is currently taking.

You may be seen by one of the team carrying out your child's operation and be asked to give

permission for the procedure by signing a consent form. If you give your consent at the pre-admission appointment, you will need to confirm that you still agree to the procedure on the day of admission.

One of the team will explain about the types of anaesthesia that are used at the hospital, and also about options for pain relief after the operation, test or procedure. If there are any questions or concerns about your child's anaesthesia, an anaesthetist may come to see your child in the pre-admission clinic.

The night before surgery

You will be asked to give your child a bath or shower and hair wash before surgery.

It is important that your child does not eat or drink anything for a few hours before the operation. This is called 'fasting' or 'nil by mouth'. Fasting reduces the risk of stomach contents entering the lungs during and after the procedure. You will be informed the night before the procedure of the time that your child should be 'nil by mouth' – in other words, have nothing to eat or drink before the anaesthetic.

It is equally important to keep giving your child food and drink until those times to ensure they remain well-hydrated and get adequate nutrition. This may involve waking your child in the night to give them a drink which we recommend.

On the day of surgery

Please come to Woodpecker Ward at the time stated in your admission letter. One of the nurses will check that your child is well enough for the operation, complete some paperwork with you and take some baseline observations of their temperature, heart rate and breathing. They will also put an identification wristband on your child.

If you did not give your consent for the operation at the pre-admission appointment, a member of

the surgical team will visit you to explain about the operation and ask you to sign a consent form.

Important

The person bringing your child for the operation should have 'Parental Responsibility' for them. Parental Responsibility refers to the individual who has legal rights, responsibilities, duties, power and authority to make decisions for a child. If the person bringing your child does not have Parental Responsibility, we may have to cancel the operation.

All children are seen by the anaesthetist on the day of the operation.

What anaesthetic is given?

Your child will be given a general anaesthetic by an anaesthetist who specialises in giving anaesthetics to babies and children. Both parents will be able to go with your child to the anaesthetic room and stay until they are asleep. This usually involves your child breathing some anaesthetic gas. Later, a tube is passed into the airway (trachea) to safeguard breathing. A cannula (thin, plastic tube) is put in a vein and usually left in place for a short time after the operation. Fluids can be given to your child through this tube during the operation and afterwards if necessary.

What does the operation involve?

When your child is under general anaesthetic, the surgeon will clip your child's hair just over the incision site and fix the rest of their hair out of the way. They will make an incision over the top of your child's head from ear to ear over both coronal sutures. They will then pull the skin and soft tissues over the forehead downwards to expose the skull.

The surgeon removes two-thirds of the front portion of the skull and re-shapes it by cutting and trimming the bone to form a more normal shape.

For very severely affected children, the back part of the skull (occiput) may also be remodelled.

Once the skull bones are in place and the surgeon is happy with the result, they will be fixed in place using strong stitches that dissolve very gradually over the next few months while the bone heals. The skin is then closed over the incision site and held in place with dissolvable stitches.

Your child will have a drain inserted which will be left in place to drain off any fluid that collects after surgery – this will be removed a day or two later when no longer needed. Finally, the surgeon will put a head bandage over the operation site. Your child will then be taken to the Recovery area to start to wake from the anaesthetic.

Are there any risks?

Healthy children usually cope well with the anaesthetic, but the risk increases if your child has other problems.

All surgery carries a small risk of infection or bleeding. To reduce the risk of infection, your child will be given an initial dose of antibiotics during the operation. This will continue as an infusion into a vein (intravenously) for 24 hours after surgery.

Your child will be monitored very closely during and after the operation to identify any blood loss inside the skull immediately. A blood transfusion is sometimes required but the surgeon will have ensured that donated blood of the correct type is available if needed.

This surgery requires separating the skull bone from the protective layer covering the brain (the dura), a process which can, in a tiny proportion of cases, cause brain injury or bleeding inside. Therefore, any craniofacial operation carries a very small chance of causing serious complications such as seizures (fits) or stroke (brain damage), which may in some very rare cases be life-threatening. The overall risk of a major

neurological event or death is much less than one per cent (less than a 1 in 100 chance).

Sometimes small holes can be made in the dura during the operation, which do not pose any risk to the brain, but which can occasionally be the source of a leak of cerebrospinal fluid (CSF; a clear, watery fluid that surrounds and cushions the brain). The surgeons usually identify and repair (stitch) any holes during the operation. Despite this, sometimes children develop a CSF leak after surgery, which may show up as a fluid-filled swelling at the operation site or a leak of clear, watery fluid from the wound. It will be explained to you what to do if you notice these problems after discharge from hospital, as sometimes further procedures may become necessary to stop the leakage if one occurs.

Your child's head and face will look swollen and bruised after the operation. This particularly affects the eyes and the nurses will clean them carefully in the days following the operation. Swelling tends to get worse for the first two to three days and then start to improve. The nurses will check your child's head bandage every few hours and re-apply it if it is getting tight.

The incision site will start to heal and will eventually fade until it can hardly be seen. The hair will also start to re-grow in the days following surgery.

Are there any alternatives?

There is an alternative to this operation called spring-assisted cranioplasty. This involves the surgeon cutting through the fused sagittal suture and removing a portion, leaving a small gap between the cut surfaces of the bone. Two metal springs will be fixed either side of this gap so that over the next few weeks, the springs open out to widen the gap. New bone tissue forms in the gap over the coming months. This surgery can only be done under around six months of age. In older

children, there is no other effective operation. The other option is no surgery.

What happens after the operation?

Once your child has started to recover from the anaesthetic, they will be brought back to Koala Ward to continue recovering. At the end of the day, the doctors will visit you to talk about the operation.

Your child will spend the first night in the High Dependency Area on the ward, where a nurse will monitor them closely to watch for any signs of bleeding and fluid imbalance. They will carry out regular observations of their breathing, heart rate and temperature throughout the rest of the day and night.

Your child may feel sick after the operation, but the doctors will give them medicines to reduce this. The sickness should pass within a couple of days. Your child will be able to start eating and drinking as soon as they feel like it.

The nurses will also assess your child's pain and give them regular pain relief for the first few days – intravenously to start with and then by mouth when they are eating and drinking. The intravenous infusion of antibiotics will continue for the first 24 hours.

Your child's eyes will be very swollen after the operation so the nurses will clean them gently to make them more comfortable. The swelling is temporary and will start to improve in a few days. The nurses will remove the head bandage and drains when they are no longer needed.

Your child should sit and lie in as upright position as possible to reduce any swelling. Over the next few days, your child will be able to start moving

around. Your child is likely to be in hospital for around four days.

Going home

When your child is recovering well and eating and drinking as normal, you and your child will be able to go home. On the day of discharge, the nurses will wash your child's hair gently with a mild shampoo and show you how to do it safely at home. They will also give you a copy of our discharge information which explains how to look after your child and what signs to look out for over the next few weeks.

Follow up appointments

Your child will have an appointment around six weeks after the operation – we will give you details before you go home. They will then have a series of follow up appointments throughout childhood and adolescence.

What is the outlook for children who have had this operation?

The outlook for children with sagittal craniosynostosis is good with the vast majority growing up to lead a normal life. This operation is a head-shape changing operation rather than one to improve function.

The results of surgery are variable but overall most parents are happy with the results. With input from a speech and language therapist any initial delays in speech development improve with no lasting effects. Raised intracranial pressure can be treated if it occurs. Children are of normal intelligence so usually do well at school, college and university.

Further surgery, often less extensive, can be performed later for any residual problems. Only a minority of children will require this.

If you have any questions, please telephone the Craniofacial Clinical Nurse Specialists on 07768 526 449 (Monday to Thursday from 9am to 5pm). Out of hours, call Koala Ward on 020 7829 8826. You can also seek medical advice out of hours by telephoning the GOSH switchboard on 020 7405 9200 and asking them to page the craniofacial doctor on call.