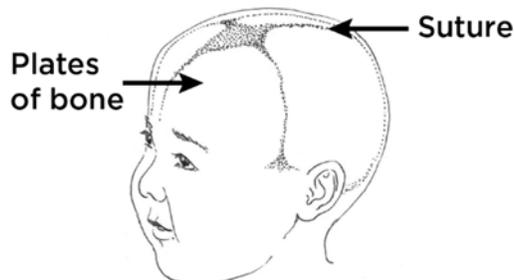


Craniosynostosis

What Is Craniosynostosis?

Your child's skull

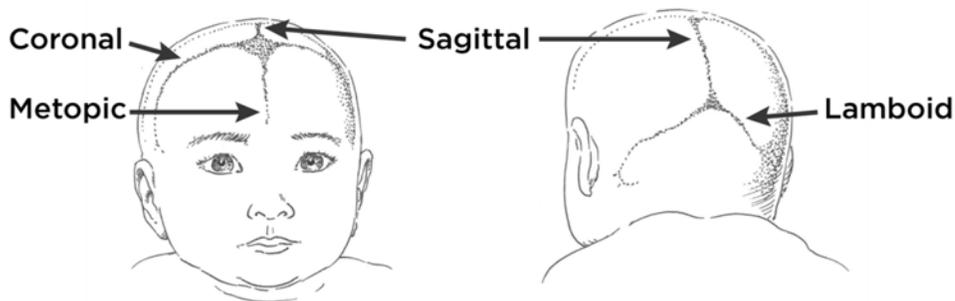
The skull is made up of plates of bone. These bones are not fused together at birth. This allows your baby's head to move through the birth canal and allows the skull to grow as the brain grows rapidly in early childhood. Between the bones are soft fibrous connections, called sutures. These normally fuse by adulthood.



What is craniosynostosis?

Craniosynostosis (crane-ee-sin-ost-O-sis) is the early closing of 1 or more of the sutures that separate the bony plates of the skull. When the sutures close too early, the skull cannot grow normally.

The shape of the skull of a baby with craniosynostosis varies depending on which suture has closed. For example, when the sagittal suture closes too early, the skull cannot grow from side to side and grows too much from front to back. This causes a skull with a shape that is long and narrow. The 4 sutures that are most often affected are shown in the picture below.



The 4 sutures most commonly affected in craniosynostosis

To Learn More

- Craniofacial
206-987-2208
- Orthotics
206-987-8448
- Ask your child's healthcare provider
- seattlechildrens.org

Free Interpreter Services

- In the hospital, ask your nurse.
- From outside the hospital, call the toll-free Family Interpreting Line, 1-866-583-1527. Tell the interpreter the name or extension you need.

What causes craniosynostosis?

We do not know why some children have craniosynostosis. Most children with craniosynostosis have only 1 affected suture and do not have any other health problems.

Craniosynostosis sometimes happens as part of genetic syndromes like Crouzon, Apert, Pfeiffer or Saethre-Chotzen. Children with genetic syndromes may have more than 1 suture that is affected. Sometimes these syndromes are passed down in the family. You may know other relatives who have it. The doctors will tell you if genetic testing is recommended for your child.

How is craniosynostosis treated?

The most common treatment is surgery. There are 2 kinds of surgery to correct craniosynostosis:

- **Open cranial vault remodeling:** In this surgery, the surgeon makes cuts in the skull bones to reshape the head to a more normal shape. Resorbable plates and screws are used to hold the bones in place while they heal. Open surgery requires a large cut (incision) across the scalp from ear to ear, more cuts in the bones, and sometimes a blood transfusion. However, the head shape is corrected at the end of surgery and your child does not require a helmet after surgery.
- **Endoscopic strip craniectomy:** In this surgery, 2 smaller incisions are made, and the surgeons use a tool like a small telescope (endoscope) to see the skull and make fewer cuts in the bones. It is a shorter procedure, can often be performed without the need for a blood transfusion and requires less time in the hospital after surgery, but the head shape is not completely corrected at the end of surgery. Your child will need a helmet to mold the head to a more normal shape after surgery. Your child will wear the helmet all the time for up to a year, except during bathing.

The type of surgery your child will have depends on their age and the sutures that are affected. Sometimes, doctors suggest waiting and watching a child with mild craniosynostosis to see how the skull grows.

Why is surgery done?

There are 2 reasons for the surgery:

1. To improve the shape of the skull. Without reshaping the skull, craniosynostosis will cause a more severe deformity as your child grows.
2. To prevent an increase in pressure inside of the skull. Pressure can build up when the skull cannot grow normally. For children with 2 or more closed sutures, this can be a serious problem and can cause brain damage over a long period of time.

What is the best age for the surgery?

The best time for surgery depends on which suture is affected and what type of surgery is done, but it is usually done in infancy. Your child's health and growth and development are also considered when deciding on the right time for surgery.

What happens before surgery?

You will come to the clinic and meet with the providers in your care team. This may include surgeons, anesthesia nurse practitioners, nurses and social workers. You will have time to ask all of your questions. Your child may need to have some blood tests to prepare for surgery.

If your child is will have endoscopic surgery, they will need an appointment in the Orthotics Clinic. They will take a scan of your child's head before surgery and again after surgery. During the scan, you will help your baby lay still for about 10 seconds. This scan is needed to make the helmet your baby will wear.

What happens on the day of surgery?

Usually, your child will be admitted early on the same day that the surgery is scheduled. We will update you during the surgery to let you know how your child is doing. After surgery, the surgeons will talk to you about the surgery while your child has a CT scan. After this, your child will be transferred to the Pediatric Intensive Care Unit (PICU) or the surgical unit for postoperative care. This is where you will be reunited with your child.

What happens after surgery?

It can be overwhelming to see your child for the first time after surgery. Your child will be sleepy and will have incisions on the head. Swelling and bruising of the head is normal and often gets worse for a few days before it gets better. When swelling is at its worst, many children are not able to open their eyes for a few days. The nurses will help you hold and comfort your child.

Your child will have an IV for fluids and medicines. Your child may also have an arterial line, or a thin plastic tube put into a blood vessel in their leg or arm to check blood pressure and get blood samples. Your child may have a small drainage tube under the scalp to help to drain extra blood and fluids for 2 or 3 days. Your child may receive oxygen and will be connected to machines that monitor the heart and breathing. This is normal after surgery.

Your child will get medicine for pain after surgery as needed. Once your child is drinking fluids, the medicine will be given by mouth. The nurses will teach you how to take care of your child at home, like how to clean the incision and give medicine.

What happens after leaving the hospital?

Once home, your child will gradually return to normal eating, sleeping and playing habits. For the first few weeks after surgery, you will need to watch your child closely to be sure that there is not a bad fall or serious hit to the head. The repair is very secure, and the minor bumps that children often get may cause swelling, but will not cause serious problems.

When do we come back for a follow-up appointment?

You will come back to the clinic 2 to 6 weeks after your child goes home for a follow-up. The nurse practitioner or doctor will check your child's incision, swelling, head shape and take out stitches (if needed). If your child had endoscopic surgery, they will need to return for more appointments in the Orthotic Clinic to check the progress with their helmet.

After this, we will want to see your child every year to watch their head shape as your child grows. We will get another CT scan to make sure all of the bones in the skull have healed completely 2 years after surgery. If you or your child's doctor has questions or concerns, we will see your child sooner.

Who do I call when I have a question?

For questions about your child before surgery, call the Craniofacial nurses at 206-987-1117 during working hours. For urgent concerns during evenings, weekends and holidays, call the hospital operator at 206-987-2000 and ask to speak with the Craniofacial provider on call.
