

Fact Sheet 18

CRANIOSYNOSTOSIS: WHAT TO EXPECT AFTER SURGERY

Understanding Craniosynostosis Surgery

Craniosynostosis is a condition where one or more of the bones in a child's skull fuse too early, before the brain has fully developed. Surgery is usually recommended to correct the head shape, relieve pressure on the brain (if present), and support normal growth and development.

There are a few different surgical techniques used in Australia and the choice depends on your child's age, the type of suture involved, and the surgical team's recommendation. The three most common are:

1. Cranial Vault Remodelling (CVR)

This is an open surgery, usually best performed around 3-6 months of age, sometimes later depending on the child's needs. Sections of the skull are reshaped and repositioned. When performed during this period of rapid brain growth, the growing brain helps guide the skull into a new shape, and the skull naturally forms new bone as it heals. When performed later, more surgical reconstruction may be required. Recovery typically involves a hospital stay of a few days.

2. Minimally Invasive Endoscopic Surgery (without springs)

Used in infants under 4-6 months of age, this less invasive technique removes the fused suture through small incisions. It is often followed by helmet therapy to guide skull growth over time. This method relies on the brain's rapid growth in infancy to reshape the skull.

3. Endoscopic Spring-Assisted Surgery

Commonly used in Australia, particularly for sagittal synostosis, this approach removes the fused suture through a small incision and inserts specially designed metal springs across the gap. These springs gently expand over time, reshaping the skull as the brain grows.

- The first surgery places the springs.
- A second surgery, usually 3-4 months later, removes them.
- Helmet therapy may or may not be used in between — your surgeon will guide this decision.

Each child's surgical plan is individual. Your craniofacial team will explain the best option for your child and what to expect during each stage of treatment.

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Post-Surgery Appearance: What's Normal

It's completely natural to feel anxious or surprised by how your child looks immediately after surgery. Healing takes time, and many of the early changes are temporary.

Some changes that may occur are:

- **Swelling and Bruising:** Particularly around your child's eyes and forehead. Swelling usually peaks 2–3 days post-surgery, then gradually settles over 1–2 weeks.
- **Eye Swelling or Temporary Closure:** After surgery, it's common for the eyelids to become very swollen. Some children may not be able to open their eyes fully for a few days. Although this can be confronting, it is expected and usually resolves quickly as the swelling settles.
- **Incision Line:** A curved or zig-zag line on the scalp with sutures, staples, or glue. This will fade and be hidden by hair over time.
- **Initial Head Shape Changes:** Your child's head may look or feel different immediately after surgery — this is expected, especially after cranial vault remodelling (CVR) or spring surgery.
- **Ongoing Head Shape Changes:** While the major reshaping will occur during surgery, your child's head shape will continue to evolve over the next 6–12 months as the brain grows and the bones settle into their new positions. Some asymmetry or small bumps are common during this healing period and usually improve over time. Your surgeon will monitor your child's progress post-surgery.
- **Adjusting to Changes in Appearance:** It is normal for parents to feel surprised, unsettled, or even shocked by their child's different head shape after surgery. These feelings are natural. If you are finding these feelings difficult to process, speak with your medical care team who may be able to arrange a referral for counselling support.

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Wound Care and Scalp Management

Caring for the incision is an important part of recovery. Your hospital team will give you detailed instructions, but here are general guidelines:

- **Keep It Dry and Clean:** Avoid washing your child's hair until you're advised it's safe — usually after 5–7 days.
- **Don't Pick at Scabs:** Let scabs and crusts fall off naturally to reduce the risk of infection or scarring.
- **Check the Wound Daily:** Watch for signs of infection:
 - Redness that worsens or spreads
 - Thick, yellow-green discharge or a bad smell
 - Increased swelling or warmth
- **Hair Regrowth:** Your child's hair will start to grow back within weeks. It may be patchy at first but usually fills in over time.

If the incision is exposed to sun in the months after surgery, ask your doctor about sun protection — fresh scars can darken if left unprotected.



Pain and Comfort

Most children experience some discomfort after surgery. You'll be given pain relief to use at home — usually paracetamol and ibuprofen.

- Stick to the medication schedule, especially in the first few days.
- Use a written log or app to keep track of doses.
- Comfort strategies like cuddles, quiet spaces, soft toys, or screen time can also help.
- If pain seems to be getting worse instead of better, contact your medical team.

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Symptoms to Watch For

While most children recover smoothly, it is important to be alert to signs that need medical attention. Call your care team or go to the emergency department if you notice:

Signs of Infection

- Fever over 38°C that lasts more than 24 hours
- Red, swollen, or hot skin around the incision
- Pus or fluid leaking from the wound
- A bad smell from the surgical site

Neurological Symptoms

- Vomiting (especially if repeated or forceful)
- Trouble waking your child or extreme sleepiness
- Seizures or jerking movements
- Poor feeding
- Bulging or sunken soft spot (fontanelle)

Other Concerns

- A soft, squishy lump near the incision that gets larger (which may indicate fluid build-up)
- Ongoing irritability or behaviour changes that don't improve

Always trust your instincts. If something does not feel right, do not wait — call your surgical team or local hospital.

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Follow-Up Care and Monitoring

Your child will need several follow-up appointments after surgery. These appointments help ensure that:

- The incision is healing well
- Your child's head shape is developing as expected
- Springs (if used) are removed at the right time
- Helmet therapy is monitored (if it is part of the plan)

Most children are ready to return to gentle play within 1-2 weeks, but rough play or contact sports should wait until your surgeon gives the all-clear.



Vaccinations After Surgery

If your child receives a blood transfusion during surgery, the timing of some vaccinations may be affected. In particular, live vaccines such as measles-mumps-rubella (MMR) and varicella (chickenpox) may need to be delayed for a few months, because the transfusion can reduce how well the vaccine works.

The exact timing may vary depending on your hospital and your state's guidelines. Your surgical team, GP, or immunisation nurse will give you the most up-to-date advice for your child.

If your child attends childcare or school, where vaccinations are mandatory, you can usually request a temporary medical exemption or a delay letter from your healthcare provider until your child is ready for the vaccine.

Tip: Keep a record of any transfusions your child receives and ask your GP to check your child's vaccination schedule afterwards.

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Emotional Support for Families

It's completely normal to feel overwhelmed, exhausted, or emotional after your child's surgery. Many parents say it takes a few weeks — or even longer — to feel "back to normal."

- **Reach out for support:** There are support groups and peer networks available — just ask us or refer to the support organisation fact sheet on this website.
- **Ask lots of questions:** Your healthcare team is there for you.
- **Take care of yourself:** Rest, eat, and accept help where you can.
- **Seek counselling support if needed:** counselling support may be available through your child's health service, or you can speak with your medical care team who may be able to arrange a referral for counselling support.

You are not alone — and your child is more resilient than you know.



Need More Help?

Contact Craniofacial Australia, we're here to support you before, during, and after surgery.

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This information is based on the expertise of clinicians who work with families affected by craniofacial conditions and the lived experience of parents with children who have been diagnosed with craniosynostosis. We thank everyone who contributed to this fact sheet.



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How we can support you:

- Care packs
- Financial assistance
- Family support coordinator
- Connection to other families

