

Fact Sheet 6

QUESTIONS THAT PARENTS MAY WISH TO ASK CLINICIANS DURING APPOINTMENTS

Preparing for appointments with your child's craniofacial team can feel overwhelming, and it is natural to have many questions. This fact sheet provides a list of questions that other parents have found helpful to ask. They cover a wide range of topics, from diagnosis and surgery, through to recovery, long-term care, and family considerations.



How to use this sheet

Start with 📌 First Appointment Essentials. Then move to the other sections as needed. You won't need every question—choose what fits your family at whichever stage you're in, and feel free to add your own.

If you can, bring a trusted person for support and to take notes. Use a small notebook (or your phone) to jot answers and next steps.

📌 **First Appointment Essentials** — start here

✅ **Important** —follow-up questions as you reach each stage

★ **Optional** — additional questions if relevant or of interest to your family

(continued overleaf)



QUESTIONS THAT PARENTS MAY WISH TO ASK CLINICIANS DURING APPOINTMENTS

▼ FIRST APPOINTMENT ESSENTIALS

- ▼ What exactly is craniosynostosis?
- ▼ Which type of craniosynostosis does our child have, and would you consider it mild, moderate or severe?
- ▼ Is our child's condition considered syndromic or non-syndromic and what is the difference between these terms?
- ▼ What can we expect for my child's appearance, learning/development and behaviour over time — if we choose monitoring/no surgery, versus surgical treatment?
- ▼ Timing: What age is best for surgery, and what happens if it is delayed?
- ▼ If surgery isn't done now, what would we watch for and how would you monitor our child?
- ▼ Risks and benefits: What are the main benefits and possible risks of this option? How often do those risks happen, and what does your team do to make surgery as safe as possible?
- ▼ What tests or scans are needed for diagnosis and planning (e.g., CT/MRI)?
- ▼ What should we expect our child to look and feel like right after surgery and in the first days?
- ▼ How can we reach you or the team after today if we have questions?
- ▼ Are there reliable, Australian-relevant resources we can read next?

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QUESTIONS THAT PARENTS MAY WISH TO ASK CLINICIANS DURING APPOINTMENTS



QUESTIONS TO ASK BEFORE SURGERY

✓ IMPORTANT

- ✓ What does your recommended surgical procedure involve and what is your experience with this technique?
- ✓ How many operations will be required?
- ✓ Are there other surgical options available for my child's specific condition (whether at this clinic or another)?
- ✓ For the risks you've mentioned, how often do they usually occur - both in your team's experience and in other published information about this type of surgery?
- ✓ What should we expect before and after surgery in terms of how our child functions?
- ✓ Other than with you (the surgeon) what medical appointments (e.g., eyes, scans, photography, anaesthetist, social worker and neurosurgeon) will be required before surgery?
- ✓ How many times before surgery will we meet with you, the surgeon?
- ✓ Who else will make up the surgical team? Will we meet them before surgery and, if so, when?

★ ADDITIONAL QUESTIONS

- ★ What is the difference between the roles of the Craniofacial Surgeon and Neurosurgeon?
- ★ What is the overall time frame for surgery and recovery, including pre-surgery appointments?
- ★ How common is follow-up surgery?
- ★ Are there any other issues around development and/or functioning that I should be aware of?
- ★ Team & experience: Who will be involved in our child's care, what are their roles, and how much experience does the team have with this procedure, including how often they perform it?

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QUESTIONS THAT PARENTS MAY WISH TO ASK CLINICIANS DURING APPOINTMENTS



SURGERY SPECIFIC QUESTIONS

✓ IMPORTANT

- ✓ Will my child need to fast before surgery?
- ✓ How long does the surgery last?
- ✓ What is the likelihood of my child needing a blood transfusion and do we need to postpone any vaccinations (such as the Measles, Mumps and Rubella [MMR] vaccine)?
- ✓ What type of anaesthesia will be used? Will the anaesthetist be a specialist in infants? What is the process for administering anaesthesia and can we be present?
- ✓ Who will be present in the operating room at the time of my child's surgery?
- ✓ What hardware will be used during surgery and will any remain long-term?
- ✓ When will my child be woken post-surgery and can we be present at that time?

★ ADDITIONAL QUESTIONS

- ★ Can I provide my own blood for a transfusion (if needed)?
- ★ Do you use or suggest Procrit injections to reduce the risk of my child needing a blood transfusion?
- ★ Is the brain ever touched during surgery?
- ★ Will you shave my child's hair?
- ★ Where exactly will the incision be?
- ★ Will it be a straight line or a zig-zag?
- ★ What type of stitching will you use?

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HOSPITAL AND EARLY RECOVERY QUESTIONS

✓ IMPORTANT

- ✓ Will my child be able to eat, sleep, and move around normally after surgery? If not, how long until they will be able to function normally?
- ✓ Will my child have stitches that will need to be removed and, if so, when?
- ✓ How and what type of medication will be administered post-surgery?
- ✓ How long will my child likely stay in the hospital?
- ✓ Will my baby need to stay in intensive care and, if so, for how long?
- ✓ What care and assistance can we expect to receive from nurses in the ward?
- ✓ Can we stay in the room with our child if an overnight stay is needed?
- ✓ Who should we speak to if we have concerns during the hospital stay?
- ✓ How do I safely lift or position my child after surgery?
- ✓ Will there be someone allocated who will help us navigate the process from now, through the surgical period and into the longer-term?

★ ADDITIONAL QUESTIONS

- ★ What amenities are available in the hospital for parents?
- ★ Will I receive meals if I stay overnight with my child? What food will be available in the hospital for my child?
- ★ Can I breastfeed my child after surgery?
- ★ Is there anywhere in the ward to pump breastmilk and/or store it?
- ★ Will we be allowed to leave the ward and go for short walks around the hospital with our child post-surgery?
- ★ Will there be regular updates on my child's progress?
- ★ What items should we pack for ourselves and our child if we're staying in hospital? (see Fact sheet 15: Packing for Hospital)
- ★ Where can I access information about accommodation options close to the hospital?
- ★ Who can I speak with about access to Ronald McDonald House during surgery?
- ★ Can we fly/travel after surgery? When would it be safe?

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POST-SURGERY CARE AND LONG-TERM EFFECTS QUESTIONS

✓ IMPORTANT

- ✓ What is the expected outcome of surgery and are you able to show us examples or photos that help explain what changes we might expect?
- ✓ Will we receive written instructions about how to care for our child at home?
- ✓ What signs of complications (such as infection or swelling) should I look for?
- ✓ How do we manage pain or discomfort at home after the operation, particularly if my child is not sleeping and showing signs of distress?
- ✓ How do we care for the incision or surgical site?
- ✓ What post-surgery management will be required (e.g., helmet use) and how long is this usually for?
- ✓ What should I do if my child bumps or knocks their head after discharge?
- ✓ When can my child return to childcare/school?
- ✓ Are there potential long-term effects or complications we should be aware of?

★ ADDITIONAL QUESTIONS

- ★ When can my child swim in a pool or the ocean?
- ★ Should my child be put to bed in a certain way to minimise damage to their wound/head?
- ★ Can we pull clothes over their head and, if not, how long should we wait?
- ★ Can we wash our child's hair?

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QUESTIONS THAT PARENTS MAY WISH TO ASK CLINICIANS DURING APPOINTMENTS



MONITORING AND SUPPORT SERVICES QUESTIONS

✓ IMPORTANT

- ✓ Who do we contact if we have questions or concerns after surgery and discharge from hospital?
- ✓ Will follow-up appointments be scheduled before we leave hospital?
- ✓ How often will my child need to be monitored by the craniofacial clinic after surgery?
- ✓ What signs or symptoms should we watch for that might indicate a need for further evaluation?
- ✓ Are there support groups or organisations specialised in craniosynostosis that you can recommend?
- ✓ Can you provide, or guide us, to educational materials or resources tailored to the Australian context?

★ ADDITIONAL QUESTIONS

- ★ Are there psychological support services available during and after treatment if our family needs additional support?

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QUESTIONS THAT PARENTS MAY WISH TO ASK CLINICIANS DURING APPOINTMENTS



QUESTIONS ABOUT GENETICS AND FAMILY CONSIDERATIONS

✓ IMPORTANT

- ✓ Is there a genetic component to craniosynostosis, and should we consider genetic testing for our child or other family members?
- ✓ Are there any implications for future pregnancies or family planning?

★ ADDITIONAL QUESTIONS

- ★ How long will genetic testing potentially take?
- ★ What are the chances of genetic testing providing a clear result?
- ★ Could genetic testing reveal predispositions to conditions unrelated to craniosynostosis? If so, can families choose not to be informed of these findings if they do not affect treatment or care?
- ★ Could the results of genetic testing affect life insurance policies or premiums?
- ★ How long are genetic samples stored, and where are they kept?
- ★ If no result is found, are samples retested in the future, and if so, how often?

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.

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

