

Fact Sheet 23

ADVOCATING FOR YOUR CHILD'S CARE

Parents are their child's strongest advocates and know them best. At times, you may need to speak up during diagnosis, before surgery, or in the recovery period to ensure your child's needs are met. This can feel daunting, but developing a sense of when and how to advocate can help you feel more confident and help your child receive the best possible care.



Advocacy During Diagnosis

- **Trust your instincts** – If you notice something unusual about your child's head shape, development, or symptoms, keep raising it even if your GP or paediatrician dismisses your concerns.
- **Seek second opinions** – It is okay to request a referral to a craniofacial specialist or to see another doctor if you feel your concerns aren't being taken seriously.
- **Keep records** – Bring photos, notes, or growth charts to show changes over time. This can help clinicians see what you are noticing.

Advocacy Before Surgery

- **Ask questions until you understand** – Use resources like Fact Sheet 4: Questions for Clinicians to guide your discussions.
- **Stay informed about timing** – If surgery dates are delayed, ask why, what impact this may have, and whether referral to another hospital is an option.
- **Involve your support network** – Bring another adult to appointments to take notes or back you up when raising concerns.

(continued overleaf)



Craniofacial Australia

204 Melbourne Street
North Adelaide
South Australia, 5006

W: craniofacial.com.au
E: familysupport@acmff.org.au
P: (08) 8267 4128



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Advocacy After Surgery

- **Pain relief and comfort** – Speak up if your child's pain is not well managed. For example: "Can Panadol be given now, as the next dose is due?"
- **Basic needs** – Request simple comforts (quiet space, extra pillow, or support with feeding) if these will make your child more comfortable.
- **Ongoing concerns** – If something doesn't feel right during recovery, ask for a review, even if staff seem busy.

Tips for Effective Advocacy

- **Be polite but persistent** – Respectful persistence often gets results.
- **Use clear language** – Say: "I'm concerned because..." rather than "You're not doing enough."
- **Write down key points** – Bring a list of questions or concerns so you don't forget under stress.
- **Know your rights** – You are entitled to information, second opinions, and to be involved in decisions about your child's care.

Advocacy doesn't mean being confrontational – it means making sure your child's needs are heard and acted on. Parents know their children best, and speaking up can make a big difference to both comfort and care.

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

