Fact Sheet 3

TIPS FOR TALKING WITH YOUR CHILD ABOUT THEIR CRANIOFACIAL CONDITION

The information and advice provided below may not be suitable for every family. Preferences and needs vary, and there's no single 'right' approach — it depends on what feels right for you. We encourage families to consider their unique circumstances and speak with healthcare professionals as needed.

It's natural to feel overwhelmed, but approaching the conversation with empathy and clarity can help your child feel more secure and understand their condition better.

The following are some additional tips to consider:

1. Check your Own State of Mind: Are you feeling calm and ready for the chat? Do you need some dot points to help you keep track of what you want to say?

2. Use Simple Language: Tailor your language to your child's age and understanding, using words that they know. Use simple, clear terms.

3. Be Honest and Reassuring: When kids are unsure about what is going on, they may imagine things to be worse than they are. Assure them that their condition is something that can be treated (if your child is still in the pre-surgery stage), or that they already had surgery as a baby (if you are explaining to your child when they are a little older).

4. Talk About It Like It's a Normal Part of Life: From an early age, speak about their condition or surgery as just another fact of life—simple and matter-of-fact. For example: "The sky is blue, things fall when we drop them, and you had surgery on your head to help your brain grow."

5. Encourage Questions: Let your child know that it is okay to ask questions. Be prepared to answer them honestly and calmly.

6. Focus on Their Strengths: Emphasize their strengths and reassure them that they are not defined by being diagnosed with a craniofacial condition.

7. Involve Them in the Process: Depending on their age, involve them in discussions about treatment options and what to expect.

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8. Emphasise Support: Reassure them that the doctors, nurses and other health professionals involved in their care will help them and that their family is with them every step of the way. Consider involving your GP, paediatrician, or a child psychologist if your child needs additional emotional support.

9. Monitor Their Emotional Response: Pay attention to how your child reacts and adjust your approach accordingly. You can choose one or two strategies that fit at the time, and come back to others later (if needed).

a. Notice the early signs: Look for cues like a suddenly quiet or very loud voice, fidgeting, tearfulness, stiff or restless body, avoiding eye contact, a 'frozen' look, tummy aches, or faster breathing. If you see two or more at once, pause the conversation.

b. Name it & normalise: Say what you notice and give it a name: "I can see your shoulders are tight—this feels big. It's okay to feel worried or confused." Keep your voice calm and slow.

c. Co-regulate (calm together): Take 3 slow breaths together (in for 4, out for 4). Offer a quick soothing action—a cuddle, hand squeeze, sip of water, or soft toy. Model your own calm breathing so they can copy.

d. Shrink the topic (one idea): Share one idea at a time and use simple, non-scary words. Offer a short break (water/stretch/draw for 2 minutes) and use a timer so they know you'll come back and finish.

e. Finish with next steps: Outline what happens next, when, and who will be there. End with a reassuring routine (e.g., a story, snack, or game).

10. You're Not Alone: Reassure them that lots of kids go through similar things and that they're part of a team of tiny warriors.

11. Use Visuals or Toys: these may help your child understand the concept of their craniofacial condition (e.g., a picture, a puzzle, a balloon or building blocks).

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12. Keep the Conversation Going: Your child might not be receptive at first, but may come back later to share questions or worries. Or, they may need to hear things explained repeatedly.

13. Use Gentle, Supportive Statements such as: “Everyone grows in different ways, this is just part of your story”; “You’re brave, you’re strong and we’re proud of you”; “We’ll get through this together”.

14. Finding the Right Moment: Some families set aside a certain time to check-in (whether that’s asking how they’re doing emotionally or physically) with their child, while others find it easier to have these conversations while doing other family activities, such as during a car ride or playing a board game.

15. Gently Explaining What’s Ahead: Your child may need multiple surgeries as they grow and develop. Letting them know this in a calm and caring way — when the time is right — can help reduce their anxiety and support their emotional wellbeing.

16. Support that Suits You: You may want to talk to your child alone or have someone else with you for support. Use your judgement as to which will work best for your family.

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