Fact Sheet 21

SUPPORTING SIBLINGS OF A CHILD WITH A CRANIOFACIAL CONDITION

A guide for parents

When a child is diagnosed with a craniofacial condition, siblings often feel confused, worried, jealous, or left out. With thoughtful support, siblings can adapt well — and even grow stronger in empathy, resilience, and connection.

It is important that siblings feel seen, heard, and valued — not just as supporters, but as individuals with their own needs. Supporting them helps strengthen the whole family.

This fact sheet offers practical and emotional strategies to help siblings feel included, secure, and supported.

1. Acknowledge Their Experience

- Talk openly and honestly, using age-appropriate language. "Your sister was born with something that affects how her face grew, and the doctors are helping her."
- Encourage questions and make space for hard feelings like fear or jealousy.

2. Provide Developmentally Appropriate Information

- **Young children:** Use picture books, puppets, and play to explain.
- **Older children:** Offer honest answers and suggest journaling or drawing.
- **Teens:** Invite open conversations and respect their need for privacy or space.

3. Include Them in the Journey

- Let them visit the hospital (or see photos) if appropriate.
- Involve them in small acts of support, such as drawing a picture or picking a toy for their sibling.
- When hospital visits are not possible, a short video call can help siblings feel connected and included.

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4. Validate and Normalise Emotions

- Recognise feelings of sadness, anger, or being left out as normal.
- Let them know it is OK to have mixed emotions – and that you're there to support them too.

5. Create One-on-One Moments

- Set aside "special time" with each sibling, even if it's short.
- Use a shared calendar or notebook to schedule regular check-ins and ask how *they're* doing – not just how they feel about their brother or sister.

6. Maintain Routines and Predictability

- Keep their daily routines as stable as possible – school, bedtime, meals.
- Prepare them in advance for big changes like surgery or travel, using visuals or stories.

7. Encourage Creative Expression

- Offer art, music, play, sport or writing as outlets to express their feelings.
- Create a "Feelings Box" or "Question Jar" where they can share or ask things that they're not ready to say out loud.

8. Foster Peer Connections

- Link siblings with other siblings of children with visible differences (e.g., online rare condition networks/groups).
- Consider age-appropriate support groups where they can talk freely – even if not specifically craniofacial related (e.g., siblingsaustralia.org.au).

9. Involve Schools and Educators

- Inform teachers and school counsellors that the family is managing a medical diagnosis.
- Ensure the sibling has access to emotional support at school, especially during their sibling's surgery or absences from home.

10. Teach Inclusive Language and Social Tools

- Practice simple, respectful responses to questions from peers. "My brother had surgery when he was little. He's doing great now!"
- Role-play how to handle stares or awkward comments confidently.

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11. Celebrate Their Role in the Family

- Acknowledge their empathy, flexibility, and love. “You’ve been such a thoughtful big sister – thank you for being so caring.”
- Show appreciation through words, drawings, or small rewards.

12. Offer Professional Support if Needed

- Seek help from a child psychologist if they show signs of distress, anger, or withdrawal. Your GP can assist you with a referral, if required.
- Therapy can give them tools to manage emotions and build confidence in their role.

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