Fact Sheet 10

HOW TO SUPPORT FAMILIES IMPACTED BY A CRANIOFACIAL CONDITION

Supporting families impacted by a craniofacial condition—especially during diagnosis and treatment—can make a meaningful difference. Here are some ways that friends and extended family can offer support:

EMOTIONAL SUPPORT

1. Listen Without Judgment

- Let them express fear, frustration, or grief without trying to "fix" it.
- Avoid minimizing their concerns with comments like “it could be worse” or “it will be alright”.

2. Be Consistently Available

- Be available to check in regularly via phone calls, text messages, or visits – at any time of the day or night.
- Small, consistent gestures mean more than large, one-off ones.

3. Acknowledge Their Reality

- Recognise that living with or caring for someone with a craniofacial condition can be emotionally draining.
- Say things like, “That sounds really hard—how are you managing today?”

4. Support Siblings Emotionally

- Give them individual attention and reassure them that their feelings matter and they are just as important.
- Let them have fun and normal interactions that aren't focused on medical issues.

(continued overleaf)

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RESPECTING BOUNDARIES

5. Respect Their Timing

- Families may not always feel ready to talk. Let them decide when to share, and avoid pressing for details if they're not in the mood.
- Don't ask very personal questions unless they start the conversation.

6. Ask Before Sharing Photos

- Always check before posting or sharing photos of their child on social media.
- Respect their wishes if they prefer to keep images private.

PRACTICAL SUPPORT

7. Offer Hands-On Help

- Prepare meals, do laundry, or help tidy the house—especially around surgery or hospital stays.
- Run errands or care for pets or other children.

8. Help With Appointments

- Offer to drive to medical appointments or sit with them in waiting rooms.
- If appropriate, go along to take notes and provide another set of ears.

9. Coordinate a Support Roster

- Organise a group of friends to take turns helping with meals, childcare, or transportation.

10. Be Sensitive in Public

- If you're with them and someone stares or makes a comment, follow their lead in responding.
- Don't speak for them unless asked, but always show quiet solidarity.

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FINANCIAL SUPPORT

11. Contribute to Medical or Travel Costs

- Where possible, you might offer direct financial help for expenses like surgery-related travel, accommodation, or lost income.
- Set up or donate to a verified fundraising page with their consent.

12. Give Thoughtful, Helpful Gifts

- Pre-paid fuel or supermarket cards, car-parking or coffee vouchers for hospitals, or activity kits for the child or siblings.
- Avoid giving unnecessary baby items or toys unless specifically requested.

RELATIONAL & LONG-TERM SUPPORT

13. Be Inclusive

- Invite them to social gatherings even if they can’t always attend.
- Ask how their child is doing, but also ask about them—their work, hobbies, or well-being.

14. Educate Yourself

- Learn about the child’s condition so they don’t always have to explain.
- Put the child first when speaking about them (e.g., “a child with a cleft lip” instead of “a cleft child” to show the condition doesn’t define who they are.

15. Celebrate Their Child

- Focus on the child’s strengths, interests, and personality—not just their diagnosis or surgeries.
- Acknowledge milestones (e.g., post-surgery recovery, birthdays, starting school).

Supporting families facing craniofacial conditions isn’t about having all the answers—it’s about showing that you care, consistently and respectfully. Your support can be a powerful reminder that they are not alone.

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