Fact Sheet 9

SUPPORTING EACH OTHER: A GUIDE FOR PARENTS OF A CHILD WITH A CRANIOFACIAL CONDITION

Caring for a child with a craniofacial condition can bring both emotional and practical challenges. During this time, maintaining a strong, supportive partnership is essential—not only for your child’s wellbeing, but for your own. This fact sheet offers practical strategies to help you and your partner communicate openly, share responsibilities, and stay connected as you navigate the journey together.

1. Open and Honest Dialogue:
- Establish a regular time to discuss your child's condition and treatment plan.
- Encourage each other to share thoughts, concerns, and feelings without judgment.

2. Active Listening:
- Practice listening attentively to each other's perspectives.
- Reflect back what you hear to ensure understanding before responding.

3. Divide Responsibilities:
- Assign tasks related to caregiving and appointments to prevent overload.
- Acknowledge each other's efforts and offer support when needed.

4. Maintain Emotional Balance:
- Understand that stress is natural during this time. Take breaks and prioritise self-care.
- Seek professional help if either of you feels overwhelmed or anxious.

5. Support Each Other:
- Validate each other's emotions and provide reassurance.
- Celebrate milestones and achievements together, no matter how small.

6. Resolve Conflicts Constructively:
- Use "I" statements to express your feelings rather than blaming each other (e.g., ‘I feel frustrated when …’).
- Take a break if discussions become heated and return to the topic later.

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7. Stay Informed Together:
- Attend medical appointments together whenever possible.
- Research treatment options and discuss decisions as a team.

8. Agree on the Treatment Plan Together
- Make sure you are both involved in treatment decisions so one of you isn’t left carrying the responsibility alone.
- Reaching agreement beforehand helps prevent blame if challenges arise later.

9. Share Knowledge About Devices
- If your child uses a device (e.g., helmet or distractors), ensure both of you know how it works and how to use it.
- This prevents the burden from falling on one of you and allows each of you to care for your child independently, giving the other a chance to rest.

10. Connect with Others:
- Join support groups or online communities for parents of children with craniosynostosis.
- Share experiences and advice with others who understand your journey.

11. Plan Quality Time:
- Schedule regular activities as a couple or family to bond outside of caregiving responsibilities.
- Keep communication channels open with other family members and friends for additional support.

12. Seek Professional Help if Needed:
- Consider counselling or therapy to strengthen your relationship during this challenging time.
- Consult with your child's healthcare team for recommendations on coping strategies.

13. Agreeing on Work Conversations About Your Child
- Making joint decisions about what to share at work helps both parents feel supported and ensures communication is consistent.

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Some ideas for managing this together:

- Pick a trusted colleague or manager as a go-to contact.
- Agree on what to share with others — avoid over- or under-sharing.
- Consider flexible work options (adjusted hours, working from home).
- Plan how to respond to questions or curiosity from colleagues.

Effective communication is key to navigating challenges together as a team. By supporting each other emotionally and practically, you can reduce stress and maintain a strong relationship.

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.