Fact Sheet 15

# HOW TO TALK ABOUT YOUR CHILD'S CRANIOFACIAL CONDITION WITH OTHERS

Talking about your child's craniofacial condition can be an act of love, advocacy, and education—but you get to decide how and when those conversations happen.

When parents discuss their child's craniofacial condition with others—whether family, friends, or acquaintances—the goal is often to provide information, set the tone for respectful understanding, and advocate for their child. These conversations can feel emotionally charged, especially in the early stages, so having a thoughtful approach can help.

It can also be useful to remember that sometimes people might stare or make comments simply because they're curious, unsure, or don't know how to react. While these moments can feel upsetting, they are usually not meant to be hurtful. The reassuring part is that most people are kind and compassionate—when they understand, their reactions are often positive and supportive.

Here are some tips for communicating with others:

**1. Start with what Feels Comfortable**

- You do not need to share everything. Choose what you feel emotionally ready to explain.
- A short, confident explanation can often go a long way:

  "Our baby has a condition called craniosynostosis, which means one of the bones in the skull fused too early. They'll have surgery, and we're working closely with a great medical team."

**2. Use Clear, Simple Language**

- Avoid overly medical terms unless the listener needs them.
- Explain it in a way that others can relate to or understand (e.g., "It affects how their face or skull is shaped but doesn't change who they are").

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**3. Model Respectful Language**

- Use positive, person-first language, as this sets the standard for how others should talk about your child: "Our daughter has a craniofacial difference" rather than "is deformed."

**4. Share Only When and With Whom You Want**

- You do not owe anyone an explanation, or have to share details about your child. It's okay to say: "We're still processing everything right now"

**5. Prepare a 'Go-to' Line for When it Gets Tough**

- Sometimes questions can feel overwhelming or emotional. Having a simple line prepared can help you step away without feeling pressured.
- For example: "Thank you for asking. I'd love to share more another time, but right now it feels too hard. If you could email me your questions, I can respond when I'm ready."

**6. Prepare for Uncomfortable Questions**

- People may ask intrusive or well-meaning but hurtful questions.
- You can gently redirect: "That's not something we want to focus on—we're just enjoying getting to know our baby."

**7. Set Boundaries Around Photos and Social Media**

- Talk with family, friends, and caregivers about your preferences for sharing your child's photo or story online.
- Setting boundaries can feel especially hard when you are already feeling emotionally overwhelmed. That's normal. Be kind to yourself and set them in ways that feel manageable. Example: "We're keeping things private right now—thanks for understanding."

**8. Empower Family and Friends to Be Allies**

- Provide a few simple facts and phrases that they can share if others ask them questions.
- Let them know how they can help challenge stigma or teach their own children about differences.

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**9. Invite Curiosity With Kindness—When You're Ready**

- If you're open to it, treat some questions as teachable moments: "Yes, she has a rare condition. It means she's had some surgeries already, but she's a tough little kid."

**10. Highlight Your Child's Strengths**

- Bring the focus to your child's personality, interests, and milestones: "He loves music and has the cheekiest laugh. His condition is just one part of his story."

**11. Lean on Support Networks**

- Practice conversations with your partner or a trusted friend.
- Connect with other parents whose child has a craniofacial condition similar to your child's. Hearing how they talk about it can give you language that feels right for your family.
- Take proactive steps to support positive mental health and wellbeing.

**12. Practice a Quick Line for Tricky Moments**

- Having a short, rehearsed sentence ready can help when emotions are high or you're caught off guard. "He was born with a craniofacial condition—it's something we've learned a lot about, and we're doing everything we can to support him."

Remember, there's no single "right" way to talk about your child's condition. Share only what feels comfortable, set boundaries where you need them, and know that you are your child's strongest advocate.

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