CONVERSATIONS IN CARE

A Practical Guide for CHWs and Care Teams Rooted in Trust and Respect

Cleft Lip & Palate

Why It Matters

Learning that a baby has a cleft lip or cleft palate can be shocking and emotional for families. Parents may feel fear, guilt, confusion, or worry about their child's future. Some families may wonder if they did something wrong, or if it is connected to spiritual beliefs or family history.

Cleft lip and cleft palate are treatable conditions, and with the right care and support, children can eat, grow, speak, and thrive. A calm, respectful conversation helps families feel hopeful, informed, and supported instead of blamed or afraid.

This conversation guide aims to support providers in delivering information with compassion, creating a safe and respectful environment, and connecting families to the resources and support they need as they begin to navigate their journey.

Before the conversation

- Create a safe, respectful environment.
- Ask about what the family already knows or believes.
- Acknowledge that some words, beliefs, or traditions may be different, and that it is okay.
- At first, listen more than speak.

Questions	Answers
What is a cleft lip or cleft palate?	A cleft lip or cleft palate happens when a baby's lip or the roof of their mouth does not fully close while they are growing during pregnancy. This happens very early in pregnancy, often before a person even knows they are pregnant. Some babies have a cleft lip, some have a cleft palate, and some have both.

Tip: Use your hands or a simple drawing, if helpful. Avoid detailed anatomy language.

Did I do something wrong to cause this?	No. This is not your fault. Nothing you ate, did, or did not do caused this. Cleft lip and cleft palate happen in families all over the world and across all cultures. Sometimes there is a family history, and sometimes there is no clear reason. This happens very early in pregnancy, often before a person knows they are pregnant. Because it happens so early, there is nothing a parent could have done to prevent it. Many parents feel shocked, sad, or confused when they first hear this news. These feelings are normal. It is okay to take time to process and ask questions. What matters most is that your baby can get care and support. With the right help, children with cleft lip or cleft palate can grow, eat, talk, and live healthy lives.

Tip: Reassure families that help is available, and they will not be expected to figure this out alone.

Questions	Answers
Will my child need surgery?	Many children with cleft lip or cleft palate have surgery to repair the lip or palate. These surgeries are common and are done by specialized doctors. Surgery is usually planned in stages as the child grows. The care team will explain the timeline and answer questions before anything happens. Each child's plan is different. Some children need one surgery, and others may need more over time. The care team will make a plan that fits your child's needs.

Tip: Avoid giving exact ages or timelines unless asked; focus on 'step by step.'

Will my child be able to talk normally?	Many children with cleft palate may need speech therapy as they grow. Speech therapy helps children learn clear speech and build confidence. With treatment and therapy, many children speak clearly and communicate well. Speech therapy often feels like play for children. Therapists use games, pictures, and fun activities to help children learn sounds and words.

Tip: Emphasize progress over perfection.

Will my child look different forever?	As your child grows, confidence also grows. Feeling accepted at home and in the community helps children feel strong and proud of who they are. After treatment and surgery, many children look like other children their age. Some may have small scars, which often fade over time. What matters most is that your child is healthy, loved, and supported.

Tip: Be careful not to minimize concerns; acknowledge feelings first, then reassure.

Questions	Answers
What kind of support will my family get?	Families are usually supported by a team of people who work together. This team may include doctors and surgeons who plan the care and treatment, nurses and feeding specialists who help with feeding and daily care, and speech therapists who support communication as the child grows. Early intervention providers and community health workers are also part of the team. They help families understand services, schedule appointments, and find support in the community.

Tip: Frame care as a partnership, not a system that families must navigate alone.

Will my child feel pain or suffer because of this?	Doctors and care teams work hard to keep babies and children comfortable. During surgeries or procedures, children are given medicine so they do not feel pain. After surgery, families are shown how to comfort and care for their child at home. Most children recover well, and care teams closely watch healing and comfort. Parents are encouraged to speak up if they notice their child seems uncomfortable or in pain. The care team will listen and adjust care as needed. Your voice matters, and you know your child best.

Tip: Normalize the fear without dismissing it. Use calm language and avoid graphic details.

How can I explain this to my family or community?	Some families may have questions, worries, or strong opinions. You can share that cleft lip and cleft palate are common medical conditions that happen before birth and are treatable. You do not need to explain everything at once. Community health workers and care teams can help families find words that feel respectful and culturally appropriate.

Tip: Offer short, simple phrases that families can repeat if they feel overwhelmed.

Questions	Answers
Will this affect my child's future?	With care and support, children with cleft lip or cleft palate can go to school, make friends, and reach their goals. Many grow up to live healthy and full lives. Children with cleft lip or cleft palate have many strengths, just like other children. They enjoy playing, learning, and being part of their community. With love, encouragement, and the right support, children can build confidence and believe in themselves as they grow.

Tip: Emphasize hope and long-term well-being without making promises.

Note: These questions and responses were gathered from community members and developed with their voices and cultural insight. For more information or resources, visit MCD's Strengthening Patient Care webpage: mcd.org/technical-assistance-training/strengthening-patient-care