

responding to people in your community

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When your child is born, you might feel tempted to isolate yourself to shield yourself from questions from strangers. You cannot avoid the community, nor should you.

People who do not know you may have questions and comments about your child or they may even stare. Some people are honest and inquisitive, and others are rude. As a parent, you will need to decide how you will address the questions and stares. There will be days you might feel like explaining the diagnosis, while other days you do not feel like explaining anything. You can do both.

It is important to face your fears and the situation — and to take your time. Try different outings and events to find your comfort level around strangers.

Once you can work through each step of interacting with the community and make a choice as to how you are going to handle it, you are more in control. You are able to move in and out of situations with more comfort.

Understand your own emotions. As a parent, you can recognize, understand and take control of your feelings and responses. You may have a variety of feelings when someone comments in a negative way towards your child.

- You may feel angry, frustrated or sad.
- You may wonder: “Why is she saying this to my child?” “Why does he have to say this to me?” “Why are they treating my child like this?”
- You may act on your emotions and thoughts of anger.
- You may feel like withdrawing.

Your reaction, your way. When you begin to understand your typical reactions, you can choose the way you would like to respond. You want to react in a way that makes you feel more in control in the situation. When you have the feelings of anger or frustration, you can make a decision to calm yourself.

- Walk away, take deep breaths or visualize a calming thought.
- Think different thoughts: “They are ignorant.” “They will never know how amazing my child is.”
- Physically control yourself: Take slow, deep breaths. Take a 15-second timeout. Squeeze a fist. Stretch your neck.

What do I say? You can judge the comment or question. Listen to the question. If it is well intentioned, you can provide a variety of information that will help them get answers and educate them. Listen and then respond. They might have never seen a child with your child’s specific craniofacial condition and want to know more. Make sure you use a name for the craniofacial condition.

What to say to an adult. Try to have a response that is not emotional.

- *In a comfortable situation*, you may respond with a specific answer each time: “She was born with microtia. She did not have an outer ear. She is a healthy child. That is all I would like to say right now.”

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- You might want to protect your time with your child, yet want to respond: “I am happy to answer a few questions, but this is our play time.”

You can provide as much information as you are comfortable. Some days you might be in the mood to elaborate and others day you may not. You may want to ask them what their experience is with people with craniofacial differences.

End the conversation by saying “Thank you for asking, I hope my answers have helped. I am going to play with my daughter now. Have a nice day.”

- *In an uncomfortable situation:* Use a flat and even tone:
 - “Why are you asking that question?”
 - “I’d like not to respond”
 - “That is an inappropriate comment”
 - “I would prefer not to talk about it”
- If they continue to ask you the same question or not show respect, repeat yourself:

You: “I would prefer not to talk about it”
Them: But I just want to know why her ear looks like that.”
You: “I would prefer not to talk about it”
Them: “But...”
You: “I would prefer not to talk about it”

What to say to a child. Children are not subtle. They will stare. They will ask what is wrong. They will ask why a body part is different. This is your time to reassure the child inquiring as well as your child that everything is all right.

Make it clear, brief and simple. Then go about your business. “Mary was born this way. It is called_____. Thank you for asking.”

Pay attention to your body language. Hold your head up high. Use direct eye contact, good posture and relaxed arms. Portray confidence, even when you might not feel it.

They are gone. Now what should you do? The interaction is over, and you need to briefly reflect and assess how you are feeling. Are you able to go back to the activity? Do you need a moment to relax yourself physically and emotionally?

- Take deep breaths and shrug your shoulders.
- Be aware of how you feel. Mad? Sad? Calm?
- Choose what you will do to let it go and enjoy your day.

Model constructive responses for your child.

Your child hears your responses. You want them to know that you are proud of them. You are modeling behavior for them. You continually work on building your child’s self-esteem. The more open and proud of your child you are, the more it will translate to their personal view of self-esteem.

When your child is old enough to understand, ask them what they would like you to say to strangers or other parents from school when questions arise. Agree on an answer and use it when you are in the community with your child.

It is an ongoing process. You might feel proud about your responses in hindsight and other times wish you had said something differently. You will continue to work on your responses. Try to remain consistent in your reactions to be a model for your child, your other children and family members.

Always remember that your child is more than a medical condition. Your child is more than a physical body. You know their gifts—cherish and celebrate them. No stranger can take that feeling away.