

Letter to the Parent of a Child Born with Cleft

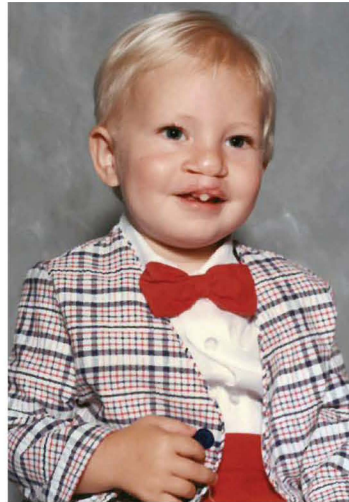
Dear Parent,

First, I would like to congratulate you on the birth of your child! A new addition to a family is something to celebrate. I hope that by sharing some of the feelings I experienced when my child was born with a cleft, I can help you know that you are not alone.

It can be upsetting to learn the news that a child has a cleft, either at birth or at a prenatal ultrasound. Like many parents, I had a picture in my mind of the "perfect baby." When that image was challenged, I felt sadness and loss. At the time I was thinking, "Why my baby?" It was important for me to take time to grieve that loss for "what was not," in order to move forward and focus on caring for myself and for my child. It's so important not to blame yourself, your spouse, or anyone for causing your child's cleft. A cleft is something that cannot be prevented.

The delivery room staff was supportive and reassured me that this was a condition that could be treated with very good results. But as a parent, there was fear of the unknown. I wondered, Was the cleft painful? How would I feed my newborn? What types of surgery would be necessary? How would other people react?

Very soon after giving birth, the local cleft team contacted me to set up a clinic visit. It was good to get factual information quickly, and to know that there were resources available if I had questions or concerns, or needed support. It is really important to find sources that give correct information. With the internet, a search for "cleft" cannot always offer that.



Going home from the hospital was scary. I was anxious about feeding my baby, and concerned about breathing, spitting up, and just the routine baby stuff. I was overwhelmed at times, as I learned how to feed and care for my child. I soon came to realize that most parents of "non-cleft" children experience anxiety about their child's basic needs too, and that my baby was not truly much different from most other newborns.

It was hard to know what to say to people when they had questions about my child's clefts. Sometimes, I would feel angry or upset by some of the stories or comments from strangers. I came to realize that most of the time these responses came from normal curiosity. People didn't always know what to say. So, I tried to use those opportunities to educate people, and not hide my child from them. I know that I didn't always have the best responses, but it made me think about how I would want my child to respond in social situations later on. I wanted my child to be able to talk to others with confidence.

Preparing for a baby's surgery can be both scary and life-changing. I was very excited to have my child's cleft repaired, but I also missed that lovely "wide" smile that I was so used to seeing, and loved. I am so grateful to all the doctors and other medical professionals for the skills and care they provided for my precious child. They also provided education, answers to my many questions, and reassurance. Over the years, your child may have many healthcare providers. It's important to know that just the way no two children are exactly alike, each child with a cleft is different and may have slightly different surgeries and timelines for care.

I would tell parents to take pictures, and to document all of the changes. It's easy to forget some of those moments. Also, your child will have questions about what he or she looked like, and will wonder about the surgeries and changes that happened during the early years.





I tried not to treat either of my children differently than I would treat any other child. I didn't want the clefts to define the people that they would become. At the same time, I knew that clefts would always be a part of their experiences. I wanted them to see that while each of us is unique, all people share many of the same qualities. As parents, we want

to protect our children from anything that can harm them. I came to realize that I would be the strongest advocate for my children, until they were old enough to take over that role. It's good to be brave, strong, and supportive, but we are only human, and it's not good to keep your feelings bottled up. I think it is important to deal with those emotions in a way that is beneficial to you and your child. Ask for help for your child or yourself if you need it. You can't take all the pain, fear, or sadness away. You can give them tools to adapt and develop their own strategies for coping.

My amazing children are so much more than "just a cleft." They have taught me so much and have given me such joy and love. I would never change the wonderful people that they have become. My hope is that you and your child realize that you are not alone, and that you are able to get the help and support you need for a bright future.

-Debbie

Debbie is the proud mother of two children, Aaron, born with bilateral cleft lip and palate, and Audrey, born with a right unilateral cleft lip and palate. She has served as the Nurse Coordinator for the University of Iowa Cleft and Craniofacial Team since 1999. She truly enjoys the opportunity to educate and support families through their cleft journey.



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