

Letter to the Parent of a Child with a Cleft

Like you, I am the parent of a child with a cleft. I would like to share some of the feelings I experienced when our child was born in the hopes that you will feel less alone in what you are going through.

Spending nearly a year planning for the birth of a child was a very exciting experience for me and my husband. However, facing the reality of a child with a cleft whose future was our responsibility was not enjoyable to say the least. A year later, however, I found it difficult to understand just why I was so upset when our baby was born. It seems now that many of the fears I had at the time were ill-founded. Although I recognize that today, I also realize that they were important simply because they were important to me.

By the time I left the hospital I had already received many encouraging messages from friends and family. The predominant themes were “don’t worry, surgery today can work miracles, it might have been worse.” Although I appreciated their sympathy, how could I be expected to stop worrying without understanding what the condition is all about?

I felt that no one understood; most people seemed curious, and a few even malicious. Some people made light of my problems and were impatient and bored with my constant concerns. I feared that they might look upon my baby with repulsion, that they might discriminate in favor of more typical-looking children. It took a while for me to realize that their reactions were their own business and that all I could do was be prepared with straightforward answers to their questions. I had to learn that the only attitude I could control was my own.

Like me, you may sometimes feel frustrated with medical professionals. Differing opinions are given, and no one offers a definite answer. We parents

soon realize that the decisions that will determine our baby’s future are ours; we may feel incompetent and insecure with the weight of that responsibility. You will find that with the assistance of doctors who specialize in cleft and craniofacial care, as well as the knowledge you gain from your own reading, you can find answers. It is certainly heartening to learn that there are men and women who have devoted their lives to helping our children. Of course, keep in mind that each cleft is different, just as each child is different. Your doctors may recommend a course of treatment for your child that is different from what other parents have been told.

Maybe you have found yourself inventing reasons why others should not come to see you and your baby—I certainly did. It’s a tough thing to accept from the beginning, but we must acknowledge that we cannot hide the truth! A cleft is nothing to be ashamed about. You couldn’t have prevented it; doctors cannot even tell us the cause of the cleft in many cases. Try not to blame anyone—yourself, your family, or your spouse. Most importantly, remember that your attitude toward your baby is going to be more important to his or her total adjustment than any surgeon will be. Our concerns are temporary if we deal with them instead of just pretending that the differences don’t exist.

I am convinced that the single most important factor in determining our child’s future is simply a commitment to focus our attention on their well-being. Granted, we want nothing more than to improve our children’s condition. However, all too frequently our egos are vitally involved. We may worry more about how we can explain the condition to other people, and what they may be thinking, than we do about how we can help our children thrive.

You must realize that your baby is normal in most ways. If you remind yourself that you have a baby

first a cleft condition second, your behavior is likely to be better for your child than if you were to focus entirely on the cleft. Certainly there are many complications created by a cleft, but they are only important as they relate to the baby as a person. Although specialized care is required for your child, as a rule of thumb your attitude toward him or her must be the same as toward a child with no cleft. Your own anxieties regarding medical and dental care are assumed by your child more readily than you can imagine. After all, children respond to emotions long before they can comprehend language. Your sensitivity to his or her appearance is likewise acquired in short order. If you pity your child, your child will pity him/herself. If you attempt to overlook your child's difference, your child will not be prepared to face it.

Just remember that you are not alone, that you are not the first or the last to face this challenge. Many other parents are dealing with the same situation this very day, and there are people and resources available to help you. Finally, don't ignore your own needs during this time. Recognize when you need help and be prepared to ask for it.

*Sincerely,
Joanne Subtelny*

About the Author
By J. Daniel Subtelny, DDS, MS

This letter was written by my wife Joanne in the early 1950s, a few years after our son was born with cleft lip and palate. Joanne died in August of 1991, and this letter was recently found among her papers in our filing cabinets. As her husband, I am sure she wanted to share it with other parents of children with clefts.

Joanne was a woman of great compassion who was dearly loved by many people. She became a speech pathologist of renown and devoted much of her research time to cleft lip/palate treatment. In later years, she added communication problems of the hearing impaired to her sphere of interests and research pursuits. Joanne is greatly missed by all who knew her.

A Note from the Author's Son

My name is Greg Subtelny, and I was born in 1949 with a complete unilateral cleft lip and palate. I had corrective surgery as an infant, then again at ages two, nine, and fifteen. I feel that I was very fortunate to be born to parents who were knowledgeable about my condition. I am writing to reassure any parent of a child with a cleft that the cleft need not be a real impediment, either physically or psychologically.

I had a successful academic career and am now a dentist in private practice. In high school I played saxophone as part of my treatment. I was active in sports, and I captained teams in both high school and college. I have ongoing friendships reaching as far back as first grade, as well as from college and dental school. I have also made new friendships through parenting my two sons.

Having a cleft was not, to the best of my memory, ever an issue with my friends. Even I was generally unaware of it except during the times preceding my two later surgeries. I do remember feeling awkward when I first started dating, though, and I know that some of that was related to my cleft. Otherwise, my **biggest "problems" were my inability** to blow up balloons or blow bubble gum bubbles and having milk come through my right nostril when eating cold cereal. These air and fluid leakage problems were corrected at my last surgery.

I was never aware that a cleft could be considered a **"disability"** until my last year of dental school, when I was involved in the treatment of a patient with a cleft palate. I learned that a cleft could definitely be a disability if left untreated! With tremendous advances in modern surgical and allied treatment techniques, however, the problems of a cleft can be greatly minimized.

I cannot say that I have been totally untouched by having been born with a cleft. However, I am sure **that my parents' attitude toward my condition,** along with the care I received, contributed greatly to my life being full and productive.

Sincerely,
Greg Subtelny