

## ***Reconstructive Surgery for Children: Big Changes Inside & Out***

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At the NYU Institute of Reconstructive Plastic Surgery (IRPS), reconstructive surgery is the primary means used to improve the quality of life of children with craniofacial conditions. Parents and children while they are expectedly anxious, also *anticipate* surgery because of the perceived benefits that an improved appearance will bring to the child's life experiences.

Even with good surgical results, there are unanticipated emotional stressors attendant to reconstructive plastic surgery that surprises the patient and his or her family. The scenarios presented here are hypothetical, based on the many families that we have come to know.

### **The Eye of the Parent**

*Mary Todd's daughter, Cassandra, had surgery to repair her cleft lip right on schedule, at the age of 3 months. Mrs. Todd was relieved to have the surgery behind them, and was looking forward to resuming a normal life with her family. Inexplicably, however, she became very troubled. Instead of feeling the satisfaction that she had anticipated upon looking at her daughter's new face, she found herself overcome with melancholy, and often on the brink of tears. At first she could not explain her sadness, even to herself, but ultimately she realized what was happening. "As much as I looked forward to the surgery that would make Cassandra look normal, it never occurred to me that I would miss the way she looked before. The truth is that I loved her exactly the way she was, and she looks so different now! I know the surgery was necessary, and was totally the right thing to do. But right now I find myself looking into Cassie's face and wondering what happened to the little baby I knew and loved. I guess this will take some getting used to."*

Parents look forward to their child's surgery with great anticipation as well as great anxiety. They hope that improving their child's appearance will normalize life and eliminate the stigma of disfigurement and difference. Surgery produces such a drastic change in a child's physical appearance that parents are often startled to see a brand new face looking back at them. For some parents, this experience is a profound loss. Indeed, virtually every parent needs time to adjust to the marked change in their child's appearance.

The weeks following a child's surgery can be a confusing time for parents as they make the emotional adjustment necessary to accept their child's changed face. It may be reassuring to know that this is a common reaction and one that stabilizes with time. Aside from letting these emotions run their natural course, parents might be well served to speak with other parents who have experienced this "transformation withdrawal". Forward Face can assist in networking you to other parents who have had these experiences.

### **Adolescence and Identity**

*17-year-old Jonathan felt like he had been waiting impatiently, his entire life, for his final surgery. Jonathan has Crouzon syndrome, and his self-consciousness about his appearance has made him reluctant to participate in extracurricular activities, social and other public events. Once his surgery was completed, Jonathan told his doctors and family that he was pleased with his new appearance. Still, for some reason, Jonathan became moody and irritable. He was unable to explain his feelings, while his parents were concerned and wanted to help.*

Having often endured years of ridicule and isolation because of how they look, teenagers hold fervent expectations that their lives will improve dramatically after surgery. It is only natural for teens to anticipate a sudden and complete life change for the better after surgery. However, the disappointment is profound if there is no immediate, drastic change in their lives.

Even when a teenager's life is markedly improved following surgery, the sudden life change can be overwhelming and disorienting. Generally, it takes time for patients to integrate into their new "selves." Teens are suddenly confronted with drastic changes in appearance, in their perceptions of themselves, and in their overall identity. It is common -- and important -- for patients to ask themselves questions like, "In what ways am I the same person, and how am I now different?"

This is especially true for teens, who typically struggle with questions about their identity - a natural part of adolescence. Parents and professionals can help teens come to grips with these issues by acknowledging the adolescent's concerns as real, and not simply another phase of growing up. Teenagers can also help

by being reassured that questioning these things after surgery is natural and important to the recovery process.

In addition, some adolescents may need guidance on how to embark on a life that will begin to include developing friendships and interests. It is important to remind teens that friends and new abilities will not appear by magic. Developing friendships takes hard work and mastering new interests takes a lot of perseverance.

### **Feeling Special**

*Abigail developed a hemangioma -- a strawberry-like birthmark -- soon after she was born. Her parents took her to specialists, who after several years decided the time had come to remove the birthmark using laser surgery. Abigail's parents were relieved that their 4-year-old daughter was finally free of her disfiguring birthmark. They were astonished, however, to find that Abigail was furious. "Why did you take away my birthmark!" she demanded. "It was MINE!" Abigail's parents soon came to realize that Abigail considered her birthmark to be something that made her special, made her stand out and be remembered. To young Abigail, her birthmark was not a disfigurement, but an asset.*

Physical appearance plays a major role in a child's developing sense of identity. Therefore, a sudden change in the way they look can be disturbing to children. A child may feel that he or she is no longer the same person because their appearance has changed. Parents can help calm these concerns by reassuring their son or daughter that the child is the same as before in every other way. Abigail's parents reminded her that there is no one else just like her and that she will always be special to them.

*Timothy was 11 when he began a series of surgeries to correct his hypertelorism (eyes spaced widely apart). He was very excited that soon he would look more like his friends and classmates, and no longer feel so different. At the same time, he became worried. He confided to the team psychologist: "If I look like everyone else, will my teacher and friends still think I am special? What if they don't want to give me extra help anymore, even when I need it, because they think I'm just like everybody?"*

Some children perceive their craniofacial condition as something special, something that makes them unique. Often extra help and attention come their way because of how they look. This becomes a focused benefit of looking different. As a child's appearance

becomes more “normalized”, parents need to remind their son or daughter to take a look at what *still* makes them unique: their personality, abilities, skills and interests.

Experiences like these are common. Most of these issues can be resolved with love and understanding by parents, and with the attention of the surgical team. Often short-term professional guidance can alleviate persistent problems before they become embedded in a child’s self-perception. Ask your surgeon or pediatrician for a referral to a mental health professional, or contact Forward Face for suggestions about how to find an appropriate referral.