

## Living (and Thriving) With Cleft Lip and Palate - ParentMap

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## Living (and Thriving) With Cleft Lip and Palate

Treatments for children with cleft lip and palate are evolving. Here's what to expect.

By Gemma Alexander



When we first considered special-needs adoption, I had to research cleft lip and palate to find out what it was. Now I see the telltale lip scar all the time. One in every 1,000 babies is born with some degree of cleft — a gap where parts were supposed to fuse together when the baby was forming in the womb.

A cleft can occur in the lip, the palate or both, and it can be on one or both sides of the face. Nobody really understands why cleft happens. Genetics and vitamin deficiencies are possible contributors, but not causes.

Cleft is usually diagnosed during a prenatal ultrasound. "It was horrible and scary, because I'd never seen it before," says Burién, Wash., mom Nolby Manzanares of how she felt when her daughter, Genesis, was diagnosed with cleft lip and palate. "They sent us to [Seattle] Children's Hospital, and they answered all my questions and made me feel a little bit better."

Feeding is the first practical issue parents must face. "Because babies with cleft palate cannot generate suction, most will not be able to sufficiently breastfeed and will need to use special cleft palate bottles. For mothers who were planning to breastfeed, this is very disheartening," says Carolyn Rogers-Vizena, M.D., a craniofacial surgeon at Boston Children's Hospital.

"Other than a learning curve on the feeding issue, life was normal," says Ashley Harris of Peoria, Ariz., whose son was born with cleft lip and palate. "I had been in contact with this before through friends." Rogers-Vizena recommends connecting with other parents for support right away. "The best advice a parent can get doesn't come from doctors or nurses, but from other parents who have gone through similar experiences."

### Going under the knife

In the past, children with cleft lip and palate suffered through dozens of surgeries. Today, better techniques, approaches and protocols have reduced the number of procedures.

"We have started to recognize the importance of caring for children in centers where there is a concentration of expertise," says Raymond Tse, M.D., a pediatric plastic surgeon at Seattle Children's. "We have placed an emphasis on team-based care, where the communication and continuity of care really make a difference."

When we adopted my daughter, who was born with cleft lip and palate, there were 10 members on our support team. For biological families facing a new diagnosis, the social worker is a critical team member who offers coaching and encouragement as parents learn to advocate for their child in the health care system, share the news with friends and family and cope with strangers' responses. (Most adoptive parents are guided through these concerns earlier as part of the adoption process.)

Manzanares wanted to stay at the hospital after Genesis was born — she worried that her new baby's appearance would frighten her two older children. "I didn't want to go out. I was afraid people would say something to hurt my feelings," she says. Eventually she overcame her fears, although she says that younger kids often ask about how her daughter looks.

She still struggles for an answer.

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— Manzanares, mother of a child with a cleft palate

Cleft palate can be hard to explain to children, but adults understand that it is a physical anomaly. Other medical concerns, such as developmental delays or eye problems, are extremely rare. The most common related medical issue is frequent ear infections.

Treatment for most children with cleft palate will include orthodontics and speech therapy, because the palate muscles cannot form certain sounds.

"Speech differences are very socially stigmatizing, and other children or adults may incorrectly make assumptions about the intelligence or ability of a child based on their speech," Rogers-Vizena says.

But surgeries are still the biggest part of treatment. Genesis had surgery to repair her lip at 6 months old and an initial palate surgery at around 1 year. She can expect more surgeries as she grows. "She's a really strong little girl," says Manzanares. Harris' son Andrew, now 12, has undergone five surgeries.

### Everyday adjustments

As children get older, Tse says, involving them in decision making becomes important. Child life specialists are available at many hospitals to help parents give kids age-appropriate explanations. When my daughter was 4, the hospital gave her an anesthesia mask and a rag doll before her surgery. She played "surgery" on that doll for months.

She understood that her mouth needed surgery, but she did not become self-conscious about her appearance until grade school. Rogers-Vizena says, "Awareness of difference typically begins around 3 years of age. At that time, awareness is not perceived as a bad thing. Peer teasing often begins around school age." Knowledge and preparation can help kids respond. "For example, if someone says, 'Your nose looks funny,' a child can say, 'It's because of my cleft' or 'This is how I was born.'"

"He had someone call him a name once or twice in grade school. That's it. He has such good self-esteem that it didn't bother him much. He has great friends that never judged him," Harris says of Andrew. "This is fixable and will not affect their ability to learn, grow, have friends and have an amazingly normal life."

Tse agrees. "Kids with cleft are like any other kid. They have had to deal with speech difficulties and to psychologically adapt to their facial difference. I often see cleft kids who have a better sense of self. Cleft is not going to hold them back."

### Family resources

[Children's Craniofacial Association](#) works to improve quality of life for people with facial differences and their families.

[Faces: The National Craniofacial Association](#) offers information, including about financial assistance, for families affected by craniofacial conditions.

[Foundation for Faces of Children](#) helps patients and families learn about facial differences and advocate for children with facial differences.

[Operation Smile](#) provides free surgeries for children around the globe.

[Smile Train](#) performs free cleft surgery in developing countries.

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