



Cleft Lip and Palate:

Your Child's Care Journey
from Infancy through Adulthood



**NATIONWIDE
CHILDREN'S®**

When your child needs a hospital, everything matters.

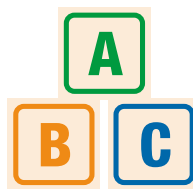
Treatment of cleft lip and palate begins at birth and continues into early adulthood. Clefts affect more than just facial appearance — they may also have profound effects on a child’s feeding, speech, hearing, dental development, facial growth, and psychosocial well-being. Because of this, children with cleft lip and cleft palate are best cared for throughout their development by an experienced team of specialists.

This guide will highlight important milestones along your child’s care journey. Once you know what to expect, you can be an informed and proactive participant in your child’s care. Although each milestone and care point can be managed individually, having the support of a comprehensive and coordinated cleft lip and palate team can benefit your child from infancy through young adulthood.

Please note: While this guide will give you a good overview of what to expect, care needs and timelines are sometimes adapted or modified based on each child’s individualized health or developmental needs.



INFANCY



**TODDLER THROUGH
KINDERGARTEN**



**ELEMENTARY THROUGH
MIDDLE SCHOOL**



**TEENAGE THROUGH
YOUNG ADULT**



INFANCY

Feeding

Establishing an effective feeding plan is essential for the growth and development of infants with cleft lip and/or palate. Infants with an unrepaired cleft palate have difficulty creating suction, so they are usually unable to sufficiently breastfeed. Your child must therefore use a special bottle system and specific sippy cups that don't require suction. Your cleft team and your child's pediatrician will follow your child closely to assist feeding after birth and later with transitioning to solids.

Genetic Testing

An evaluation by a geneticist is recommended for routine genetic screening and to evaluate for the presence of an underlying syndrome or other genetic disorder.

Hearing Checks

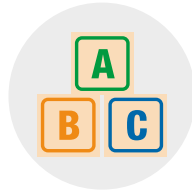
Infants with cleft palate may present with fluid in the middle ear and are therefore at risk for ear infections and hearing loss. Many require ear tube placement to help clear the fluid, improve hearing, and promote normal speech-language development. The ENT surgeon and audiologist will work together to create a plan for the management of your child's ears/hearing.

Surgery

Surgery for cleft lip may be performed in 1 or 2 stages, depending on the type and severity of clefting. Surgery for cleft palate is typically completed in one surgery around one year of age. Surgery should be performed by a surgeon with experience and expertise in cleft lip and palate procedures. In some cases, pre-surgical lip taping or nasoalveolar molding (NAM) will be performed. The cleft surgeon will work closely with the other members of the cleft team to coordinate cleft lip and palate repairs with other procedures, if needed.

Speech-Language Development

Children with cleft lip and/or palate are at risk for speech-language difficulties. A speech-language evaluation should be performed at 8-10 months of age, before cleft palate repair. At that time, you will be given suggestions for working with your child to support speech-language development and be connected with local early intervention services.



TODDLER THROUGH KINDERGARTEN

Feeding

Shortly after palate repair, most children are able to drink from a regular sippy cup without difficulty and to progress with table foods. A feeding therapist can help if your child is unable to eat regular table foods or if your child has other difficulties when eating or drinking. A dietitian, pediatrician or nurse practitioner can help if your child is not gaining weight well or not eating a balanced diet.

Dental Care

An evaluation by a pediatric dentist should be done by 12 months of age. Brush your child's teeth twice daily with toothpaste. Ask the dentist on your cleft team about tips on how to brush teeth around the cleft area and other hard to reach places. A dental cleft specialist should help guide decisions about preserving or removing decayed teeth.

Hearing Checks

Good hearing is essential for normal speech and language development. Your child should have his/her hearing tested every year until he/she is at least 6 years old. If your child has a history of ear infections, he/she may need to be tested more frequently and have regular hearing tests beyond 6 years of age.

Speech-Language Development

Children with cleft lip and/or palate are at risk for speech-language difficulties. A speech-language pathologist (SLP) should assess your child's need for speech-language therapy services every 6-12 months. If you are traveling long distances to reach your cleft team, the cleft team SLP can also work with local speech therapy providers to coordinate an individualized treatment plan.

Surgery

A cleft surgeon can collaborate with SLPs to monitor for symptoms of velopharyngeal dysfunction (VPD, or hypernasal speech), which is typically addressed before your child enters first grade. Cleft surgeons can also assess lip and nasal tip shape and scarring and discuss revision surgery, if needed and desired.

Psychosocial Support

If learning or attention problems arise, psychologists can evaluate these concerns and help you advocate for appropriate interventions, including learning support services at school. Self-confidence or other psychosocial issues may arise, particularly if your child feels self-conscious about differences in her/his speech or facial appearance. Psychologists specializing in cleft care can provide your child with short answers to questions from peers to help build confidence and reduce teasing.



ELEMENTARY THROUGH MIDDLE SCHOOL

Annual Well Visits

Your cleft care provider should collaborate with your pediatrician to ensure yearly screenings are performed, develop an individualized plan of care and assist with any referrals needed.

Dental Care

When permanent teeth come in, take excellent care of them. Visit the dentist every six months for cleanings to minimize dental problems. If your child has cleft alveolus (gumline), a specialty screening to plan for bone grafting should begin around 6 years of age.

Hearing Checks

If your child has middle ear problems or hearing loss, he/she should get a hearing test annually and medical management as needed.

Speech-Language Development

Cleft team speech-language pathologists should continue to evaluate your child's speech annually to determine needs for speech therapy or additional surgery. The impact of teeth and orthodontic treatments on speech is also typically considered during this period.

Surgery

The cleft surgeon and orthodontist should prepare for and perform alveolar bone grafting, if needed. The cleft surgeon and speech-language pathologist will continue to monitor your child for signs of VPD and may recommend surgical management if indicated. Revision surgery for the lip and nose can be performed if needed and desired.

Psychosocial Support

Psychologists and social workers can provide support and offer strategies to build self-confidence, social skills, and to help you and your child prepare for and cope with surgical procedures and other treatments.



TEENAGE THROUGH YOUNG ADULT

Genetic Testing

Due to changes in research and technology, it may be beneficial to meet with a geneticist/genetic counselor again. The geneticist can provide helpful information regarding family planning.

Dental Care

Your cleft dental specialist and surgeon should evaluate and help guide care for orthodontics, dental implants and jaw surgery, if needed.

Speech-Language Needs

While most children achieve normal speech in the school-age years, some teens may continue to require speech-language therapy services or additional surgery to improve speech. In these cases, cleft team SLPs should perform regular evaluations to monitor speech until growth and development are complete.

Surgery

Additional surgical procedures to improve the appearance of the lip and nose may be performed at this time. For those with restricted growth of the upper jaw, surgery to move the jaw forward may be recommended once growth is complete.

Psychosocial Support

Transitions in life and education can be challenging. Social workers and psychologists can help connect your child with local resources for a smooth transition. They can discuss treatment-related decisions, provide resources and referrals, and offer support for issues such as guardianship and transitioning to college or work.

Your child deserves specialized care.

We believe that best outcomes are achieved by a team that works together to take care of your child as a whole person. The Cleft Lip and Palate Center at Nationwide Children's Hospital is composed of experts in cleft lip and palate and related syndromes. Specialists in plastic surgery, psychology, social work, audiology, speech-language pathology, nursing, nutrition, genetics, dentistry, oral surgery, orthodontics and the otolaryngology (ENT) work together to maximize your child's health and wellbeing — from birth to adulthood. Our Cleft Lip and Palate Center is recognized as an approved team of the American Cleft Palate - Craniofacial Association (ACPA).

Come see what a difference it can make in your child's care to have the compassionate support of a specialized and coordinated team.

Contact Us

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