



ACPA

American Cleft Palate
Craniofacial Association

[ACPACares.org](https://www.acpacares.org)



Your Baby's First Year

2021 Edition

Table of Contents

Introduction.....2
Welcome.....2

Overview of Cleft Lip and Palate3
What is Cleft Lip and/or Palate?3
Types of Clefts3
Causes of Clefts4

Caring for a Baby with a Cleft 4
Feeding.....4
Physical and Emotional Health.....5
Drinking from a Cup.....5
Sharing the News with Family and Friends5

Cleft Treatment5
Individualized Care5
Selecting a Team5
Surgical Repairs6
Lip Repair6
Palate Repair.....6
Preparing for Surgery7

The Ears, Speech/Language, and Teeth.....7
Caring for the Ears and Hearing.....7
Tests for Hearing.....7
Dental Care8
Sharing the News with Family and Friends9

Support for Parents.....9
Paying for Treatment9
Using the Internet.....9
Support Groups.....9
Mental Health9

Closing Words9
Reflections from a Parent9

Appendix A 10
Glossary.....10

Appendix B 11
Recommended Questions for the Team.....11

2021 Edition

Copyright 2021 by American Cleft Palate Craniofacial Association. All rights reserved.

This publication is protected by copyright. Permission should be obtained from the ACPA prior to any reproduction.

Special thanks to:
Subject Matter Experts: Patricia L. Bender, DNP, APRN-CNS, Rachel M. Hogan, MA, and Travis T. Tollefson, MD, MPH, FACS
Editors in Chief: Angela J. Dixon, MA, Lynn Fox, MA, MEd, CCC-SLP and Ron Aronovich, DMD
Managing Editor: Oluwaseun A. Adetayo, MD, FAAP, FACS
Associate Editors: Michael S. Jaskolka, DDS, MD, FACS, Leanne Magee, PhD, and Albert K. Oh, MD
Medical Illustrator: Marie Rossettie, CMI
Writing Consultant: Amy Mendillo, MM, MPP
Special thanks to all those who have contributed to previous editions

Introduction

Welcome

Waiting for the birth of a child is an exciting time. Most expectant parents feel nervous, happy, and worried about the arrival of their baby. It can be surprising to find out that your baby has a cleft lip and/or palate. You may not know anyone born with a facial cleft. It is normal to experience a range of feelings and have questions about clefts.

This booklet provides information about caring for a baby born with cleft lip and/or palate and answers common questions. It was written by members of the American Cleft Palate Craniofacial Association (ACPA) along with parents and individuals who were born with cleft lip and/or palate.

Each child born with cleft lip and/or palate follows a unique treatment path. This booklet gives information to parents, caregivers, and professionals on typical care and treatment. Not all of the information will apply to your child.

Your baby's cleft palate or craniofacial team (commonly referred to as a cleft team) may recommend a plan for treatment that is not included in this booklet. You should always discuss the details of your baby's care with your team.

The information in this booklet is for educational purposes and is not meant to replace health care or advice from your baby's team. This information may not apply to babies with additional health conditions.

Overview of Cleft Lip and Palate

What is Cleft Lip and/or Palate?

A cleft is a split or opening. A cleft occurs when parts of the skin, muscle, and bone of the mouth do not come together during weeks 5 to 12 of a pregnancy. A cleft lip is an opening in the lip, most commonly the upper lip. A cleft palate is an opening in the roof of the mouth. A baby can be born with a cleft lip, a cleft palate, or both.

When a person is born with a cleft palate, it may appear that the roof of the mouth is missing. In fact, the two sides of the palate didn't join together. When this happens, there is no pain or bleeding associated with the cleft palate.

The opening of a cleft lip varies in size from person to person. There may be a slight notch in the red portion of the lip (called the vermilion) or a complete separation of the lip that extends into the tip and side of the nose. A cleft lip can extend to the bones of the upper gum line (alveolar ridge) and the upper jaw (maxilla).

Types of Clefts

A cleft lip can occur on one or both sides of the lip. If it occurs on one side, it is called a unilateral cleft lip. If the cleft occurs on both sides of the lip, it is called a bilateral cleft lip.

The front part of the palate contains bone and is hard. This part is called the hard palate. The back part, called the soft palate, does not contain bone and is soft. The figure below shows a typical palate and its parts.

A cleft that occurs only in the palate (not the lip or the gum line) is sometimes referred to as isolated cleft palate or cleft palate only. Just like a cleft lip, an isolated cleft palate varies in size from person to person. At its smallest size, an isolated cleft palate may look like a notch or slit in the very back of the palate or it may extend somewhat into the soft palate. In more severe cases, the cleft may involve all of the soft palate and part of the back of the hard palate. A complete cleft palate extends all the way through soft and hard palates.

Because the lip and palate develop separately in utero, it is possible for a child to have a cleft lip only, a cleft palate only, or a cleft lip and cleft palate. When cleft lip and palate occur together they can involve one side (unilateral) or both sides (bilateral) of the lip, gum and/or palate. The first figure below shows the intraoral view (a view from inside the mouth) of a complete-unilateral cleft palate. The second figure shows a complete-bilateral cleft palate.



Figure 1: Typical Lip and Nose



Figure 2a: The Unilateral Cleft and Nose



Figure 2b: The Bilateral Cleft Lip and Nose



Figure 3: The Typical Palate



Figure 4a: The Unilateral Cleft and Nose



Figure 4b: The Bilateral Cleft Lip and Nose

Causes of Clefts

Clefts are one of the most common birth defects in the United States. Cleft lip and/or palate occur in about one out of every 700 births. Cleft lip (with or without cleft palate) is most common in individuals with Native American and Asian ancestry and is least common in those of African ancestry. Cleft palate without cleft lip occurs equally in all racial groups.

While researchers continue to study the causes of cleft lip and/or palate, they are not able to give answers on why or how every cleft occurs. They do know that clefts have multiple causes. Most cases of cleft lip are thought to be caused by a combination of inherited information (genes) interacting with specific and often unknown environmental factors. Clefts occur very early in pregnancy and are often out of the control of the pregnant mother.

Some parents want to learn more about the possibility of having another child with a cleft. Since each family is different, this question is best addressed by health care specialists who are trained in genetic counseling. These specialists may be physicians, genetic counselors, nurses, and researchers who concentrate on the study of genetics and birth defects (dysmorphology) and have earned advanced degrees (masters or doctoral) or certifications in genetics. The ACPA publishes a booklet on this topic entitled Genetics and You. ACPA Family Resources can also refer you to a cleft team that provides genetic counseling.

Caring for a Baby with a Cleft

Feeding

The American Academy of Pediatrics recommends that babies consume breast milk or formula as their sole liquids until their first birthday. Babies born with an isolated cleft lip (cleft lip only) may be able to breast feed and use regular baby bottles. Babies born with a cleft palate (with or without cleft lip) are in most cases not able to create enough suction to pull milk from the breast or from a regular baby bottle. These babies will likely need to use a special, modified bottle that delivers formula or pumped breast milk into the mouth without requiring suction. For information on bottle and breast-feeding, talk to your baby's healthcare provider and also see the ACPA booklet and video series, Feeding Your Baby.

Infants born with a cleft lip and/or palate are usually ready to eat solid foods at the same time as any other baby. Foods should be offered by spoon while the infant is in an upright position. Start with a thin mixture of cereal and formula/breast milk (or start with Stage One baby

food). As your baby gets used to the texture of the cereal, you can make the cereal thicker. Milk or food may come out of your baby's nose during feedings. This is normal for babies with a cleft palate and does not bother them. Cereal or baby food should not be added to a bottle.

Your treatment team will provide more specific questions as it pertains to your baby's particular situation for feeding, types of bottle to use, and other related topics. It is also important to build a good relationship with your baby's primary care provider (pediatrician). The primary care provider can answer questions or concerns about weight gain, formula intake, and transitions to solid foods. He or she can also help you understand the information you've heard from other specialists.

Physical and Emotional Health

Your biggest job as a new parent is to tend to the growth and health of your baby. A baby born with a cleft needs the same love, care, and attention as any other child. Your child's primary care provider and his or her cleft team will work with you to ensure your infant's good health and development. It is also important to spend time each day cuddling and playing with your baby. You can't spoil your new baby with too much love and attention.

While caring for an infant with a cleft is similar in many ways to caring for a baby without a cleft, your baby may require special treatment. A cleft lip and a cleft palate are typically closed during infancy through surgery. Although treatment plans vary based on a baby's needs, your child may need extra care and attention both before and after these procedures. Feeding, too, may be affected by clefts, as will hearing, speech, and dental care (all described below).

Drinking from a Cup

Some cleft surgeons do not recommend or allow a baby to return to a baby bottle following palate repair surgery (usually at around age 12 months, discussed below). Surgeons and team members usually advise parents of babies born with a cleft palate to teach their baby to drink from a cup in the weeks and months before the procedure. Talk to your surgeon about any specific protocols they would like you to observe as part of your baby's care.

Fortunately, most cleft-affected babies (lip and/or palate) are able to learn to use a cup at the same time as other infants. Many types are available. Some teams recommend open cups. Others suggest sippy cups that have been modified to eliminate the suction. Prior to choosing and starting a cup, we recommend you ask your team for advice on which one is best for your baby. You may need to experiment with several styles to suit your baby's needs

or preferences. All babies, regardless of cleft type, should be drinking exclusively from a cup (not a bottle) by 12 months of age.

Sharing the News with Family and Friends

Many parents struggle with sharing the news of their baby's clefts with family and friends. As you learn more about clefts and their treatment, you will have more information to share. The more your family and friends know about clefts, the easier it will be for them to see your baby as a healthy, typical child with a physical difference.

Your comfort with answering questions about clefts will set the tone for family, friends, and most importantly, your child. When children or adults ask questions, simple answers are best. For example, "He was born with a cleft, an opening in the roof of his mouth. The doctors will close it soon." Or, "She was born with a separation in her lip, but the doctors will close it in a few weeks." Children and even some adults often need reassurance that the cleft does not hurt the baby. Answering questions honestly and openly in front of your child builds his or her confidence. It also serves as a model for how your child may answer questions from friends, teachers and others throughout childhood and adolescence.

It is important to take and share pictures of your baby with family and friends. Just like brown eyes or chubby cheeks, a cleft is part of your baby's identity. Children love to look at their baby pictures and hear stories about their birth, their early family visits, their favorite babyhood toys, and other details. Pictures and stories let them know that they were special from the very first moment. Your child takes cues from you. An open and accepting approach to picture-taking and sharing will help foster your child's self-awareness and self-esteem. Photos also help you remember your child at every age, from infancy onward.

Cleft Treatment

Individualized Care

Cleft treatment usually starts early in a child's life in order to ensure his or her best possible health and development. Your child's care may include a variety of treatments such as dental care, speech therapy, and surgery. As mentioned previously in this booklet, it is important to talk with your child's team about an individualized treatment plan that best meets his or her needs.

Selecting a Team

One of the first and most important decisions you will make is the selection of the team of professionals who

will help you manage your child's cleft care. Most cleft palate teams and craniofacial teams (both commonly referred to as cleft teams) include professionals from the following fields:

Dentistry

Oral-maxillofacial surgery, orthodontics, pediatric dentistry, prosthodontics

Medicine

Genetics, nursing, otolaryngology (ENT-ear, nose and throat), pediatrics, plastic surgery, neurosurgery, pulmonology

Allied Health Care Professionals

Psychiatry, psychology, social work, nursing, audiology, speech-language pathology

You can find ACPA Approved Teams on the ACPA Family Resources website, ACPAcares.org, or by asking your local physician or other healthcare provider.

The best way to choose a team is to consider the experience of the team as a whole and the capabilities of the individual specialists on the team. Your first visit with the team will include a consultation and an examination of the child. Then, the team will organize a full treatment plan for the short- and long-term care of your child.

Caregivers are the most important members of the team. It is important to have open communication with the medical professionals on the team in order to explain your child's needs and share your concerns. Any treatment plan requires parental consent, including consent for a surgical procedure. Your input is vital for ensuring your child receives the best possible care. When you meet with the team, be prepared to ask questions and request additional information and resources. For sample questions to ask the team, see Recommended Questions for the Team at the end of this booklet.

Surgical Repairs

Most children born with cleft lip and/or cleft palate undergo surgery within the first year of life. The goals of lip repair surgery (described further in the section below) are to close a cleft lip with minimal scarring, to create a natural appearance, and to ensure typical growth of the face. The goal of palate repair surgery (also described below) is to close the cleft in the palate so that the palate will function normally during eating, drinking, and talking.

It is important that you feel comfortable with your baby's surgeon and confident in his or her skills, experience, education, and training. The timing and technique of

surgical repair can vary from one surgeon to another. Be sure to ask to ask lots of questions and expect clear answers.

Lip Repair

The timing of cleft lip repair surgery varies from one team to the next. Cleft teams in the United States usually recommend performing this procedure after a baby has gained a certain amount of weight, after he or she has been screened for other health problems, and at a time when he or she is healthy enough to undergo general anesthesia. The repair can be accomplished in one procedure, but is sometimes done in two stages. Lip surgery usually requires a hospital stay of one or two days, but in some cases, the operation is performed on an outpatient basis.

Your child's surgeon and/or nurse will give you instructions for caring for your baby postoperatively. After surgery, your team may recommend that your baby wear arm restraints made of stiff material. These restraints are comfortable for a baby. They are designed to keep his or her hands away from the surgical site so it can heal. Most teams recommend that a baby return to bottle- or breast-feeding after lip repair.

The scar on the lip may be red and stiff at first, but will begin to look less noticeable and become softer within several months. A scar takes over a full year to heal completely, and will always be present.

Palate Repair

In the United States, cleft surgeons usually close the palate between six and eighteen months of age, but a surgeon may recommend operating earlier or later in life depending on a variety of factors. Palate repair surgery may be performed in one or two stages, depending on a child's needs and the recommendations of the team. The operation usually involves a hospital stay of one to three days.

After palate surgery, you will need to follow special instructions for feeding your baby. The cleft team may require the baby to drink from a cup that will not harm the surgical site (as described above) and may recommend that all solid foods be pureed or liquefied. Be sure to talk with your team about these requirements before surgery. As described above, you can ease this transition by introducing cup feeding to the baby well before the operation.

As with lip repair, the team may recommend that a baby wear arm or elbow restraints following surgery. Always ask questions as they arise, and be sure you have a contact phone number for your child's team should you need support in the early post-operative days.

Preparing for Surgery

Before your baby is admitted to the hospital for surgery, you will need to take care of a number of details, like arranging for accommodations and meals, setting up care for your other children, and organizing your baby's care during the hospital stay and afterwards. Be sure to find out whether the hospital provides diapers, formula, bottles/cups, and other items so that you will know what to bring from home. Also, many babies feel comforted to have their security blanket or favorite soft toy. As mentioned above, your team will instruct you on any special feeding techniques and dietary restrictions required after surgery. Be sure to ask for information about your baby's surgery a few weeks to months prior to the procedure so you will have time to prepare.

As your child grows and matures, he or she may need additional surgery on the lip, nose, gums, and/or palate. For more information on these procedures, look at ACPA publications on the toddler, school-aged child and teenager.

The Ears, Speech/Language, and Teeth

Caring for the Ears and Hearing

Children born with a cleft palate are more likely to have ear infections than those not born with cleft palate. These problems occur because the muscles of the palate may not work the way they are supposed to. Under normal circumstances, the palatal muscles open the Eustachian tubes, the small tubes connecting the throat to the middle ear. When the Eustachian tubes do not open properly, air cannot enter the middle ear and fluid may build up, sometimes causing infections. This condition is called otitis media. Because this problem occurs often for children born with a cleft palate, the ACPA recommends that these children see their primary care doctor or the otolaryngologist (ENT) on the team for an ear exam within the first few weeks of life.

If a child has fluid in the middle ear, a doctor's first step is usually to prescribe medication. If the fluid persists or if the infant has repeated ear infections requiring antibiotics, the child's doctor may recommend a minor surgical procedure called a myringotomy. For this procedure, a surgeon makes a small slit in the eardrum to drain the fluid, then inserts tiny, plastic or metal tubes called pressure equalization tubes (also called PE tubes). PE tubes allow air to enter the middle ear and prevent fluid from building up. As a child grows, PE tubes fall out on their own, usually after several months. Once the tubes fall out, the small slits heal well and

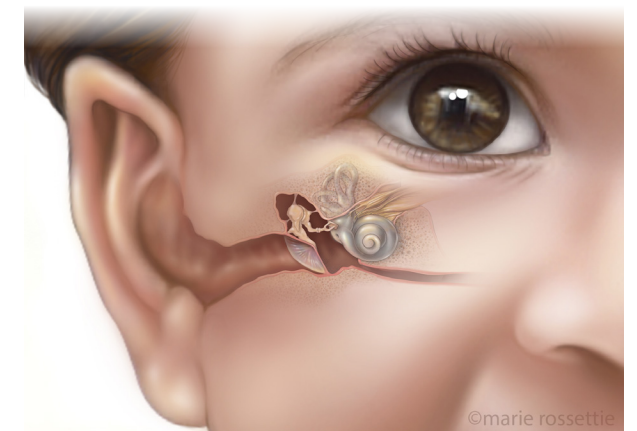


Figure 5: The Ear Canal

usually do not damage the eardrum. This operation is often performed when a child is under anesthesia for lip and/or palate surgery.

PE tubes allow air to enter the middle ear and prevent fluid from building up. As a child grows, PE tubes fall out on their own, usually after several months. Once the tubes fall out, the small slits heal well and usually do not damage the eardrum. This operation is often performed when a child is under anesthesia for lip and/or palate surgery.

It is important for a child born with a cleft palate to have frequent ear exams with a primary care doctor or ENT. Fluid in the middle ear can be hard to detect at home because it does not always result in clear symptoms like earaches or fevers. Fluid in the middle ear can cause hearing loss. Unfortunately, even mild hearing loss can affect a child's speech and language. Constant fluid can permanently damage the eardrum. Your child's team will usually monitor for hearing loss and ear disease. In most cases, frequent check-ups and timely treatment (like the PE tubes described above) can readily solve problems with the ears and with hearing.

Tests for Hearing

In addition to having frequent check-ups with a primary care provider (pediatrician) or ENT for fluid in the ears, a child should have regular hearing tests. As described in the section above, the build-up of fluid in the middle ear can cause hearing loss. Hearing tests are an important part of treatment during the early years.

There are several ways to evaluate a child's hearing. Certain hearing tests can be performed on babies as young as one-day old. These tests should be done by an audiologist who has the specialized training and equipment to test very young children.

Screenings are types of early, broad testing performed by nurses, speech-language pathologists, or other professionals. One type of screening, called acoustic immittance testing or tympanometry, measures the response to sound in the middle ear cavity. Otoacoustic emissions testing (OAE) is another type of screen that measures the response of the cochlea, the hearing nerve in the innermost part of the ear. Depending on the results of these early screens, a professional may recommend that a child have further tests. An Auditory Brainstem Response test, for example, shows how a baby’s brain reacts to sound. For more information on tests for hearing, talk to your baby’s healthcare provider and also see the ACPA booklet *Help With Hearing*.

Speech and language skills begin to develop even before a baby uses real words. Months before babies say their first words, they make cooing and babbling sounds. Babbling usually starts at around age six to eight-months of age. Children with a cleft palate may develop babbling sounds differently than other children. They typically produce nasal sounds (M and N sounds, like mama and nana) and vowels (in combinations such as yaya, nana, nini, and mama), but may not babble with other sounds (B, P, D, T, G, K) until after palate surgery.

Sometimes, children with a cleft palate produce sounds in their throat (they may grunt or growl the “uh” sound in “uh-oh”) or seem like they are leaving sounds off words. If these errors are present or if your child is not producing a variety of sounds several months after palate surgery, speech therapy may be needed.

A child with an isolated cleft lip should develop normal speech as long as he or she does not have hearing loss or other problems. Approximately 80% of children born with a cleft palate develop speech normally once the palate is repaired. As members of the team plan for your child’s palate surgery, the speech-language pathologist on the team will consult with the surgeon and other specialists on the type of repair and its timing.

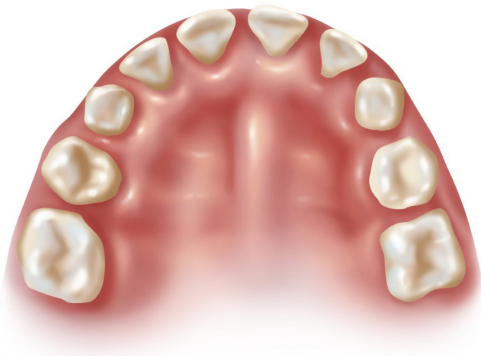
A child with a cleft palate should have frequent speech evaluations during the first year of life and throughout childhood. Children with a cleft palate may produce fewer words or use shorter phrases or sentences than their peers. They may also have difficulty following instructions or longer phrases and sentences. If your child has shortcomings with speech, you should discuss them with the speech-language pathologist and other members of the treatment team.

Dental Care

A baby born with cleft lip and/or palate needs routine dental care throughout life, just like any baby. Dental care begins when the first teeth erupt. The first teeth to appear in the mouth are usually the two lower central incisors (the two front teeth in the center of the lower jaw). These teeth typically come in around six to nine months of age.

A baby born with cleft lip and/or palate needs routine dental care throughout life, just like any baby. Dental care begins when the first teeth erupt. The first teeth to appear in the mouth are usually the two lower central incisors (the two front teeth in the center of the lower jaw). These teeth typically come in around six to nine months of age. The upper central incisors follow shortly afterwards, between eight and ten months of age.

As soon as a baby’s first teeth erupt, they need to be cleaned. At first, a caregiver can clean the teeth by wiping the new tooth/teeth with a damp cloth after each feeding.



©marie rossettie

Figure 6: The Primary Teeth

It is important to clean the teeth because there is a form of sugar in milk that can cause tooth decay and cavities. It is also extremely important that your baby should not go to sleep with a bottle of milk in his or her mouth because this can cause what dental specialists call bottle caries (cavities). The results are devastating to the teeth. No baby should ever be given any type of sweetened drink like soda, pop, or juice. If you decide to put your baby to bed with a bottle for comfort, be sure to put water in the bottle, never put milk or formula.

By the end of the first year, it is likely that the four central incisors (two upper and two lower) will have come in, as well as two lateral incisors in the upper jaw, two lower canines (also called cuspids), and possibly the lower first molars—for a total of ten teeth.

Sharing the News with Family and Friends

A baby should have his or her first appointment with a dentist after the first tooth erupts and no later than 12 months of age. At the first appointment, the dentist will examine the baby’s mouth and educate parents on good oral health habits for life. He or she may also recommend a home fluoride treatment. The American Dental Association (ADA) recommends early brushing and the use of fluoride in infants and toddlers.

Children born with clefts usually get all of their baby teeth but not all of their adult teeth. If a child is born with a cleft in the maxillary alveolar ridge (the upper gum) he or she may have teeth that are turned, misshapen, or missing. The teeth most commonly affected are the upper incisors and the canines on the side of the cleft. During pre-school or school-age years, a dentist on the team will take x-rays to identify missing tooth buds. As your child grows, the dental specialists on the team will talk with you about these needs and their treatment.

Support for Parents

Paying for Treatment

Private or group health insurance policies usually cover at least a portion of the cost of cleft treatment. If a private insurance company initially rejects payment for a treatment, you should discuss the case with the company. In some cases, the reviewers are not aware of the problems associated with clefts. They may authorize payment once they learn more. Also, many states have laws prohibiting insurance companies from denying payment for medical needs due to congenital (birth) defects such as cleft lip and/or palate. Don’t hesitate to ask your team and/or your primary care provider to help with the appeals process.

Some children and families are eligible for federal or state programs such as Champus, Medicaid, and Children’s Special Health Services. Ask your team for information about sources of financial assistance in your area. Some private and non-profit agencies provide funds or special services for children born with clefts.

Using the Internet

There is a vast amount of information on the Internet about cleft lip and palate. Unfortunately, some of it is inaccurate, outdated, and unreliable. Remember, anyone can put information on a website. We advise looking for websites that offer objective, educational information that can be verified by members of your team. The ACPA Family Resources website, ACPAcares.org, lists reliable resources.

Support Groups

Parents of cleft-affected children often find it helpful to connect with other families with similar experiences. Several support groups are available on the Internet. Also, many families find continuous support from in-person groups. Parent/patient support groups are organizations of individuals and families who meet to share common concerns and ideas. Ask your cleft team, your local health providers, or ACPA Family Resources for help finding a group in your area.

Mental Health

As the parent of a child born with cleft lip and/or palate, you already understand the surprise of being told that your child has a condition that will require treatment, possibly over a period of years. It is not unusual to feel overwhelmed by this news, and also overwhelmed by the adjustments required of any new parent. The first step in coping is to learn to acknowledge and accept these unfamiliar and possibly painful feelings. It is important to take time during the first year to allow these emotions to surface and heal for you and other family members.

At first, it is common to seek comfort and support from family and friends, and then from support groups made up of other parents in similar situations. If the emotional pain does not lessen after the first six months of your child’s life, or if it interferes with your ability to function at home, at work, or in your relationships, you may want to speak with a qualified mental health professional. Your team or your primary care doctor may be able to recommend someone. They may also know of a mental health facility that accepts fee reductions or third-party payments. Your emotional health is essential to your ability to help your child.

Closing Words

Reflections from a Parent

As a parent of a child with cleft lip and palate, and as a past-president of a cleft palate parents’ society, I have learned much about clefts. Still, I cannot offer “words of wisdom” or absolute truths. However, from the depths of my heart I can share my thoughts on your child with a cleft. Be strong, for it is from you that your child will draw strength. Be knowledgeable about cleft procedures and new medical advances so that you and your doctors can decide and design a program for your child in a relationship of respect and trust. Share your experiences with others. You will find that you are not alone and that discussions spawn solutions to problems that we all share.

Most importantly, you will direct your child’s future. Make sure your child is given all possible programs of development starting at birth, so that by school age he/she has progressed naturally into the mainstream. These programs are available through the state and through school districts, but you as a parent must make them work for your child. You must instill self-esteem and project a bright future for your child. Learn from your mistakes and strive for the best medical and educational resources for your child.

Above all else, be kind and patient with yourself. While the birth of a child with a cleft seems very overwhelming in the beginning, the experience of countless parents testifies that this fact will not continue to dominate your life. You will begin to see beyond the cleft to the love, the sense of fun and mischief, the wonder and sensitivity, and all the traits that define the unique character of your child. You will begin to appreciate that you can have the same hopes and dreams for your child born with a cleft as for any other child.

Appendix A

Glossary

ACOUSTIC IMMITTANCE TESTING (*also known as TYMPANOMETRY*): A type of hearing test that measures the response to sound in the middle ear cavity.

ALVEOLAR RIDGE: The bony ridges of the maxilla (upper jaw) and mandible (lower jaw) containing the teeth, commonly referred to as the gum.

AUDIOLOGY: An area of health care concerned with hearing. An audiologist is an individual with a degree, license, and certification in audiology who measures hearing, identifies hearing loss, and participates in rehabilitation of hearing impairment.

BOTTLE CARIES (*sometimes referred to as BOTTLE ROT or BOTTLE MOUTH*): Cavities caused by milk or formula left on a baby’s teeth. These cavities often form when a baby is put to sleep with a bottle of milk in his or her mouth.

CLEFT PALATE TEAM or CRANIOFACIAL TEAM: Any team of specialists from several disciplines who work together, and with a family, to create, carry out, and update an individual’s care plan as it relates to cleft lip and/or palate.

COCHLEA: The inner-most portion of the ear which is responsible for hearing.

CONGENITAL: A disease, deformity, or deficiency existing at the time of birth.

EARDRUM (TYMPANIC MEMBRANE): The membrane located at the end of the ear canal which separates the canal from the inner ear cavity. This membrane vibrates and transmits sound to the middle ear.

ENT (*abbreviation for Ear, Nose, and Throat; OTOLARYNGOLOGIST—HEAD AND NECK SURGERY*): A surgeon who specializes in a wide array of problems of the head and neck.

EUSTACHIAN TUBE: A structure that connects the middle part of the ear with the back of the nose and equalizes pressure between those two spaces. Some children born with cleft palate have problems with the function of the Eustachian tube. PE tubes (defined below) can help a child avoid problems with ear infections and with hearing.

GENETICS: The study of heredity and how characteristics are passed down from one generation to the next.

MAXILLA: The upper jaw.

MIDDLE EAR: The part of the ear located behind the eardrum. The middle ear contains three small bones that transfer sound from the eardrum to the inner ear.

MYRINGOTOMY: A minor surgical procedure in which a small cut is made in the eardrum to allow fluid to drain from the middle ear.

NASOALVEOLAR MOLDING (NAM THERAPY, also referred to as a type of PRESURGICAL ORTHOPEDICS): A non-surgical method for reshaping the lip, gums, and nostrils prior to cleft lip and cleft palate surgery. A NAM device is made of wire and acrylic nasal stents attached to a plastic plate.

ORAL-MAXILLOFACIAL SURGERY: The branch of dentistry concerned with managing deformities of the dental and facial bones and soft tissue.

ORTHODONTICS: The branch of dentistry concerned with the correction and prevention of irregularities and misalignment of the teeth and jaws.

OTITIS MEDIA: Inflammation of the middle ear with accumulation of thick, mucous-like fluid.

OTOACOUSTIC EMISSIONS TESTING (*commonly referred to as OAE*): A type of hearing test that measures the response of the cochlea.

OTOLARYNGOLOGY—HEAD AND NECK SURGERY (commonly referred to as ENT, which stands for Ear, Nose and Throat): The branch of medicine concerned with diagnosis and treatment of patients with ear, nose, and throat disorders.

PEDIATRIC DENTISTRY: The branch of dentistry concerned with care of children’s teeth.

PE TUBES (PRESSURE EQUALIZATION TUBES, also called VENTILATION TUBES, GROMMETS, TYMPANOSTOMY TUBES): Tiny tubes inserted into the eardrum during a myringotomy that allow air to enter the middle ear and fluid to drain from the behind the eardrum.

PLASTIC SURGERY: The branch of surgery concerned with surgical repairs to establish appearance and function for congenital and acquired conditions.

PROSTHODONTICS:
The branch of dentistry concerned with the replacement of teeth and related mouth or jaw structures with artificial devices.

PSYCHIATRY:
The branch of medicine dealing with the diagnosis and treatment of mental disorders.

PSYCHOLOGY:
The branch of medicine concerned with the study of the mind and mental processes, especially in relation to behavior.

SOCIAL WORK:
A human service field that may involve specialized training in social welfare, and/or individual, family, group, and community health services.

SPEECH-LANGUAGE PATHOLOGY:
An area of health care focused on disorders of speech, language, cognition, voice, resonance, and swallowing (dysphagia). A licensed and/or certified speech-language pathologist has had the academic training and experience necessary to diagnose and treat disorders of speech, language, resonance, and feeding.

TYMPANOMETRY (*also known as ACOUSTIC IMMITTANCE TESTING*): A type of screening that measures the response to sound in the middle ear cavity.

TYMPANOGRAM:
A test that measures how well the eardrum moves when air pressure is applied to the ear canal.

Appendix B

Recommended Questions for the Team

1. Which specialists are on the team?

2. What are the qualifications of the individual members of the team?

3. What kind of experience does the team have?

4. How does the team communicate?:

- a) With each other?
 - In face-to-face conference?
 - Via email?
 - Via written reports?
- b) With patients and families?
 - In face-to-face conference?
 - Via phone?
 - Via email?
 - Via written reports?

5. Who will be the team contact person after our baby is born or following surgeries?

6. Does the team prefer a particular modified cleft palate bottle to another?

7. Who can assist with feeding if needed at the birth hospital? During the first year of life?



For More Information

This booklet and many others have been produced by:

**The American Cleft Palate
Craniofacial Association**

510 Meadowmont Village Cir, Suite 377
Chapel Hill, NC 27517

919.933.9044
info@ACPACares.org | ACPACares.org