Cleft Lip and Palate Resource Handbook

Children's℠
Healthcare of Atlanta

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Welcome

Welcome to the Children's Healthcare of Atlanta Center for Cleft and Craniofacial Disorders. Our center is a recognized leader in pediatric craniofacial care. We evaluate and treat the full range of craniofacial conditions for children from birth to age 21.

Our comprehensive services include:

- Pediatric dentistry
- Oral and maxillofacial surgery
- Orthodontic services
- Plastic surgery
- Speech pathology laboratory
- Screenings and evaluations
- Feeding and lactation
- Genetics
- Ear, Nose and Throat (ENT)
- Audiology
- Psychological counseling and consultation

The Children's Center for Cleft and Craniofacial Disorders is located on the second floor of the Children's Medical Office Building at Scottish Rite.

Our promise to you

The craniofacial team wants to provide you and your child with quality, family-centered care. Our team can help support you during your child's treatment. At each visit, you will encounter nurturing, caring people.

About the handbook

We hope you find this handbook useful. Many parents of children with cleft lip and cleft palate say that they have a lot of questions, concerns and fears about caring for their child. Sometimes, your child's care will be the same as that for other children; at other times, it may be unique. This handbook has been prepared by the Children's Center for Cleft and Craniofacial Disorders to answer your many questions. We hope you keep this handbook and refer to it often. Bring it to clinic appointments and make notes. It can help you learn more about your child's cleft lip and palate.

Some of the terms used in this manual can be found in the glossary at the back of the handbook. Other words may be followed by phonetic spellings to help you learn how to pronounce them.

Many of the words and terms in this booklet may be new and confusing. Our craniofacial team can explain them to you and teach you what you need to know. For easier reading, we will use the words "he or him" when we talk about your child—even if your child is a girl.

Please note, this handbook should not replace instruction given to you by your child's healthcare team. It is not meant to be medical advice or a complete resource for all information on this subject. Your child's doctor is the best resource for information about what is right for your child's treatment. If you have any questions about this handbook, please contact the Children's Center for Cleft and Craniofacial Disorders at 404-785-5437 and a nurse will help you.

In case of an urgent concern or emergency, call 911 or go to the nearest emergency department right away.

Some physicians and affiliated healthcare professionals on the Children's Healthcare of Atlanta team are independent providers and are not our employees.

Important information

Child's name: _____

Medical condition(s): _____

Primary care physician (PCP): _____

PCP phone number: _____

Emergency numbers: _____

Closest emergency department: _____

Georgia Poison Center: 404-616-9000 or 800-222-1222

Children's emergency departments:

Egleston: 404-485-6400
Scottish Rite: 404-785-2273
Hughes Spalding: 404-785-9650

Craniofacial team

The Children's Center for Cleft
and Craniofacial Disorders: 404-785-5437

Craniofacial surgeon: _____

Craniofacial nurse practitioner: _____

Speech pathologist: _____

Audiologist: _____

Occupational therapist: _____

Nutritionist: _____

Lactation consultant: _____

Feeding specialist: _____

Pediatric dentist: _____

Orthodontist: _____

Geneticist: _____

Psychologist: _____

Neuropsychologist: _____

Social worker: _____

In the hospital

Chaplain: _____

Child life specialist: _____

School teacher: _____

Primary nurse (inpatient): _____

Other numbers

Pharmacy: _____

Closest relative or neighbor: _____

Insurance company: _____

Medicaid number: _____

Your child's care timeline

Stage 1: Birth to 2 weeks of age

- Feeding team evaluation

Stage 2: 3 to 8 weeks of age

- Clinic visit with craniofacial surgeon
- Genetics evaluation
- Dentist or orthodontist visit for pre-surgical molding devices
- Referral to ear, nose and throat (ENT) doctor if needed or hearing (audiologist) screening

Stage 3: Weekly or biweekly clinic visits for next 2 to 3 months

- Feeding follow-up and weight check
- If using a presurgical appliance - Nasal Alveolar Molding (NAM) or Latham Appliance - visit with orthodontist or pediatric dentist to adjust appliance

Stage 4: Surgery 3 to 12 months

- Cleft lip closure 3 to 5 months of age
- Cleft palate closure 9 to 12 months of age

Stage 5: Toddler years

- Team visits including the craniofacial surgeon every year to 2 years. First speech evaluation at 12 to 18 months of age
- First dental evaluation after the eruption of first tooth or least by 12 months of age. Then, regular follow up dental visits as advised by pediatric dentist. NOTE: Speech and dental visits are often done together at this visit.
- Possible speech surgery, if needed
- Continued well-child exams with your child's primary care provider

Stage 6: School-age years

- Team visit including the craniofacial surgeon every 1 to 2 years, based on need
- Possible cleft lip revision, cleft nasal (nose) revision at 5 to 6 years of age
- Speech therapy
- Possible speech surgery, if needed
- Dental check-ups/cleaning every 6 months
- Dental and orthodontics if needed 6 to 11 years of age
- Audiologist or ENT screening
- Continued well child exams with your child's primary care provider

Stage 7: Teenage Years

- Team visit including craniofacial surgeon
- Cleft lip and scar revision, cleft nasal (nose) surgery, if needed
- Jaw advancement, if needed
- Dental check-ups and orthodontics visit
- Braces, surgery, prosthetic dentistry, if needed

Family reactions and emotions

Having a child with a cleft lip or palate can stir many emotions. At first, it may be hard to accept that years of treatment and progress lie ahead. Keep this in mind: The outlook is good. Advances continue to be made in the treatment of people with clefts. Your child can reach adulthood with a good sense of self, an acceptable appearance and healthy social skills.

Your ability to deal with your feelings is vital to your child's health. Your child will look to you for hope and strength. Your reaction will also set an example for other family members.

Tips to help you prepare for caring for your child

Take care of yourself.
Parents are the most important people in a child's life, so you must stay healthy and strong. Maintain a healthy diet and exercise often. Take time to rest and relax each day. When you are relaxed, it is easier for your child to relax.

Ask for help when you need it.
You can't do it all. Ask family members and friends to lend a hand when they can. If you feel scared or unsure about your feelings, ask to speak to one of our staff at Children's right away. We can help you feel better about caring for your child.

Beware of burnout.
Sometimes you might not know when your "battery" needs to charge. Watch for these signs in your life:

- Constant fatigue (tiredness)
- Constant depression (feeling down)
- Desire to avoid others
- Family arguments
- Increased use of alcohol or drugs

If you notice any of these signs, you may need to get some rest and ask for help.

Play with your baby.
You and your baby can still enjoy the pleasures of cuddling, rocking, talking and playing. Babies and parents need these kinds of things to help form bonds. They satisfy our need for love, closeness and nurturing. Set aside time to enjoy your baby after feedings, baths and naps. Your smile, voice and touch are vital to your child.

Set a positive example for your child.
Children can sense the feelings of the adults around them.

Your child will form his feelings about the cleft from your feelings and actions. If you dwell on problems and act ashamed, so will your child. But if you treat your child as a whole person with many good features, he will feel better about himself.

Be prepared for teasing and other social problems.
Do not shelter your child from other children to protect him. The more time he spends with other children, the sooner your child will learn to manage social situations. There are three points in time when this may be extra :

- The first year in school, when a child goes outside the home and loses some "special" status
- The early teen years, when a child is very aware of changes in his body and feels an increased need to fit in with others
- The later teens, when young people begin to desire closer relationships and to be seen as "special" by someone else it may be helpful to role-play a teasing event at home to help a young child rehearse new ways to manage these events.

Use the Children's craniofacial team as a resource.

The Children's craniofacial team can help you prepare for and deal with many of the problems you may face. Our team members can help provide:

- A plan of care that is made for your child over time
- Teaching and updates on your child's status and treatment schedule
- Financial guidance
- Emotional counseling and support

The craniofacial team is always here for you. You may speak with us during your visits or call us from home. Do not be afraid to ask for any type of help you need. We want to help.

Talk with your partner.

The birth of a baby can cause stress for a couple. It is easy for your relationship to become strained while you are both focused on your child. Parents need to talk and offer support to each other as much as possible. Share your feelings and listen to those of your partner; you can be each other's best source of support and help.

Remember siblings (brothers and sisters).

Your child's care will affect every member of your family. At first, young siblings may be scared by the cleft. They may become jealous because they don't know why you need to spend extra time with their new sibling. This is natural.

- Tell your other children that they are also important to you.
- Hold, comfort and love all your children—including your child with a cleft. Find time each day to spend with them.
- As you learn about clefts and your child's treatment plan, make sure that your other children learn, too. Give them plenty of chances to ask questions, and let them help as much as they can. Older siblings may be able to help by babysitting. All children can help by doing small chores around the house.
- Offer lots of praise when your children help you. Let them know they are a special part of a team effort. This can help them feel more important and independent. When you learn more about caring for your child, you may even include siblings in some care tasks.

What is cleft lip and palate?

As a baby's face forms in the womb, a space remains between the nose and mouth (Image 2). This occurs in weeks 8 to 12 during pregnancy. As the face nears its final form, this space closes as the left and right halves of the upper lip and palate (the roof of the mouth) join. When this space does not fully close, a baby may be born with a cleft lip or a cleft palate or both. ("Cleft" means a split or separation.)

- A cleft lip is a split in the upper lip and base of the nose. (Images 3, 4, 5 and 6)
- A cleft palate is a split in the roof of the mouth and back of the nose. (Images 7, 8 and 9)

A cleft is not usually dangerous or a medical emergency. It causes no pain for your child. A cleft lip or palate may be on one side of a baby's face (unilateral) (Images 3 and 4) or on both sides (bilateral) (Images 5 and 6). Both types can be repaired, but treatment for a cleft is a gradual process. There are many steps that may need to be taken during the next few years or more.

What causes cleft lip and palate?

Your child may have “inherited” his cleft from one or both parents. But other factors can also occur during pregnancy to cause it. The exact cause of a cleft is often unknown.

Genetic inheritance

Genes are the smallest unit of heredity. Heredity is the passing of genes from parent to child. Each cell in the human body contains genes. Genes contain the “blueprint” for everything in our bodies, such as our height, hair color, skin color and eye color. Genetic inheritance means that a child’s features are “inherited” or passed from parent to child through the genes.

There are two types of inheritance:

- In single gene inheritance, a feature appears as a result of a single gene carried by one parent.
- In multifactorial inheritance, a feature appears as a result of a number of genetic and nongenetic factors.

Your geneticist

Genetics is the study of genes; a geneticist is a doctor who studies genes. The geneticist or genetic counselor on the craniofacial team can help you try to find the reason for your child’s cleft. Your geneticist may need to:

- Check you and your family members
- Take X-rays and conduct genetic tests—usually blood tests
- Ask you for a detailed family medical history
- Ask you for a detailed pregnancy history

After completing these studies, the geneticist will talk to you about the possible cause of the cleft. Your geneticist will also discuss your risk of having another child with a cleft.

Syndromes

Sometimes, groups of problems appear together in newborn babies. These groups are called syndromes. A cleft lip or palate may be only one part of a larger syndrome such as Pierre Robin Syndrome (Image 1). Like clefts, syndromes may be the result of single gene or multifactorial inheritance. Your geneticist will talk with other members of our craniofacial team to learn if your child has other problems that point to a syndrome. This will help the geneticist tell you more about the risk of clefts in children you may have in the future.

Image 1: Pierre Robin Syndrome— Micrognathia (small jaw) and cleft palate

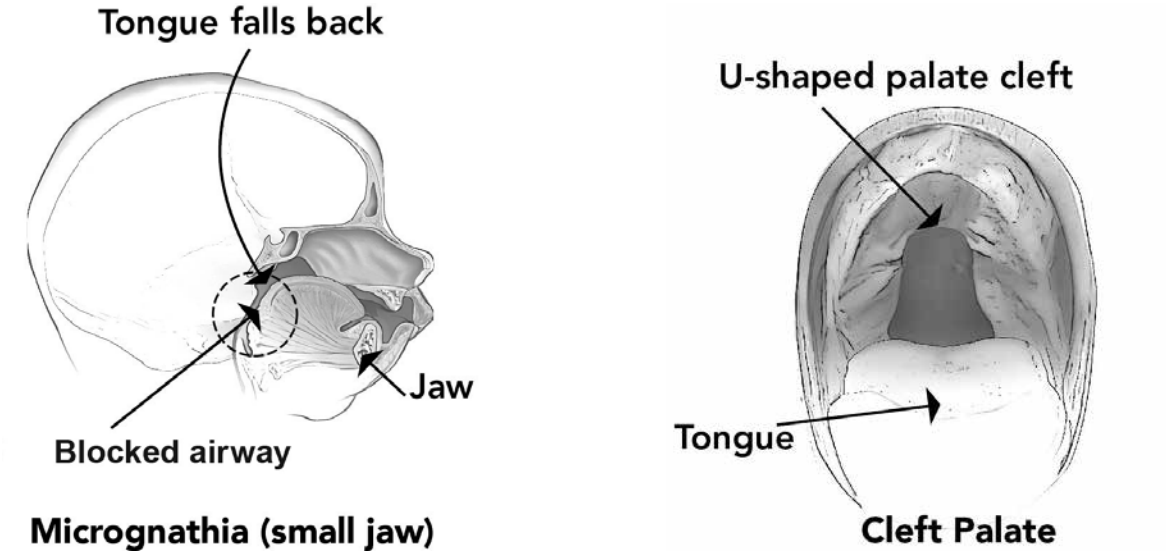


Image 2: Normal anatomy of the mouth

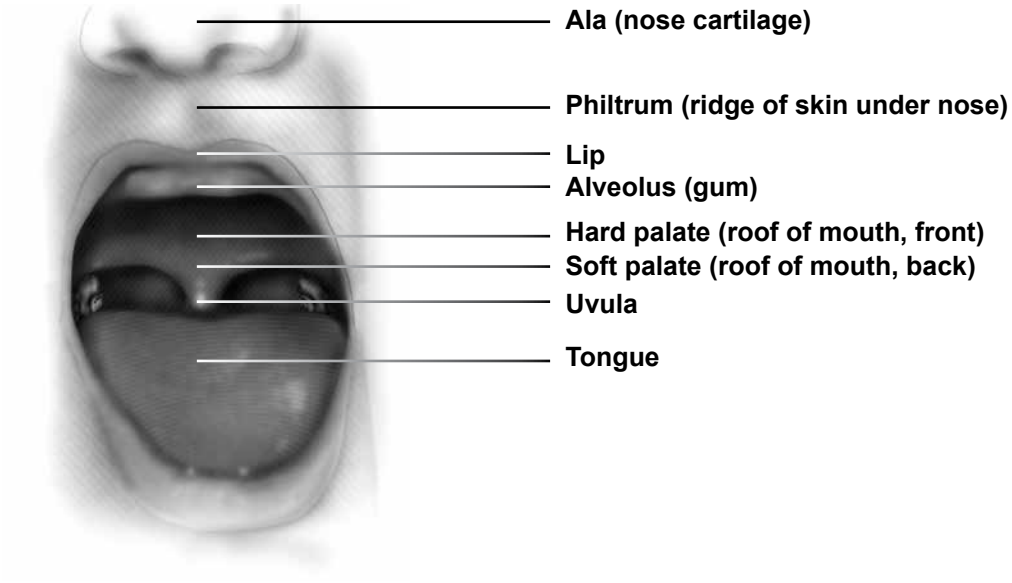


Image 3: Unilateral (one-sided) complete cleft lip

Image 4: Unilateral incomplete cleft lip

Image 5: Bilateral (both sides) complete cleft lip

Image 6: Bilateral incomplete cleft lip

Image 7: Unilateral complete cleft lip and palate

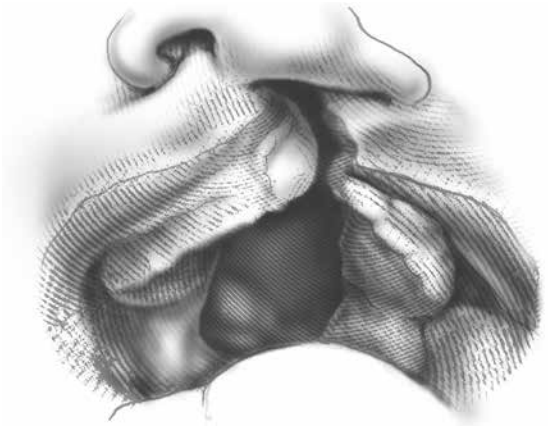
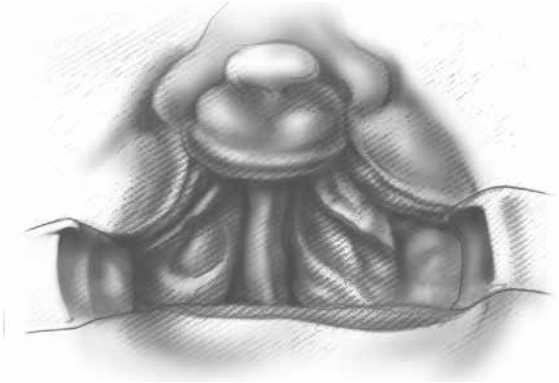


Image 8: Incomplete cleft palate

Image 9: Bilateral complete cleft lip and palate



Who treats cleft lip and palate?

Your child needs a treatment plan that is made just for him. The plan requires a team of people who play different roles in your child's care. This team is called the craniofacial team. Our craniofacial team includes these professionals:

- Audiologist (aw dee ah' lah jist): A person who studies and tests sound and hearing
- Craniofacial surgeon (cray' nee o fay shul/sur' jen): The doctor who performs many of your child's facial surgeries
- Dental hygienist (hi jen' ist) and assistants: People who provide many types of dental care and education for parents
- Geneticist (jen et' ah sist): A doctor who studies genetics (the study of genes)
- Lactation (lack tay' shun) consultant: A person who helps with breast-feeding and pumping breastmilk
- Neuropsychologist (ner o sy call' a jist): A person who tests children to find out about and help with cognitive (mental skills) problems
- Nurse: Someone who coordinates care and provides education
- Nutritionist (new trish' on ist): A person who plans healthy diets and helps with feedings
- Occupational (oc you pay' shun ul) therapist: A person who helps children with daily care activities like feeding and bathing
- Orthodontist (orth ah don' tist): A dentist who uses braces and other devices to correct problems in the teeth and jaws
- Otolaryngologist (o to lair in gol' ah jist): An ear, nose and throat (ENT) doctor
- Pediatric (pee dee at' rick) dentist: A dentist with advanced training to help children with special dental problems
- Prosthodontist (pros thah don' tist): A dentist who makes artificial teeth and fits dental or surgical appliances (devices) to correct your child's condition
- Psychologist (sy call' a jist): A person with special training to help people with emotional or behavioral needs
- Social worker: A person who provides counseling and resources to people
- Speech/language pathologist (path ah' lah jist): A therapist who helps children improve their speech

Feeding your baby

Feeding your baby

Our feeding team will check your baby to see how feeding is going and to determine what type of help your baby needs. Our goals are that you feel comfortable and supported and that your baby begins to grow and thrive. The help we can provide during your visits may include:

- Trying out specialty bottles
- Showing techniques for how to hold your baby during feeds
- Reviewing common signs of difficulty swallowing

Babies with a cleft lip/palate can tire easily when eating. For this reason, feedings should last no more than 30 minutes. Based on the type and size of the cleft, they will likely not have enough suction to drink from a standard bottle or feed directly from the breast.

Nutrition

Nutrition is very important for your baby to gain weight and contributes to successful surgery. A nutritionist with the feeding team will assess your baby's nutritional status during feeding visits. The nutritionist will check for:

- Weight gain
- What you are feeding (breast milk or formula)
- How much your baby is feeding
- Your baby's feeding schedule

As a general rule, it is best that a baby regains his birth weight by 14 days of age. Weight gain is most often very rapid for the first few months of life with a desirable daily gain of about 1 ounce per day.

Since nutrition is important throughout your child's life, a craniofacial nutritionist is available to work with your child and/or to connect you with the appropriate resources.

Breastfeeding and breast milk

Babies with a cleft lip alone are more likely to be able to nurse from the breast than those with a cleft palate. Very few babies with a cleft palate are successful at maintaining a latch for a full feed with good suction. Pumping breast milk (mother's milk) is critical from the beginning. We advise you use a double electric pump to make this process as efficient as possible. Pumps can be obtained via insurance or the lactation team at your birth hospital. Having enough freezer storage is important, as breast milk may be stored frozen for a longer period of time and allows you to build up a supply.

Even though your baby may not nurse at the breast, breast milk is the preferred choice for babies with clefts. Also, spending "skin to skin" time with your baby will help you bond even if your baby is not latched to the breast.

Breast milk helps your baby in many ways. It:

- Strengthens health before surgery and aids recovery afterward
- Provides protection against infection
- Is easily digested and provides many nutritional benefits

Special bottles and nipples

Avoid pre-purchasing bottles before the baby is born. Your baby will often require something different than what you expected. The feeding team will help choose the best bottle and nipple for your baby. They will provide you with resources on how to get these bottles at the first visit. Your baby's birth hospital will likely get you started with a bottle, but we might change that at your first visit.

Specialty cleft bottles include:

- Dr. Brown's Specialty Feeder
- Pigeon Nipple
- Medela Special Needs Feeder
- The Mead Johnson Cleft Palate Nurser

Tips for feeding your baby

- During feeding, make sure to keep the baby in an upright position between 45 and 90 degrees unless told otherwise.
- Keep your baby's mouth and nose clean. Bulb syringe or other nasal suction devices will help. You may use nasal saline spray 20 to 30 minutes before feeding to help clear congestion.
- Liquid and food will probably come through the nose at some point. Take a moment to wipe, let your baby sneeze or cough, and then, resume feeding.
- Burp your baby often during feedings (every 10 to 15 minutes) as cleft lip/palate babies tend to swallow more air. This can make babies more prone to spitting up. Or, it can make them pull away from a feeding because the stomach is full of air, and they feel full.
- Wait 30 minutes after feeding before you lay your baby flat. This can help reduce the chance of spit ups.

Feeding and NAM therapy

It is not unusual for babies with cleft lip to have a period of difficulty after/if NAM therapy begins. Plan to see the feeding team after the first fitting to make sure the bottle and nipple you have been using are still okay. Some babies may need help to self-calm with the device in place at first. There are many strategies to help make this transition easier.

Feeding milestones

Your pediatrician will advise for purees (baby cereal and baby food) around 6 months of age. Having a cleft lip/palate does not mean your child will be late to eat these foods. When starting purees, you should feed your baby with a spoon. Do not put the purees in the bottle or let your baby suck from a pouch. Be sure to keep the nose and mouth clean after meals as you begin feeding these thicker textures.

Feeding after surgery

Your baby's feeding schedule may be different for a few days after surgery. We will discuss how to prepare your baby for surgery in-clinic visits. In general, bottles and pacifiers are not allowed after palate repair. Instead, we advise for spoon feeding puree foods and drinking from an open cup. Your baby will need to be familiar with an open or 360 cup before surgery for this to be successful. Around 6 months of age (after spoon feeding is in place) is a good time to begin using an open cup for drinking practice. There are other options if needed, so please contact our team if you have concerns.

Treatment before surgery

Children's Center for Cleft and Craniofacial Disorders is one of the few centers in the U. S. that can use both the Latham Appliance and Nasal Alveolar Molding (NAM). These devices are used before surgery to help bring a baby's lips and gums together. They help ready the lips and palate for surgery. Your child's doctors will help decide if a device is needed.

Nasal Alveolar Molding (NAM)

What is Nasal Alveolar Molding (NAM)?

Nasal Alveolar Molding (NAM) is a way to treat cleft lip and palate.

- Nasal means that it fits up into the nose.
- Alveolar means that it fits around the gums.
- Molding means that it is a hard, plastic mold.

The NAM mold brings your baby's lip and gum together by helping to move and reshape the cleft area as your baby grows. This is needed to prepare your baby for further cleft repair during surgery.

How does a NAM work?

At your child's first visit to the center, a dentist who treats cleft problems (pediatric orthodontist) will make a plastic mold of your baby's mouth, lip and nostrils.

- The mold will be specially made just for your baby.
- Your baby will wear the mold 24 hours a day for about three to four months.
- The mold is held in the mouth by surgical skin tape. The tape will also help guide the growth of your baby's face.
- Each week, the orthodontist will reshape the mold. This will help to make your baby's cleft smaller and reshape his nose.

Why should my child use NAM?

Children with cleft lip and palate may need five to seven surgeries. Sometimes, they even need surgery into their teen years.

- It helps during the first surgery and helps mold the nose.
- NAM can help to reduce the number of surgeries your child needs during his life.
- Since the mold covers the roof of your baby's mouth, it also helps with feeding.
- NAM can also help to improve your child's appearance.

When should my baby be fitted for a NAM mold?.

- It is usually fitted when a baby is about 2 weeks old.
- It is worn 24 hours a day until his first surgery. This is usually when he is about 4 to 5 months old.
  - NAM is used when your baby is young because his tissues (cartilage) are flexible.
  - After 2 months of age, his cartilage is not as flexible, his teeth begin to come in and he is able to take out the device himself.

What do I need to do?

The NAM device means that you will need to give your baby extra care and time. You will be caring for the NAM at home, so your help is vital in order for it to work. This means that you will need to:

- Bring your baby to the center each week. The center's orthodontist and team will check your baby and adjust the NAM device as needed.
- Attach the tape to your child's face as needed to keep the NAM device in place.

Latham appliance

What is a Latham appliance?

A Latham appliance is a plastic device used to bring a baby's lip and gum together. It helps to better align and shape the cleft area before surgery.

How does the Latham appliance work?

At one of your child's first visit to the center, a dentist will make a mold of your baby's mouth.

- Using the mold, a dental laboratory will make a plastic and metal appliance to fit inside your baby's mouth.

During surgery the appliance will be attached to the roof of your baby's mouth using screws.

- This happens in the operating room while your baby is asleep under general anesthesia.
- It takes about 30 minutes to place the device.
- Your baby may need to stay in the hospital overnight.
- Your baby will need to wear the appliance for about four weeks.
- Your doctor will remove it when your baby has surgery to repair his cleft.

Why should my baby use a Latham appliance?.

The Latham appliance can help make the width of the cleft smaller, which helps in the first surgical repair.

When should my baby be fitted with a Latham appliance?

Your baby will be fitted before he is 6 months old. It is usually done when a baby is about 2 to 3 months old. It is used when your baby is young because:

- The tissues in the mouth are still flexible
- Your baby does not have any teeth yet

What do I need to do?

The appliance means that you will need to give your baby extra care and time. This is vital in order for it to work well. You will need to:

- Bring your baby to the center every one to two weeks. The dental team will check your baby and adjust the appliance as needed.
- You may need to adjust it at home as well. If so, we will teach you what you need to do.

Surgery

All children with cleft lip and palate can have surgery to help:

- Restore function for feeding, eating and talking.
- Give them a more normal appearance.

Cleft lip and palate repair is most often done in stages.

- Surgeries are planned to occur with your child's facial growth.
  - Some surgeries are done when your child is a baby and some when your child is older and more developed.
  - Some surgeries may not be done until he is a teenager.
- Your child's craniofacial surgeon will explain what types of surgery your child may need and when surgery may occur.

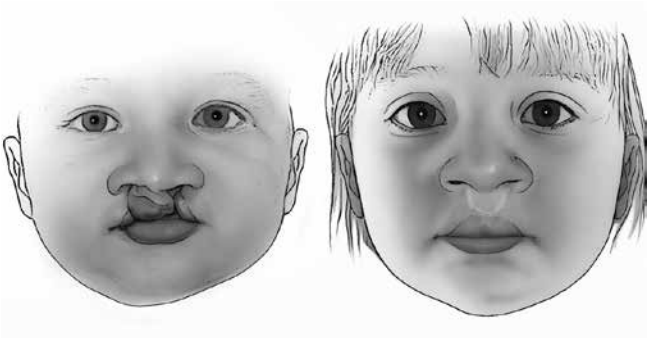
First year surgeries

Your baby will have surgery done at an early age to rebuild the muscles and tissues around his mouth and nose. Surgery may include:

- A cleft lip repair at 3 to 5 months of age (Images 10 and 11)
- A cleft palate repair at 9 to 12 months of age (Image 12)
- A mandibular distraction (lengthening the jaw) surgery (Image 13)

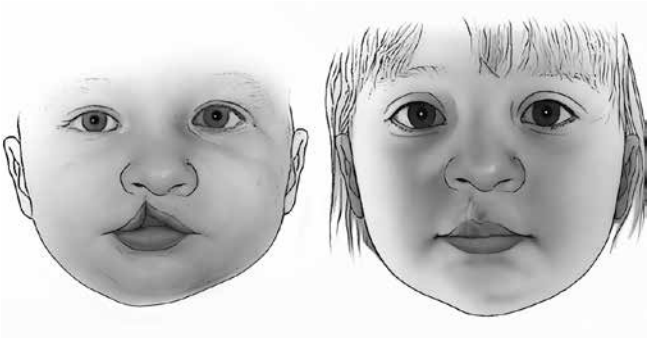
Each surgery takes about one and a half to 2 hours and your baby will likely need to stay in the hospital overnight. Your child's doctor will tell you what type of surgery your child needs.

Image 10: Bilateral (both sides) complete cleft lip repair



Before Surgery After Surgery

Image 11: Unilateral (one side) complete cleft lip repair



Before Surgery After Surgery

Image 12: Cleft palate repair surgery

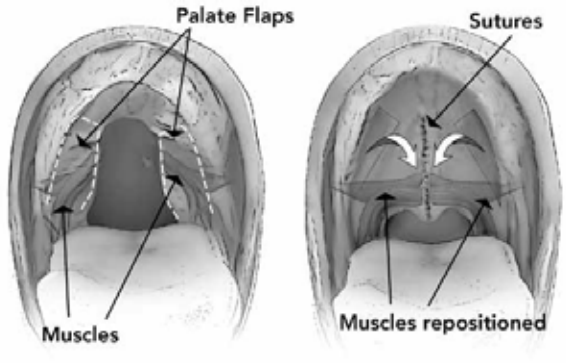
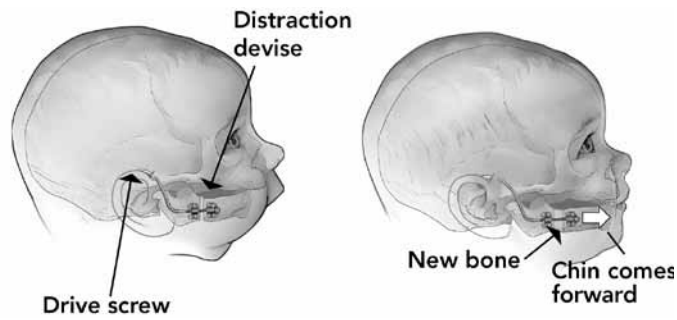


Image 13: Mandibular distraction (lengthening the jaw) surgery



After surgery

It is best to stay in your baby's room after surgery and help care for him. We will teach you how to care for your baby at home.

Here are some tips to help you prepare for caring for your baby right after surgery.

In the hospital

- Your child will have a few tubes and wires attached to him. These may include:
  - A pulse oximeter—This is a monitor that measures the oxygen in your child's blood. A soft, plastic wire leads from the monitor and is attached to your child's finger with a bandage. The wire will not hurt or shock your child.
  - An I. V. (intravenous) line—This is a thin, soft, plastic tube that goes into your child's veins. It lets us give your child food, fluids and medicines that he cannot take by mouth.
- Your child may have some discomfort after surgery. We can give him pain medicine through the I. V. or by mouth.
  - Pain medicines can make him unsteady on his feet.
  - To help prevent falls, be sure to keep your child's side rails up and watch him carefully if he tries to stand or walk.
  - Also make sure his shoe strings are tied and pant cuffs are turned up.
- We may also give your child other medicines (antibiotics) to help prevent infections caused by germs or yeast.
- You may notice some bloody drainage from the surgery site. Do not be alarmed—this is normal for a day or so.
- Your child may be extra fussy for a while after surgery. This is also quite normal for three to five days.
- Your child may need arm immobilizers to keep his arms straight. These help prevent him from touching his mouth area.
  - If so, loosen the restraints a few times each day to check for skin problems.
  - Loosen only one at a time and do not let your child's hand near his mouth.
- Ask your child's nurse how to work with the arm immobilizers.
- After cleft lip surgery, your surgeon may tell you that he would prefer that you not use a pacifier for 2 weeks.
- After palate repair surgery, you will not be allowed to feed your child from a bottle for 2 weeks. Syringe feeds or liquids from a sippy cup WILL be encouraged and allowed.
- You will be able to begin to feed your baby by mouth soon after surgery. To prepare for the restrictions in feeding in the early stages after palate surgery, start your child on solid foods as advised by your pediatrician between 5 to 6 months so that, if possible, they are tolerating spoon-feeding and not dependent on the bottle at the time of surgery.

After you go home

- Your child will return to the doctor's office in several weeks. Any sutures that will not dissolve will be removed at this time. Most sutures used for cleft repairs dissolve in three to six weeks. At this visit, we may teach you how to help reduce the scar on the lip.
- If your child had a cleft palate repair, your doctor will see if any openings have formed in the new palate. If so, they will need to be repaired at a later date.
- At first, every 6 to 12 months, depending on needs, you will bring your child to be checked by our craniofacial team. They will check on your child's facial growth, hearing, speech, and mental and motor development and provide treatment as needed. You will need to make clinic visits less often with time.

Future surgeries

As your child grows, he may need more surgeries at different ages. Whether your child needs more surgeries depends on his treatment plan and any problems that might arise.

- Your child will be screened regularly by a speech and language pathologist to monitor his progress with speech. If air is escaping from your child's nose, this may need to be repaired in surgery (Images 14 and 15).
- Before your child reaches school age, he may have a revision of the lip scar (Image 16).
- When your child is 8 to 11 years old, the cleft in his upper gum will be repaired using bone graft.
- During your child's midteens, he will have the final repairs to the lip, nose and/or palate. He may also need surgery to move one or both of their jaws to improve the position of their teeth (Image 16).
- Regular hearing checkups can tell if a visit to an ear, nose and throat doctor is needed. Children with chronic ear infections may need ear tubes.

Image 14: Pharyngeal (back part of the roof of the mouth)

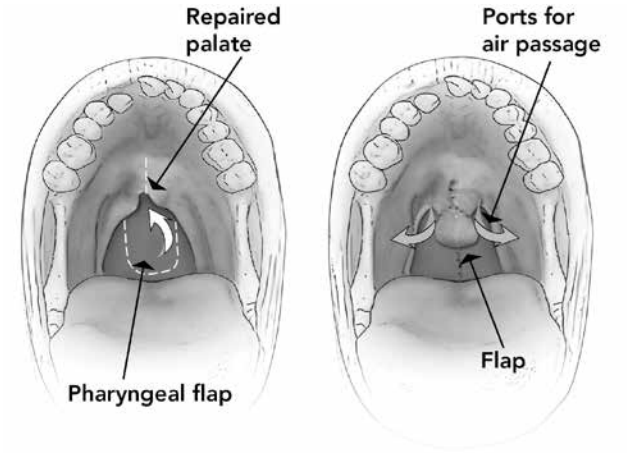


Image 15: Pharyngoplasty (repair of the back part of the roof of the mouth)

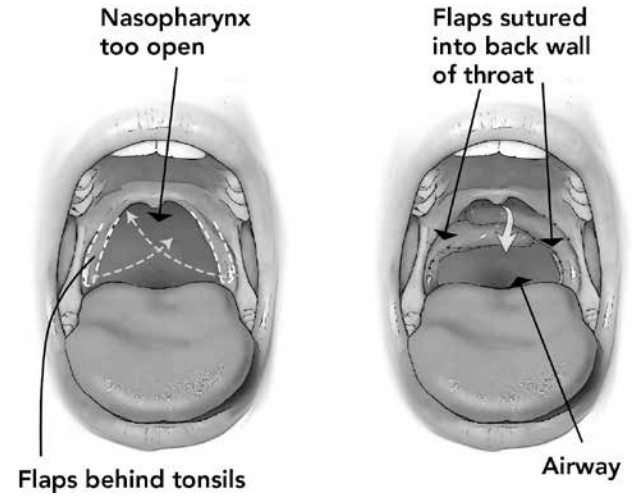
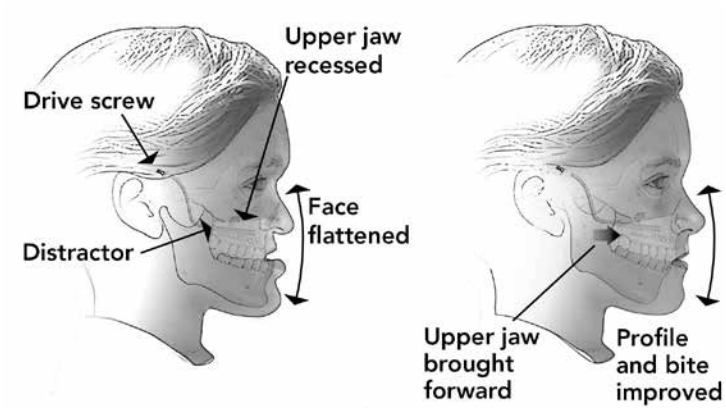


Image 16: Maxillary and mandibular Distraction (Jaw repair) Surgery



Hospital visits

Most of your child's surgeries at Children's will be done as an outpatient. This means he may be sent home on the same day. At other times, he may need to stay in the hospital overnight.

Your child's doctor will tell you as soon as possible if your child needs to spend the night. Just in case, we suggest that you always pack a bag. If your child stays overnight, you are welcome to stay also. Having a parent or family member nearby is important for your child. He will be less fearful and more secure with you nearby. Each of our hospital rooms at Scottish Rite hospital is private and includes a:

- Hide-a-bed sofa
- Full bathroom
- Television
- Telephone

When you stay overnight at the hospital, you may not get a lot of sleep. We must check your child often during the night and you may wake up during our nurses' visits. We have a cafeteria for you to eat in or you may order meals to be bought to your child's room for an additional cost. You may also bring food and snacks from home. There is a refrigerator, microwave and coffee maker for parent use on each floor of the hospital.

Visiting guidelines

We want to provide you with quality, family-centered care. Please follow these guidelines to help us keep your child safe and provide the best possible care and service.

- Visiting hours are from 8:30 a. m. to 8:30 p. m. We may need to limit the number of visitors in your child's room to two at a time. Your nurse will let you know if a limit is needed.
- It is best for your child if one parent spends the night. Other family members may use the Ronald McDonald House at 5420 Peachtree-Dunwoody Road, Atlanta, GA 30342. The number of rooms available may be limited. Getting a room depends on such factors as how far away your home is from the hospital and family need. Call for information about reservations and house rules (office: 404-847-0760; contact hours: Monday to Friday, 8:30 a. m. to 8:30 p. m. ; Saturday, 9 a. m. to 1 p. m. ; and Sunday, 4 p. m. to 8 p. m.). A shuttle can take you to and from the Ronald McDonald House and the hospital at all hours.
- All visitors less than 12 years of age must stop at the nurses' station for screening before they enter your child's room. The nurse will ask questions about any possible illness. This includes brothers and sisters and is done with each visit. The visiting child will receive a special sticker to wear during the visit.
- Brothers, sisters and other visitors less than 12 years of age must be with a parent and remain in the room at all
- times, unless they are taking part in activity center or family activities.
- Because of the risk of illness to our patients, we ask that babies, toddlers and young school-aged children keep visits brief.
- Siblings are not allowed in the play room until after 3:30 p. m. unless approved by the child life specialist.
- Children less than 12 years of age must be with a parent, volunteer or child life specialist while in the playroom or on the playground.

At times, we may need to alter these guidelines for our patients' safety and health.

Notes about surgery

Date of surgery:

Type of surgery:

Doctor:

Notes:

Speech and language

The person on the craniofacial team who works with your child's speech and language is the speech and language pathologist (SLP). Your SLP will:

- Check your child as he grows to see how his speech and language function develops.
- Advise treatment based on the check-ups.

Your child's treatment may include speech therapy and surgery. A child can usually be ready to speak in a normal way for his age by the first year in school.

Needs for normal speech

In order for your child to speak well, certain things must be in place. A few of these things are listed below.

1. Your child must hear spoken words clearly. We all must hear clearly before we can speak. The audiologist will test your child's hearing and talk with you about any needed treatments.

2. Your child must have someone teach him to speak.

   Children learn to speak by listening to people speak. You can help your child begin to link spoken words to objects and actions.
   - Talk to your child about the objects and actions in his world often. This includes people, toys, food, playing, bathing and feeding.
   - Read two or three books each day to your child. Reading is a great way to help him learn to speak. Point to and talk about the names of characters and things in the book.

3. Your child must have a proper mouth structure. Most children with clefts can speak normally once their palates are repaired.
   - Some children still have a nasal resonance due to voice escaping from the nose.
   - These children may need more surgery to close the opening.
   - Your SLP can test your child to check on his speech.

4. Your child's intelligence must grow in order for his speech to do the same. Not all children with speech problems have cognitive (thinking and learning) problems.
   - Some children with cleft lip or palate do have delays with thinking, learning and development.
   - A neuropsychologist can help you check on your child's cognitive growth.

Learning, speech and language

Children begin practicing for speech early in the first year of life. Speech begins with sounds that are easy to make—vowels such as a, e, i, o and u. In time, speech moves onto sounds that are harder such as "th," "st" and "str. " For children, learning speech happens like this:

- First, they make general sounds, such as cooing and vowel sounds.
- Then, they make sounds that sound like speech, such as babbling and consonant sounds. For example, they may say, "Dadada," or "Mamama."
- Then, they make real speech sounds and words.
- After putting speech sounds together to form words, children begin to make sentences.

For a child with a cleft, it may be hard to move through these steps due to an opening into the nose, missing teeth or teeth that are out of line.

How we speak

In English, we use about 46 sounds to speak. Some of these are vowel sounds like “a,” “o” and “ow.” Other sounds are consonant sounds like “p” and “d.”

- There are three consonant sounds that are spoken through the nose—“m,” “n” and “ng.” These are the nasal sounds.
- To make the other 43 oral sounds, the soft palate (the rear part of the upper mouth) must seal off the nose and force sound out the mouth.
- For the 16 pressure consonants sounds, this is vital because air pressure is needed to pronounce words clearly (enunciation). Pressure sounds include letters like “b,” “d,” “p” and “t.”

Children with cleft lip and palate often develop other ways to make speech sounds. Once they learn bad speech habits, they are very hard to “un-learn.” It is vital that you work with your child to make sure that early speech habits are learned correctly the first time.

How does the soft palate work?

The soft palate is a muscular door in the back of the mouth. It sits behind the hard palate in the roof of the mouth.

- During speech, the soft palate opens and closes a doorway called the nasopharynx. This doorway is hidden and you cannot see it by looking in the mouth.
- It adjusts sounds and air flow from the throat to make speech sounds.
- If the soft palate doesn’t close the doorway when it should, speech will be too nasal from too much air coming out of the nose.

Speech problems

There are many types of speech problems, but some are common when a child has a cleft palate: hypernasality, hyponasality and articulation errors.

- If the soft palate is too small or if the nasopharynx too big, speech may be hypernasal. This is when the soft palate allows sound to pass through the nose when making words that should not be nasal. As a result, speech sounds too nasal (HYPERnasal).
- If the doorway is too small, speech may be HYPOnasal. This is when sound can’t pass through the nose when it should. As a result, it may be hard to make nasal speech sounds like “m”, “n” and “ing.” A small doorway can also cause breathing problems and snoring.
- Articulation refers to how the sounds are produced. Articulation problems are caused by air leaking out of the nose or by teeth that are out of line. Poor speech habits often result when a child tries to find other ways to make sounds that are hard to make. Many consonant sounds are hard to make if the sound passes through the nose.

Speech and language modeling

Your SLP and the rest of the Children’s craniofacial team will do all they can to make sure your child has the tools to build normal speech and language skills. But you and your family play the most vital roles in this process. Your child will pattern speech after the voices he hears around him each day, so you and your family members are all “models. ”

Children who do not hear enough spoken language may have problems learning speech and language skills. They may not learn certain skills such as using words and grammar because they do not hear them often enough. This is why your role as a speech and language model is so important. As a model, there are a few things you can do to help your child improve his skills:

- Speak clearly and pronounce words well.
- Use short sentences when you speak to your child.
- Avoid “baby talk,” as it does not help your child learn to speak properly.

Repeat words and phrases after your child. Make the sounds clear and add other information. If your child points to a truck and says “ruck” you might say, “That is a red truck. Let’s make it go.”

Since children learn “object” words first, teach your child the names of objects. This includes the names of people, toys, food, utensils and furniture. Name and talk about new objects during shopping trips, walks and visits.

Between 12 to 18 months, children learn that some objects also have parts. Talk about your child’s eyes, nose and hair. A toy car also has parts. Talk about the wheels, doors and lights.

Between the first and second year, children often learn “action” words like walk, eat and play. They also learn words that describe an object like soft, wet and furry.

When your child begins to show interest in books, begin by talking about the pictures. Take turns naming objects and talking about what is taking place in the pictures.

Surgery to improve speech

Surgeries to repair clefts are different for each child. Correcting a soft palate problem often involves the combined skills of your craniofacial surgeon, orthodontist and SLP. Our craniofacial team will study your child and perform many tests to decide how surgery will be done. The structure and function of the soft palate are tested by:

- Looking at and checking your child
- X-rays and videofluoroscopy (motion X-ray pictures)
- Special fiber-optic scopes
- Computerized instruments

These studies help us decide how to treat your child’s problem. If needed, your SLP will teach you about the tests. Most children need only one surgery, but some need follow-up work as well. Your craniofacial surgeon, orthodontist and SLP will talk with you if your child needs further surgery.

After surgery, your SLP may give your child a set of sounds to practice. These speech exercises will most likely become much easier as your child heals. Follow your SLP’s advice to help your child improve his speech as quickly as possible.

Notes about speech and language

Date:

SLP:

Practice sounds for your child:

Notes:

Hearing and the ears

Babies and young children have more ear infections than adults because their ears are different. Babies' eustachian (ear) tubes are shorter and straighter, so fluid cannot drain out as easily. When fluid builds up in the middle ear, it can cause an infection or a hearing loss.

A cleft palate may affect the structure of the upper throat and the eustachian tubes. So, children with cleft palates are more likely to have ear infections and other middle ear problems than most children. Even very mild hearing losses can cause big problems for young children, as they are just starting to learn speech and language skills. Since children with clefts are at a higher risk, their hearing must be watched very closely for any problems. Some doctors prefer to insert tubes in the ears of children with clefts to prevent problems before they occur. As a child with a cleft grows older, ear problems tend to occur less often and be less severe.

Tests

There are a number of tests that help us prevent, locate and treat ear problems. The audiologist on the craniofacial team will discuss your child's tests with you. The audiologist can also tell you how you can prepare your child for them.

Here are some of the most common tests:

- **Tympanometry test** measures pressure in the middle ear and how the eardrum reacts to pressure changes. It can also identify or find holes in the eardrum and show if tubes are working well. This test may be done on children of all ages. It does not hurt.
- **Otoacoustic Emissions (OAEs) test** records how the inner ear responds to sound. A series of tones are played through a small tip that is placed in the ear. The inner ear responds by emitting tones of its own. The test takes only a few minutes, and your child must remain still and quiet. It does not hurt.
- **Auditory Brainstem Response (ABR) test** measures how the hearing nerve and base of the brainstem respond to sound. In an ABR, electrodes are placed on your child's forehead and in front of his ears. ABR testing can tell how much hearing is in each ear.
  - Electrodes are soft pads that connect to the ABR machine by covered wires. They do not hurt or shock your child.
  - Various sounds are made through the earphones and a computer records the brainstem's response.
  - The test takes up to one hour and your child must remain very still the whole time. Most children are given medicine to help them sleep during the test.
- **Behavioral tests** measure hearing by the way that a child responds to sound. They can be done with children as young as 6 to 7 months old. If your child is fussy or distracted, it may take several sessions to complete a test. There are many types of behavioral tests and they all need your child to be involved during the test. The test your child has depends mostly on his age:
  - Your child may sit on your lap while sounds are played through speakers. When your child turns toward the sound, a video will play or a toy will move above the speaker that made the sound.
  - Your child may play a listening game such as dropping a block in a bucket when he hears a sound.
  - Older children may wear earphones and raise their hands when they hear tones.

After your child's hearing is tested, the audiologist will talk with you about the results. The audiologist will also discuss treatment options with you and the Children's craniofacial team.

If you have any questions about your child's ears, hearing or hearing tests, please feel free to ask your audiologist.

Notes about hearing tests

Date of test:

Type of test:

Audiologist:

Notes:

Teeth and other dental issues

A cleft lip and cleft palate often create problems with the upper jaw and teeth. These problems can almost always be solved over time by treatment from a skilled pediatric dental team. Your child's dental team is an important part of the craniofacial team. Members of the dental team may include a pediatric dentist, an orthodontist, a prosthodontist, dental hygienists and assistants, and a craniofacial surgeon. Your child's dental team can take a number of steps to correct problems with your child's teeth and jaws. These steps may be spaced over years.

Common problems

- **Poor occlusion/tooth alignment**
  Occlusion is the way the upper and lower teeth fit together when the mouth is closed. A cleft palate may affect the size and shape of the upper jaw and cause a poor fit.
- **Altered facial appearance**
  A cleft in the upper jaw can affect the shape of your child's face. Such problems can be treated and corrected over time.
- **Early or late appearance of teeth**
  The teeth in the cleft area may appear earlier or later than the teeth around them. Their position in the jaw causes this. These teeth may grow into a normal position. When this occurs with the permanent teeth, they often need to be straightened.
- **Missing, extra and poorly formed teeth**
  Like any other child, a child with a cleft may have a number of problems as teeth grow into the mouth. Poorly formed teeth are more likely to have tooth decay. Your pediatric dentist will talk with you about your child's problems and review treatment options with you as needed.

Orthodontic treatment

Your child's orthodontist at Children's will perform different types of treatments as your child grows older.

Young children

Your dental team at Children's will watch your child's teeth develop for several years until it is time for the bone graft.

- This is surgery to insert bone into the area of the cleft.
- To prepare for the bone graft, the craniofacial team will study X-rays, photographs and models of your child's mouth.
- From these studies, the team will make a treatment plan that is best for your child's needs.

Quite often, a child's upper jaw must be expanded before a bone graft may be done. There are a number of devices to accomplish this goal. The dental team will explain the device that is best for your child.

- An expansion device is usually worn for several months before the bone graft is completed.
- After the bone graft, the device is left in place as a "retainer" for several more months.

Your child may also need other treatments at this time to correct his teeth and jaws. This phase of treatment can take up to a year and a half.

Teenagers

The final phase of treatment usually begins after all adult teeth appear and skeletal growth is complete. The orthodontist will study X-rays, photographs and models of your child's mouth. From these studies, the orthodontist will make a treatment plan that is best for your child's needs.

- More expansion of the upper jaw may also be needed. If your child needs surgery, it will occur about 1 to 1½ years after braces are placed on the teeth. Braces will remain in place after surgery.
- During this phase of treatment, your child will likely begin orthodontic care with braces.

If your child is missing teeth, we may correct the problem with some type of implant. It depends on how many and which teeth are missing. Your dental team will discuss types of implants with you as needed. This phase of treatment often takes two to three years.

Oral hygiene

Teach your child about good oral hygiene as soon as possible. This means keeping the teeth and mouth clean. It begins when your child's first baby tooth appears, and it includes:

- Brushing with a toothbrush and toothpaste that contains fluoride at least 2 times each day
- Using dental floss after meals to clean between teeth
- Visiting the pediatric dentist at least 2 times each year for routine checkups and cleanings

Good oral hygiene can help prevent many problems. It can also help your child achieve the best possible results from treatment.

Notes about dental care

Date of visit:

Type of exam:

Dentist:

Notes:

Neuropsychology services

A neuropsychologist can help check your child's cognitive (thinking and learning) growth. While not all children with cleft lip or palate have cognitive problems, some do have delays in development and learning problems.

Screenings and evaluations

Your child may have a screening test to look for problems with thinking, movement, social and behavioral growth. Screenings may begin when your child is a baby and continue into the teen years. If we find any problems, we can complete more tests to help find the type and extent of the problems. These tests can also point to ways to help your child do better in many areas.

The tests may measure:

- Learning
- Attention
- Memory
- Ability to see and move well
- Problem solving
- Social and emotional function
- Effort and motivation (the desire to do something)

Before the evaluation, we will:

- Look at your child's medical and school records.
- Ask about your child's developmental, social and family histories.
- Ask you and your child's teacher to fill out forms about his learning and behavior.

During the evaluation, we will:

- Use tests to check how your child thinks and behaves. The tests can take one to five hours. This might happen on more than one day.

After the evaluation, we will:

- Look at your child's test results. We will talk to you about the results. We will make suggestions to help him at home and school.
- Make a plan to help your child. We will work with your child's teachers and doctors.
- Help you start your child's plan so he can reach his goals.

When is an evaluation needed?

If your child has problems with:

- Thinking and planning
- Paying attention, learning and remembering
- Doing well in school
- Controlling his negative emotions or reactions about medical treatment

Formal testing is key to learning about your child's cognitive strengths and weaknesses. It can also help your child do his best at home, at school and in the community.

Contact our Neuropsychology Department at 404-785-2849 or visit choa. org/neuropsych for more information.

Notes about neuropsychology

Date of test:

Type of test:

Neuropsychologist:

Notes:

Resources

The social worker as a family resource

Having a child with a cleft lip or palate can be a scary, confusing time. You may have many questions about:

- What resources are available to your child and your family
- What to expect during your hospital visits
- How your child's care will be paid for

The social worker on the Children's craniofacial team can help you find the answers.

The social worker's role is to:

- Help you and your child deal with emotions
- Serve as a link between your family and the hospital
- Direct you to support groups and other sources of information
- Help you find and use available resources

During your first meeting, the social worker may ask you many questions about your family, lifestyle, job and finances. This is to help the social worker learn about your needs and direct you to resources. Your social worker may contact agencies for you or explain how you can contact agencies on your own. You may speak with your social worker in person during your visits and call between visits.

Financial resources

Because each child's needs are different, there is no way to know how much your child's treatment will cost.

- If your child is covered by private insurance, you must let them know about the cleft and your visits to the Children's Center for Cleft and Craniofacial Disorders. Our staff and the staff of your child's doctor's office can help you arrange payment for surgeries and other treatments. You must stay in close contact with your insurance company and keep up with records and bills.
- If your child is covered by Medicaid, you must stay in close contact with your caseworker. When your caseworker asks for information, provide it as soon as possible to prevent problems with your coverage.
- Please tell your social worker if your child is not covered by private insurance or Medicaid, so your social worker can help you apply for other types of financial help.

Community resources

There are many groups that can help you care for your child. Your social worker can discuss these groups with you and help you contact them. They include:

About Face
123 Edward St. Suite 1003
Toronto ON Canada M5G 1E2
Phone: 800-665-FACE
aboutfaceusa.org
Email: info@aboutface. ca

This group provides support and guidance to people with facial differences. They also publish a newsletter and sponsor support groups. Call to find a local chapter.

Children's Craniofacial Association
13140 Coit Road, Suite 517
Dallas, TX 75240
Phone: 800-535-3643
ccakids.com
Email: contactCCA@ccakids. com

This group provides information, a newsletter, parents' networks and an assistance fund for families who must travel for medical care.

Children's Medical Services
Georgia Division of Public Health
2 Peachtree Street NW Room 11-205
Atlanta, GA 30303
Phone: 404-657-4855
health.state.ga.us/programs/cms

This agency can help with the cost of medical treatment and equipment for needy patients and families.

Families of Children Under Stress (FOCUS)
3825 Presidential Parkway, Suite 103
Atlanta, GA 30340
Phone: 770-234-9111
focus-ga. org
Email: inquiry@focus-ga. org

This is a support group for parents of very ill children. It provides a newsletter, a hotline number, monthly support meetings, annual conferences and family get-togethers.

Cleft Palate Foundation
1504 East Franklin Street, Suite 102
Chapel Hill, NC 27514
Phone: 800-242-5338
cleftline. org
Email: info@cleftline. org

This is a nonprofit agency that provides information and doctor referrals to families.

Georgia Advocacy Office
150 East Ponce de Leon Avenue, Suite 430
Decatur, GA 30030
Phone: 404-885-1234
thegao.org

This group provides information, training, referrals and legal advice and representation to people in Georgia with disabilities and mental illnesses. It works with families having problems with public school systems.

Parent to Parent of Georgia
3070 Presidential Parkway, Suite 130
Atlanta, GA 30340-3720
770-451-5484 or 800-229-2038
Fax: 770-458-4091
http://p2pga.org

Provides emotional support and information for parents whose children experience disability or chronic illness. Parents are matched with other parents as closely as possible based on their child's diagnosis. They also host trainings and connect to an online database for resources.

Resources you may want to order

Children With Facial Difference: A Parent's Guide
Published by: Woodbine House 6510 Bells Mill Road Bethesda, MD 20817
Phone: 800-843-7323

This book is a very detailed resource for parents. It explains treatments, emotional issues, children's self-esteem, speech, language, education issues and legal rights.

Children's Healthcare of Atlanta has not reviewed all of the sites listed as resources and does not make any

representations regarding their content or accuracy. Children's Healthcare of Atlanta does not recommend or endorse any particular products or services or the content or use of any third-party websites, or make any determination that such products or services or websites are necessary or appropriate for you or for the use in rendering care to patients. Children's Healthcare of Atlanta is not responsible for the content of any of the above-referenced sites or any sites linked to these sites. Use of the services referenced and/or links provided in this manual is at your sole risk.

GLOSSARY

Some of these terms are used in this manual. You may hear others used by the Children's craniofacial team.

Acoustic nerve: a nerve in the inner ear that sends sound information to the brain.

Alveolar ridge: the bony ridge where the teeth are held in the jaw.

Anterior: the front side.

Antibiotics: medicines to prevent or treat infections.

Articulation: the ability to use the mouth to make speech.

Audiologist: a person who studies sound and hearing.

Audiology: the study of sounds and hearing.

Auditory brainstem response (ABR): a test that measures the response of the brainstem to sound.

Bilateral cleft: a cleft on both sides of a lip or palate.

Bilateral myringotomy: a surgery to implant tubes through the ear drum to allow fluid to drain.

Bone graft: a surgery to insert bone into the area of a cleft lip or palate.

Brainstem: the base of the brain.

Chromosome: a part of a cell that carries genes and other information related to genetic inheritance.

Cleft: a split or separation.

Cleft lip: a congenital split in the upper lip.

Cleft palate: a congenital split in the roof of the mouth.

Columella: the front part of the tissue between the nostrils.

Conductive hearing loss: a hearing loss caused by a problem in the middle or outer ear. Common causes include fluid in the middle ear or wax blocking the ear canal. Conductive hearing losses can usually be corrected with medicine or surgery.

Congenital: this means "born with. "

Craniofacial: relating to the skull (cranio) and face (facial).

Craniofacial surgeon: a surgeon who treats problems with the skull and facial bones.

Craniofacial team: a group of medical professionals who work together to treat people with craniofacial anomalies.

Cuspid teeth: the pointed "canine" teeth on either side of the front teeth.

Dietitian: a person who plans healthy diets for people.

ENT: an ear, nose and throat doctor.

Electrodes: soft pads that stick to parts of the body during some tests. Covered wires connect the electrodes to machines. Electrodes do not hurt or shock your child.

Enamel: the outer layer of a tooth.

Eustachian tube: a tube that runs from the middle ear to the back of the throat. It allows air pressure on both sides of the ear drum to stay equal.

Fistula: an abnormal opening or gap.

Functional: an adjective meaning "working properly. "

Gene: the smallest unit of heredity. Genes contain the "blueprint" for everything in our bodies, such as our height, hair color, skin color and eye color.

Genetic counseling: a study to help find issues of genetic inheritance. It includes physical exams, family histories, X-rays and chromosome testing.

Genetic inheritance: the natural process by which children "inherit" their features from their parents.

Geneticist: a doctor who studies genetics (the study of genes).

Genetics: the study of genes and genetic inheritance.

Gestation: the amount of time a baby spends growing in the womb.

Hard palate: the bony part of the roof of the mouth just behind the teeth.

Hypernasality: a speech problem in which a person's voice sounds too nasal. It is often caused by an opening in (or behind) the palate that lets sound move through the nose.

Hyponasality: a speech problem in which a person has trouble producing nasal sounds because the voice sounds cannot move into the nose.

I. V. : a tube in a vein that allows food, fluids and medicines to be passed directly into the bloodstream.

Inner ear: the innermost part of the ear where sound information is sent to the brain through the acoustic nerve.

Larynx: the area of the throat containing the vocal folds

Malocclusion: a poor alignment of the upper and lower teeth.

Mandible: the lower jaw bone.

Maxilla: the upper jaw bone.

Middle ear: the eardrum and the space just behind it.

Mixed hearing loss: a hearing loss that is partly conductive and partly sensorineural.

Multifactorial inheritance: a type of genetic inheritance in which a feature appears as a result of a number of genetic and nongenetic factors.

Nasal: related to the nose.

Nasal air escape: the escape of air through the nose when pronouncing consonants.

Nasal ala: the part of the nostril that joins the cheek.

Nasal regurgitation: the escape of food through the nostrils during feedings.

Nasal septum: the wall of tissue that divides the nostrils.

Nasal tip reconstruction: surgical repair of the end of the nose.

Nasendoscopy: an imaging study using a camera attached to a very thin fiberoptic scope that passes through the nose to record how the soft palate is working.

Obturator: a device that fits in the roof of the mouth to cover a cleft palate opening.

Occlusion: the way the upper and lower teeth fit together.

Occupational therapist: a person who helps people with daily care activities like feeding and bathing.

Oral hygiene: care and regular cleaning of the teeth and mouth.

Orthodontist: a dentist who uses braces and other devices to correct problems with teeth and jaws.

Otitis media: a middle ear infection.

Otoacoustic emissions (OAEs): a test that records how the inner ear responds to sound.

Otolaryngologist: an ear, nose and throat (ENT) doctor.

Outer ear: the part of the ear you can see and the ear canal.

Palate: the roof of the mouth.

Pediatric dentist: a dentist who treats infant, children, and adolescents.

Pharyngeal flap repair: one type of surgery to improve the function of the palate.

Pharynx: the throat.

Plastic surgeon: a doctor who repairs the function and appearance of parts of the body.

Pre-maxilla: the center of the bony ridge that holds the upper teeth.

Pressure equalization (PE) tubes: tubes that are inserted through the eardrum to allow fluid to drain from the middle ear.

Primary teeth: baby teeth. There are 20 of them.

Prolabium: the central part of the upper lip between the mouth and the nose.

Prosthesis: a man-made replacement for a body part.

Prosthodontist: a dentist who makes and fits false teeth and other oral appliances.

Psychologist: a person with special training to help people with emotional or behavioral concerns.

Pulse oximeter: a wire that attaches to a person's finger and measures the oxygen in the blood.

Secondary teeth: adult teeth. There are normally 32 of them.

Sensorineural hearing loss: a hearing loss caused by a problem in the inner ear or the acoustic nerve. Common causes include genetic inheritance, aging and constant loud noise. Sensorineural hearing losses usually cannot be repaired.

Single gene inheritance: a type of genetic inheritance in which a feature appears as a result of a single gene carried by one parent.

Social worker: a person who provides counseling and resources to people.

Soft palate (also called the "velum"): the movable part of the roof of the mouth behind the hard palate. It is needed for speech.

Speech/language pathologist (SLP): a clinician who evaluates speech and helps people improve their speech.

Speech therapy: treatment given by a speech therapist to help people with speech problems improve their speech. Speech therapy often involves practicing certain speech sounds and patterns.

Sphincter pharyngoplasty: a type of surgery to improve the function of the palate. It places extra muscle on the back wall of the throat.

Supernumerary tooth: an extra tooth.

Sutures: surgical stitches.

Syndrome: a group of congenital problems that appear together in newborn babies. Syndromes may be the result of single gene or multifactorial inheritance.

Tympanic membrane: the eardrum.

Tympanometry: a test that measures pressure in the middle ear and how the eardrum reacts to pressure changes. It can also find holes in the eardrum and show if PE tubes are working properly.

Unilateral cleft: a cleft on one side of the lip or face.

Notes

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