

# Cleft Lip and Palate Resource Handbook

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**Children's**<sup>SM</sup>  
Healthcare of Atlanta



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# Welcome

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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 Hospital.

## 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. 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 visits and make notes. It can help you learn more about your child’s cleft lip and palate.

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

Many of the words and terms in this handbook may be new and confusing. Our craniofacial team can explain them to you and teach you what you need to know.

Please note, this handbook should not replace instruction given to you by your child’s care 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.**

# 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**

Primary nurse (inpatient): \_\_\_\_\_

## 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 old

- Feeding team evaluation

## Stage 2: 3 to 8 weeks old

- 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: Clinic visits for the next 2 to 3 months

- Clinic visits every 1 or 2 weeks
- Feeding follow-up and weight check
- If using a pre-surgical device - Nasal Alveolar Molding (NAM) or Latham Appliance - visit with orthodontist or pediatric dentist to adjust device

## Stage 4: Surgery 3 to 12 months old

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

## Stage 5: Toddler years

- Team visits including the craniofacial surgeon every 1 to 2 years
- First speech evaluation at 12 to 18 months old
- First dental evaluation after the first tooth comes in (or at least by 12 months old). 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 pediatrician

## Stage 6: School-age years

- Team visits 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 old
- Speech therapy
- Possible speech surgery, if needed
- Dental check-ups and cleaning every 6 months
- Dental and orthodontics at 6 to 11 years old, if needed
- Audiologist or ENT screening
- Continued well child exams with your child's pediatrician

## 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

You may have many different feelings as you care for your child. At first, it may be hard to accept that years of treatment and progress lie ahead. Keep in mind the outlook is good. Treatment advances continue to be made. Your child can reach adulthood with a good sense of self, an acceptable appearance and healthy social skills.

- How you cope with your feelings is important to your child's health.
- Your child will look to you for hope and strength.
- How you react 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 not 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 important to your child.

### Set a positive example for your child.

Children can sense the feelings of the adults around them.

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

### Be prepared for teasing and other social problems.

Do not shelter your child from other children to protect them. The more time they spend with other children, the sooner your child will learn to manage social situations. There are 3 points in time when this may be extra challenging:

- The first year in school. This is when your child goes outside the home and loses some "special" status.
- The early teen years. This is when your child is very aware of changes in their body. They may feel an increased need to fit in with others.
- The later teens. This is when your child will start to want closer relationships. They will want to be seen as "special" by someone else. It may be helpful to role-play a teasing event at home. This can help your child practice new ways to cope with these events.

### Use the Children's craniofacial team as a resource.

The Children's craniofacial team can help you prepare for and cope 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 scared 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 get jealous because they do not know why you need to spend extra time with their new sibling. This is normal.

- Tell your other children that they are also important to you.
- Hold, comfort and love all of your children (this includes 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. 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?

Your child may have "inherited" their cleft from one or both parents. Other factors can also happen 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 2 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 non-genetic 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 do genetic tests (such as blood tests).
- Ask you for a detailed family health history.
- Ask you for a detailed pregnancy history.

After these are done, the geneticist will talk with you about:

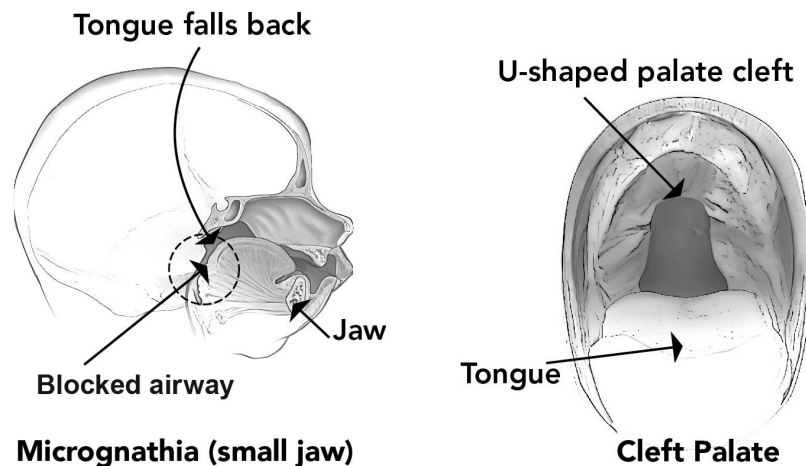
- The possible cause of the cleft.
- Your risk of having another child with a cleft.

### Syndromes

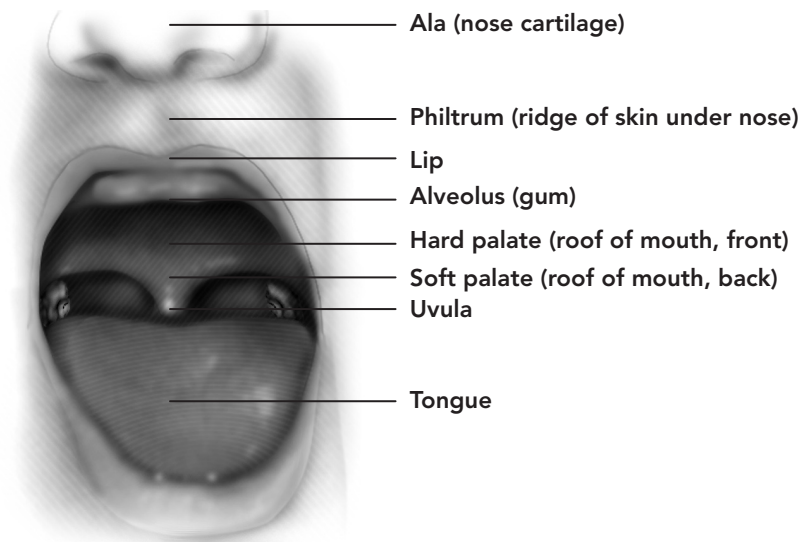
Sometimes, groups of problems appear together in newborn babies. These groups are called syndromes. A cleft lip or palate may be only one part of a larger syndrome, such as Pierre Robin Syndrome (Picture 1).

- 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**



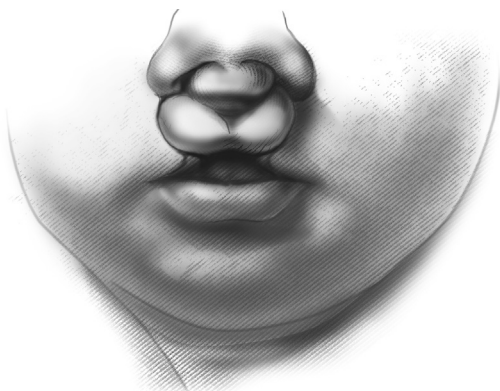
**Image 3: Unilateral (one-sided) complete cleft lip**



**Image 4: Unilateral incomplete cleft lip**



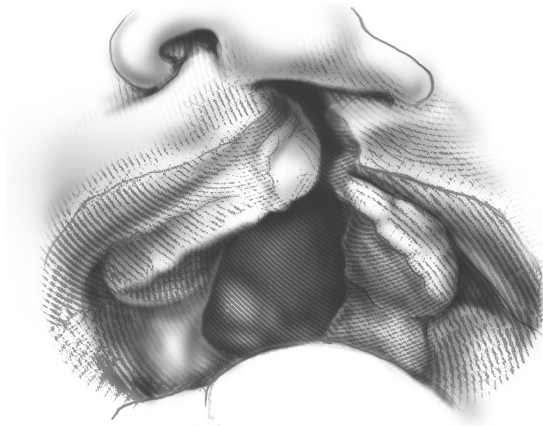
**Image 5: Bilateral (both sides) complete cleft lip**



**Image 6: Bilateral incomplete cleft lip**



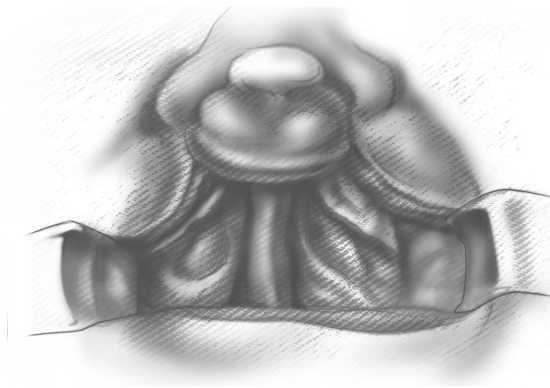
**Image 7: Unilateral complete cleft lip and palate**



**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 them. The plan will need 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 does many of your child's facial surgeries.
- Dental hygienist (hi jen' ist) or assistant: A person who provides many types of dental care and teaching 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 breastfeeding and pumping breast milk.
- Neuropsychologist (ner o sy call' a jist): A person who tests children to find out about and help with cognitive (mental skills) problems.
- Nurse: A person who coordinates care and provides teaching.
- Nutritionist (new trish' on ist): A person who plans healthy diets and helps with feedings. Also called a dietician.
- 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.
- Speech-language pathologist (path ah' lah jist): A person who helps children improve their speech. Also called a speech therapist.

# Feeding your baby

Our feeding team will check to see how your baby is feeding and to see what type of help your baby needs. Our goals are for you to feel comfortable and supported and for your baby to grow and thrive. The feeding team can help:

- Try special bottles.
- Show you ways to hold your baby during feeds.
- Teach you common signs of trouble swallowing.

Babies with a cleft lip or palate can tire easily when feeding. For this reason, feedings should last no more than 30 minutes. Your baby may not have enough suction to drink from a standard bottle or feed directly from the breast. This is based on the type and size of their cleft.

## Nutrition

Nutrition is very important for your baby to gain weight. It can also help towards a successful surgery. A nutritionist with the feeding team will check your baby's nutrition status at 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

Most often, it is best if your baby regains their birth weight by 14 days of age. Most often, your baby will gain weight very fast for the first few months of life (about 1 ounce per day).

Nutrition is important throughout your child's life. Our nutritionist can work with your child or connect you with the right 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 can maintain a latch with good suction for a full feed.

- It is important to pump breast milk from the start.
- Use a double electric pump for best results. If you can, use a hospital grade, multi-user pump. You may borrow one from WIC or rent one.
- You may be able to get a pump through your insurance. Ask the lactation team at your birth hospital for more details.
- It is important to have enough freezer storage. You can store frozen breast milk for a longer amount of time. This way, you can build up a supply.

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

Your breast milk helps your baby in many ways, such as:

- Strengthens your baby's health before surgery
- Helps your baby's health after surgery
- Protects your baby from infection
- Is easy to digest and has many nutrition benefits

## Special bottles and nipples

Avoid buying bottles before your baby is born. Your baby will often need something different than what you thought. The feeding team will help choose the best bottle and nipple for your baby. They will give you 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

- When you feed your baby, keep their in an upright position between 45 and 90 degrees (unless told otherwise).
- Keep your baby's mouth and nose clean. You may use:
  - A bulb syringe to help suction their nose.
  - Nasal saline spray 20 to 30 minutes before you feed them. This is to help clear congestion.
- Liquid and food may come through your baby's nose at some point. When this happens:
  - Take a moment to wipe it away.
  - Let your baby sneeze or cough.
  - Then, start feeding again.
- Burp your baby often during feedings (about every 10 to 15 minutes).
  - Cleft lip or palate babies tend to swallow more air.
  - This can make your baby more prone to spitting up.
  - Your baby may pull away from a feeding because their stomach is full of air (and they feels full).
- After you feed your baby, wait 30 minutes before you lay them down flat. This can help reduce the chance of spit ups.

## Feeding and NAM therapy

If your baby needs NAM therapy, they may go through a time where feeding is hard. Our feeding team is here for you and can help your baby adjust. Some babies may need help to self-calm when the NAM device is first put in place. There are many tips to help make this time easier. Talk with a member of your baby's care team for more details.

## Feeding milestones

When your baby is about 6 months old, talk with their pediatrician about purees (such as baby cereal and baby food).

- Your baby's cleft lip or palate does not need to cause them to be late to eat these foods.
- Feed your baby purees with a spoon. Do not put purees in the bottle or let your baby suck from a pouch.
- Be sure to keep their nose and mouth clean after meals.

## Feeding after surgery

Your baby's feeding schedule may be different for a few days after surgery. During clinic visits, talk with your baby's care team about how to prepare your baby for surgery.

Most often, after a palate repair:

- No bottles after surgery (check with your baby's surgeon for more details).
- No pacifiers after surgery (check with your baby's surgeon for more details).
- Use an open cup or 360 cup.
  - You may start to use an open cup when your baby is about 6 months old and has started spoon feeds. This way they can practice drinking.
  - If you have concerns, please talk with your baby's care team for more options.
- Use the side of the spoon to offer spoon feeds (instead of straight on).

# 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 get your baby's lips and palate ready for surgery. Your child's doctors will help decide if your baby needs a device.

## 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. It helps to move and reshape the cleft area as your baby grows. This will help get your baby ready for more cleft repair during surgery.

### How does a NAM work?

At your baby'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 3 to 4 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 their nose.

### Why should my baby use NAM?

Children with cleft lip and palate may need 5 to 7 surgeries. Sometimes, they even need surgery into their teen years. The NAM mold helps:

- During the first surgery and helps mold the nose.
- Reduce the number of surgeries your baby needs during their life.
- With feeding (it covers the roof of your baby's mouth).
- Improve your baby's appearance.

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

- Most often, it is fitted when a baby is about 2 weeks old.
- Your baby will wear the mold 24 hours a day until their first surgery. Most often, this happens at about 4 to 5 months old.
  - NAM is used when your baby is young because their tissues (cartilage) are flexible.
  - After they are 2 months old: their cartilage is not as flexible, their teeth start to come in and they are able to take out the device on their own.

### What do I need to do?

You will need to give your baby extra care and time. You will be caring for the NAM at home. Your help is important 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 mold as needed.
- Attach the tape to your baby's face as needed. This is to keep the NAM mold in place.

# Surgery

Children with cleft lip and palate can have surgery to help:

- Restore function to help them feed, eat and talk.
- Give them a more normal appearance.

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

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

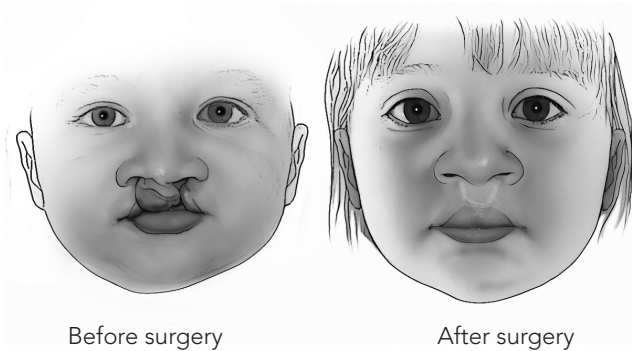
## First year surgeries

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

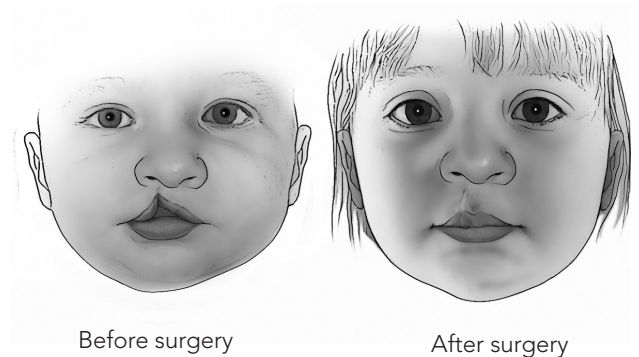
- A cleft lip repair at 3 to 5 months of age (Pictures 10 and 11)
- A cleft palate repair at 9 to 12 months of age (Picture 12)
- A mandibular distraction (lengthening the jaw) surgery (Picture 13)

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

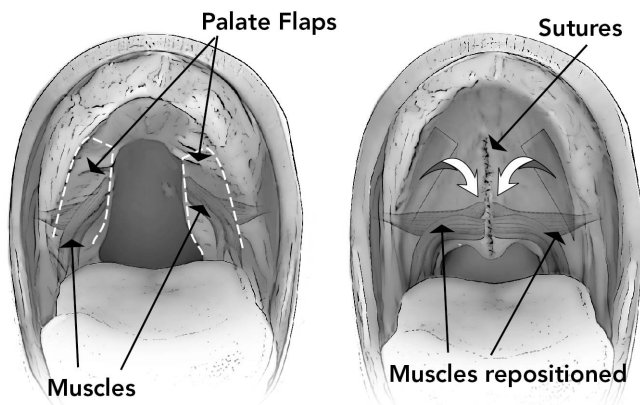
**Image 10: Bilateral (both sides) complete cleft lip repair**



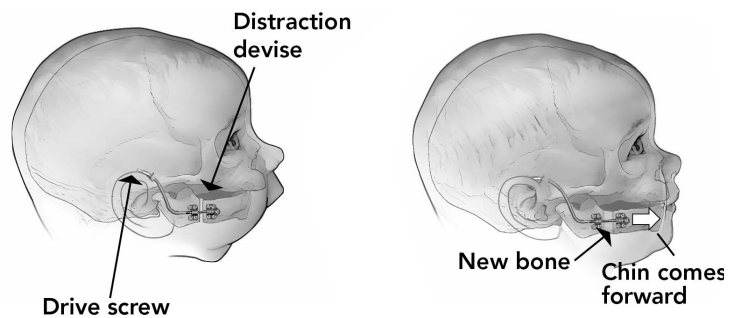
**Image 11: Unilateral (one side) complete cleft lip repair**



**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 them. 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 baby will have a few tubes and wires attached to them. These may include:
  - A pulse oximeter. This is a monitor that measures the oxygen in your baby's blood. A soft, plastic wire leads from the monitor and is attached to your baby's finger with a bandage. The wire will not hurt or shock them.
  - An I. V. (intravenous) line. This is a thin, soft, plastic tube that goes into your baby's veins. It gives your baby food, fluids and medicines that they cannot take by mouth.
- Your baby may have some discomfort after surgery. They may get pain medicine through the I.V. or by mouth.
  - Pain medicines can make them unsteady on his feet.
  - To help prevent falls, be sure to keep their side rails up. Watch them carefully if they try to stand or walk.
  - Make sure their shoe strings are tied and pant cuffs are turned up.
- Your baby may get other medicines (such as antibiotics) to help prevent infections caused by germs or yeast.
- There may be some bloody drainage from the surgery site. Do not be alarmed. This is normal for the first 1 to 2 days.
- Your baby may be extra fussy for a while after surgery. This is normal for the first 3 to 5 days.
- Your baby may need arm immobilizers (restraints) at home to keep their arms straight. These help prevent them from touching their mouth area.
  - If so, loosen the restraints a few times each day to check for skin problems.
  - Only loosen one at a time. Do not let your baby's hand near their mouth.

- Ask your baby's nurse how to work with the arm restraints.
- After cleft lip surgery, your baby may not be able to use a pacifier for 2 weeks. Talk with your baby's surgeon for more details.
- After palate repair surgery, your baby may not have a bottle for 2 weeks. Your baby may have syringe feeds or liquids from a sippy cup. Talk with your baby's surgeon for more details.
- You may start to feed your baby by mouth soon after surgery.
  - Start to give your baby solid food when they are 5 to 6 months old (or as advised by their pediatrician). This will help prepare them for the feeding restrictions that happen in the early stages after palate surgery.
  - This way, your baby knows how to spoon feed and is not dependent on the bottle at the time of surgery.

### After you go home

- Your baby 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 3 to 6 weeks.
  - At this visit, we may teach you how to help reduce the scar on the lip.
- If your baby 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, your baby will need clinic visits every 6 to 12 months. This depends on their needs.
  - The team will check on your child's facial growth, hearing, speech, and mental and motor development.
  - The team will provide treatment as needed.
  - You will need to make clinic visits less often with time.



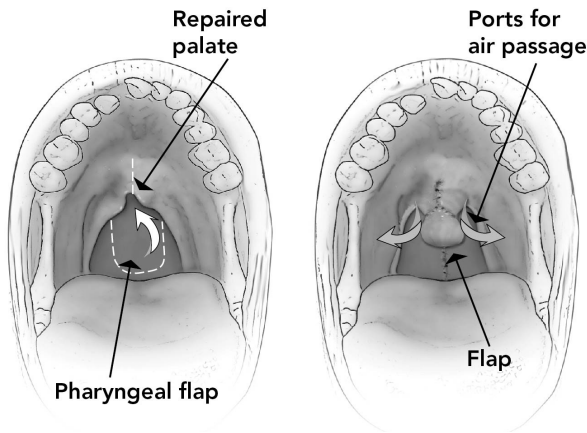
## Future surgeries

As your child grows, they may need more surgeries at different ages. This depends on their treatment plan and any problems that might arise.

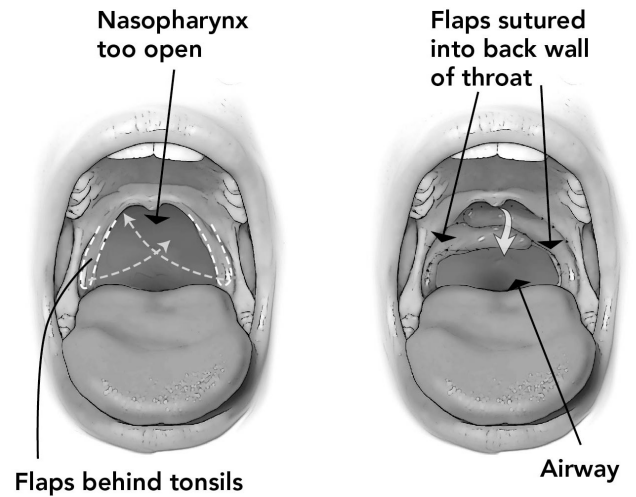
- Your child will be screened on a regular basis by a speech-language pathologist. This is to watch their speech progress. If air is escaping from your child's nose, this may need to be repaired in surgery (Pictures 14 and 15).
- Before your child reaches school age, they may have a revision of the lip scar (Picture 16).

- When your child is 8 to 11 years old, the cleft in their upper gum will be repaired using bone graft.
- During your child's mid-teens, they will have the final repairs to the lip, nose or palate. They may also need surgery to move one or both of their jaws to improve the position of their teeth (Picture 16).
- Your child should have regular hearing checkups. This is to see if they needs to visit to an ear, nose and throat doctor. Children with chronic ear infections may need ear tubes.

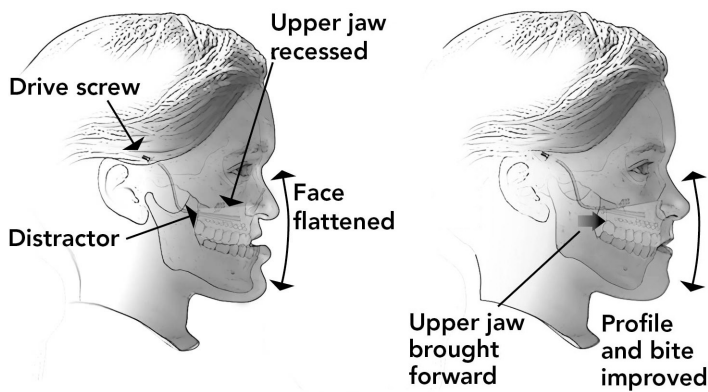
**Image 14: Pharyngeal (back part of the roof of the mouth) flap surgery**



**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 they may be sent home on the same day. At other times, they 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. It is important for your child to have a parent or family member nearby. They 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 brought to your child's room for an extra 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. The address is 5420 Peachtree-Dunwoody Road, Atlanta, GA 30342.
  - Rooms may be limited. Rooms are assigned based on how far away your home is from the hospital and family need.
  - Call 404-847-0760 for more details. You may call Monday through Friday from 8:30 a.m. to 8:30 p.m.
  - You may call Saturday from 9 a.m. to 1 p.m. and Sunday from 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. They must be screened before they can go into your child's room.
  - The nurse will ask questions about any possible illness.
  - This includes brothers and sisters. It is done with each visit.
  - The visiting child will get a special sticker to wear during the visit.
- Brothers, sisters and other visitors less than 12 years of age must be with a parent. They must stay 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:

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Type of surgery:

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Doctor:

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Notes:

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# Speech and language

A speech-language pathologist (SLP) will work with your child on speech and language. Your SLP will:

- Check your child as they grow to see how their speech and language function develops.
- Give treatment advice based on the check-ups.

Your child's treatment may include speech therapy and surgery. Most often, your child can speak in a normal way for their age by their 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 treatments your child may need.
2. Your child must have someone teach them to speak.

Children learn to speak by listening to people speak. You can help your child start to link spoken words to objects and actions.

- Talk to your child about the objects and actions in their world often. This includes people, toys, food, playing, bathing and feeding.
- Read 2 or 3 books to your child each day. Reading is a great way to help them 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 their speech.
4. Your child's intelligence must grow in order for their 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 start to practice for speech early in the first year of life. Speech starts with sounds that are easy to make.

- This includes vowel sounds such as a, e, i, o and u.
- In time, speech moves onto harder sounds 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). This includes sounds like "Dadada," or "Mamama."
- Then, they make real speech sounds and words.
- Once a child can put speech sounds together to form words, then they can start to make sentences.

It may be hard for your child to move through these steps. This may be due to an opening into their 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 3 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 of the mouth.
- For the 16 pressure consonants sounds, this is vital because air pressure is needed to say 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 important for you work with your child. Make sure that he learns early speech habits right 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. 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 does not close the doorway when it should, speech will be too nasal. This is from too much air coming out of the nose.

## Speech problems

There are many types of speech problems. Common speech problems for a child with a cleft palate include:

- Hypernasal
- Hyponasal
- Articulation

### Hypernasal (too nasal)

- If the soft palate is too small or if the nasopharynx is too big, speech may be hypernasal.
- This is when the soft palate lets sound pass through the nose when making words that should not be nasal.
- As a result, speech sounds too nasal

### Hyponasal

- If the doorway is too small, speech may be hyponasal.
- This is when sound can not 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 (how sounds are made)

- Articulation problems are caused by air that leaks 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 child's SLP and care team will help make sure your child has the tools to build normal speech and language skills. But you and your family play the most important roles in this process. Your child will pattern speech after the voices they hear around them each day. 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 the right way.

Other tips include:

- 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."
- 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 1 and 2 years old, 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 starts to show interest in books, talk to them 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 do many tests to decide how surgery will be done. The tests will look at the structure of your child’s soft palate and how it works. These tests help us decide how to treat your child. If needed, your SLP will teach you more about the tests.

Tests may include:

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

Most children only 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.
- Most often, these speech exercises will get much easier as your child heals.
- Follow your SLP’s advice to help your child improve their speech as quickly as possible.

# Notes about speech and language

Date:

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Speech-language pathologist (SLP):

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Doctor:

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Practice sounds for your child:

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# 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. 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. This is because 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.
- Your child's doctor may want to place tubes in your child's ears. This is to prevent problems before they happen.
- As your child grows older, ear problems tend to happen 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 fix 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 giving off tones of its own. The test only takes a few minutes. Your child must stay 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. Electrodes are placed on your child's forehead and in front of their 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.
  - Different sounds are made through the earphones. A computer records the brainstem's response.
  - The test takes up to 1 hour. Your child must stay 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. Most often, the test your child has depends on their 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 they hear 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 talk about treatment options with you and your child's care team.

Please ask your child's audiologist if you have any questions about your child's ears, hearing or hearing tests



# Notes about hearing tests

Date of test:

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Type of test:

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Audiologist:

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# 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
- Orthodontist
- Prosthodontist
- Dental hygienist and assistants
- 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 or 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. Your child's care team can treat and correct these problems over time.

### • Teeth come in early or late

The teeth in the cleft area may come in 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 happens with the permanent teeth, they often need to be straightened.

### • Missing, extra and poorly formed teeth

Your child may have problems as their teeth grow into their 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 place bone into the area of the cleft.

- To prepare for the bone graft, the craniofacial team will look at X-rays, pictures and models of your child's mouth.
- Your child's care 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 help with this. The dental team will explain the device that is best for your child.

- Most often, your child will need to wear an expansion device for several months before the bone graft.
- After the bone graft, the device is left in place as a "retainer" for several more months. Most often, your child will get top braces 4 to 6 months after the bone graft to help align those teeth.
- After the expander and braces are removed, your child will get a retainer to wear until they are ready for the next phase of orthodontic treatment.

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

### Teenagers

Most often, the final phase of treatment starts after all the adult teeth come in and skeletal growth is complete. The orthodontist will study X-rays, pictures 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.

Your child may need:

- More expansion of his upper jaw. Orthodontic care with braces.
- Surgery. This will happen about 1 to 1½ years after their braces are placed. Braces will stay in place during and after surgery.
- Retainers (after braces are removed). They will always need to wear these at night time to maintain the alignment.

If your child is missing teeth, they may need artificial teeth on their braces or retainer. This is to maintain space for future implants. It depends on how many and which teeth are missing.

Your dental team will discuss types of implants with you as needed, but these implants will not be done at Children's Healthcare of Atlanta. As those are adult dental needs, your family dentist will help you get those implants placed. This phase of treatment often takes 2 to 3 years.

## Oral hygiene

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

- Brush with a toothbrush and toothpaste (with fluoride) at least 2 times each day.
- Use dental floss after meals to clean between teeth.

- Visit 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:**

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**Type of exam:**

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**Dentist:**

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**Notes:**

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# 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 start when your child is a baby and continue into the teen years. If we find any problems, we can do 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 health 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 their learning and behavior.

### During the evaluation, we will:

- Use tests to check how your child thinks and behaves.
- The tests can take 1 to 5 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 suggest things to help them 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 they can reach their goals.

### When does my child need an evaluation?

If your child has problems with:

- Thinking and planning
- Paying attention, learning and remembering
- Doing well in school
- How they control their negative emotions or reactions about health treatment

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

Contact our Neuropsychology Department at 404-785-2849 or visit [choa.org/neuropsych](http://choa.org/neuropsych) for more information.

# Notes about neuropsychology

Date of visit:

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Type of test:

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Neuropsychologist:

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# 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 to pay for your child's care.

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 cope 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 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 you can. This is to help prevent problems with your coverage.
- Please tell your social worker if your child is not covered by private insurance or Medicaid. 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 talk with you about these groups 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 patients and families in need.

### 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 handbook. 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 brainstem's response 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. Most often, conductive hearing losses can 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 healthcare team that works together to treat people with craniofacial needs.

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

**Dietitian:** A person who plans healthy diets for people. Also called a nutritionist.

**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 lets air pressure on both sides of the ear drum 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 tests.

**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 making nasal sounds. This is because the voice sounds cannot move into the nose.



**I. V.:** A tube in a vein that lets food, fluid and medicines go straight 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 part of the throat that has 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 saying consonant sounds.

**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:** A test that uses a camera attached to a very thin fiberoptic scope. The scope 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 teens.

**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 placed through the eardrum to let fluid 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 devices.

**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. Most often, this type of hearing loss 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 person who evaluates speech and helps people improve their speech. Also called a speech therapist.

**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 the right way.

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

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