



A guide for families of children with cleft lip and palate



**Written by the Regional Cleft Lip and Palate Team
at Hamilton Health Sciences**

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Introduction

Welcome to the Cleft Lip and Palate Team. We are dedicated to helping families of children born with cleft lip and palate.

As parents, you are important members of the team. You will work closely with many different health care providers. Each health care provider will contribute to your child's care and give you information and support.

Please feel free to ask us questions at any time. We want you to feel comfortable caring for your child and making decisions about his or her care.



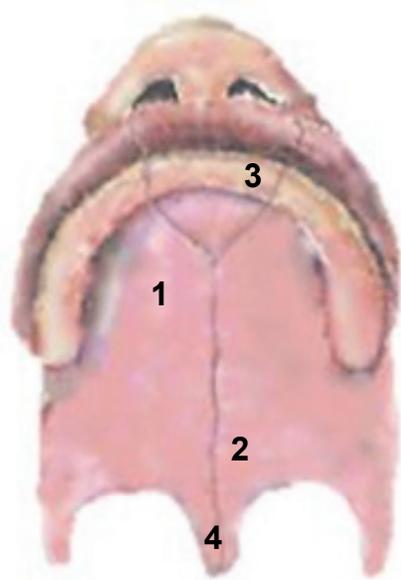
Reading this book can help you learn about:

- Cleft lip and palate, and how this may affect your child
- The health care providers on the team
- Services available to help your child, from birth to 22 years of age

The normal palate

A normal palate or roof of the mouth is divided into the following parts:

1. Hard palate
2. Soft palate
3. Alveolar ridge, where teeth come in
4. Uvula



One in every 600 to 700 children is born with a cleft lip and/or palate.

Clefts often run in families, which means there are inherited factors that may cause a cleft. Environmental factors may cause a cleft as well.

What is cleft lip and palate?

A **cleft lip** means an opening or a separation of the lip. A cleft can be on one or both sides of the lip. It can range from a small notch in the red portion of the lip, to the complete separation of the lip running into the base of the nose.

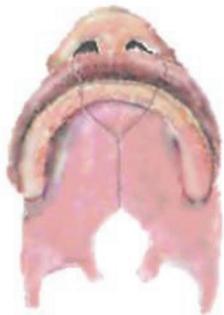


Complete Unilateral

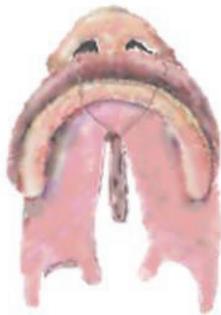


Complete Bilateral

A **cleft palate** means an opening or separation of the roof of the mouth. A cleft can be on one or both sides of the palate. It can be complete and separate the entire length of the palate, or incomplete and only part of the palate is affected.



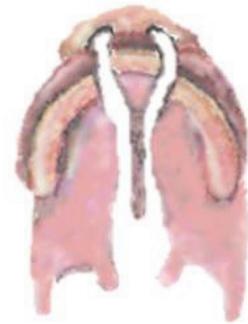
Soft Palate Cleft



Cleft of Hard
& Soft Palate



Complete Unilateral
Cleft Lip & Palate



Complete Bilateral
Cleft Lip & Palate

A child can have:

- a cleft of the lip and palate together, or
- just the palate alone, or
- just the lip.

The type of cleft and the severity range from child to child. Clefts of the lip and palate can be repaired with surgery.

How important is the palate?

We use our palate when eating and to speak. Muscles attached to the palate are important for preventing ear and hearing problems. The alveolar ridge of the palate is where our teeth come from. These are all areas where a cleft palate can cause a problem.

A cleft palate can cause problems with:

Feeding

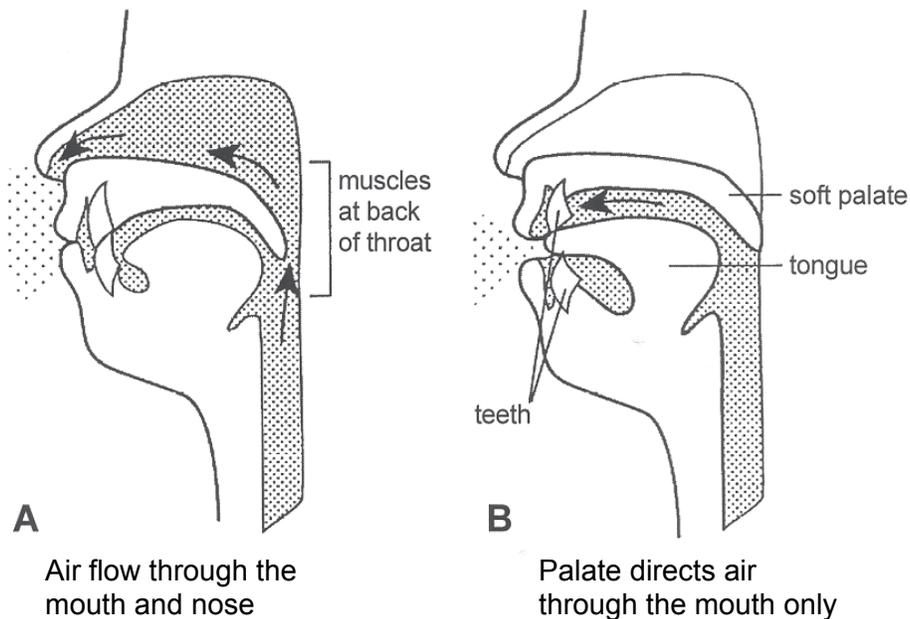
- Feeding can be difficult before the palate is repaired.
- The cleft in the palate creates an opening between the roof of the mouth and the nose. This makes it difficult for the baby to create the vacuum necessary to withdraw fluid from the nipple.
- The use of special feeding bottles may be necessary and will be arranged for you by the newborn consultant on the team or your baby's birth hospital.

Hearing

- Many children with cleft lip and palate have fluid build-up behind the eardrum. These children have some temporary hearing loss during the fluid build-up.
- Many children with cleft lip and palate need to have ear tubes to get rid of the fluid build-up and to prevent more fluid from developing.

Dental

- If the alveolar ridge is separated, there can be problems with teeth coming in straight. There may even be some teeth missing.



Speech

- There may be problems with speech development, even after the palate is repaired.
- Some children with cleft palate have difficulty using the soft palate to stop air from flowing through their nose while speaking. This can lead to nasal sounding speech. In some cases it can also cause problems when learning to pronounce letters and speech sounds.

Other areas

- Some children may have some additional medical problems.
- Sometimes a syndrome will be identified. A syndrome is a pattern of features occurring together. Knowing that there is a syndrome can alert us to other potential problems or health risks. Knowing this allows us to address them earlier.

The McMaster Children's Hospital Cleft Lip and Palate Team can help you and your child deal with any of these problems.

Team members

Audiologist

- A specialist in hearing testing and hearing aids. An audiologist tests the middle ear function and identifies hearing loss.

Coordinator

- The team coordinator manages the dental funding program and the team's activities.

Developmental Pediatrician

- A doctor who provides care for children with developmental needs.

Ear, Nose and Throat (ENT) Specialist

- A doctor who specializes in difficulties with the ears, nose and throat. These doctors may also be called otolaryngologists.

Newborn Consultant

- A newborn consultant helps with early feeding and weight gain, and helps co-ordinate your baby's early appointments.

Oral Surgeon

- A dental specialist who performs surgeries involving the bony structures of the mouth and jaws.

Orthodontist

- A dental specialist concerned with the correction of misalignment of the teeth and jaws.

Most team members work from the Ron Joyce Children's Health Centre located at 325 Wellington Street North, Hamilton.

Pediatric Dentist

- A dentist that specializes in the care of children.

Plastic Surgeon

- A doctor who specializes in surgeries involving the soft tissue such as the lip, nose and palate.

Prosthodontist

- A dental specialist who makes appliances for the mouth. This may be to replace missing teeth. Appliances can also be made to correct nasal speech.

Secretary

- Arranges appointments and clinics. Handles dental billing.

Social Worker

- A health professional who provides support and counseling to help parents, children and/or other family members cope with concerns related to cleft lip and/or palate.

Speech-Language Pathologist

- A specialist involved in the assessment and treatment of communication difficulties. A speech-language pathologist helps your child with pronunciation, language and nasal sounding speech.

Sometimes you will need to see medical specialists in their offices in the community.

What services are available?

Children with cleft lip and palate have needs that change as they grow and develop. The services of the team start at birth. These services are available until your child is 22 years old.

The team sees your child regularly. The team tries to anticipate his or her needs so that possible problems can be dealt with early or even prevented.

The following pages outline how the team checks your child, and the services offered.

The Cleft Lip and Palate program is divided into 3 age ranges:

- Birth to 2 years
- Two to 6 years
- Seven to 22 years



Birth to 2 years



In the first 2 years, a number of members of the team will see you and your child.

If possible, the team secretary will help arrange appointments on the same day.

This may include visits with the following team members.

Newborn Consultant

The newborn consultant is often the first team member you will meet. She or he will:

- Visit you in the hospital, help you feed your baby and show you special bottles to make feeding easier
- Be available to follow up with you to check that your child is gaining weight and help with any feeding problems
- Give you information about cleft lip and palate and answer your questions
- Show you a scrapbook of photographs before and after cleft lip surgery
- Introduce you to the services of the Cleft Lip and Palate Team
- Help you co-ordinate early appointments with other team members

Developmental Pediatrician

The pediatrician will see your child in the first month. In this visit the pediatrician will:

- Review pregnancy history, family history and examine your baby
- Evaluate if there are other medical problems related to the cleft
- Review how your child is feeding and your child's weight gain
- Answer any questions you may have about your child's cleft lip and palate
- Arrange other appointments with other specialists as needed
- Schedule a follow-up visit depending on your child's physical and developmental needs

Social Worker

The social worker may be at your first pediatric appointment. The social worker is available throughout your child's involvement with the Cleft Lip and Palate Team to:

- Provide emotional support and counseling related to diagnosis, surgery, starting school and becoming a teen and young adult
- Offer individual, couple, family and group counseling
- Help you find resources and parent information groups in your community
- Help your child and family deal with issues such as bullying, self-esteem and anxiety

Pediatric Dentist

Your baby may be referred to the pediatric dentist for **lip taping** and/or other dental devices. This helps bring the sides of the gum closer together and make it easier to do surgery. This will help the surgeon repair your child's cleft lip or palate.

All children will see the pediatric dentist at about 1 year of age.

Plastic Surgeon

- If your child was born with a cleft of the lip, you will see the plastic surgeon within the first few weeks. If your child was born with a cleft palate only, your first appointment may be several months later.
- The plastic surgeon will discuss what is involved in the lip repair surgery. This surgery is usually done at about 3 months of age.
- If your child has a cleft palate, the plastic surgeon will discuss what is involved in the palate repair surgery. Palate surgery is usually done at about 12 months of age. It may be done as early as 9 months, or as late as 18 months of age.

Ear, Nose and Throat (ENT) Specialist

The pediatrician or the audiologist may refer you to the ENT Specialist if there are concerns with repeated ear problems. Your child may see the ENT Specialist in his or her office. All children with cleft palate see the ENT specialist at about 7 months of age.

The ENT specialist may recommend:

- Medical treatment for your child's ear problems, such as antibiotics
- Surgery to place **ear tubes** in the ear drum. This is usually done at the same time as palate surgery.

Audiologist

The audiologist will monitor your child's hearing. The timing will depend on the results of the newborn screening in hospital. Young babies are tested while sleeping. Older babies are tested wide awake.

After that, the audiologist will recommend:

- A review every 6 months up to age 2 to check hearing and to watch for problems with fluid in the middle ear. This care is often co-ordinated with the pediatrician or speech-language pathologist
- Reviews more often if there are ear problems
- A review with the ENT Specialist if needed

Speech-Language Pathologist

If your child has a cleft palate, he or she will see the speech-language pathologist at about 1 year of age. If your child has a cleft lip only, the first appointment will be around 2 years of age. This appointment is to assess early communication skills and give you ideas to help your child's speech develop.

The speech-language pathologist may recommend:

- Seeing your child again in three to six months
- Seeing you and your child every month for therapy. These visits are to show you what you can do to help.

Other areas of concern

If your child has problems with development in other areas such as delays in walking, your child may be referred:

- To Infant Development Services close to where you live
- For a consultation with a geneticist, occupational therapist or physiotherapist

Procedures that may be considered in the birth to 2 year range:

- Infant orthopedic dental plates
- Lip repair surgery
- Palate repair surgery
- Ear tubes, often at time of palate repair surgery

Two to 6 years

When your child is 2 years old, he or she will come to the **2 to 6 Clinic**.

In one afternoon, you and your child will see the:

- Pediatrician with the Social Worker (as needed)
- Audiologist
- Speech-Language Pathologist



Each appointment is for one half hour. A summary report will be written. You will receive a copy of this report in the mail. If there are concerns with your child, follow up appointments for treatment will be necessary.

Your child may attend the 2 to 6 Clinic once a year, or less often.

Also in the 2 to 6 year range, your child:

- May need hearing assessments
- May need a review with the ENT specialist in his or her office
- May need speech therapy. If you live in the area, it will be provided by the team. If you live further away, the team speech-language pathologist will help you find therapy for your child in your community.
- May attend the VPI CLINIC to investigate nasal sounding speech
- Should be followed by a family dentist or pediatric dentist
- May see the plastic surgeon in his or her office
- May be referred for a consultation with a geneticist, occupational therapist or psychometrist

Procedures that may be considered in the 2 to 6 year range:

- Ear tubes
- Lip revision
- Pharyngeal flap surgery
- Reconstruction of the nose

Seven to 22 years



When your child is 7 years old, he or she begins to attend the **7 Plus Clinic**.

In the morning you will have pediatric, audiology and speech-language appointments. The Social Worker may also attend.

In the afternoon, your child will see the:

- Pediatric Dentist
- Orthodontist
- Oral Surgeon
- Prosthodontist
- Plastic Surgeon
- ENT Specialist

A summary report will be written and a copy mailed to you.

Children and young adults return to this clinic as needed. It may be needed every 1 to 3 years.

Also in the 7 to 22 year range, your child or teen:

- May need hearing assessments
- May need speech therapy. This would be arranged through the school system and provided at the school. The team speech-language pathologist would be available as a resource for the school.
- May attend the VPI Clinic to investigate nasal sounding speech
- May need a review with the ENT specialist in his or her office
- May be referred for a consultation with a geneticist

Procedures that may be considered in the 7 to 22 year range:

- Alveolar bone grafting
- Orthodontics (braces)
- Pharyngeal flap surgery
- Maxillary advancement
- Prosthetics
- Reconstruction of the nose

Dental and orthodontic funding

Through the Cleft Lip and Palate Program, the Ministry of Health will provide up to 75% of the cost of specialized dental treatment not covered by private dental insurance. Our team dentist reviews all requests for funding. The Ministry of Health requires at least one team assessment to help develop a treatment plan. A team assessment takes place in the 7 Plus Clinic and will be organized by our Team Secretary.

If you have any questions about dental funding, you can contact the Team Coordinator or Team Secretary.

Where is the team located?

McMaster Children's Hospital is part of Hamilton Health Sciences, a "family" of hospitals and a cancer centre. The services of McMaster Children's Hospital are provided at two locations in Hamilton. Depending on your child's needs you may need to visit both locations.

Ron Joyce Children's Health Centre (RJCHC)

- 325 Wellington Street North.
- Most clinic appointments are on the 2nd floor of the RJCHC

McMaster University Medical Centre

- 1200 Main Street West (near the Main Street West exit of Highway 403).
- Surgeries are done at the McMaster University Medical Centre.
- You may also need to visit the medical and dental specialists in their offices in the community.

How do you find out more?

Talk with a team member

- You may have questions or want to know more about the team and its services. The team also has more information about cleft lip and palate, and related conditions.
- Contact a team member by telephone or ask your questions the next time you are in for an appointment.

Visit the McMaster Children's Hospital website

- Go to the Cleft Lip and Palate Team webpages:
www.mcmasterchildrenshospital.ca/clp

Watch for our newsletter

- Cleft Connection, our team newsletter is mailed to the homes of all families registered with the team.

Visit the Family Resource Centre

- The Family Resource Centre is located on the 1st floor of the Ron Joyce Children's Health Centre. The Centre has books, magazines, pamphlets and videotapes that you can borrow. They cover a wide range of topics including cleft lip and palate.
- The Centre also has information about free talks and workshops for parents.

Join AboutFace

- AboutFace is a support and information network about facial differences. Services include networking, publications, school programs, hospital support visits and public awareness.
- AboutFace can send you a newsletter four times a year.
- To find out more, call 1-800-665-FACE or visit their website:
www.aboutface.ca

Definitions

Alveolar bone graft

- Surgery which takes bone fragments from the hip and places them in the cleft of the upper gum line (alveolar ridge). This is so that teeth may grow into the cleft space. This is usually done in pre-teen years.

Ear tubes

- A surgical procedure in which a small slit is made in the eardrum and fluid build up is drained from behind the ear drum. A tiny tube is inserted to prevent fluid from building up again.

Lip taping

- The use of special tape across the upper lip to reduce the opening or space of the cleft.

Maxillary advancement

- Surgery which moves the upper jaw (maxilla) forward. This is usually done in the late teen years and is co-ordinated with orthodontics.

Nasendoscopy testing

- A very tiny scope is inserted into the nose. A video is taken showing how well the palate and the muscles of the throat move during speech to direct the flow of air through the mouth.

Pharyngeal flap surgery

- Surgery in which a flap of muscle is taken from the back wall of the throat and is attached to the soft palate. The flap makes the large space at the back of the throat into 2 smaller spaces. This can help correct speech which is too nasal sounding.

Submucous cleft palate

- A separation of the muscle in the midline of the soft palate. It is often difficult to see because the mucus membrane covering the palate is intact. The uvula is split.

Velopharyngeal inadequacy (VPI)

- Air and sound travel through the nose during speech when it should go through the mouth. Speech is nasal sounding.

VPI Clinic

- The Velopharyngeal Inadequacy (VPI) Clinic determines whether nasal sounding speech is due to a physical problem that requires pharyngeal flap surgery or is due to mislearning and requires speech therapy.
- Your child may have appointments for a speech assessment, videofluoroscopy x-rays and nasendoscopy testing.

Videofluoroscopy x-rays

- Special video x-rays taken while talking. X-rays show how well the palate and muscles of the throat move during speech to direct the flow of air through the mouth.

How do you contact us?



Call the Team Coordinator:
905-521-2100, ext. 77069

Or the Team Secretary:
905-521-2100, ext. 77210



Mailing address:
MCH Regional Cleft Lip and Palate Team
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