

2018

## Cleft lip and palate: An educational guide for families

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## Cleft lip and palate: An educational guide for families

### Abstract

Cleft lip and palate are craniofacial anomalies affecting more than 200,000 infants in the United States per year. Although this condition is quite common, parents are often confused and uninformed when they discover their newborn has a cleft lip and/or palate. In time, parents can learn of the surgical repairs and therapies, but what about the management, treatment, effects on education, risk factors, genetics, and any other lasting effects on the newborn? Many parents often wonder if their baby can be fed properly, if the child will have trouble learning to talk, or how to tell relatives and friends about the matter. There are a lot of concerns and questions that play into this condition. The goal of the educational guide is to provide resources and knowledge to families experiencing CL/P disorders to eliminate confusion and anxiety, and, instead, promote confidence, support, advocacy, and understanding for those impacted by CL/P.

### Degree Type

Open Access Senior Honors Thesis

### Department

Special Education

### First Advisor

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### Keywords

Feeding, Newborn, Education, Craniofacial, Treatment

### Subject Categories

Special Education and Teaching

**CLEFT LIP AND PALATE: AN EDUCATIONAL GUIDE FOR FAMILIES**

**By**

**Ciara Woods**

**A Senior Thesis Submitted to the**

**Eastern Michigan University**

**Honors College**

**in Partial Fulfillment of the Requirements for Graduation**

**with Honors in Special Education:**

**Speech-Language Pathology**

Approved at Ypsilanti, Michigan, on this date 7 May 2018

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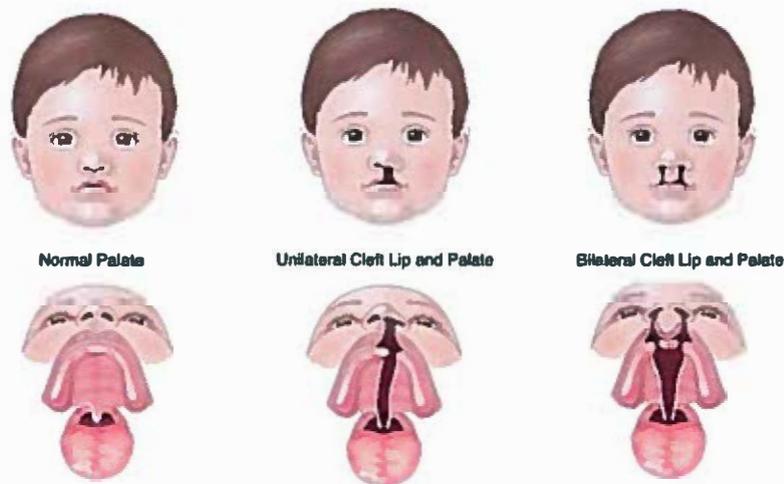
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## What is Cleft Lip and Palate?

A cleft lip is characterized by a separation of the sides of the upper lip. In fact, the term “cleft” means to be separated, divided, or split. Cleft lip often includes the separation between the upper jaw bone and/or the gums. A cleft palate affects the hard and soft palate on the roof of the mouth and results in an opening. Both cleft lip and cleft palate can occur on both sides of the mouth (bilateral) or on just one side (unilateral). It is possible for an infant to have one or the other, as well as both. There is also a sub-mucous cleft palate where a mucous membrane covers the roof of the mouth, making it difficult to see the cleft.



Having a cleft lip and/or palate (CL/P) without having any other major defects is the most common birth defect in the United States. In fact, cleft lip and palate are craniofacial anomalies affecting one in every 940 infants in the United States per year. CL/P can impact a child’s speech, hearing, social-emotional abilities, and education. Although this condition is quite common, parents are often confused and uninformed when they discover their newborn has a cleft lip and/or palate. In time, parents can learn of the surgical repairs and therapies, but what about the management, treatment, effects on education, risk factors, genetics, and any other lasting effects on the newborn? Many parents often wonder if their baby can be fed properly, if the child will have trouble learning to talk, or how to tell relatives and friends about the matter. There are a lot of concerns and questions that play into this condition. The purpose of this educational guide is to provide resources and knowledge to families experiencing CL/P disorders, without any other associated syndrome or craniofacial anomalies, to eliminate confusion and anxiety, as well as promote confidence, support, advocacy, and understanding for those impacted by CL/P.

## Diagnosis and Causes

With the ever-increasing developments in ultrasound technology, the ability to diagnose CL/P of the fetus is possible. There have been reports of diagnosing CL/P as early as 12 weeks of pregnancy by transvaginal ultrasound. There is a technique that ultrasound technicians follow to diagnose a cleft, which involves obtaining two planes (frontal and coronal) of the fetal face (Gomez, 2006). On the frontal plane, medical professionals observe a disruption of “the normal mid-facial architecture” and the roof of the mouth before the upper teeth and hard palate is absent (Gomez, 2006). Also, there is a definite broadening of the nasal cavity. On the coronal plane, a mass of soft tissue in front of the midline of the nasal septum below the nose is observed. Once the CL/P has officially been diagnosed, a complete anatomical survey is conducted.



The occurrence of cleft lip and palate is quite common, occurring in 1 in 940 live births in the United States. It occurs when face and mouth tissues are not fused together properly during fetal development, which occurs between the fifth and sixth week for the lips and between the tenth and eleventh week for the palate. Like numerous congenital abnormalities, the presence of CL/P can still occur in an infant without a family history of CL/P or any birth defects, also known as “isolated incidents” (Young, O’Riordan, Goldstein, & Robin, 2001). Although there is a wide range of possible causes of CL/P, there has not been one identifiable cause at this point. Most hypotheses point to the combination of genetics and environmental factors, while others fall under the category of isolated incidents as mentioned above. The Center for Disease Control and Prevention and research groups have recognized other factors that increase the chances of giving birth to a baby with CL/P, such as smoking during pregnancy, diabetes, substance abuse, certain medications, and poor prenatal health care.

## Treatment

One or more surgeries are required in cases of CL/P to correct malformation. Usually, the family and child will work with a craniofacial team who will plan the line of treatment for the child. A craniofacial team can be made up of, but not limited to, a plastic surgeon, an orthodontist, and a speech-language pathologist. This interdisciplinary team can assist families and alleviate their stress and anxiety since they are trained to provide high-quality care in diagnosing and treatment, as well as provide resources and support. Below is a list of core craniofacial team members, along with their specialties and responsibilities (Capone & Sykes, 2007):

**Audiologist:** Provides hearing screenings to diagnose any hearing deficits, information for the prevention of speech delays, and parental education in the case of congenital hearing loss.

**Geneticist:** Provides expertise in the diagnosis and treatment of congenital anomalies, counseling and education for parents regarding the etiology of their child's diagnosis, and probability testing for occurrence in future children/grandchildren.

**Pediatrician:** Supplies expertise in the growth and developmental milestones for children, referrals to specialists, and direct communication regarding health issues to the child's health care provider.

**Orthodontist:** Provides care in aligning the teeth, expanding the palate, and occluding the cleft.

**Otolaryngologist:** Provides proficiency in upper airway obstruction, hearing loss, tympanostomy tube placement evaluations (preventing the accumulation of fluid in the middle ear).

**Surgeons:** Contribute to the complex surgical correction of the cleft lip and/or palate, which is often performed in multiple stages.

**Social worker:** Administers help with social issues for families, as well as assistance with financial trouble, transportation, health care coverage, unemployment/missed work, and appropriate social/educational programs.

**Speech-language pathologist:** Evaluates oral motor and velopharyngeal function, feeding and speech abilities, language development, as well as administers speech therapy and feeding techniques.



## Area of Need: Feeding

Any new parent places nutritional needs as a top priority, regardless of the infant's condition. It is important to note, however, that in cases of CL/P, feeding issues are quite common. Luckily there are numerous techniques, equipment, and bottles, that any parent can familiarize themselves with to ensure their infant is receiving the nutrients necessary to thrive.



### Breast-Feeding: Techniques



Breast-feeding is typically the preferred method of feeding among caregivers due to the various benefits. Infants with an isolated cleft lip have shown to respond positively to breast-feeding. Due to the flexibility of breast tissue, it can assist the infant's mouth when the cleft lip is healing. Also, the action of breast-feeding can increase the strength of the infant's facial musculature. On the other hand, the likelihood of an infant with cleft lip and palate, or with an isolated cleft palate, successfully taking in milk is poor. If the infant is unable to latch onto the breast, the mother should pump her breast milk into a bottle and bottle-feed the infant.

1. Before feeding, the caregiver should express breast milk manually to stimulate the let-down reflex roughly 1-2 minutes by applying a warm compress to the breast. This will increase the flexibility of breast tissue and the areola will soften, which will in turn facilitate the infant's latch to seal the cleft.
2. Position the infant in an upright manner (60-degree angle or higher). The chances of the infant regurgitating the milk or having milk enter the Eustachian tube and middle ear space will be decreased, thus reducing the chances for ear infections. The infant should be placed at the top of the breast while the mother uses her thumb to obstruct the cleft. Additionally, externally supporting the cheeks and lips of the infant during feeding can aid in lip closure around the breast.
3. Support the infant's chin. When the infant's body is in a neutral, upright alignment, jaw stabilization will facilitate oral-motor movements for milk intake and chin support will ensure that the nipple will remain in the infant's mouth during breast-feeding.
4. Utilize a pacing technique to create a proper feeding rhythm. Feeding an infant with CL/P can be lengthy, lasting up to one hour when a pacing technique is not utilized. If a proper feeding rhythm is not followed, then the infant can become exhausted and fatigued, causing him/her to fall asleep in the middle of feeding. To prevent these outcomes, the caregiver is encouraged to monitor the infant's reactions during various points in the feeding process. These reactions include the infant's color, oxygen saturation, respiratory rate, and sucking rhythm (Burca et

al., 2016). The caregiver can accomplish pacing by carefully placing their index finger upon the infant's tongue to stimulate the suck reflex. When the parent paces the rhythm of feeding with the infant's reactions, the infant can learn to control their sucking, swallowing, and breathing, because of increased control of oral intake

5. Burp the infant regularly to decrease the amount of air in the stomach and reduce the chances of regurgitation after feeding.



## Bottle-Feeding: Techniques and Specialized Equipment

### Techniques:

In most cases, parents choose to bottle-feed their child rather than breast-feed. Although breast-feeding is typically the preferred choice, mothers should not worry if breast-feeding does not work out in their favor. The main goal is for the infant to receive proper amounts of nutrition to grow and be healthy, which can be done in whichever method works best.

- Position the infant in an upright, sitting position
- Develop a rhythm (pacing) to establish swallowing, sucking, and resting
- Keep the bottle tilted to ensure the nipple is always filled with milk
- Burp the infant frequently to avoid taking in excessive amounts of air



### Specialized Equipment:

Even though babies who have a cleft lip and/or palate have sucking and swallowing reflexes, they do need help allowing the milk to flow smoothly. This is where specialized bottles and nipples come into play. Using specialized feeding equipment can increase milk intake to control the infant's ability to suck and swallow, as well as significantly decrease the chances of infant malnourishment and the need to produce suction (Burca et al., 2016). Adaptive equipments, such as compressible plastic bottles, force milk to flow to the tip of the nipple, decreasing the need for the infant to rely on negative intraoral pressure during the suck. Thus, the infant will not feel fatigued and malnourished after feedings.

## Types of Bottles:

**Enfamil Cleft Palate Nurser Bottle:** Created by Mead Johnson™

Simply squeeze the bottle, regularly and gently, in a pulsing fashion to create a rhythm with the infant's suck and swallow pattern. If the pulsing is too forceful, the infant may take in excess milk. During breaks, the bottle does not need to be squeezed, but the nipple can remain in the infant's mouth for when he/she begins feeding again.



**Special Needs Feeder:** Created by Medela™

This bottle is like the Enfamil Cleft Palate Nurser, except it is available in smaller sizes and contains markings that indicate the flow of milk. To begin, hold the bottle vertically, squeeze the nipple between two fingers, and flip the bottle upside down. When the nipple is released, milk should begin to fill it up (this step should be repeated until the nipple is full of milk).

**Pigeon Bottle:** Created by Respirationics™

The infant sucks the milk out of the bottle on his/her own, rather than the parent squeezing the bottle to control the flow of milk. To use, hold the bottle vertically, squeeze the nipple between two fingers, and flip the bottle upside down. When the nipple is released, milk should begin to fill it up (this step should be repeated until the nipple is full of milk).



Nasal regurgitation is a possible occurrence during feeding, but the parent should not panic. If this happens, hold the baby in a more upright position. By doing so, the milk is unable to come out of the nose. If the infant starts to sneeze or cough, this is a good sign as he/she is attempting to clear out the nasal passageway. As a parent, you do not need to use a syringe to clear out the baby's nose because this is not a dangerous situation and does not indicate that the baby is choking.

Signs that show if the feeding techniques mentioned above are working include: feedings are taking 30 minutes or less and the infant is gaining a half pound per week on average. If feedings are taking longer than 30 minutes, the infant will become fatigued and burn up too many calories.



## Area of Need: Speech



50% of children (or more) will require speech therapy, but it is important to keep in mind that, as any other child, children with CL/P may simply develop speech and language more slowly than others.

Speech difficulties play a significant role in parental concerns. Parents will wonder what kind of speech problems their child may have, what to do, and how soon their child should receive speech therapy. According to American Speech-Language Hearing Association (ASHA, n.d.), if a child only has a cleft lip, then speech development should be typical. On the other hand, children who have a cleft palate or CL/P often require speech intervention to track speech development and correct any delays or errors in speech.

Why are children with a cleft palate (or cleft lip and palate) at a higher risk for developing speech problems?

1. Since there is not a separation between the nasal cavity and the oral cavity for children with a cleft palate, the child is unable to build up air pressure in her/his mouth because air is instead rerouted through the nose.
2. There is less tissue on the hard palate for the tongue to touch.

The combination of these two issues result in a child who has difficulty learning how to make certain sounds, however, the speech-pathologist who is involved in the child's craniofacial team can recommend therapy and assess the progress of speech production. Below are two types of speech difficulties that a child with CL/P or an isolated cleft palate will potentially experience.

## Velopharyngeal Insufficiency (VPI)

In typically produced speech, the soft palate elevates and touches against the back of the throat. This occurs to close off the oral cavity (mouth) from the nasal cavity (nose) so that certain sounds come out of the mouth instead of the nose. When sounds are produced through the nose, such as /m/ and /n/, the soft palate will remain down to allow the sound to travel through the nasal cavity. Velopharyngeal Insufficiency (VPI) occurs when the soft palate of the mouth does not reach the back of the throat to produce normal sounding speech, resulting in nasal sounding speech. This is very common among children who have cleft palate. In most cases, surgical repair of the cleft will eliminate the problem of VPI; however, there is a slight chance that some children will continue to have VPI, thus requiring another surgery and/or speech therapy. Also, there is a number of children who develop misarticulations as compensatory errors due to VPI, and in those cases, they will require speech therapy to address the misarticulations.

## Articulation

Articulation is the motor movement involved in the production of sounds to create meaningful speech. There are three articulators involved with producing speech: tongue, lips, and teeth. For children with cleft lip and/or palate, these articulators may be altered, resulting in an articulation disorder. An articulation disorder, as defined by ASHA, is a type of speech sound disorder that is characterized by atypical speech production. For example, a child may substitute, omit, add, or distort sounds when speaking, making it difficult for others to understand the child's speech. There are certain articulation errors that are typical due to the child's age (age-appropriate errors); however, errors become atypical when the child is at a later developmental stage (non-age-appropriate errors). Children with CL/P often present with misarticulations as compensatory errors due to VPI. Surgical repair and speech therapy are usually required to address articulatory errors among children with CL.P.



## Area of Need: Hearing



The possibility of hearing loss is another topic of concern among parents whose child has CL/P. Parents commonly ask what to do if their child is frequently experiencing hearing problems and how to monitor their child's hearing. Children who are born with a cleft lip have the same chances of developing hearing problems as children who are not born with a cleft lip (ASHA, n.d.). On the other hand, children who are born with cleft palate (with or without cleft lip) have a greater risk for developing middle ear effusion, which is fluid in the ears, as well as otitis media, which is an infection of the middle ear. The majority of ear problems begin in the first year of life (P. Sheahan, Miller, J. Sheahan, Earley, Blayney, 2003). In addition, children within this population may experience recurrent ear infections (Sheahan et al., 2003). Studies and research has shown that there is a strong association between cleft palate and ear infections. If a child is frequently experiencing problems with fluid in the ears and infections, then his/her chances of developing permanent hearing loss increases. These problems, however, can be assessed and managed by an ENT (ear-nose-throat specialist) and an audiologist (hearing specialist). Thus, it is prudent for parents to monitor their child's hearing regularly to prevent and detect any hearing loss as soon as possible.



## Area of Need: Education



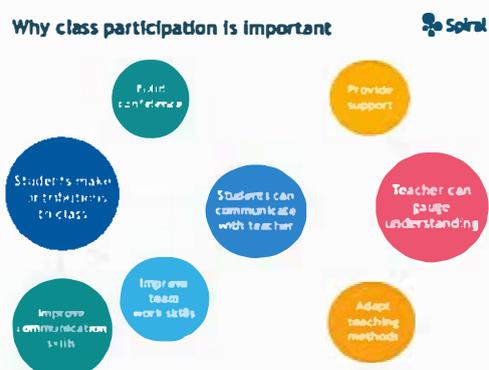
Once a child who has experienced CL/P reaches school-age, parents begin to worry about their child's academic success. Parents often wonder how the school will know of their child's needs/concerns, or how their child will make up/access missed assignments. It is important to note that having a cleft palate does not indicate poor educational outcomes. In fact, children who have a cleft can perform well in school and may not require additional help. The following sub-categories highlight parental concerns regarding their child's academic success, as well as ways to reduce these concerns.

### Missing School

Depending on the severity of the CL/P, children may have to miss multiple days of school for doctor's appointments and surgeries, resulting in concerns over accessing missed assignments. These types of situations are unavoidable, as well as pertinent to the child's progress. Parents should communicate with the school personnel to ensure their

child will stay on track with the rest of the class. Parents should let the teacher know in advance when their child will be missing school so the teacher can gather up assignments for the child to work on. Also, parents can try to schedule doctor's appointments during the late afternoon so their child can miss as little school as possible.

## Class Participation



A second concern that may influence a child's academic success is class participation. If a child who has a cleft palate experiences speech difficulties, he/she may shy away from activities that involve reading aloud, learning languages, and playing instruments/singing. This lack of confidence can also be influenced by how the child's teacher and peers react to their speech, such as constantly asking the child to repeat his/herself during class. If the child is putting up a barrier between himself

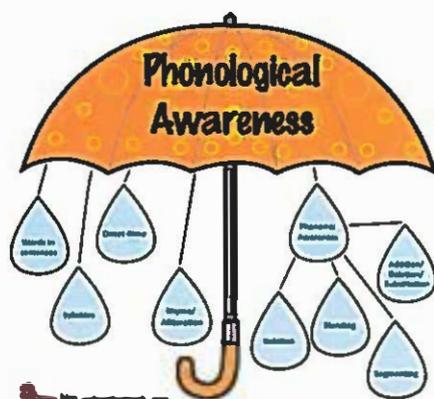
and the activities mentioned above, then grades are going to suffer. The Cleft Lip and Palate Association (CLAPA, 2015) emphasizes that both the parents and teachers should form a partnership with the speech-language pathologist to support the therapy goals at home and in the classroom. Parents should incorporate reading and phonics activities at home, a place where the child feels comfortable. By practicing at home, the child may have less feelings of anxiety while in the classroom. Teachers should avoid interrupting the child or asking the child to repeat him/herself more than once. Instead, teachers can repeat what they thought the child said until an understanding can be reached (CLAPA, 2015). Also, teachers should praise and encourage the child during successful moments.

## Hearing Difficulties

In addition to speech problems, a child may also experience hearing problems in school without realizing anything is wrong. As stated in the hearing section, children who have a cleft palate are especially at risk for developing hearing issues due to Eustachian tube dysfunction. A child who cannot hear the teacher during lessons may become restless and uninterested during lessons. The child's comprehension levels will begin to drop because he/she is not absorbing any of the necessary information. The child may also feel mentally fatigued at the end of the day because of all the energy he/she put forth just to hear the teacher or to read lips. It is vital for parents to ensure their child has regular hearing evaluations to monitor any hearing loss. Even if the child has a mild hearing loss, a noisy classroom can absolutely put a strain on his/her ability to hear. Teachers should be informed of any hearing problems so the best learning environment can be provided for the child. Discuss the option of having the child sit at a location in the classroom where he/she will always be able to clearly see the teacher's face, as well as be near the teacher during lessons.

## Learning Disabilities

Academic deficits that children with CL/P often encounter in school are spelling and reading issues associated with speech difficulties, phonological awareness disorder, and auditory processing disorder. Phonological awareness refers to the understanding that words can be broken down into smaller units (Lee, Young, Liow, Purcell, 2015). Strong reading abilities are tied to phonological awareness; thus, it is important for literacy development. If a child has trouble with phonological awareness, he/she may show difficulty discriminating between sounds, combining sounds to form words, and retrieving sounds from short-term memory. The prevalence of ear infections or hearing loss during the first few years of life typically indicates a high risk of developing an auditory



processing disorder, which affects the ability to understand speech. The disorders mentioned, although troubling, can be managed. In fact, schools have a duty to provide any additional support a child may need. There are plenty of assessments that can be performed to decide if the child has a need for extra support.



## Area of Need: Social-Emotional



Children who have grown up with CL/P can show low self-esteem and difficulties in social interaction. Additionally, research has shown that children with a facial anomaly experience greater superficial psychological issues and psychosocial limitations compared to children without a facial anomaly (Sousa, Devare, & Ghanshani, 2009). For most children, school will be the first time they need to answer questions about their cleft on their own. Parents should talk to their child about how to answer those questions, such as by using role playing techniques. Additionally, psychologists and psychiatrists can be an important asset to have on the craniofacial team if your child is experiencing these issues.



## Resources for Parents

Cleft Palate Foundation  
<http://www.cleftline.org/>

Cleft Advocate  
<http://www.cleftadvocate.org/>

FACES – The National Craniofacial Association  
<http://faces-cranio.org/home.html>

National Foundation of Facial Reconstruction  
<http://www.nffr.org/>

Specialized Training of Military Parents (STOMP)  
<https://wapave.org>

Cleft Meetup  
<https://www.meetup.com/topics/cleft/>

About Face  
<https://www.aboutface.ca/>

Children’s Craniofacial Association  
<https://ccakids.org/>

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