



ACPA

American Cleft Palate
Craniofacial Association

acpacares.org



The School-Aged Child

2026 Edition

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Foreword

This booklet is a continuation of a developmental series produced by the American Cleft Palate Craniofacial Association. It discusses concerns parents may feel as their children begin kindergarten and elementary school and progress to middle school (ages 5 to 12 years). During these school years, the child's focus widens to include not only the family but also the larger world of the neighborhood and school. Children may become concerned about how they look and talk. They may worry about making friends, being teased, doing well in school, and being included in activities. Parents want their children to succeed and develop a strong self-concept. However, children born with clefts sometimes need help to achieve these goals. This booklet suggests ways to help these children.

This booklet was written for families. It is intended to be shared with the child with a cleft, other family members, friends, and teachers. The first part, "Achieving the Best Possible Appearance, Speech, and Teeth," focuses on the medical, dental, and speech decisions needed to promote the best appearance and good speech. The second part, "Making School a Good Experience," focuses on school life. It stresses the importance of maintaining normal hearing, explores possible learning problems and ways to manage them, and explains how children can handle teasing and improve their ability to make friends. It concludes with a teacher's presentation to the class on what it means to have a child with a cleft or craniofacial birth difference.

Background Information

Cleft lip and/or palate is one of the most common birth differences, affecting about one out of every 600 individuals. Despite this fact, children and families affected by clefts may feel alone and isolated. Most families have never heard of cleft lip and palate until their child was born. Many children seldom see another child with a cleft. Information about cleft lip and palate, along with contact with other affected individuals and their families, can help people access care, choose among options, and reduce feelings of isolation.

Children with cleft lip and/or palate can reach their full potential when a team of specialists from a variety of healthcare fields provides care. This is because children with clefts are at higher risk than others for differences in facial growth, dental abnormalities, speech problems, ear infections, hearing loss, and some types of learning disabilities. Because these problems are interrelated, a child is best served by a team of professionals experienced in cleft care who communicate with each other to plan and provide treatment. The American Cleft Palate Craniofacial Association maintains a list of such cleft palate/craniofacial teams in the United States, Canada, and other countries. Families and professionals can access this list at www.ACPAcares.org. Children and families should also have the opportunity to meet and talk with other families affected by cleft lip and palate. Such support may help the child and family to feel less alone and provide opportunities for sharing and friendship.

Treatment for cleft lip and/or palate varies by child because no two children have exactly the same needs. For example, some children may require one or two operations, while others may require more. Speech therapy is needed by some children and not by others. Because each child is unique, treatment must be individualized.

The causes of cleft lip and palate are not well understood. Research programs are currently working to better understand whether these disorders are caused by inheritance (genetic factors) or by conditions in the womb (environmental factors). As of this writing, no simple

cause/effect relationships have been found between genetic or environmental factors in most cases of clefting. While it is advisable to plan all pregnancies so they occur when the mother and the developing baby may have the benefit of prenatal care provided by a qualified physician, the lack of prenatal care does not necessarily increase the chance that the child will be born with a cleft. Families already affected by clefting should request a consultation with a geneticist (a specialist in genetic factors) to estimate the chance that future children and the offspring of their affected children may also have clefts.

Achieving the Best Possible Appearance, Speech, and Teeth

FACIAL APPEARANCE: SURGICAL CONSIDERATIONS

Entering elementary school is a milestone for your child. As horizons expand, he or she will be influenced by many new adults and children. You want your child to enter this new situation with confidence. Most of this confidence will come from your support, encouragement, and approval. You will also want your child to embrace their appearance as much as possible and speak as clearly as possible when entering school. A cleft palate team will conduct detailed evaluations before this time to address any special needs your child may have. If needed, the team will recommend surgical correction when it feels right, considering your child's overall health and development.

Some children need only the initial cleft lip and/or palate surgery in the first years of life. Scarring may be minimal, and appearance may be relatively unaffected. Speech may be easily understood. Many children, however, will need more surgery as they grow and develop to improve their appearance and their speech.

One important advantage of having your child seen by a team of cleft experts is that all aspects of his or her care can be coordinated, minimizing trips to the operating room. Sometimes you can combine procedures and save time, money, and discomfort. This works best with regular evaluations by the cleft team as a whole, with input from all cleft care specialties.

In general, the fewer the number of operations that your child has, the better. Although it is tempting to want touch-up procedures, it is also important to understand that each surgery increases scarring. Remember, your child is still growing. What may look like an irregularity now may improve with time. Young men's facial features continue to develop until they are 16 to 18 years of age, and young women's faces until they are 14 to 16 years of age. If too many operations are done during these times of active growth, they may interfere with the natural development of your child's face. Therefore, it may be best to delay certain operations for growth reasons.

However, delaying touch-up surgery is not always the best choice. Some children feel more psychological pressure than others. For psychological benefit, your surgeon may recommend a touch-up operation even though it would not be recommended at that time if only physical development were being considered. As long as everyone understands that additional surgery may be necessary in the future, there is nothing wrong with choosing to win a small battle while waiting to win the war.

Consultation with your surgeon and other members of the cleft team will help you decide which operations at which times are best for your child. Surgical decisions and techniques are, and should be,

as different and special as your child. It is important that you understand in advance exactly what the surgery will involve and what is expected after the operation, so you can help your child prepare for and recover from it.

Appearance and Function of the Lip

How do you decide if additional surgery on the lip is best for your child? The upper lip should look as balanced as possible, with both sides matching. The scar between the nostril and upper lip should be smooth, flat, and match the skin color. The center of the upper lip should have graceful curves (what is sometimes described as the Cupid's Bow). Ideally, the red portion of the lip should be equally full on both sides. The muscle that allows the lip to pucker (to suck from a straw, whistle, or kiss) should be united under the skin repair. There should be a balance in position and size between the upper and lower lips. If the lips do not appear almost normal, and if the difference disturbs your child or causes teasing or staring by others, a touch-up operation before starting school may be a good idea. Touch-ups tend to be more common in double (bilateral) than in single (unilateral) cleft lip. In either case, the goal is to make the lip look as normal as possible.

Appearance and Function of the Nose

If your child has a cleft lip, the nose is probably also affected. Usually, the nostril on the side of the cleft initially appears flattened. While this may have been corrected at the time of lip repair, some flattening may remain. The bones and cartilage inside the nose that divide it into right and left halves may also be out of position, interfering with nasal breathing. Touch-up nose surgery can be done with lip touch-up or on its own.

How do you decide whether additional nose surgery is best for your child? First, the nose should have right/left balance (symmetry). The tip of the nose should be elevated above the lips, and the nasal airway should be open on both sides. The goal is to have a nose with a normal appearance and open air passages. Final nose surgery is often postponed until the teenage years, when the face has finished growing.

Appearance and Function of the Teeth and Gums

What about your child's teeth and gums? For many children with clefts, the upper front teeth erupt crooked. Additionally, your child may be missing teeth, have malformed teeth, and/or have extra teeth, especially in the cleft area. Your child's upper and lower teeth may not come together normally either. Attention to these problems now may prevent additional problems later. Your child's doctors may recommend X-rays of the teeth, jaws, and/or skull to determine the exact situation so they can plan the best course of treatment.

If your child's cleft went through the gum, there may not be enough bone to support permanent tooth eruption. If you don't take the right steps, those teeth may be lost. In this situation, filling the cleft gap with bone (bone graft surgery) may be helpful. A bone graft is an operation designed to provide the permanent teeth with bone support when they erupt and to close the connection between the mouth and nose. The operation involves taking a very small amount of your child's bone from one place (usually the hip, head, ribs, or leg) and placing it in the area of the cleft near the teeth. The bone cannot come from another person's body because your child's body will not accept it. Sometimes doctors use an artificial bone source for the graft. Doctors should perform bone graft surgery before the permanent teeth erupt next to the cleft. This usually occurs between ages 5 and 10, but it depends on your child's dental development and the surgeon's preferences. Another benefit of a bone graft is that it may help support your child's lip and nose and make the left and right sides of the face look more alike. If your surgeon recommends one, they should explain bone grafts in more detail.

Some children with clefts have a small hole, called a fistula, in the gum and/or the roof of the mouth (palate), which may allow air and/or food to pass from the mouth into the nose. Some gum fistulas are so small that they may not cause obvious problems, and the child may not even be aware of their presence. However, many palate fistulas interfere with speech. If your child has a gum fistula, it will probably be closed during bone graft surgery. Close a fistula that causes speech problems as soon as you identify it.

Sometimes orthodontic treatment is necessary before the bone graft, and almost always after. Orthodontic treatment will improve the position of your child's teeth. Sometimes, the cleft affects how the top and bottom jaws grow. When jaw growth is affected, the dental, surgical, and speech members of your child's cleft team should consult to determine the best treatment plan. Occasionally, jaw surgery (orthognathic surgery) on one or both jaws provides the best function and appearance. Such surgery should be coordinated by your orthodontist and surgeon. If this surgery is necessary, it usually isn't until facial growth is complete in the mid-to-late teen years. While jaw surgery will affect the appearance of the lips and nose, lip and/or nose revision may still be done earlier if it is considered psychologically beneficial.

Another approach to having the upper and lower jaws meet together for normal function and appearance is called distraction osteogenesis. This process allows new bone to form through gradual separation by placing a device either inside the mouth or outside the skin. In areas with insufficient bone, distraction osteogenesis has provided good results without additional bone grafting. And because of this new bone formation, the chance of relapse is minimal.

During this procedure, your child will be taken to the operating room, and the distractor device will be placed in the jaw. After several hours or days, depending on your child's age, the device is gradually turned on to start separating the bones. Children are initially fed intravenously (IV) and then by mouth. Parents can usually complete the distraction course at home, with regular visits to the surgeon's office. Once the process is completed, several weeks are allowed for the new bones to harden, and then the device is removed.

SPEAKING CLEARLY: SPEECH AND LANGUAGE CONSIDERATIONS

Will your child's speech be affected by the cleft? In general, we expect four-year-old children without cleft palate to produce speech that is understandable almost all of the time. However, not all consonant sounds may be produced perfectly at this time, and it may take another four to five years for all sounds to be produced correctly. So you should understand that most children's speech characteristics, even without cleft palate, are not perfect by first grade. Many years ago, it was fairly common for children with repaired cleft palates to start school with untreated speech problems that set them apart from their classmates. Although this still may be true for some children, improved surgery, early identification of speech concerns, and earlier treatment have resulted in more understandable speech, better articulation, and less nasal sound quality by the time children with cleft palate enter school. Therefore, we now believe that the speech expectations for children with repaired cleft palate should be much the same as those for children without clefts.

There are, however, exceptions. We expect some children with cleft palate to make the same kinds of errors in language usage and speech sound production as children without cleft palate. In addition, some children with cleft lip and palate may be at higher risk for other speech differences. Causes include an inability to seal off the nose from the mouth sufficiently for normal speech, dental problems that affect precise sound production, and recurrent middle ear problems and hearing loss.

By age five, your child should have been evaluated regularly to identify any problems with speech and language development, as well as hearing and middle ear health. Your cleft palate team or others, such as the school speech-language pathologist or an ear doctor, may have done these evaluations. Your child may have already participated in speech treatment. The federal government requires states to provide speech/language evaluation and treatment services for individuals ages 3 to 21. (Individuals with Disabilities Education Act, or IDEA, Public Law 101-476).

Speech Production

To better understand your child's speech problems and participate in treatment decisions, it is important to understand how speech sounds are made.

Figure 1 shows the structures used to produce speech. We will focus on the structures involved in velopharyngeal closure (velum=soft palate, pharynx=throat), since these are most likely to cause problems for your child's speech. Velopharyngeal closure refers to closing or sealing off the nose (nasal cavity) from the mouth (oral cavity). This closure is important for good speech for both vowel and consonant sounds.

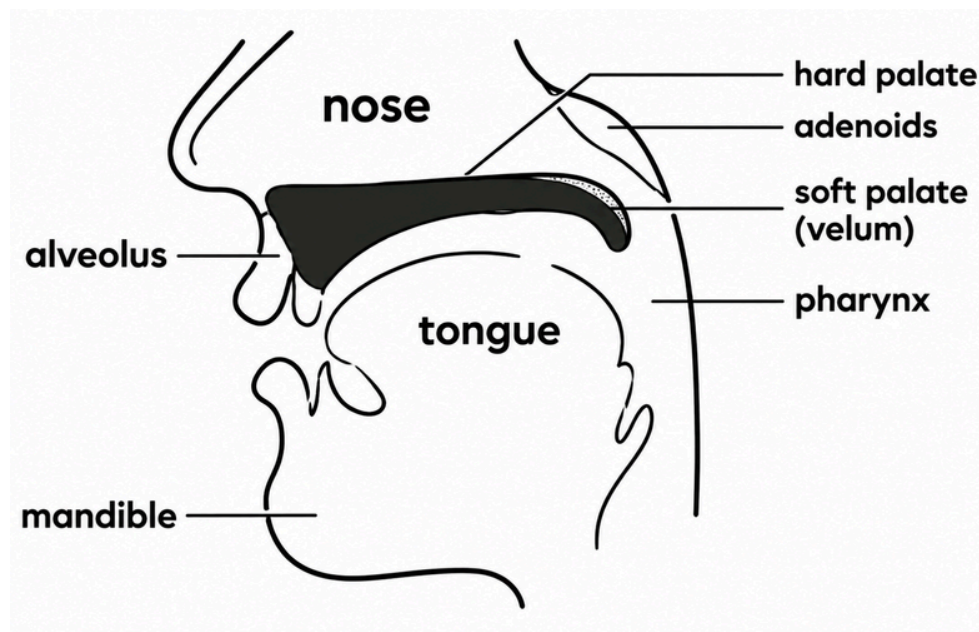


Figure 1: The human speech mechanism. Human speech is produced by the functioning of many complex structures in the mouth and throat.

For the production of many speech sounds, the soft palate lifts and stretches back against the back wall of the throat (posterior pharyngeal wall), as seen in Figure 2. This action separates the nose from the mouth. If this separation does not occur, as in Figure 3, the result is “nasalized” speech. Excessive nasal resonance of the vowel sounds A-E-I-O-U will occur throughout conversational speech. We describe speech with excessive nasal resonance as “hypernasal.”

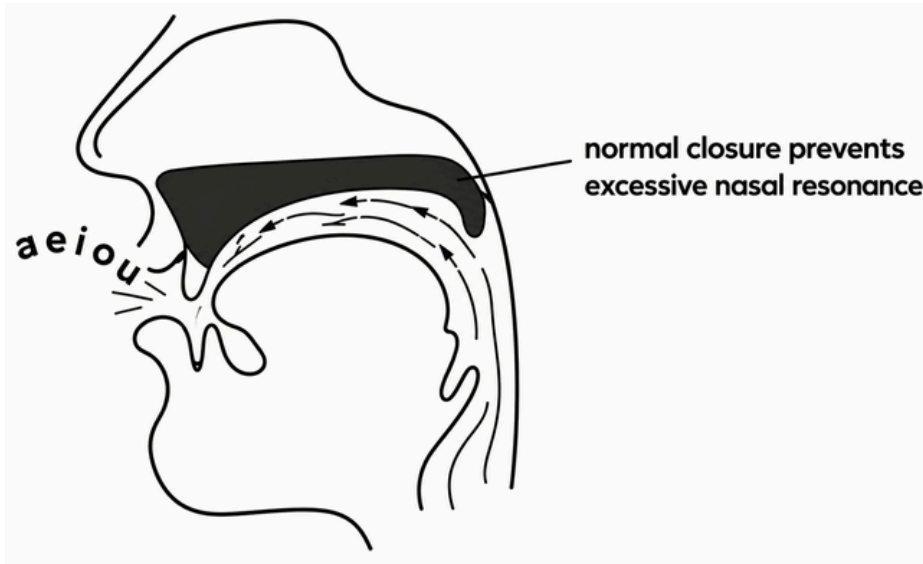


Figure 2: Normal closure during vowel production. The soft palate normally rises to close off the nose from the mouth and prevent vowels from sounding nasal.

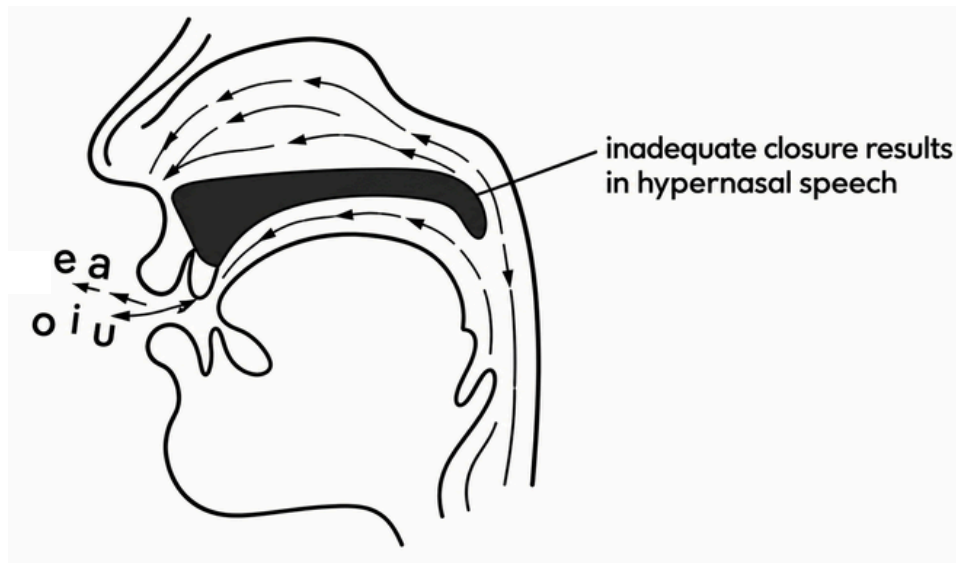


Figure 3: Inadequate closure during vowel production. If the soft palate cannot completely close off the nose from the mouth, the speaker will produce nasal-sounding vowels.

Velopharyngeal closure is important for producing consonants and vowels. By closing off the nose from the mouth, the speaker directs airflow into the mouth and creates the air pressure required for almost all consonant sounds (Figure 4).

Specific names describe groups of consonant sounds. These are plosives (p, b, t, d, k, g), fricatives (s, z, sh, f, v, th), and affricates (ch and the dj sound). Consonants are produced in different parts of the

mouth. For example, /p/ and /b/ are produced with the lips, /t/ and /d/ with the tongue tip just behind the upper teeth, and /f/ and /v/ with the upper teeth touching the lower lip. Figure 4 shows the place of production (articulation) for the /d/ sound in the word “day.” You can see that the only way to build up air pressure behind the tongue is to close off the nose and direct the airflow into the mouth – that is, to achieve velopharyngeal closure. In Figure 5, you can see how the air “escapes” into the nasal cavity and out the nose if the soft palate and the throat do not work normally. This condition may result in weak sounds, consonant sounds accompanied by extra noise from air escaping through the nose (audible nasal air escape), or abnormal consonant production that is hard to understand.

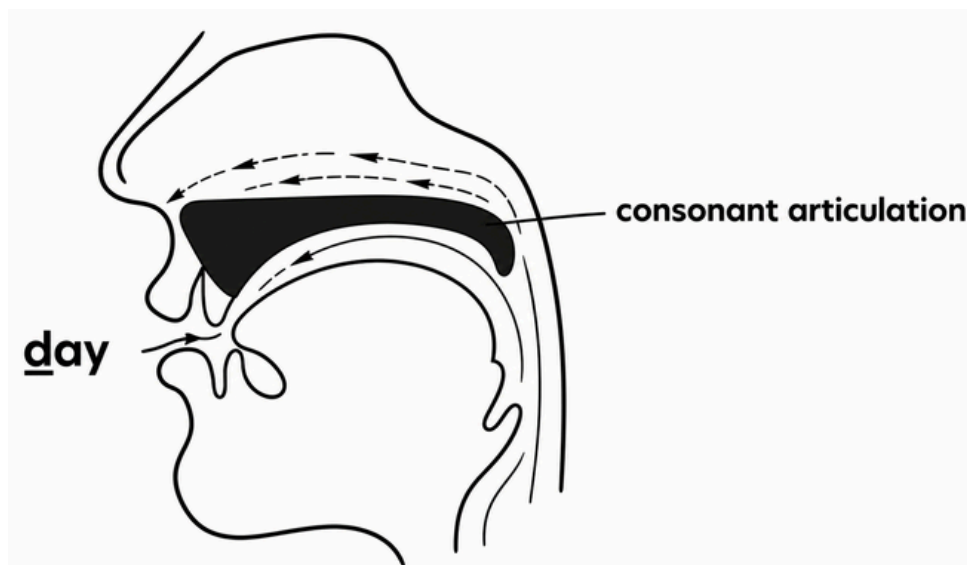


Figure 4: Normal closure during consonant production. A normal soft palate closes off the nose from the mouth and allows the pressure buildup needed to pronounce many consonants.

There are only three consonant sounds that do not need velopharyngeal closure to be produced correctly, and these are called the “nasal consonants.” They are /m/, /n/, and /ng/. For those sounds, the soft palate must stay down so that sound and air can move into and through the nasal cavities.

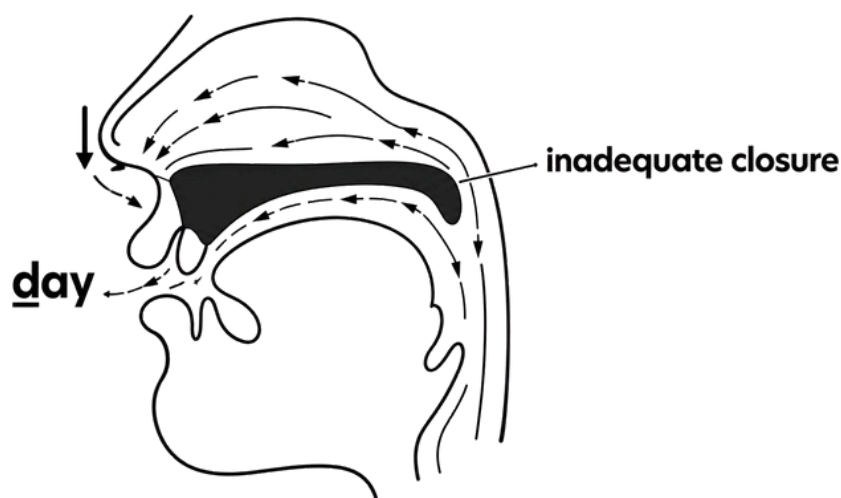


Figure 5: Inadequate closure during consonant production. When closure is inadequate because of soft palate problems, air escapes through the nose, and consonants become weak or disappear.

Management of Speech Problems

Creating velopharyngeal closure is necessary for good speech. Inadequate velopharyngeal closure is the most frequent cause of speech problems in school-aged children with cleft palate. When a child cannot achieve velopharyngeal closure, the child may need surgery (such as a pharyngeal flap or pharyngoplasty) or a speech prosthesis. The cleft palate team specialists and the parent(s) decide to physically improve velopharyngeal closure only when they agree the child cannot produce acceptable speech even with speech therapy. They should make these treatment decisions before the child reaches age 5.

However, it is not always simple to decide whether velopharyngeal closure is adequate for speech. Children sometimes learn unusual ways of making speech sounds. These incorrect speech patterns can make it difficult to evaluate the adequacy of the velopharyngeal closure mechanism because the child is not using the mechanism properly. Speech-language pathologists listen for these patterns and work with your child to help correct them.

The speech-language pathologist's main task is to determine if your child's speech structures are adequate to produce good speech. The important questions for speech-language pathologists are:

1. How is the child speaking now?
2. Can the child improve the current velopharyngeal closure mechanism?
3. If the mechanism is not working well, why is it inadequate?

To answer these questions, the speech-language pathologist may perform several examinations to test the speech mechanism. First, the speech-language pathologist will listen to your child speak spontaneously and repeat standard words and phrases, making detailed notes on the accuracy and quality of the speech sounds your child produces. Depending on the results, the speech-language pathologist may recommend other examinations to supplement the speech evaluation. For example, one test involves placing a small tube with a camera in the nose to videotape the velopharynx during speech tasks (nasoscopy). Another test records X-ray pictures on videotape while your child speaks (videofluoroscopy). The results of tests such as these will help determine whether your child could benefit from speech therapy alone or will need surgical management or a prosthesis.

If the speech-language pathologist decides your child's speech can improve without additional surgery, speech treatment should continue until speech is judged to have improved as much as possible. On the other hand, if the speech-language pathologist decides your child's speech cannot improve because velopharyngeal closure does not occur, he or she will recommend additional surgery or, sometimes, a speech prosthesis. The choice of which type of physical management treatment to use depends on the reason for the inadequacy, the child's general health, and the care providers' experience and preferences. As with any treatment, you should always ask about benefits, risks, and alternative management options. If physical management is necessary, speech therapy will either continue or be delayed until after surgery is completed or the prosthesis is designed. After either surgery or the introduction of a speech prosthesis, speech therapy may be needed to help your child adapt to the new mechanism. Remember that the recommended procedures (surgery, prosthesis, or speech therapy) are designed to help your child achieve the best possible speech result.

Most of the time, velopharyngeal closure is adequate after your child's original palate repair as a baby. There are some instances, though not very common, in which velopharyngeal closure may have once been considered adequate, but with time, evidence of problems with closure begins to be heard

in speech (hypernasality and/or audible nasal air emission). Therefore, regular visits to your interdisciplinary team are important to monitor your child's speech. The team, the school, the private speech pathologist, and the parent(s) should communicate frequently.

Hypernasality may develop in 10- to 14-year-olds for two possible reasons. The most likely cause is the shrinkage of the adenoid tissue, which grows on the back wall of the throat. This tissue helps with velopharyngeal closure by providing an extra "pillow" for the soft palate to close against during speech (see Figure 1). It is normal for the adenoids to grow during childhood and then begin to shrink. The age at which the adenoid pad begins to shrink is difficult to predict. If your child's soft palate is short, adequate velopharyngeal closure during speech may still be possible as long as the adenoid pad is present. However, as this pad shrinks, a short soft palate may no longer reach the back of the throat, resulting in incomplete velopharyngeal closure for speech. For this reason, you should be very cautious about having your child's adenoids removed.

Velopharyngeal closure problems may also become apparent as a natural consequence of normal facial growth. The normal pattern of facial growth is downward and forward, which tends to carry the hard and soft palate away from the back wall of the throat. Thus, a palate that could make closure in a small child may not be able to do so in an older child. Although this is relatively uncommon, it is another reason why your child's cleft team wants to follow them until growth is complete.

Dental Problems and Speech

If your child's cleft went through the gum, he or she may have dental differences that can affect speech. Missing teeth, extra teeth, and/or teeth out of place are common. Your child's upper and lower teeth or jaws may not fit together very well either. Normally, the upper teeth close in front of the lower teeth, but in some children with clefts, the upper teeth (upper jaw) sit behind the lower teeth (lower jaw). In addition, children between the ages of five and ten are losing their baby teeth so their permanent teeth can come in. These dental and jaw conditions can negatively affect precise speech production (articulation), especially sounds like s, z, sh, ch, and j. During the school years, orthodontic appliances worn for a period of time can also affect precise articulation. The speech-language pathologist can work with your child to help make speech as clear as possible during these times. Eventually, the teeth and dental structures will be more favorable for speech articulation.

Hearing and Speech

By this time, if your child's ears have been well managed, his or her hearing should be at least close to normal. Regular monitoring of hearing and ear function is important and can be done in the school setting. If you suspect hearing problems or school personnel identify them, an immediate visit to your family physician or ear, nose, and throat (ENT) specialist is very important. Your speech-language pathologist or educational audiologist (hearing specialist) can suggest a classroom seating position that will best support your child.

As a final note, most children notice when other children have speech problems, which creates a real possibility of teasing. A child with a cleft lip and palate has the option of saying, "Back off! My doctors aren't finished yet!" If your school-aged child's speech is noticeably different from that of his or her classmates, give your child the information to handle potential problems. It's also important that his or her teachers understand the status of treatment and what to expect this school year.

"Our seven-year-old son, Joseph, just recently began to be teased about his speech by the boys on his school bus. Joseph wanted them to know why he sometimes had difficulty with speech. So his speech therapist presented a brief explanation of cleft lip and palate to his second-grade class. Joseph shared his pictures with his classmates. The best part came when his teacher and all the children placed large marshmallows in their mouths and tried to talk. All benefited and learned a little about speech impairments. Joseph's self-confidence has increased as a result of this class program."

Anita and Michael Lange (Joseph's parents) - St. Louis, Missouri

CREATING AN ATTRACTIVE SMILE: DENTAL CONSIDERATIONS

Most children do not have perfect teeth. An attractive smile may result from extensive dental work combined with proper dental care. Children with cleft lip and palate have special concerns related to their teeth and jaws, but, fortunately, much can be done to minimize these problems.

Treatment of a cleft is most efficient and effective when done in conjunction with a multidisciplinary cleft team. The team includes all relevant medical and dental specialists who recommend, as a group, what to do and when to carry out treatment. Dental specialists on the team may include pediatric dentists (who specialize in the care of children's teeth), orthodontists (who specialize in tooth movement and the orthopedic movement of jaws), prosthodontists (who make appliances that either replace teeth or help compensate for a short or poorly functioning palate), and oral and maxillofacial surgeons (who perform surgery on the mouth and jaws).

The Role of General Dentistry

Preventing tooth decay is especially important for children of all ages. All children should have their teeth examined regularly for signs of decay and infection starting in early childhood. The dentist can offer valuable advice on maintaining good oral hygiene. Brushing and flossing are very important. Applications of fluoride can also help strengthen children's teeth and prevent decay, especially if fluoride has not been



added to the drinking water. When decay develops in the primary (baby) teeth, the dentist will usually make every effort to save them. Primary teeth are important because they preserve space for the permanent teeth underneath. If a primary tooth is removed, the other teeth may drift into its place and reduce the space available for the permanent tooth. If all efforts fail and a baby tooth must be removed, a space maintainer should be placed to hold open the space for the permanent tooth.

Children with clefts are more likely to experience tooth decay for several reasons. First, the teeth next to the cleft sometimes have defective enamel, so decay can develop quickly. A cap or layer of plastic filling material can protect that tooth. In addition, the teeth surrounding the cleft often erupt in crowded or abnormal positions, making cleaning difficult. Finally, some children eat only soft foods due to missing or out-of-place teeth, which can increase the chance

of decay by making cleaning difficult. Because of this increased risk, children with clefts should brush their teeth properly and often, limit refined sugar, and see a pediatric dentist regularly for preventive care.

The Role of Orthodontics

The goals of orthodontic treatment are three-fold: function (a bite that works well), aesthetics (a bite that looks good), and stability. Treatment is planned with all of these needs in mind. Orthodontic treatment does not usually begin before the eruption of permanent teeth, but some treatment (such as palatal or upper jaw expansion) may be done at a younger age. Palatal expansion is accomplished by placing an appliance on the tongue (lingual) side of the upper jaw teeth to widen the dental arch. This process is often performed with a bone graft, which corrects the gum defect at the cleft site.

Orthodontic tooth movement is achieved with wires, bonded brackets, and bands cemented onto the teeth. The springiness of the archwires moves the teeth into a new position, and different wires progressively correct each tooth's position. Occasionally, an appliance worn outside the mouth (headgear) is used to move the upper teeth back or to influence the growth or position of the upper jaw. Oral hygiene is a special concern among all orthodontic patients, since the orthodontic appliances provide many additional places for food particles to lodge. Without meticulous oral hygiene, decay can easily result.

Children with clefts can have any or all of the typical orthodontic problems of children without clefts – crowding, overbite, crossbite – but having a cleft may bring additional problems. Because the cleft site has no bone, one or more teeth may be missing; teeth may be defective in shape or enamel covering, or they may erupt in an abnormal position. A cleft palate is also associated with an increased chance of posterior crossbite, where the top molars bite inside the bottom ones. The size of the entire maxilla (upper jaw) may also be affected. It may fail to grow in coordination with the lower jaw, leading to an anterior crossbite (upper front teeth behind the lower ones). As a result, the middle part of the face may appear depressed or sunken in. This problem usually requires the combined efforts of the orthodontist and the surgeon to correct. First, the teeth are placed properly within their respective jaws, and then the upper jaw is surgically moved forward. This may be done through traditional orthognathic surgery or distraction osteogenesis.

Orthodontic treatment alone cannot solve the problem, since merely tipping the teeth places them in an unstable position, and they will quickly move back to their original positions.

Once the teeth have been moved to their proper positions and surgery is complete, the appliances are removed, and retainers are placed. Retainers are passive appliances that do not apply force to the teeth; they simply hold them in their new position. A retainer is required for at least one year after treatment and is extremely important to ensure the orthodontic result lasts.

The Role of Prosthodontics

Despite all of the care given, some children with clefts will have missing or misshapen teeth. The dentist who most often replaces teeth is called the prosthodontist. Several methods can replace missing teeth. The simplest and least expensive method is to make a denture or partial denture with artificial teeth attached. The biggest drawback is that it is not permanently attached, which may not be socially acceptable to the patient. Missing teeth can also be replaced by a fixed bridge. This appliance consists of a series of caps or crowns joined together and cemented to the teeth on either side of the space. This is a relatively permanent restoration and can look very natural, but it is expensive and usually requires cutting adjacent teeth. Bridges also require good oral hygiene to

prevent tooth decay. The newest and most ideal way to replace a missing tooth is with a dental implant. Implants are cylinders made from various materials that are inserted into the bone beneath the gap. After about six months, the implants fuse with the surrounding bone. Once this happens, dentists can attach artificial teeth to the implants. Implants are expensive because of material costs. They also require excellent oral hygiene and are unsuitable for growing children or people with very narrow bone ridges.

“Our son Daryl is now eight years old. Original surgeries are complete, speech therapy is progressing very nicely, and the orthodontist has begun palatal expansion. Daryl continues to be very outgoing and has a true love of life – until his self-doubt sets in as a result of peer pressure. During one of these temporary setbacks, Daryl told a new boy in school who had been ‘bugging’ him that he got the scar on his lip from falling off his bicycle. He told me that if he and the boy ever get to be friends, he will tell the boy about his cleft. Daryl says that he tries to ‘just be myself and let my friends help.’ I believe it is important that we, as parents, provide our children with the support and encouragement they need to develop the inner strength that comes from believing in themselves. The cleft should never be used as a ‘crutch.’

Jody and Daryl Robinson (Daryl's parents) - Pasadena, Texas

If your child has a velopharyngeal closure problem that makes speech sound too nasal, one treatment option is a speech prosthesis, which a prosthodontist also constructs. This removable, retainer-type appliance is made of plastic and comes in two types: lift and bulb (or obturator). The lift appliance is designed to raise a soft palate that is long enough to reach the back of the throat but does not do so because of movement problems. In a patient with a shorter soft palate, a plastic extension on the back of the prosthesis, called a speech bulb, blocks airflow into the nose, keeping it in the oral cavity and allowing clearer speech production. Prosthetic speech aids can be made for children at almost any time. If the cleft palate team recommends one, the prosthodontist will examine the child, take dental impressions of the oral cavity, and make an appliance tailored to the child. The prosthodontist and speech-language pathologist will work together to design the appliance to ensure it effectively improves your child's speech. The appliance should be checked periodically and modified as needed for growth.

HEARING WHAT THE TEACHER SAYS: PROTECTING HEARING

Good hearing and a good school experience go hand in hand. Protecting your child's hearing is especially important if he or she has a cleft palate, because children with cleft palate are at a greater risk for hearing problems than children without clefts. Since children with cleft palate have a disruption in the muscles that ensure good middle ear function, over 90% of them have recurrent or persistent ear infections or fluid buildup. About two-thirds of children with cleft palate have had ventilation (PE) tubes in their eardrums to try to eliminate this problem. However, when present, infections and fluid can both cause a measurable hearing loss. Although the loss is usually mild, hearing may still be impaired enough so that sounds presented at normal conversational levels are barely heard. As a result, children with a mild hearing loss often misunderstand or do not hear what their teachers are saying. Examples of speech sounds that are soft and easily missed if there is fluid or infection in the middle ear include the th in three and the p in cap.



Testing Hearing

Most children with cleft palate know how to take a hearing test. Since these children were very young, they have accompanied an audiologist into a sound suite, put on earphones, and responded to different tones or speech. This test determines whether there is hearing loss and, if so, what kind. The type of hearing loss caused by fluid and infection in the middle ear is called "conductive" hearing loss, which is usually correctable. About 15% of children and adults with cleft palate have a "sensorineural" hearing loss. This means that there is a problem in the inner ear that is not medically treatable. For these patients, a hearing aid may be recommended.

Impedance audiometry is a test that can identify middle ear problems. A tube with a rubber tip is placed in the ear canal, and a small amount of air is directed through the rubber tip to the eardrum. The air makes the eardrum move, and a machine called an impedance bridge records the movement. The graph of the movement is called a tympanogram and tells the audiologist whether there is a middle ear problem. If a problem is discovered, your child will be referred to a pediatrician or to an ear, nose, and throat (ENT) specialist.

If your child has had ear surgery and has ventilating (PE) tubes in his or her eardrums, keep water out of the ears. As a general rule, children with tubes in their ears should use earplugs when they go swimming. Also check ventilating tubes periodically to make sure the openings aren't clogged with fluid or wax. Your doctor will tell you how often your child needs check-ups.

Other Types of Hearing Tests

The audiologist may also perform other tests that are important when evaluating a child who is experiencing problems in school. Auditory discrimination tests measure a child's ability to detect, discriminate, and understand subtle differences in speech. Auditory discrimination is tested by having a child repeat a word or point to a picture of the word when the examiner says it at a comfortable loudness level. These tests are also done with background noise to see whether the child has trouble in a relatively noisy place, like a busy classroom, the lunchroom, or the school bus. Some children may also have problems understanding what they hear. Central auditory processing (CAP) tests allow the audiologist to understand how your child processes speech.

Types of Help Available

For children who don't need a hearing aid but still have trouble listening in noisy places like a classroom, a personal FM unit may help. The child wears headphones like those on a Walkman, and the teacher wears a small microphone. Similar equipment can also be used in an entire classroom, with the teacher wearing a microphone and speakers placed around the room.

Special tutoring or therapy is available for children with problems in speech discrimination or central auditory processing. The audiologist can usually recommend community services to address your child's specific needs. Both parents and teachers need to realize that some children may have problems at school not because they are not paying attention, but because they have a specific auditory system problem.

Throughout childhood, test your child's hearing periodically to ensure healthy ears and create optimal listening and learning conditions. If you discover a hearing problem, inform your child's teachers so they can provide the best learning environment for him or her.

ACHIEVING THE BEST LEARNING OUTCOMES

Most children born with cleft lip and palate do as well in school as other children their age. However, some children with clefts experience specific learning difficulties even though they have normal intellectual abilities. Many factors associated with clefting may increase the likelihood of learning problems. These include fluctuating hearing loss (see "Hearing What the Teacher Says") and the possibility of specific problems learning to read, speak, solve math problems, or write, which will be discussed in this section. Both parents and teachers need to be aware of these factors.

Learning Problems or Disabilities

An estimated 10% to 20% of school children have learning disabilities, the most common source of school-learning problems today. Most people have heard the term "learning disability," but few people really understand what it means.

Specific definitions of learning disabilities vary by region. However, most definitions share some basic principles. In general, learning disabilities are related to weaknesses in one or more of the cognitive (thinking) processes that influence learning. These processes include: (1) language-expressive (speaking), receptive (listening), and associative reasoning (the ability to understand new ideas or the relationships between ideas or objects); (2) memory (visual and/or auditory; short-term and/or long-term recall); (3) visual perception skills (the ability to copy designs and/or orient oneself in space); and/or (4) motor coordination.

Studies have shown that some specific learning problems do occur more frequently in children with clefts. These include early developmental reading problems, short-term memory problems, and associative language (comprehension) problems.

Some children with clefts have an increased risk of reading and learning problems, likely related to early speech and language delays. More specifically, an early speech delay may affect beginning reading skills. In addition, children with clefts tend to have more verbal/language problems than other children. Early identification and treatment of these problems is important. If a child with a cleft shows any problems learning color names, numbers, or alphabet sounds once he or she has begun school, a thorough psycho-educational evaluation should be performed. This may be done by a private or school-based psychologist, or a neuropsychologist, and could include testing of

intellectual ability (IQ), academic skills (reading, writing, math), memory, attention, visual-motor or spatial skills, and/or language skills.

Some children with clefts are at higher risk of verbal/memory problems that interfere with the child's ability to remember words, recall spelling lists, and memorize math facts. Early recognition of this learning characteristic can lead to treatment and teaching methods that can correct or prevent many difficulties. If this memory problem goes unrecognized, parents and/or teachers may think the child is not trying, is inattentive, or cannot learn. If any of these symptoms occur, it is important to assess the child's memory. Memory can be evaluated in several ways, including by comparing verbal versus visual memory and memory for isolated facts versus general information.

Growing evidence suggests that some children with clefts experience a language problem more serious than a memory problem. This type of problem is called an "associative language" or "comprehension" problem. Studies suggest that it may occur more frequently in children with cleft palate only; however, children with cleft lip and palate may also have it. Children with an associative-language problem have difficulty understanding verbal directions, switching between activities, and comprehending what they read, even when they can read individual words. A professional trained and experienced in testing children with speech, hearing, and/or oral and written language disorders should evaluate this condition. This professional is often a psychologist, neuropsychologist, and/or speech-language pathologist.

If parents or teachers have questions about how to obtain an evaluation for learning concerns, they should contact their local cleft palate or craniofacial team, a major university, or a large teaching or private hospital. Information is also available through the American Cleft Palate Craniofacial Association.

Treatment

Careful diagnosis of these learning problems usually leads to recommendations for specific ways to teach the child to read, write, spell, or do math, which may differ from what is done in a regular classroom. Some children need to work several times a week with a special resource teacher who instructs them in specific learning strategies, while they continue to receive most of their education in a regular classroom. Children with more extensive problems (such as associative-language disabilities) may need to receive all of their education in a classroom setting that offers more individualized support. Some children educated in the public school system may require an Individualized Education Program (IEP) or a Section 504 Plan, which legally affords them access to a variety of supports and services. Parents may request a meeting with their child's school administrators to see if their child may be eligible.

Most researchers agree that the most successful way to treat problems with reading, writing, or spelling is to teach the child by using strategies that draw on his or her strengths. For example, if a child has difficulty with short-term memory but has good abstract-reasoning skills, it is best to avoid a sight/word approach to reading (e.g., flash cards, whole-word learning) and instead use the child's strong abstract-reasoning skills to teach reading through phonics. This child may also benefit from memorization strategies, such as rhymes, verbal associations, or visual images. A psychologist, neuropsychologist, or educator can refer you to evidence-based programs that can help your child make progress in learning.

A child with an associative-language problem may also benefit from language therapy, which is different from speech therapy. For example, the teacher may read the child a short passage and then

ask the child to retell the story in his or her own words in order to increase comprehension. The same procedure is repeated as children learn to read stories on their own. Other children with associative-language problems may have difficulty with sound blending (putting together a series of letters to make a word, such as “c” - “a” - “t”). These children may need to be taught using a whole-word approach rather than a phonics approach.* It is also possible that children with associative-language problems may need to be taught reading through the use of combined oral and visual approaches; still others may need to have material taped.

“I’m a senior in high school, and I was born with a cleft lip and palate. One thing I have found to be true is that how I see myself determines who I am. I like who I am. I had a series of operations up to age 14, and I went to speech therapy. The last operation enabled me to speak clearly with no need for more therapy. However, I still had a crooked nose that stood out plain as day. A few kids teased me and treated me differently. They didn’t know how to react to me because they didn’t understand. The doctors promised me that when I stopped growing, I would have an operation to straighten my nose. They kept their promise. Today I feel very comfortable with my looks. My cleft has not kept me from sports. I made the varsity swim team and water polo team. I have also wrestled. I have been a Scholar Athlete throughout high school. I’m proud of my grades because I also have a learning disability. I plan to attend college and become a mechanical engineer, and I know I can.”

Geoff Mueller - Flintridge, California

In summary, most children with clefts do not experience learning problems. However, parents and teachers should be aware of the signs of these learning problems so they can recognize them and seek assistance if necessary.

*Note: Teachers should not avoid using a phonics approach for reading and spelling with all children who have a cleft or a speech problem. A speech problem does not automatically mean a child has a sound-blending problem. If a child with a cleft is experiencing learning difficulties, he or she must undergo an evaluation and receive a diagnosis before a specific treatment method can be identified.

HANDLING TEASING AND MAKING FRIENDS

Most children are teased about one thing or another at some time. Children with cleft lip and palate may be targets of teasing because peers see them as different. Other children may not understand why a child with a cleft looks and/or speaks differently, and your child may become an easy target for a cruel remark. The self-concept of a teased child can suffer long-term damage from the feelings of inferiority this ridicule can cause.

Fortunately, this cycle can be broken. Educating both the individual and the peer group about clefting can increase acceptance and reduce teasing from fellow students. This process involves several important steps.

Self-Education: For many children, school will be the first time they must answer questions about their cleft without a parent or other adult to help. The first step in preparing for this experience is role-playing actual questions and answers with your child, so he or she is comfortable talking about the

cleft. Use age-appropriate language that provides enough information without overwhelming other children. For example:

Role-playing parent – “What happened to your lip?”

Role-playing child – “I was born with a split in my lip. It is called a cleft lip. The doctors fixed it. This is a scar from an operation.”

Being ready to answer questions removes the element of surprise and makes it easier to respond.

Deciding How to React to Teasing

Both the parents and the teased child tend to react to teasing. Parents often feel very angry at children who tease their child. You may feel like rushing out to confront the teaser, their parents, or the teacher. However, before you do anything, it is a good idea to ask your child how they want to handle the situation. Let your child express his or her feelings, and guide your actions based on what will make him or her feel most comfortable.



Regardless of age, when someone is teased, it is natural to feel like a victim. It is also common to feel powerless and hurt. However, it is empowering to remember that the teased person has several options. In fact, once the initial comment is made, the person being teased is the one in the power seat. He or she can decide how to respond. First, think about who did the teasing and what was said. You can decide how, or whether, to respond by analyzing the WHO, WHAT, and WHY of the remark.

WHO did the teasing? A friend, acquaintance, stranger, or bully?

WHAT was the tease? Was it a mean comment, or maybe a joke that went wrong? Was it based on a lack of understanding?

WHY did the tease occur? Was it a single comment, or has there been a history of teasing?

Looking at these three factors, the child can decide how to respond. The choices include ignoring the remark, responding with a joke or good-natured tease, or educating the teaser. For example, a new classmate may make a remark out of ignorance. Since this is someone your child sees regularly, a simple explanation may be a good option. For example, your child can say, “I was born with a cleft lip and have to see doctors/get surgery sometimes,” and, if they want to limit attention to their cleft, offer a statement to change the topic: “Anyway, what are you doing this weekend?” For a known bully, however, a firmer response plus involvement of teachers and administrators may be required.

The child with the cleft should understand how his or her body language affects the response. In other words, how you look when you answer is as important as what you say. When responding to a bully, crying or withdrawing reinforces the teasing. The child must look and sound in charge by planting his or her feet firmly and speaking up.

Many individuals find that responding with humor works in some situations. Developing a repertoire of quips can throw the teaser off guard. The person being teased can then refocus the situation and bridge the communication gap without becoming defensive.

Parents may wonder if role-playing teaches children to expect problems. Experience shows that preparing for social encounters and maintaining open communication among the child, parent, and teacher creates the best setting for developing competence and self-worth.

Evidence shows that role-playing gives children a noticeable self-confidence boost in social situations. As a result, the expected teasing may never even materialize.

Educating the Group: Because teasing is often a group activity performed in front of an audience, educating the group can also change the outcome. If the other students disapprove of the tease, it will be unsuccessful. Educating them will also satisfy their curiosity, promote acceptance and empathy, and prevent scapegoating. This task can be accomplished in several ways. In their own class, the student with the cleft may choose to write or give a speech about the condition. For more self-conscious children, the class can have a general discussion about why others may look or sound different, rather than singling out one individual.

"My name is Lisa, and I am twenty-two years old. I was born with birth defects, which were mainly facial. I have had over forty reconstructive operations, so I feel I am qualified to talk to parents and to young people with similar problems. The following 'ingredients' make up what I call 'Lisa's Recipe for Life.'

1. The love and support of parents who really listen to what you say and compliment you on your accomplishments is most important. Parents who show their faith in you by letting you try things, even things you might fail to achieve, help you to foster independence and self-sufficiency.

2. I had to learn to tell the difference between the feelings that everyone experiences and those that pertain to my physical problems. I had to remind myself that every teenager worries about being attractive. They wonder if they are too tall/short or too fat/skinny. They wonder if any boy/girl will ever be interested in them. I found that even the most attractive, athletic, intelligent, wealthy, etc., teenager has his or her own insecurities.

3. I felt it was my job to allow others to get to know me by getting involved in school and special projects. People fear what they do not know."

Lisa Gutierrez - Houston, Texas

However, strong evidence shows that most teasing occurs outside the classroom peer group. In fact, the most likely teasers are those who do not have an opportunity to get to know the student as a classmate. The schoolyard and school bus are common settings for teasing. A school assembly on disabilities and individual differences is an excellent forum for students who don't know your child personally to ask questions and satisfy their curiosity.

These preventive measures can also begin at home. Repeated positive reinforcement from family members builds self-confidence and helps the child believe he or she deserves respect from peers.

Making Friends: A student who enters school feeling good about himself or herself sends the message that he or she is interesting to get to know. How can you help develop this trait in your child?

Early exposure to other children teaches social skills and a sense of belonging. Meeting others with clefts, either children the same age or older individuals who may be role models, is very valuable, as it provides your child with a special link to those with the same concerns. Giving your child the chance to interact with others will also help build social skills.

Developing a special ability or talent gives a child an aura of expertise and builds self-confidence. Belonging to teams and clubs, both in and out of school, will also give him or her chances to make friends with others who share similar interests.

A child with a cleft may have to work a bit harder to get others to look past their difference. Being interested in others, developing a sense of humor, and knowing how to be a good friend are all important skills that will help your child to make friends more easily. Encouraging your child's behavior through positive reinforcement will teach them that this extra effort leads to success.

"I'm 15 years old, and I find it helpful to remember that I am not the only person with a cleft. It is a big comfort for me to know that. My cleft hasn't really bothered me, because I have friends with clefts, too. Some children don't get to see other kids with clefts very often. My suggestion is to remember that you are not the only one. Other people with clefts have made it, and so can you!"

Jen Onyx - Limekiln, Pennsylvania

A TEACHER TALKS TO OTHER TEACHERS

In your years as a teacher, you may only have one or two children with cleft lip and palate in your class. In the classroom, you should generally treat them like any other student. If a student with a cleft begins to exhibit behavioral or learning problems, you should approach and assess him or her as you would any other student.

A child with cleft lip and palate may have a few potential problem areas you should be aware of. First, because cleft palate increases a child's susceptibility to ear infections, you should check him or her regularly for hearing loss. A hearing loss may impact (1) where you should position yourself while teaching so that the student is certain to hear you, and (2) how you should arrange classroom seating, depending on your teaching style and the room arrangements.

Second, if the child has any visible signs of the cleft (e.g., a scar on his or her lip), you may want to keep a "third ear" attuned to whether other students are harassing or teasing the child. One preventive approach is to do an activity like a magic circle, in which you lead a group discussion about the various ways we are all different. This activity can lead to a more accepting attitude toward differences among people. Also, if a specific teasing problem appears between the child with the cleft and one or two other students, you might sit down with these children to find a resolution (e.g., help them talk about their fears and learn what mutual interests they may have).

Third, a child with a cleft may need speech therapy. As with all pull-out services, this can draw attention to the child and make him or her feel different. If you can help the child leave the

room in a subtle way, it will help to prevent negative attention from being directed at the student at such times.

Fourth, it is important to remember that many children with cleft lip and palate have had repeated hospitalizations and surgeries before entering school. It is not unusual for them to need additional surgeries between the ages of 5 and 12 years. They may miss some school time. Make every effort to help them keep up with the class so they do not fall behind and again become the object of negative attention. Support from you and their classmates is also helpful at this time. Teachers of older children might have the class make Get Well cards for the child having surgery. Funny cards are especially appropriate. Receiving these cards makes the child feel popular and more eager to return to school.

Fifth, because the ears, teeth, and speech mechanism may be involved, the child may have many medical appointments. Although parents should try to schedule them during non-school hours, it is impossible to fit all appointments around the school schedule. As teachers, we need to be understanding with both the child and the family. As much as possible, we need to work together to ensure the child does not miss important instructional and informational materials presented on those days of absence. Remember that these medical appointments are essential to the child's successful habilitation.

A child with cleft lip and palate will likely progress through all developmental stages in a typical way. Generally, there is no connection between a cleft and a child's intelligence. Most children with cleft lip and palate do quite well in school, although recent research has shown an increased risk of some learning disabilities in a small portion of the cleft population (primarily in children with clefts of the palate only). Your approach to assessing a child with a cleft should be no different than with any other child. However, if the student is having difficulty learning, recommend a diagnostic psychoeducational evaluation immediately so appropriate educational planning can begin. Intervention at the earliest possible age can improve a child's ability to learn and prevent secondary problems with self-esteem and behavior, which often develop when a child has difficulty keeping up in school.

As with all your students, it is important to meet with the parents of a child with a cleft. They can share information about their child's history of medical appointments, surgeries, etc. Keep in mind that the treatment process is different for each child, depending on the severity of the cleft and how the child's physical development progresses as he or she grows older. When conferencing with these parents, remember that they must balance work, home, and family with many medical appointments, surgeries, insurance claims, and other unusual demands on their time and energy. At times, they may appear defensive or fragile; your encouragement can make a difference.

A child with a cleft needs to be seen holistically. If you are understanding about occasional absences from school, supportive around surgery times, careful not to draw attention to him or her during pull-out times, and attentive to any social interaction difficulties, the child will move through the year in your classroom as smoothly as the other students will. If you would like more detailed information about cleft lip and palate, read this entire pamphlet along with others available from the American Cleft Palate Craniofacial Association (see the end of this booklet for more information).

Having a child with a cleft lip and palate in your classroom is another opportunity for you and the other students to learn about differences. The key to this child's successful learning and social development, as with any child, is a positive self-concept. You can support that positive self-concept by offering your teaching skills and the gift of your compassion.



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FOR MORE INFORMATION

This booklet and many others have been produced by:

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