



ACPA

American Cleft Palate
Craniofacial Association

acpacares.org



Information for Adults with Cleft

2026 Edition

Copyright 2026 American Cleft Palate Craniofacial Association. All rights reserved. This publication is protected by copyright. Permission should be obtained from the ACPA prior to any reproduction.

Special thanks to:

- Subject Matter Experts and 2024-2026 Family Resources Committee Chair, Pat Ricalde, DDS, MD, and all other Members of the Committee
- Consulting Medical Copy Editor: Katharine O'Moore-Klopf, ELS
- All ACPA members who have contributed to previous editions and the evolution of this booklet
- ACPA's Graphic Design and Marketing Team, RLR Strategic Communications

Scan the QR code to be directed to the ACPA Family Resource Center webpage:



Table of Contents



Foreword.....	2
Background Information.....	2
One Adult's Perspective.....	3
Another Adult's Perspective.....	4
Getting Along With Others.....	6
Facial Appearance.....	7
Creating an Attractive Smile.....	8
The Adult Patient.....	10
Ear, Nose, and Throat Health.....	14
Working With Insurance Companies.....	15

Foreword

This publication continues a developmental series produced by the American Cleft Palate Craniofacial Association. The first publications are written for families of children with cleft lip and/or palate, from the infant's birth through the teen years. This publication discusses issues affecting adults born with clefts.

Ideally, by adulthood, a cleft should not affect self-confidence, relationships with others, employment, or physical function. While this is the case for some adults with clefts, others continue to experience the effects of having a cleft.

Adults with clefts may be concerned about issues such as hearing, speech, dentistry, psychological development, physical appearance, or reproduction concerns. Adults with clefts may seek a support group to meet others with clefts and may desire to share experiences with others. Financial concerns may also be important when seeking additional services in adulthood. This publication addresses each of these issues so you can better understand your options for seeking additional help and support.

Background Information

Cleft lip and palate are the most common birth differences in the U.S., affecting 1 in every 1,050 live births. As a person born with a cleft, you may wish to seek information and possibly treatment in your adult years for many reasons:

- to continue with treatment started at an earlier age,
- to start treatment in the adult years,
- to discuss new treatments that may not have been available when you were younger,
- to become involved in a support group,
- to update yourself on current genetic information, or
- to explore financial choices available to you for services/treatment.

Treatments for many of the problems associated with cleft lip and palate continue to change and improve over the years. If you want to discuss these advances, have concerns about possible treatment choices, or want to meet others with similar questions or concerns, seek out professionals associated with a cleft palate/craniofacial team in your area. The American Cleft Palate Craniofacial Association has a list of cleft palate/craniofacial teams in the United States and many other countries. Although many teams do not treat adults, ACPA has select Approved Teams that treat adults.

COMMENTS FROM AN ADULT WITH CLEFT LIP AND PALATE

As a female, I have always been very aware of the images the media presents as beautiful in our society. Many of us have long known that we don't fit these stereotypical images, whether we have a cleft or not. Somewhere along the way, I learned to measure my worth by something other than the media's criteria.

Like many of you, I experienced many hospitalizations due to my cleft, as well as the stares, teasing, and confused looks of others when they could not understand my speech. I grew up in an environment where those in my family and community did not openly discuss my responses to these moments, so others did not know the pain and isolation I felt throughout my youth. I believe those of us who struggle with something out of the ordinary from a very young age learn to be resilient. Resilience can carry us far, even if we don't realize it.

Would I have chosen this path? Of course not! Who among us would choose such events in our lives? Yet somewhere, somehow, even though I did not experience direct support for my emotional well-being while growing up, there were individuals in my family who loved and cared for me in the best ways they knew how at the time. That was enough to keep me surviving. A few individuals in school and in my church community were strong supporters of my family, too.

I did not date much at all as a teenager or well into my adult years. I often wondered if I would ever meet anyone who would want to be in a relationship with me. When I met someone who seemed quite serious about me, I wondered what was wrong with him if he wanted to be with me! I knew then I had much more to learn about trust. I did learn, and I trusted this male who affirmed me in a way I had never before experienced.

One of the greatest challenges was when our son was also born with a cleft. As an adult, I again struggled with my anger and frustration. One brief conversation I had about my possibility of having a child with a cleft did not seem to present much of a possibility for that occurrence. Well, so much for statistics! Life seemed unjust again! I had not chosen this!

Through much of the medical treatment and care for our son, I learned of new possibilities for treatment for myself as an adult. Again, I became aware of the media images and the professionals' images of how I might be "improved." But each improvement could come with a trade-off. I could have a pharyngeal flap surgery and get rid of my prosthesis, but my speech might not improve.

Did I want to have surgery when there was only about a 50% chance of improved speech, particularly since my speech seemed to be fairly acceptable to others already? Yet continuing with my current prosthesis over the long run could cause some dental difficulties in later years. Whose criteria do I use? Each of us faces dilemmas like this as adults.

We may not want to try a modern technique just because it is available. Financial concerns may also matter, especially when trying to convince insurance companies that there are issues beyond cosmetics when seeking future treatment.

Each of us needs to weigh our own individual situation carefully. We need to know who we are and whom we want to be. We need to discuss all details and implications of each procedure and treatment carefully with professionals. We need to decide whether others' images and perceptions are the criteria we use to make decisions about ourselves.

Fortunately, at points in my early adulthood, I sought help through counseling to sort through some of my dilemmas. When our son was born, I joined a support group for parents of children with clefts, which helped me in my role as a parent. Just because I had grown up with a cleft did not automatically qualify me to parent a child with a cleft. That does not negate the insights I learned from my own experience, which have helped me support our son through some of his tougher moments.

Through my involvement in the support group and in a national group for parents and patients, I also came in contact with other adult patients. That became a wonderful resource for healing, as I shared with others who had walked in my shoes. I remember the tremendous connection when I spoke with another woman with a cleft who had also had a child with a cleft. I was not alone!

I have been fortunate to contribute to society by working, pursuing further education, and entering a profession. Growing up, I learned a lot by dealing with others who viewed my difference negatively. I have used these experiences to view the world and individuals with sensitivity and compassion. I did not ask for the experience of growing up with a cleft, nor to be the parent of a child with a cleft. What I have decided to do with those events has made it a learning and growth experience for me. At some point, I decided I could either stay stuck in my anger and frustration and feel sorry for myself, or move on and let these experiences count for something more positive.

I have been affected by all the aspects of clefting discussed in this booklet—speech, dentition, hearing, physical appearance, emotional/ social development, and certainly genetic issues. Nevertheless, I am a person who feels, who cares, and who stands ready to share with others the pains and joys of life. I have had my struggles and made some tough decisions. I am my own unique individual. I am no more than the next person, nor am I any less!

Another Adult's Perspective

COMMENTS FROM AN ADULT WITH CLEFT LIP AND PALATE

I realize I cannot represent the opinions of all adults born with cleft lip/palate, because the impact of having a cleft is certainly not the same for everyone. What I can do is share my thoughts, along with the experiences and concerns other adults have shared with me. Although I underwent approximately 15 surgeries during childhood and adolescence, I know that I am very fortunate to be able to say that having a cleft has never been a major issue in my life.

I am also well aware that for many, having a cleft has been a painful experience, both in childhood and adulthood. Regardless of our experiences, I think it is true for everyone that having a cleft has influenced who we are today. Interestingly, although many people can't imagine what it would be like to live with a cleft, we probably can't imagine life without it.

By the time we are adults, most of us have had at least 20 years of experience with looking and/or sounding different from most everyone else. For the most part, we're quite used to the idea of being different. Although we are generally no longer subjected to the teasing we may have faced as children, we still know some people stare at us and do double-takes when we go out. Our childhood experiences have no doubt shaped how we feel about ourselves today. For some, having a cleft has become a fact of life. For others, it can still hurt.

If you are reading this publication, you may be considering some sort of further treatment. As children, most of us had treatment decisions made for us by health care professionals and/or our parents. As we face the prospect of additional treatment in adulthood, we realize that the decisions are now in our hands. Those without a cleft may assume we would want to do as much as possible to change our appearance, speech, or teeth. This may indeed be true for some, but for many, treatment decisions do not come that easily. Several factors can influence how we feel about further treatment.

First, by the time we are adults, many of us have simply had enough of surgeons and hospitals. To go through surgery can mean that you must ride on a roller coaster of emotions. There is the fear of physical pain and discomfort, the hope that you will like the results of the surgery, the hope that others will like the results, and the fear that the surgery won't do what you hoped it would. Make sure your expectations for treatment are realistic. Also, to pursue further treatment as an adult can mean we must revisit the emotions we felt as children, when we were learning to deal with our differences the first time around. Those childhood memories of dealing with a cleft can come rushing back, and some may choose not to relive those experiences.

Second, when we had surgery in childhood, I think the whole environment for us was safer. We could rely on the support of our parents, relatives, and close friends from school. We had more control over social situations where we had to interact with people who didn't know us. We could go home and hide if we wanted. As adults, we may feel that our safety net is gone. We are forced to interact with strangers daily. Even with our friends and coworkers, we may not want to call attention to ourselves or the fact that we are getting treatment for our cleft, yet the process of getting further treatment can do just that. So we have to be ready to answer questions such as "Hey, why were you off work last week?" or "Why do you have braces on your teeth?" or "Is it me, or do you sound different than you used to?"

Finally, it can be difficult to decide on further treatment because change, whether positive or negative, can uncover emotions and make us reflect. By the time we are adults, we have looked in the mirror for years at a face we have learned to accept, like, and love. We have looked or sounded a certain way for quite a long time. Our faces and our voices have become parts of our personalities, of who we are. Even if our treatment is successful, our faces or our speech will change, and it can take time to get used to it. Some of us would like a new face or to change the way we sound, and that's fine. Some of us are perfectly comfortable with the way we are, so why change?

Some of us may be interested in further treatment, but are afraid that the result will be no better or maybe worse than our current appearance. Some adults have told me they feel guilty for wanting further treatment. They feel this means that they haven't learned to accept themselves as they are or that they aren't strong enough to deal with having a cleft. I think the people who feel this way are being too hard on themselves. After all, tens of thousands of people go to surgeons for nose jobs, facelifts, and tummy-tucks every year, so why should we be expected to be different? More importantly, no one else knows all the emotions surrounding your decision about further treatment; no one else has had to walk in your shoes. Do what you want to do.

ATTITUDES TOWARDS ADULTS WITH VISIBLE DIFFERENCES

As an adult with a cleft, you have lived all your life with the residual scars of the cleft surgery. The extent of facial scarring from a repaired cleft varies from person to person. The impact of having a visible difference is also very individual.

Perhaps you have been able to accept your visible differences. Facial scars have faded into the background of awareness and do not play a pivotal role when interacting with friends, colleagues, or other individuals with whom you have long-term relationships. Nevertheless, you may still experience irritation or a twinge of self-consciousness when someone asks about your scar, or when you notice that someone is looking a bit too long. Why is this?

If you have ever taken time to really study the appearance of others, you have probably realized that people come in many different sizes, shapes, and degrees of attractiveness. Yet as variable as appearance is, most people can walk into a room without drawing attention to themselves. However, this may not be the case for a person with visible scarring or asymmetry of facial features. If you have a visible difference, it is more difficult to fade into the crowd.

Looking different carries with it a particular social burden. There are social conventions for most interpersonal interactions. That is, people know how to behave, what to say, or what not to say in a social interaction. However, people feel quite self-conscious when they are in conversation for the first time with someone who looks different. They may be unsure where to look or whether to ignore the difference or acknowledge it by asking a question.

You may have already learned ways to help other people feel more comfortable with your facial difference. While it may feel unfair, often in initial encounters the responsibility for establishing a comfortable relationship with another person will fall to you. When you are introduced to a new person, you may be able to ease the situation by looking directly at the other person, meeting his or her eyes, and smiling.

At other times, a confident but brief explanation of your facial difference may be in order. Still other situations call for a humorous response. What is important is that you have several techniques you can use to help put the other person at ease and thus help you both to move on to other areas of conversation.

In order to handle social interactions comfortably and confidently, you must feel good about yourself. For some adults, the memories of teasing and social exclusion they experienced during their school years make it very difficult for them to feel socially confident. Some adults continue to be embarrassed about their appearance or feel angry because they were born with a cleft. If you have feelings which you believe interfere with your ability to get along with other people, be successful at work, or interact comfortably in romantic relationships, you are not alone. Joining a support group may provide you with the opportunity to interact with individuals who have had similar experiences. Professional counseling, often available through your local cleft/craniofacial team, may also be of benefit to you. In addition to support groups and professional counseling, further management of remaining physical and aesthetic problems related to the cleft may help.

SURGICAL CONSIDERATIONS FOR THE ADULT

Patient Input and Surgeon Selection

A major difference between adults considering reconstructive surgery or cleft repair and children undergoing cleft surgery is that adults can actively participate in setting surgical goals. Most adults considering reconstructive surgery can express fairly clear desires and expectations. The surgeon should address these concerns before any surgery.

As a patient, you must be comfortable with how much time you spend with your surgeon discussing your concerns before surgery. The success of the operation may depend upon how much you and your surgeon agree. It cannot be overstated that what matters is what you consider important. Some surgeons may be uncomfortable with your particular goals and desires. If that happens, keep seeking consultations with other surgeons, with the understanding that no reputable surgeon will agree to do something he/she cannot accomplish or does not believe is right.

Since many aspects of cleft treatment are based on the surgeon's personal experience rather than hard scientific fact, you should expect a variety of opinions and treatment suggestions among surgeons. Although this may be confusing, it does not mean that any individual surgical plan is right or wrong. View the variety of opinions as an opportunity to find a surgeon who understands you and is willing to proceed with a mutually agreeable plan.

Functional vs. Aesthetic

It is not unusual for functional problems related to the cleft to remain into adulthood. These may include speech problems, hearing problems, fistulas (small holes in the palate), dental problems, or breathing problems due to nasal obstruction, among others. You and your surgeon should agree on which, if any, of these problems to address first so your long-term health and function are as good as possible. If you have more than one functional problem, you are best positioned to decide how much each problem interferes with your daily activities. Of course, this may differ for different people because of personal desires or job demands.

If you have more than one problem, it is important that you and your surgeon develop a list of all the problems and consider them individually and as a whole. This may allow you to treat more than one problem surgically under the same anesthetic or during the same operation. Some of these problems may require the involvement of various surgical, dental, or other specialists. A team of specialists can best deliver this coordinated care and address all problems that may arise after the initial repair of a cleft lip or palate.

Concerns about facial appearance after initial or primary cleft repair are more personal than the functional (e.g., speech, chewing, swallowing) problems just discussed. Scarring, lip irregularities, and nasal differences are probably the most common reasons you may seek later or secondary surgical correction.

Before surgery, you should understand exactly what is and is not possible. It is also important to understand what the surgeon anticipates the recovery period to be and what limitations, if any, you will experience after surgery.

Because insurance often does not cover the cost of aesthetic procedures, you should clearly understand your financial obligation before the procedure. Most surgeons who perform secondary surgery consider it reconstructive (to restore function) rather than merely cosmetic (to improve appearance), because its purpose is to reconstruct the structures affected by the cleft. Increasingly, though, insurance companies take the position that these procedures are performed for cosmetic reasons only, and they refuse to pay for some or all of the costs.

In summary, the needs and desires of adults with clefts are as varied as each person. Before any procedure, you should ask questions and explain your desires and expectations to your surgeon and, perhaps, other members of the cleft palate team. After discussing your options with your surgeon, you should understand the goals and limitations of surgery. Last, but certainly not least, you should understand the financial arrangements required for any proposed procedure.

Creating an Attractive Smile

GOALS AND PROCEDURES

The overall goal of treatment for cleft lip and palate is to achieve the best possible facial appearance and function. An attractive, functional smile depends on many factors, including well-positioned jaws that harmonize with the rest of the face, a comfortable, stable bite, and healthy, attractive teeth. The function and harmonious appearance of the lip and nose are also critical in achieving this goal.

When considering surgical ways to improve facial appearance, keep a few important things in mind. A cleft involves all soft and hard tissue layers, not just the skin. Although a scar on the lip may be the most obvious issue, you may need more than scar revision to achieve the best possible improvement.

Your lip and nose are supported by the underlying skeleton (bone and cartilage) and teeth. If these supporting structures are not properly formed or are not in the correct position, your lip and nose will not appear balanced, regardless of how noticeable the scar may be. Clefts can cause bone differences that interrupt or alter dental development. Missing or malformed teeth in the cleft area are likely. The cleft itself disrupts the continuity of the upper jaw, often leading to instability of the two bony segments on either side of the cleft. The bony segments may be misaligned. In addition, the growth of the upper jaw is often disturbed by either scarring from previous surgeries or other unknown factors. As a result, the upper jaw (maxilla) may be smaller, narrower, and positioned farther back than is usual relative to the lower jaw (mandible), causing the upper teeth to be inside the lower teeth. In addition, teeth in the cleft area may erupt out of position.

Fortunately, these problems can be corrected to create an attractive, functional smile. The procedures are best done in a series of steps that may take years to complete. Therefore, a coordinated team of specialists should plan them. As stated earlier, this is usually accomplished through an interdisciplinary cleft palate team.

Orthodontic appliances move the teeth into the best position within their respective jaws. Extraction of certain teeth may be necessary to reposition the teeth and may sometimes temporarily worsen the bite. Ultimately, however, this leads to the best possible facial and dental form and function. If surgical widening of your upper jaw is needed, an orthodontic expansion device may be fixed to several teeth.

Your facial bones form the foundation of your face, and the bony dental ridges support your teeth. These bones must be properly positioned to achieve a good bite. Various surgical procedures can widen or reposition the upper jaw. The lower jaw and chin can also be repositioned if necessary. The orthodontist and surgeon must plan these procedures together to ensure an acceptable bite and facial harmony. Orthodontic appliances are usually placed first, and surgery is only undertaken after adequate orthodontic preparation. An exception may apply if bone grafting in the upper jaw is planned.

Bone grafting in the tooth-bearing dental (alveolar) ridge is an operation performed to stabilize the bony segments of the upper jaw and provide better support for permanent teeth. Usually, this is done in childhood or early adolescence, but it may also be necessary in adults to achieve the best possible result. Surgeons remove bone from one part of the body and place it in the jaw to fill the missing bone in the gum or dental ridge. While some surgeons use artificial materials in place of the body's own bone, most surgeons believe natural bone gives a better result. The bone can be taken (harvested) from a variety of places, including your hip, head, rib, or leg. Discuss your bone graft donor site choice with your surgeon.

You may also benefit from a bone graft to highlight your cheekbones or nose. If you and your surgeon agree these procedures may help, they can usually be done at the same time. When jaw bones are moved, you must hold them in position until they heal solidly. Traditionally, patients had to wire their teeth together after surgery for up to six weeks to support healing. (If your teeth are wired together, you must follow a liquid diet, since normal chewing is not possible.) Increasingly, surgeons use metal plates and screws to hold repositioned jaw segments and bone grafts in place during healing. This is known as "rigid internal fixation." Even if your teeth are not wired together, chewing is discouraged to prevent movement of healing bones. In this case, you will need a soft diet for about eight weeks after surgery.

After surgery, you may need continued orthodontic treatment to move your teeth into their final position. The usual length of treatment from start to finish (both orthodontics and jaw surgery) is eighteen to twenty-four months. If preoperative orthodontic treatment was performed, additional adjustments following surgery may be made to ensure that all teeth come together in the best possible way.

An important consideration in planning the final dental result is whether teeth are either missing or malformed. If a tooth is missing, you must decide whether to close the space it would have occupied by moving teeth into it or to leave the space open and replace the tooth with a prosthetic (artificial) tooth. Many different prosthetic replacements are available, such as removable partial dentures, fixed bridges, bonded bridges, and implants.

Factors influencing the decision of which option is best include the quality of the existing bite, the degree of crowding among the teeth, the location of the missing tooth, and the amount of bone support at that site. Plans must also address any malformed teeth. If a tooth is small or misshapen and needs to be restored to a larger size, you must reserve adequate space for the final size.

If you have any of these problems, a dentist who makes dentures and other dental appliances (prosthodontist) or an experienced general dentist, together with the dentist who moves teeth (orthodontist), should work together to develop the best possible plan and discuss the available choices with you before treatment.

The final phase of making an attractive smile involves attention to the scar on the lip and the shape of the lip. It is important to keep in mind, as has been emphasized above, that your lip will not look its

best unless it is adequately supported by the skeletal and dental structures underneath the lip. Ideally, lip revision surgery should follow tooth and jaw restoration or reconstruction.

Sometimes speech is changed after jaw surgery. Your tongue will need to adjust to the new space. In fact, the new jaw position may make it easier to produce better speech sounds. Right after surgery, you will naturally adapt to the new jaw position. Even so, it may be helpful to see a speech-language pathologist for evaluation and treatment. Although jaw surgery may help with some aspects of speech, such as making certain sounds more precisely, it could also change the nasality of your speech. That is, moving the upper jaw forward may affect your soft palate and change your ability to seal off your nose from your mouth during speech. Your surgeon and speech-language pathologist should discuss these possibilities with you before jaw surgery.

In summary, several stages of treatment, including surgery, orthodontics, and prosthodontics, are often necessary to achieve the most pleasing and functional smile possible. The key to the success of these varied steps is coordinated planning. Good results can be achieved with careful planning before any treatment is started.

The Adult Patient

SPEAKING CLEARLY

Although certain facial and jaw structures may continue to grow and develop into the late teens, and sometimes beyond, your speech structures have probably been adult size for several years. All body tissues, including those of the mouth and throat, mature and change to some degree throughout our lives, but generally, the size and shape of the structures involved in speech are finalized by about 13 to 16 years of age.

Let's assume you are at least 20 years old and, most likely, no longer visit your interdisciplinary team annually. In fact, you may have assumed you've done all that can be done and that you're getting on with your life. But you may still have some questions about your speech. If you do, try to answer them.

Am I satisfied with my speech now?

This is a very important question, and only you know the answer. Perhaps you are quite satisfied, and that is good. But perhaps you are not! You may not know precisely what concerns you about your speech, only that you are not totally satisfied. Your speech is part of your self-image, and your opinion is important.

What were my expectations for my speech some years ago?

This question is somewhat related to the first, because your current satisfaction likely reflects what you expected your speech to be like as an adult. Was your expectation perfect speech? Normal speech? Acceptable speech? Able to get along speech? Acceptable speech is the minimum goal that your medical, dental, and speech-language professionals had for you from the start. They all wanted your speech to be the best it could be. Perhaps your speech has always been very good, and you have not really thought much about it. But for many, what they expected has fallen somewhat short. You should feel comfortable expressing that feeling of dissatisfaction. Speech improvement may still be possible.

What impression does my speech make in comparison with other speakers?

You may remember negative comments others made about your speech, or your speech-language pathologist reminding you to monitor your articulation or nasality during conversation. In many respects, this is the bottom-line concern of speech-language pathologists: to carry over what you can do in therapy sessions to all speaking situations. Perhaps you remember your team telling you that improved speech required a physical procedure like a speech prosthesis or surgery. Perhaps you, or your parents, weren't interested at the time. You may be interested now. A recent comment from a listener may have sparked your concern and interest. Perhaps you feel you didn't get a certain job because your speech wasn't good enough, or maybe your current job requires effective communication skills and you want to improve your speech. You may have options now that you weren't aware of before.

Is my speech understandable to others?

Ideally, your speech is almost totally understandable to others, a quality known as speech intelligibility. As an adult, your speech should be readily intelligible all the time or, at a minimum, have only occasional unintelligible words. If your listeners do not understand frequent words and phrases, evaluate the reasons why. Even some speakers who are readily intelligible still have concerns about other aspects of speech, as described below.

Is my speech too nasal? Too denasal?

You may believe, or you may have heard, that you sound like you are talking through your nose, or like you are stuffed up or have a cold. These descriptions refer to the balance of sound between the nose and the mouth during speech. This balance normally changes when we speak, depending on the speech sounds being produced. It is not normal when the balance does not change properly. Too much nasality is common in children or adults with a cleft palate. This part of speech depends on how your speech structures function. You may recall hearing as a child, if you received speech therapy, how important it was to seal off, close off, or separate the nasal cavity from the mouth and throat to produce good speech.

You use your soft palate and throat walls to accomplish this closure. This is called velopharyngeal closure, and it is required for normal vowels and almost all consonant sounds (Figures 1 and 2).

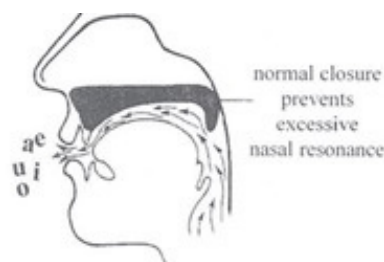


Figure 1: Normal closure during vowel production. Raising the soft palate normally closes off the nose from the mouth and prevents vowels from sounding nasal.

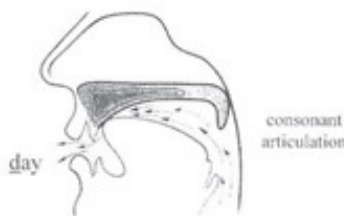


Figure 2: Normal closure during consonant production. A normal soft palate closes off the nose from the mouth and allows pressure to build up, which is needed to pronounce many consonants.

If you have had your soft palate repaired, it may still be too short to contact the back wall of your throat, or your throat walls may not move sufficiently. This is called velopharyngeal insufficiency (VPI), and it causes too much sound to pass through your nose when you speak (Figures 3 and 4).

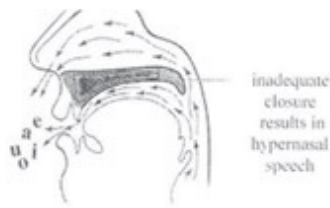


Figure 3: Inadequate closure during vowel production. If the soft palate cannot completely close off the nose from the mouth, the speaker will produce nasal-sounding vowels.

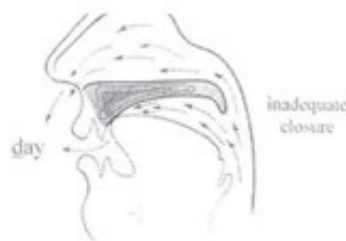


Figure 4: Inadequate closure during consonant production. When closure is inadequate because of soft palate problems, air escapes through the nose, and the consonants become weak or disappear.

You may have had surgery, such as a pharyngeal flap or a pharyngoplasty, or you may have had a speech prosthesis made for you that was intended to improve velopharyngeal closure for speech. Even if you have had one of these treatments, you may still be concerned about too much nasality.

You may believe that the opposite is true of your speech; that is, you may have too little nasality (denasality). Although most consonants require complete closure between the nose and mouth, nasal consonants are the exception. In English, there are three nasal consonants (/m/ as in “make,” /n/ as in “new,” and /ng/ as in “ring”). When you produce these sounds, the soft palate needs to stay down and leave an opening to the nasal cavity. If crooked or enlarged structures obstruct your nose, your nasal consonants will sound denasal, and you may sound “stuffed up,” like you have a cold. This is usually treated by surgically opening up the nasal passages.

You may also sound denasal if you have persistent congestion or allergies. Nasal congestion is temporary for most of us, and we return to normal speech when the congestion subsides. But for some, persistent nasal congestion prevents the free flow of sound and air into the nose, making it impossible for the denasal quality to go away. You may need to consult an allergist for treatment if allergies are the problem.

You may also have too much and too little nasality at the same time. Careful evaluation by professionals experienced in cleft care should identify the cause and recommend treatment. Finally, there may be a mild degree of nasality in your speech, but you and others consider it to be within acceptable limits. Unless you or those you interact with are concerned, mild nasality is not really a problem.

Is the way I make individual consonants different from others?

Perhaps you're concerned about the accuracy or precision of your consonant sounds. This is called articulation. For people with cleft lip and palate, there is no reason to believe they cannot make all consonant sounds in the correct place in the mouth. Many of the hazards to precise articulation were removed when your final dental work (dental bridge, crowns, jaw surgery) was done. Hopefully, the original surgery to repair the hard and soft palate and any other surgery to improve velopharyngeal closure gave you an adequate mechanism for acceptable speech. But perhaps not. You may still be concerned about the precision of your articulation - making better /s/ and /z/ sounds or /sh/ and /ch/ sounds. Also, you may still be concerned about the audible escape of air from your nose (audible nasal air emission) that sometimes occurs when you produce words containing sounds like /p/ or /b/ and /ch/ and /j/.

Is my voice okay?

Your voice is the sound produced by your larynx, or "voice box." Your voice may sound too high or too low in pitch, too soft or too loud, or too hoarse or raspy. A cleft lip and palate does not involve the larynx directly, but the way you use the voice box to compensate for or adjust to velopharyngeal problems may affect voice quality. Perhaps you have experienced laryngitis after yelling, screaming, or cheering too much. This usually goes away after a couple of days. But misuse or abuse of the voice structures over time can cause some persistent problems. It may be this aspect of your speech that concerns you.

Any one or a combination of the above aspects of speech can be responsible for your dissatisfaction and concern. Speech that is socially and vocationally acceptable is a very reasonable expectation and goal for you. You may have heard professionals refer to your speech as acceptable, but you may or may not agree with that judgment. What is acceptable speech for some may not be for others. Perfect speech or normal speech may or may not be realistic for you, and you have the right to disagree. Your opinion is important. But you need to understand that your current speech structures may have limitations. The treatment options that could improve your speech may be similarly limited. Whether you pursue treatment depends on how much the problem bothers you and whether it interferes with others' understanding and ability to relate to you.

What is required to improve certain aspects of my speech?

Speech treatment or therapy may be all you need. After a qualified speech-language pathologist evaluates you, they may conclude that your current speech structures will allow you to change your speech with professional instruction. On the other hand, it may be concluded that physical treatment is definitely needed to improve your speech. For example, after a complete evaluation, you may be doing the best you can with your current structures, but your soft palate may be too short to achieve velopharyngeal closure for acceptable speech. There may be a variety of physical treatments that can help—perhaps a surgical procedure or a speech prosthesis. Your hearing may also affect your speech performance. A careful, complete evaluation is key to determining what you need.

Where can I get help?

A professional speech and hearing evaluation can tell you whether your speech and hearing mechanisms are working properly, which aspects of speech are involved, and what treatment options might be available. Some speech-language pathologists work in public schools and, in many states, provide evaluation and treatment services for people up to age 21. Other resources for speech, language, and hearing evaluation are through community-based speech and hearing clinics, university speech and hearing clinics, hospital rehabilitation centers, and private practitioners. Don't forget that your interdisciplinary cleft palate team is a very important resource for you at any time.

Most cleft palate teams evaluate and treat adults with clefts, even if the team is located in a children's hospital. The medical, dental, speech/language, and hearing professionals on your team can evaluate you and provide treatment or recommend treatment resources. It is never too late to change if you want to change. You can obtain a list of cleft teams in your geographic area by visiting the American Cleft Palate Craniofacial Association's website at www.acpacares.org.

EAR, NOSE, AND THROAT HEALTH

Children with clefts of the palate almost always experience problems with middle ear infections during the first few years of life. Some continue to have difficulty with hearing and ear infections as adults.

If you have persistent ear problems in adulthood, you need an ear, nose, and throat specialist. Signs of possible problems include hearing loss in one or both ears, ear drainage, or earaches that keep coming back or never really go away. You may have a hearing loss caused by damage to the delicate middle ear bones or the eardrum, preventing sound vibrations from reaching the nerves that sense sound. This type of damage can often be repaired surgically.

Ear drainage or recurrent earaches may result from a minor but persistent infection in the bone surrounding the middle ear. Surgery may be required to remove the infection and prevent irreversible damage and hearing loss. If medical or surgical treatment cannot correct hearing loss, a hearing aid can help compensate.

In some persons who have had "nasal" speech for a long period of time, small growths (nodules) can develop on the vocal folds and give the voice a hoarse quality. Usually, you can improve your voice by treating the cause of the nasality. Speech therapy may be helpful in some cases. Surgical removal of vocal fold nodules is necessary only as a last resort.

Unlike the ears, the nose, sinuses, and throat are usually not prone to infection in people with cleft palate. However, if the degree of nasal leakage allows liquid and food material to pass into the nasal cavity when you swallow, sinusitis can develop. This is generally not a problem and can be resolved with appropriate treatment to improve separation between the nose and mouth (velopharyngeal closure) during swallowing. However, if symptoms persist, a thorough nasal examination, including special X-rays, may be desirable, and sinus surgery may be required.

Some adults with cleft palate may have problems breathing during sleep. Many adults who have had operations to improve speech (pharyngeal flap or pharyngoplasty, for example) snore loudly during sleep. While snoring may not bother the affected individual, it might bother a sleep partner. A few adults may stop breathing altogether (sleep apnea) during sleep for more than a few seconds, and this can be a serious, even life-threatening, problem. If your sleep partner has noticed that you seem to stop breathing while sleeping, or if you have restless sleep with excessive daytime drowsiness, you may have sleep apnea. Your local cleft team can help if you are concerned about sleep problems.

WORKING WITH INSURANCE COMPANIES

Once you decide to seriously consider additional treatment, you will need to explore financing. Financial support for treatment may be challenging for adult patients, as standard health insurance companies often reject such claims because of preexisting condition clauses. Also, with recent changes in health care and the rise of managed care, coverage for adult services has become harder to obtain. Adults can use several strategies to determine what financial resources may be available, how to access them, and how to handle denials or refusals for desired treatments.

1. See a cleft palate team and ask its members to provide an updated, coordinated treatment plan.
2. Be prepared to document every phone call/contact you have made regarding insurance coverage. Write down the person's complete name, date and time of contact, and a brief summary of your conversation. This is important because you may need this documentation to support your claim.
3. If you have a private insurance plan (private indemnity, PPO, or HMO), the following suggestions may be helpful:
 - a. Read your policy thoroughly, then contact your insurance/benefits representative. This may be someone at your workplace or in the company's benefits division.
 - b. If you are told no benefits are available for the requested services, ask to speak with the department manager. Don't take NO for an answer yet. Offer to provide any information that would support your request for services. Keep going. If you are still denied, ask the company for the denial in writing. Offer to send the clinic report, physician letters, and any other documentation supporting the need for treatment. Use the Parameters for Evaluation and Treatment to help support your claim.
 - c. If the benefits division denies your claim, ask to speak with a case manager. This is usually someone with a medical background who reviews individual cases. Try to find someone who seems willing to help you.
 - d. Keep asking for the denial in writing if you haven't received it.
4. If you are still denied/refused approval for treatment, consider the following:
 - a. Contact your state insurance commissioner to submit an appeal.
 - b. Find out if your state has a state advocate or ombudsman who may be helpful.
 - c. Seek help from your State Commission on Persons with Disabilities.
 - d. Ask your State Vocational Rehabilitation Office to assist you.
 - e. Write letters to the insurance company or the insurance commissioner to appeal the decision. Keep copies of all correspondence.
5. Consider contacting one or more of your state legislators. They may be interested in your situation and may be able to help.
6. BE PERSISTENT. It may take time and energy, but you may succeed in getting the treatment you want.



acpacares.org

FOR MORE INFORMATION

This booklet and many others have been produced by:

The American Cleft Palate Craniofacial Association
510 Meadowmont Village Circle, Suite 377
Chapel Hill, NC 27517

919.933.9044
info@acpacares.org | acpacares.org