

INFORMATION FOR ADULTS

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TABLE OF CONTENTS

FOREWORD	2
BACKGROUND INFORMATION	2
A WOMAN'S PERSPECTIVE	3
A MAN'S PERSPECTIVE	5
GETTING ALONG WITH OTHERS	8
FACIAL APPEARANCE	9
CREATING AN ATTRACTIVE SMILE	11
THE ADULT PATIENT	15
EAR, NOSE AND THROAT HEALTH	20
WORKING WITH INSURANCE COMPANIES	22
REFERENCES	23
FOR MORE INFORMATION	23

FOREWORD

This booklet is a continuation of a developmental series produced by the American Cleft Palate-Craniofacial Association. The first booklets are written for families of children with cleft lip and/or palate starting with the birth of the infant and continuing through the teen years. This booklet discusses some of the issues affecting adults born with clefts.

Ideally, by the time an individual with a cleft reaches adulthood, the cleft should not affect self-confidence, relations 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 particular 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 very important in seeking additional services in the adult years. This booklet attempts to address each of these issues so that you can be more knowledgeable in seeking additional help and in understanding your options regarding your cleft.

BACKGROUND INFORMATION

Cleft lip and palate are the most frequently occurring birth defects in the U.S., affecting one out of every 600 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:

1. to continue with treatment started at an earlier age,
2. to start treatment in the adult years,
3. to discuss new treatments that may not have been available when you were younger,
4. to become involved in a support group,
5. to update yourself on current genetic information, or
6. 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 wish to discuss these advances, if you have concerns about possible treatment choices, or if you are interested in meeting others who may have questions

or concerns similar to your own, you should 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. Call 1-800-24-CLEFT (1-800-242-5338) or visit www.cleftline.org.

A WOMAN'S PERSPECTIVE

COMMENTS FROM AN ADULT FEMALE WITH CLEFT LIP AND PALATE



As a female, I have always been very aware of the images that the media presents of what is beautiful in our society. Many of us have long recognized that we do not fit these stereotypical images, whether we have a cleft or not. Somewhere along the way, I learned that there were some other measures by which I could determine my worth rather than relying on 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 that those of us who have to struggle with something out of the ordinary from a very young age learn to be resilient. Resilience can carry us a long way, even if we are not aware of 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 to my emotional 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 did meet someone who seemed quite serious about me, I wondered what was wrong with him if he wanted to be with me! I knew then that I had a lot 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 for each improvement, there could be 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 to continue with my current prosthesis over the long run could cause some dental difficulties in later years. Whose criteria do I use? Each of us face such dilemmas as adults.

We may not want to try a modern technique just because it is available. There may also be financial concerns, especially in trying to convince insurance companies that there are issues besides cosmetic concerns in seeking future treatment.

Each of us needs to weigh carefully our own individual situation. We need to know who we are and who we want to be. We need to carefully discuss all details and implications of each procedure and treatment with the professionals. We need to determine if others' images and perceptions are the criteria by which we wish to make our 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 became a part of a support group for parents of children with clefts that helped me in my parental role. Just because I had grown up with a cleft did not automatically qualify me to parent a child with a cleft. That is not to negate the insights learned from my own experience, which have helped me support our son in 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 some healing, as I shared with other individuals 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 be a contributing citizen of society by working, going on for further education, and entering a profession. While growing up, I learned a lot by having to deal with others who viewed my difference in a negative way. I have used these experiences to help me view the world and individuals in a sensitive and compassionate way. I did not ask for the experience of growing up with a cleft, nor to be the parent of a child with a cleft. It is what I have decided to do with those events that has made it a learning and growing experience for me. At some point, I decided that I could remain stuck with my anger and frustration, feeling sorry for myself, or I could move on and have 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 some tough decisions to make. I am my own unique individual. I am no more than the next person, nor am I any less!

I am a person who feels, who cares, and who stands ready to share with others the pains and joys of life.

A MAN'S PERSPECTIVE

COMMENTS FROM AN ADULT MALE WITH CLEFT LIP AND PALATE



I realize that I cannot represent the opinions of all adults who have been 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 some of my thoughts as well as the experiences and concerns that 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 what our experiences have been, I think it is true for everyone that having a cleft has had some influence on who we are as individuals 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 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 that may have occurred when we were children, we still know that some people stare at us and do doubletakes when we go out. No doubt, our childhood experiences have shaped the way we feel about ourselves today. For some, having a cleft is something that has just become a fact of life. For others, it can still hurt.

If you are reading this booklet, it is quite possible that you are 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 who do not have a cleft assume that we would want to do as much as possible to change our appearance, or our speech, or our teeth. This may indeed be true for some, but for many, decisions about treatment do not come that easily. There can be several factors that 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. It is important to make sure that 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 on a daily basis. 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?"

We have been looking in the mirror for years at a face we have learned to accept, to like, to love.

Finally, it can be difficult to decide about further treatment because change, whether it is positive or negative, is something that can uncover emotions and cause us to

reflect. By the time we are adults, we have been looking in the mirror for years at a face we have learned to accept, to like, to 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 be different, and it can take some time to get used to that. Some of us would like to look at a new face or 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, face lifts, and tummy-tucks every year, so why should we be expected to be different from them? More importantly, no one else knows all of the emotions that may be surrounding your decision for further treatment; no one else has had to walk in your shoes. Do what you want to do.

GETTING ALONG WITH OTHERS

ATTITUDES TOWARD ADULTS WITH VISIBLE DIFFERENCE

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 are uncertain about where to look or whether they should ignore the difference or acknowledge it by asking a question.



You may have already learned there are ways to help other people become 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 makes 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.

FACIAL APPEARANCE

SURGICAL CONSIDERATIONS IN THE ADULT

Patient Input and Surgeon Selection

There is a major difference between adults considering reconstructive surgery or repair of a cleft problem and children undergoing cleft surgery: the adult can actively participate in the surgical goals. Most adults who are considering reconstructive surgery are able to express fairly clear desires and expectations. It is important for the surgeon to address these concerns before any surgery is done.

As a patient, you must be comfortable with the amount of time spent 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 overemphasized that what is important is what you consider important. You should know that some surgeons may be uncomfortable with your particular goals and desires. If that happens, you should continue to seek consul-

What is important is what you consider important.

tations with other surgeons with the understanding that no reputable surgeon will agree to do something that 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. The variety of opinions should be viewed as an opportunity for you to find a surgeon who understands you and who 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, to name only a few. You and your surgeon should agree about which, if any, of these problems should be dealt with first so that your long-term health and function will be the best it can be. If there is more than one functional problem, you are in the best position to decide how much each problem interferes with your daily activities. Of course, this may be different for different people due to personal desires or job demands.



If there is more than one problem, it is important that you and your surgeon develop a list of all the problems that are present and consider them individually and as a whole. This may allow more than one problem to be treated surgically while under the same anesthetic or during the same

operation. Some of these problems may require the involvement of a variety of surgical, dental, or other specialists. This type of coordinated care is best delivered by a team of specialists who can address all problems that may be present 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 defor-

mities are probably the most common reasons you may seek later or secondary surgical correction. It is important that you understand before the surgery exactly what is and is not possible. It is also important to understand what the surgeon anticipates the recovery period to be and what, if any, limitations you will experience after the surgery is done.

Because insurance often does not cover the cost of aesthetic procedures, it is important that you have a clear understanding of exactly what your financial obligation will be before the procedure is done. Most surgeons who do secondary surgery feel that this type of surgery is reconstructive (to restore function) and not merely cosmetic (to improve appearance), because its purpose is to try to reconstruct the structures affected by the cleft. Increasingly, though, insurance companies are taking the position that these types of procedures are performed for cosmetic reasons only, and they are refusing 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 discussions with your surgeon, you should understand the goals and limitations of surgery. Last, but certainly not least, you should understand the necessary financial arrangements associated with 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 upon many things, including jaws that are positioned well and in harmony with the rest of the face, a bite that is comfortable and stable, and teeth that are healthy and attractive. The function and harmonious appearance of the lip and nose are also critical in achieving this goal.



When considering ways of improving facial appearance by surgery, there are several important things to remember. A cleft involves all soft and hard tissue layers, not just the skin. Although a scar on the lip may be the most obvious thing to you, more extensive treatment than scar revision may be necessary 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 result in defects in the bone which may interrupt or alter dental development. Missing or malformed teeth in the area of the cleft 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 out of line with one another. 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, the teeth in the area of the cleft may erupt out of position.

Fortunately, these problems can be corrected to make an attractive and functional smile. The procedures are best done in a series of steps which may take years to fully complete. Therefore, they are done best when planned by a coordinated team of specialists. As stated earlier, this is usually accomplished through an interdisciplinary cleft palate team.

The procedures...are done best when planned by a coordinated team of specialists.

Orthodontic appliances move the teeth into the best position within their respective jaws. Extraction of certain teeth may be necessary in order to reposition the teeth and may sometimes result in the bite temporarily worsening. 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 need to be properly positioned before a good bite can be achieved. A variety of surgical procedures can be performed to widen or reposition the upper jaw. The lower jaw and chin can also be repositioned if necessary. These procedures must be planned jointly by the orthodontist and surgeon to insure that an acceptable bite and facial harmony will result. Orthodontic appliances are usually placed first, and surgery is only undertaken after adequate orthodontic preparation. An exception to this may be 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. Bone is removed from one part of the body and placed in the jaw to fill in 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. You should discuss the choice of bone graft donor site with your surgeon.

You may also benefit from a bone graft to highlight your cheek bones or nose. If you and your surgeon agree these procedures may be helpful, they can usually be done at the same time. When jaw bones are moved, it is necessary to hold them in position until they heal solidly. Traditionally, it was necessary to wire the patient's teeth together after surgery for up to six weeks to assist the healing process. (If your teeth are wired together, it is necessary to have a liquid diet, since normal chewing is not possible.) Increasingly, surgeons are using metal plates and screws to hold repositioned jaw segments and bone grafts in position 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, it will be necessary to have a soft diet for approximately eight weeks after surgery.

Following surgery, continued orthodontic treatment may be necessary to move the 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 assure 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, a decision must be made either to close the space it would have occupied by moving teeth into that space 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 about which might be 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 also must be made to restore any malformed teeth. If a tooth is small or misshapen and needs to be restored to a larger size, adequate space must be reserved 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 arrive at the best possible plan together and discuss with you the various choices available prior to 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 restoration or reconstruction of the teeth and jaws.

Sometimes speech is changed after jaw surgery. Your tongue will need to get used to the different space. In fact, the new jaw position may make it easier to produce better speech sounds. There will be a period of time right after surgery when you will naturally adapt to the new jaw positions. Even so, it may be helpful to see a speech-language pathologist for evaluation and treatment. Although the jaw surgery might be helpful for some aspects of speech, like making certain sounds more precisely, the surgery could change the nasality in your speech. That is, when the upper jaw is moved forward, this 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. It is true that all body tissues



including those of the mouth and throat mature and change to some degree all our lives, but in general, the size and shape of the structures involved in speech are finalized by approximately 13 to 16 years of age.

Let's assume you are at least 20 years old and, most likely, no longer making annual visits to your interdisciplinary team. In fact, you may have assumed that all that can be done has already been done, and you are getting on with your life. But you may still have some questions about your speech. If you do, it is important to 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 current satisfaction is most likely the result of 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, the expectation of what they hoped for has fallen somewhat short. You should feel comfortable expressing that feeling of dissatisfaction. Speech improvement may still be possible.

Speech improvement may still be possible.

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

You probably remember some negative comments made by others about your speech, or you may recall your speech-language pathologist reminding you to watch or monitor your articulation or nasality during conversational speech. In many respects, this is the bottom line concern of speech-language pathologists—to carry over what you could do in therapy sessions to all speaking situations. Perhaps you remember being told by your team that improved speech required some physical

You may have options now that you were not previously aware of.

procedure like a speech prosthesis or surgery. Perhaps you, or your parents, were not interested at that time. You may be interested now. Your recent concern and interest may have been sparked by a comment you heard from a listener. Perhaps you feel you did not get that certain job because your speech was not good enough, or maybe your current job requires effective communication skills and you want your speech to be better. You may have options now of which you were not previously aware.

Is my speech understandable to others?

Ideally, your speech is almost totally understandable to others, a quality known as speech intelligibility. The expectation for your speech as an adult is that it should be either readily intelligible all the time or, at a minimum, that there are only occasional words that are not intelligible. If frequent words and phrases are not understood by your listeners, the reasons why should be evaluated further. Even some speakers who are readily intelligible continue to have concerns with 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 you sound like you are all 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 with children or adults with cleft palate. This part of speech depends on the function of your speech structures. 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 an important requirement for normal vowels and for almost all consonant sounds (Figures 1 and 2).

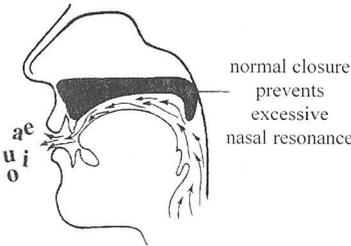


Figure 1
Normal closure during vowel production. The raising of the soft palate normally closes off the nose from the mouth and prevents vowels from sounding nasal.

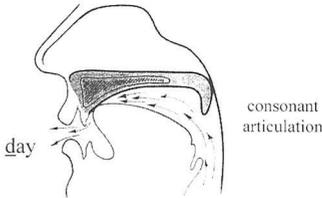


Figure 2
Normal closure during the production of consonants. A normal soft palate closes off the nose from the mouth and allows the build-up of pressure that is needed for the pronunciation of many consonants.

If you have had your soft palate repaired, it may still be too short to contact the back wall of your throat, or it may be that your throat walls do 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).

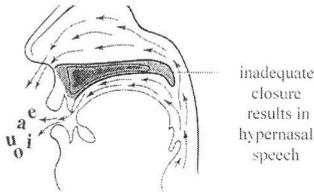


Figure 3
Inadequate closure during vowel production. If the soft palate cannot completely close off the nose from the mouth, nasal-sounding vowels will be produced.

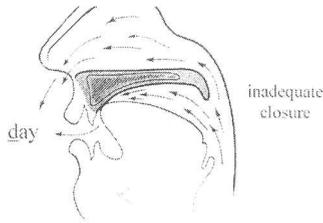


Figure 4

Inadequate closure during the production of consonants. When closure is inadequate because of problems with the soft palate, air escapes through the nose, and 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, too much nasality may still concern you.

You may believe that the opposite is true of your speech; that is, you may have too little nasality (denasality). Although a complete closure between the nose and the mouth is required for most consonants, the nasal consonants are the exception. In the English language, there are three nasal consonants (/m/ as in “make,” /n/ as in “new,” and /ng/ as in “ring”). When these sounds are produced, the soft palate needs to stay down and leave an opening into the nasal cavity. If your nose is obstructed by crooked or enlarged structures within it, the 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.

It is also possible to have too much and too little nasality at the same time. Careful evaluation by professionals with experience in cleft care should result in identification of the cause of the problem and recommendations for 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 at all.

Is the way I make individual consonants different from others?

Perhaps your concern is the accuracy or preciseness of your consonant sounds. This is called articulation. For persons with cleft lip and palate, there is no reason to believe that all consonant sounds cannot be made 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 preciseness 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?

Voice is the part of speech that is 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. Having a cleft lip and palate does not involve the larynx directly, but sometimes the way we use the voice box to compensate or adjust for velopharyngeal problems may affect the quality of voice. Perhaps you have experienced laryngitis when you have yelled, screamed, or cheered 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 there may be limitations to your current speech structures. Your choices for treatment that can make your speech better may or may not be similarly limited. Whether you decide to have treatment will depend

Speech that is socially and vocationally acceptable is a very reasonable expectation and goal for you.

on how much the problem bothers you and whether it interferes with others understanding and relating to you.

What is required to improve certain aspects of my speech?

Speech treatment or therapy may be all you need to help you. Following an evaluation by a qualified speech-language pathologist, it may be concluded that your present speech structures will allow you to change your speech with the help of some professional instruction. On the other hand, it may be concluded that in order to improve your speech, physical treatment is definitely needed. For example, after a complete evaluation, it may be found that you are doing the best you can with your current structures but your soft palate is too short to accomplish velopharyngeal closure for acceptable speech. There may be a variety of physical treatments that can help—perhaps a surgical procedure or a speech prosthesis. Perhaps your hearing affects your speech performance. Careful and complete evaluation is the key to determine what is needed.

Where can I get help?

A professional speech and hearing evaluation can tell you whether your speech and hearing mechanisms are working properly, what aspects of speech are involved, and what the treatment options might be. Some speech-language pathologists work in the public schools and, in many states, provide evaluative and treatment services for persons up to 21 years of age. 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 provide treatment for adults with clefts even if the team is located in a children's hospital. The medical, dental, speech/language, and hearing professionals who make up your team will be able to evaluate and provide treatment or recommend treatment resources for you. 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 contacting the American Cleft Palate-Craniofacial Association's CLEFTLINE at 1-800-24-CLEFT (1-800-242-5338).

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. A few continue to experience difficulty with hearing and ear infections as adults.

If you have persistent ear problems during adulthood, you need the attention of an ear, nose, and throat specialist. Signs of possible problems include hearing loss in one or both ears, drainage from the ears, or ear aches that keep coming back or that never really go away. You may have a hearing loss caused by damage to the delicate middle ear bones or the ear drum, 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 be due to 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 hearing loss cannot be corrected by medical or surgical treatment, a hearing aid can help compensate for lost hearing.

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, voice improvement can be achieved 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 usually are not prone to infection in persons with cleft palate. If the degree of nasal leakage allows liquid and food material to pass into the nasal cavity when you swallow, however, sinusitis can develop. This is generally not a problem and can be resolved with appropriate treatment to improve effective separation of the nose from the 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 be a problem for 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 have decided to seriously consider additional treatment, you will need to investigate financing for it. Financial support for treatment may present a challenge to the adult patient, as standard health insurance companies often reject such claims due to preexisting condition clauses. Also, with the recent changes in health care and the advent of managed care, coverage for services for adults has become more difficult to obtain. There are a number of strategies that adults may use to determine what financial resources might be available, how to access these resources, and how to deal with denials/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 very important, because this documentation may be needed to support your claim.
3. If you have a private insurance plan (private indemnity, PPO or HMO) the following suggestions may be helpful:
 - a. Thoroughly read your policy, then contact your insurance/ benefits representative. This may be someone at your workplace or in the company benefits division.
 - b. If you are told there are no benefits 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 for the denial in writing from the company. Offer to send the clinic report, physician letters, and any other documentation supporting the need for treatment. Use the Parameters for Evaluation and Treatment¹ to help support your claim.
 - c. If your claim is denied by the benefits division, ask to speak to a case manager. This is usually someone with a medical background who reviews individual cases. Try to find one person who seems to want to help you.
 - d. Continue to ask for denial in writing if this has not been sent to you.

4. If you are still denied/refused approval for treatment, consider the following:
 - a. Ask your doctor for names of other adults who have appealed for services. They may provide valuable help and support.
 - b. Contact your state insurance commissioner to submit an appeal.²
 - c. Find out if your state has a state advocate or ombudsman who may be helpful.²
 - d. Seek help from your State Commission on Persons with Disabilities.
 - e. Ask your State Vocational Rehabilitation Office to assist you.
 - f. Write letters to the insurance company or insurance commissioner appealing the decision. Be sure to keep copies of all correspondence.²
5. Consider contacting one or more of your state legislators. They may be interested in your situation and may be able to provide assistance for you.
6. BE PERSISTENT. It may take time and energy, but you may succeed in getting the treatment you want.

REFERENCES

¹ Parameters for the Evaluation and Treatment of Patients with Cleft Lip/ Palate or Other Craniofacial Anomalies. American Cleft Palate-Craniofacial Association. Cleft Palate-Craniofacial Journal 1993; 30 (Suppl 1). Also available by contacting the Cleft Palate Foundation (see address, p. 31).

² Health Insurance Resource Guide (2001). Genetic Alliance, Washington, DC. Phone: 1-800-336-GENE. Has listings of State Insurance Commissions, State Advocacy Agencies, sample letters. You may also call the National Association of Insurance Commissioners, 2301 McGee St. Suite 800, Kansas City, MO 64108. Phone: 816-842-3600.

FOR MORE INFORMATION

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