



As You Get Older

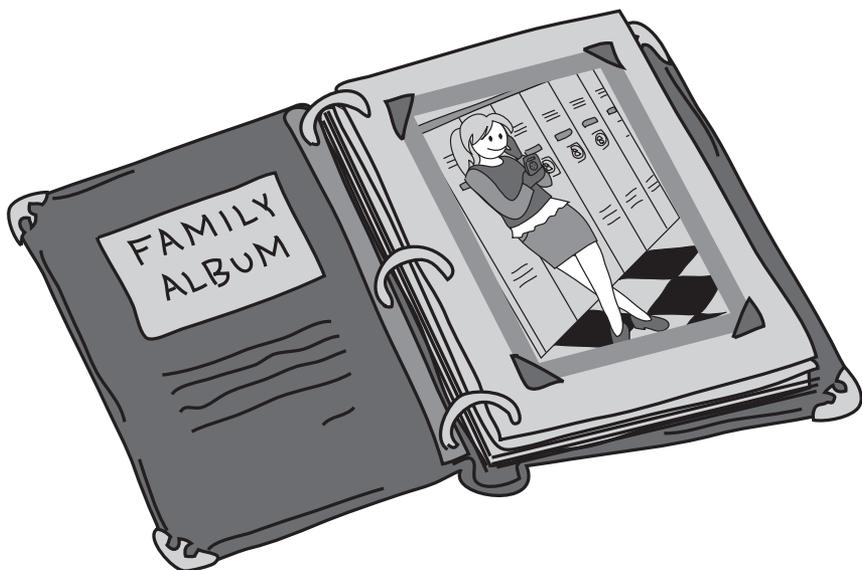


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As You Get Older



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Introduction

As a teenager, you are starting to decide how you want to live your life, and that includes making choices about treatment for your cleft lip or cleft palate. Until now, your parents have probably made most of these decisions. You may become more comfortable with treatment now that you can be involved. However, you might also be a little scared. You may even disagree with your parents about whether you should have the recommended treatment. You may now understand how hard these decisions were for your parents to make when you were little.

You need to do several things to make good treatment plans. First of all, you must decide what is important to you. Second, you need to learn what can be done. Finally, you should understand that there may be more than one way to complete your treatment. Reading this pamphlet should help you learn what your treatment options are. If you have questions that still aren't answered, you can contact the Cleft Palate Foundation at 1-800-242-5338 or www.cleftline.org.

Deciding what is important to you is not always easy. Some teens want all the recommended treatment, and sometimes even more than is possible. Others want to avoid surgery and doctors' appointments at all costs. It is better if you are flexible with these decisions. Try to identify your concerns and then ask questions to help resolve them. Ask your doctors what they think can be done to provide you with the best possible result. You can then determine whether their recommendations are important to you. Your opinion counts!

Remember that your parents will still be involved in the decision-making process. If you and your parents have been talking openly about your treatment, you will find it fairly easy to take a bigger part in decisions from now on. However, if you and your parents have been having a hard time agreeing about what is important, decisions may be harder. You may need to ask for help from the psychologist or social worker on your cleft team, or perhaps from your school counselor.

Maybe you want to put off the hassle of having more treatment, and that is an understandable feeling. Keep in mind, though, that it may be easier to have treatment while you are still a teenager. Once you are an adult, you may have a harder time getting insurance to pay for treatment. Plus you may have to take time off work to have additional surgeries. It may actually be more of an inconvenience to wait until you are older to have treatment.

Throughout this booklet, you will learn about doctors, dentists, and other specialists who can help you deal with the problems caused by a cleft. Hopefully you have met these people before. In many places, they work together as a cleft palate “team.” Just like a high school team, their goal is to help each other achieve a winning result—in this case, a happy and healthy patient, YOU! The Cleft Palate Foundation can help your family find a team in your area, if you don’t already have one.

Getting Braces

Your doctor’s word for braces will be orthodontic treatment, and an orthodontist is the person who will put them on your teeth if you need them. In many ways, your orthodontic treatment will be like that of your friends who



didn't have a cleft lip or palate. You will need to keep your teeth clean and avoid eating hard or sticky foods. You will all have archwires to line up your teeth, and you may also need to wear rubber bands to help move your teeth. And you may experience some discomfort or pressure as your teeth move. It is important to keep regular appointments during treatment and wear your retainer faithfully after treatment to get the best results.

There are some important differences in orthodontic treatment, however, for people born with a cleft. These differences are caused by the lack of bone or missing teeth in the area where the cleft was. Even a person born with just a cleft lip may be missing a tooth. On the other hand, you may have extra teeth, malformed teeth, or teeth that are simply out of position. Your jaws may also not have grown correctly because of the cleft.

When a tooth is missing, your orthodontist may eventually want to have it replaced with an artificial tooth or move a nearby tooth into the empty space. An artificial tooth could either be planted directly into the bone or held in place with a bridge connected to your other teeth. The best choice will depend on how crowded your teeth are, how your teeth come together when you bite, and whether you have a tooth that could substitute for the missing tooth. Your orthodontist may ask you to see a prosthodontist to help choose the best treatment plan.

If you had a cleft in your hard palate (the bony part of the roof of your mouth) or gum, your upper jaw may be collapsed inward leaving you with a crossbite. A crossbite means that your upper teeth are behind or inside your bottom teeth when you bite down. In other words, your top teeth may not fit

evenly on your bottom teeth when your mouth is closed. When this occurs, the upper jaw must be expanded to bite normally with the lower jaw. When your teeth come together correctly, you can chew more easily. This treatment will also help your smile look better.

Expansion can be done with a cemented palatal expander, or during jaw surgery if you need that. The expander fits along the inside of your teeth, not on the outside like braces. If you use an expander, you will probably have it before you get braces. It is typically attached to the teeth in some way (either using bands or an acrylic pad) and tightened on a regular schedule so your palate will get wider. The goal is to make the roof of your mouth the right size so you can bite down correctly.

If your cleft went through your alveolus (the bony ridge where your teeth are), you will also need special treatment. Most young patients with this type of cleft have bone graft surgery during childhood so they will have enough bone to support their permanent teeth. This surgery allows the orthodontist to move teeth into the area where the cleft was. It also allows new teeth to come through with enough bone to support them.

TIP: You can learn more about bone grafting from the “Jaw Surgery section.”

Bone graft surgery is a good example of how treatment must be coordinated by all your doctors and dentists for the best results. Before straightening your teeth, the orthodontist may need the surgeon to place a bone graft to provide enough bone support for your permanent teeth. However, before performing this surgery, the surgeon may first need the orthodontist to expand your upper jaw.

The upper jaw (maxilla) does not always grow as far forward as the lower jaw (mandible) in people born with clefts. This problem can make it difficult to bite down correctly and may keep you from being pleased with how your face looks. In that case, you may need to have your upper jaw surgically repositioned (moved forward slightly). Unfortunately, the orthodontic treatment you must receive before this surgery may make your teeth look worse instead of better for a while. In this case, your orthodontist's goal is to place the teeth in their correct positions in each jawbone. Then, when the surgeon moves your jaw, the upper teeth will be lined up correctly with the lower teeth.

Your Options for Surgery

The word “surgery” may seem like a bad word to you. You may have been to the hospital so many times that you won’t even consider having anything else done. On the other hand, maybe you have hope that just one more surgery will make your problems go away. It is important to discuss your feelings, whatever they may be, with your surgeon, your parents, and your other doctors, dentists, and counselors. You need to be sure that you understand what surgery does – and does not – offer for you.



One teenager gives this advice. “You may just want to be done with treatment and refuse to think about another surgery. You have been through a lot, and the feeling of not wanting to go through any more is common and understandable. But it is best to consider all your options. Though it may seem like a lot right now, when you are older you may look back and see it as the best decision you made. Those are my feelings. I was completely close-minded about any more surgeries until I started seeing what they had to offer me. Even throughout treatment, I regretted my decisions. But now I am very happy. I have a smile that I love and the confidence to use it.”

If you were born with a cleft lip, then you have a scar on your lip from the first surgery. Now that you are older, you may be interested in having another surgery to improve the appearance of your lip. This surgery might also help your lip muscles work better when you speak. Cleft repair is considered “reconstructive” surgery, not “cosmetic” surgery. The goal is not just to make you happy with your appearance—it may also be to improve the function of your lip.

While scars cannot be removed, their appearance can sometimes be improved. Girls may find that re-aligning the red part of the lip will help them apply lipstick more easily. Boys may find that re-aligning the scar will help if they want to grow a moustache. In some cases, your surgeon may want to move tissue from your lower lip to your upper lip. The goal is for the upper lip to look fuller and have a more normal size and shape.

Lip surgery does not usually require you to spend the night in the hospital. You will be able to control any pain with medicine taken by mouth. Your lip will be swollen after surgery, but the swelling should begin to go away within 5 to 15 days. You may bleed a little from the incision, too. While some stitches dissolve on their own, you may need to go back to the doctor to have stitches removed.

Some teenagers are interested in nose surgery, which is called rhinoplasty. Your surgeon may have done some minor work on your nose when you were younger. However, people's noses continue to grow until they are teenagers. That's why many surgeons prefer to wait until you are a teenager to perform major surgery on your nose.

The goal of this surgery is to improve your breathing and the shape of your nose. The surgeon works from the inside of your nose to straighten the septum and the base of your nose. He or she may do several different things to your nose. Reshaping your nose may require breaking your nasal bones in order to put them into better position. If one or both of your nostrils are "flat," the surgeon may be able to make them rounder to improve your breathing. Your surgeon may also need to make a small incision under your nose to work on the cartilage in the tip of your nose.

Nose surgery is generally not very painful and usually requires only oral pain medication. You may have some packing material (like a cotton ball) or splints in your nose for the first few days after surgery. If your nasal bones were straightened, you may have a splint on the outside of your nose to help keep it positioned and protected for some time after surgery.

You may notice some swelling and difficulty breathing through your nose after the surgery. Most of the swelling will go away during the first month after surgery. You may also notice that breathing through your nose continues to get easier over the next six months as the swelling decreases.

Sometimes further surgery is necessary to help your speech, too. If you think your speech is too "nasal," or if air comes through your nose while you are talking, you may want to consider a surgery to reduce the space behind your soft palate (the muscular part of the roof of your mouth back near your throat). Your team can help you make this decision.

TIP: The Cleft Palate Foundation produces several publications on speech problems and their treatment.

Jaw Surgery

The clinical term for jaw surgery is orthognathic surgery, and you may see a plastic surgeon or an oral/maxillofacial surgeon if you need to have it done. About a third of teenagers born with cleft lip and palate will. Surgery to move your upper or lower jaw, or sometimes both, may help your appearance and the way you speak and chew. Specifically, jaw surgery may help you make some speech sounds more precisely. Your surgeon can tell you more and may

even be able to use a computer or drawings to show you what changes you can expect.

People born with a cleft lip generally don't have enough bone support in their nose, their top lip, and sometimes their cheeks. Bone grafts are commonly used to help this problem, and they involve moving bone from another part of the body into the face. The bone may come from your head, hip, ribs, or sometimes your bottom jaw. However, some doctors prefer to use artificial material rather than bone. The goal is to improve the overall shape, proportion, and symmetry of your face.

TIP: You can read more about this surgery in the factsheet “Bone Grafting the Cleft Maxilla” from the Cleft Palate Foundation.

Your surgeon and your orthodontist will work together to get your jaws and teeth lined up correctly. For some people, it may be helpful to move the chin (a procedure called genioplasty) or shape the cheek bones. These surgeries are done from the inside of your mouth to avoid scars on your face. Typically, the bones of a person's upper and lower jaw are cut. Then the pieces are put together using small plates and screws to hold the bones in the new position while they heal.

You may already have braces on your teeth when you are preparing for surgery. Your surgeon will use your braces to control the position of your jaws while you are recovering from the surgery. Usually small elastic bands are used between the top and bottom teeth to help hold your jaws in place. However, you may also need to have your jaw wired shut. In either case, you will not be able to chew your food. If your teeth are wired together, your diet will be limited to liquids for a few weeks after surgery. If your teeth are not wired, you will need to eat soft foods like mashed potatoes and scrambled eggs. It is very important to keep your teeth and mouth clean following surgery to help with healing and reduce the risk of infection. Your surgeon will give you a small toothbrush and special instructions to help you.

Although this surgery may sound painful, you will probably not experience a lot of pain. Almost everyone feels some uncomfortable pressure, though, which comes from the swelling. You may also feel numbness in your lips, cheeks, chin, nose, gums, and palate. This numbness is usually temporary, and your surgeon should discuss it with you prior to your surgery. After jaw surgery, you will probably still need some additional orthodontic treatment. While your jaw is healing, this treatment may be painful, too.

There are risks with any surgery. Now that you are older, you should discuss

these risks with your doctor yourself. You will be given an antibiotic to prevent infection, but sometimes infections still occur. Loss of teeth, bone and soft tissue are other risks, but they do not happen very often. If you have a repaired cleft palate and your top jaw (maxilla) is moved forward, there is always the possibility of developing nasal speech. The entire cleft team should discuss these issues with you.

You may lose some weight after surgery, but if you lose more than 8-10 pounds, you are not eating enough. Your surgeon can perform the procedure but cannot make you heal. Healing is your responsibility, and maintaining good nutrition will help. Your surgeon may refer you to a dietician to help you plan your diet after surgery.

Appliances For Your Mouth

Sometimes, even after cleft palate surgery and braces, you may still have an opening in the roof of your mouth. Or you may be missing some teeth or have some wide spaces between your teeth. These problems may affect the way you speak and look. A prosthodontist is a dental member of the cleft team who can help. He or she specializes in making an appliance or prosthesis to replace missing parts of the mouth.

For example, to cover an opening in the roof of your mouth, you may need a small plastic plate called an obturator. It is usually held in place by a couple of wire clips attached to your teeth, and it covers the opening to improve your speech and stop food from going into your nose. Usually this is a temporary measure until surgery may be performed to close the opening permanently.

In some cases, special speech appliances can be made to improve your speech. These appliances can help you sound less “nasal” and keep air from escaping out of your nose when you talk. One type of appliance lifts your palate (palatal lift), and another reduces the space behind your soft palate in your throat (speech bulb). These speech appliances may be temporary until you can have surgery or while you learn to better control your palate muscles. Your team can explain what might be best for you.

If you are missing a tooth, you have a couple of choices to help deal with this problem. As a temporary step, an artificial tooth may be attached to your obturator (if you need one) or your orthodontic retainer. The permanent solution may involve using a dental implant. This is an artificial tooth attached to a small metal post that is placed into the bone where you are missing a tooth.

Another option involves covering or capping a tooth on each side of the space and then attaching the missing tooth to these caps. This is called a bridge since it “bridges” across the space. The caps are made of porcelain and

look just like real teeth. In either case, the tooth is permanently fixed in your mouth and will look great! Of course, caps can also be used to improve the appearance of any of your own teeth. Your prosthodontist will help the rest of the team decide which tooth replacement technique is best for you.



Get ready to smile!

Your Speech

As a teenager, you want to feel confident that you can communicate well with other people. A speech-language pathologist is a person who is trained to evaluate your speech and advise you about what treatment, if any, might be helpful. There is probably a speech-language pathologist on your cleft palate team and one at school. They can help you answer the following questions:

- Does my speech sound different from others my age?
- Do I have “nasal” speech? Why does air come out of my nose when I talk?
- What makes my speech sound different?
- Can I overcome these problems with speech therapy, or will I need another surgery or a special device to help improve my speech?
- What are all my options to help with my speech?
- Will future surgeries on my nose, lips or jaw affect my speech?
- Is my speech really “normal,” or is it just normal for someone who has a cleft?

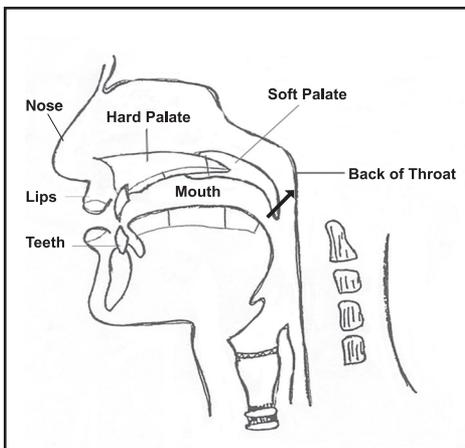
If you are concerned about your speech, you may want to have a speech evaluation. Speech pathologists can perform many tests to get the best information on what is causing your speech difficulties. This evaluation could include a very simple test like just listening to your speech. Or the speech pathologist might use a computer (nasometer) to measure the air and sound that come out of your nose and mouth when you talk. You might also have a type of test called an endoscopy that uses a narrow tube with a tiny camera to take pictures inside your nose and throat. This test lets the speech pathologist see how your palate and throat muscles are working during speech. Speech evaluations will vary greatly depending on your concerns. The speech pathologist consults with other members of the cleft palate team (including the orthodontist, prosthodontist, and surgeon) to develop a plan to help your speech. Always feel free to ask the speech pathologist any questions you may have about your speech.

Some people born with clefts do not experience any speech problems. Others will need lots of speech therapy and perhaps additional treatment. Because your facial structure changes as you grow, your speech may change as you get older. Remember that future surgeries on your jaw or palate could also affect your speech. That is just one more reason to have a speech pathologist involved in your team care!

If you were born with just a cleft lip, you probably have not had any speech problems. However, there is a chance that your lip repair has left your lip very short or unable to move well. It may be hard for you to bring your lips together for words with “b” and “p” sounds. In this case, the speech pathologist should be able to work with your surgeon to develop a plan for a lip revision.

If you were born with a cleft palate, you may have different concerns. Maybe you are worried about hypernasality (too much sound and air coming through your nose when you talk) or articulation problems (not being able to say some sounds correctly). Sometimes your braces or palatal expander can affect your speech. Speech therapy may be helpful to you.

Since you are going to be more responsible for your treatment now, you should understand why your cleft palate might have caused you to have speech problems. In order to make most consonant sounds in English (except the nasal sounds – m,n, and “ing,” as in “ring”), the soft palate has to lift and touch the back of your throat. This action should keep air from escaping into your nose when you talk. (Look at the diagram and caption to help understand this idea. The soft palate is the muscular part of your palate near the back of your mouth.)

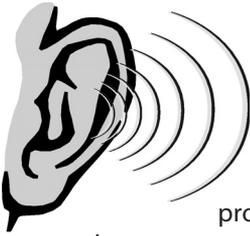


Find the arrow in the diagram. Your soft palate should lift there until it touches the back of your throat. If your palate doesn't reach the back of your throat, air can escape into your nasal cavity, causing your speech to sound “nasal.”

If your soft palate cannot lift well enough or reach back far enough to touch your throat, then air may come out of your nose when it is not supposed to. Your speech pathologist may call this problem hypernasality or velopharyngeal dysfunction. It may also cause food or liquid to come through your nose when you are eating or drinking. Similar problems can exist if you have a fistula, or a small hole, still open in your palate. If one of these problems is bothering you, you should talk with your surgeon or your speech pathologist.

It's possible that your speech only sounds nasal when you are talking quickly, having a long conversation, or are very tired. You may be able to control your soft palate well enough when saying one word at a time, but it may be difficult to maintain this good control of your speech for an entire conversation. Your speech pathologist can help you evaluate this problem and will make suggestions that can help. If you are concerned that your speech sounds too nasal, your speech-language pathologist may recommend speech therapy. He/she may also refer you to a surgeon for an additional surgery or a prosthodontist for a speech appliance.

Your Ears, Nose and Throat



The doctor who treats your ears, nose, and throat is called an otolaryngologist, but you can use the abbreviation ENT. ENT is short for “ears, nose, and throat.”

As a teenager, communication is probably very important to you, which is just one reason why ear problems can be especially annoying. If there is a hole in your eardrum, you may have some hearing loss or frequent drainage from your ears. Although ear infections can be treated with antibiotic drops, having surgery to close the hole is usually the best plan for preserving hearing in the long run. It is not a major operation, and generally doesn't mean a painful recovery.

Some hearing problems that are common for people who have had cleft palate are best treated with a hearing aid. You may think that hearing aids are only for old people, but the new hearing aids can't easily be seen by other people and can really help a lot. It's like wearing glasses: you don't realize how much you are missing until you get the glasses and see the world so clearly. The same applies to hearing aids and hearing.

Your nose has many jobs. Not only does it affect the appearance of your face, it also adds moisture to the air you breathe, filters air before it enters your lungs, and gives you a sense of smell. However, if your nose is partially blocked or always infected, it can be more of a pain than a help. The rhinoplasty surgery described in the section “Your Options for Surgery” can also help you with breathing. You may want to consider having this surgery if you are not able to breathe through both nostrils.

Sinus infections are more common in young adults who have had cleft palate. These can cause headaches, bad breath, a poor sense of smell, a drip in the back of your throat, and a blocked nose with congestion. Most of the time, sinus infections can be treated with antibiotics and anti-allergy medications, but occasionally will require sinus surgery.

You may also have some hoarseness in your voice. Your voice may sound scratchier as the day goes on, and you may be extremely hoarse by bedtime. If your voice is hoarse, the ENT doctor can send you to a speech pathologist for an evaluation. This problem can usually be treated with either speech therapy or medications. It is uncommon to need surgery for hoarseness.



People born with cleft palate, especially those who have had surgery in their throat for speech problems, may have a big problem with snoring. (Ask your parents if you aren't sure whether you've had a pharyngeal flap or another surgery to help your speech.) You may only think of this problem as an embarrassing nuisance, but it could also be sleep apnea, which can have serious health effects. People with sleep apnea actually stop breathing for short periods of time during sleep. If you have this problem, it can cause you to be extremely sleepy during the day, do poorly at work or school, or even be mislabeled as having attention deficit problems. There are devices and surgeries that can help. Your surgeon and team will help you decide what may be best for you. Be sure to tell your parents or your team if you think you are having sleep problems so they can help correct the problem.

Social Relationships



For everyone, adolescence is a time of change. Sensitive issues will come up, and only some of them will relate to being born with a cleft. Don't blame every challenge on that.

Your teen years are an important time for you to build relationships outside of your immediate family. Every person meets this challenge in a unique way. You are no different. Yet, there may be challenges that are special to you because of your history with a cleft lip or cleft palate.

One teen writes, "I think my teenage years were the first time I started to deal with all that I had gone through. Sometimes it's hard to know what to do with all those thoughts. Thoughts like, 'My cleft has been such a big part of my life, and now the work for it is decreasing. Who am I now that my cleft doesn't really exist anymore? Do I tell people or pretend I never had it? I don't want my cleft to define who I am as a person, yet it is a part of me.' How do I move on from there?"

You have your own way of thinking about your cleft. Perhaps for you it is nothing more than an inconvenience in your life whenever you need to keep a doctor's appointment or schedule a surgery. What's really important is your next soccer game, your role in the school play, or a math competition that your team is entering. Like other teens, you worry about dating and your appearance, but you know that most of your friends worry about these things, too.

On the other hand, maybe you still encounter people who tease you about being born with a cleft. You may find it difficult to fit in at your school and hesitate to join a club or team. You may try to tell yourself that you don't really care – that you'd rather be alone. Yet you know deep down that that isn't true. You'd like to be part of a group. You'd like to feel accepted. Remember that you are not alone in these feelings. Many teens, even those without clefts, struggle to find a place for themselves in high school. You may believe that your cleft is the reason you have difficulty fitting in with other teens, but that may not be true. You may not be so different after all.

In order to handle social situations effectively, you must believe in yourself. You may find this difficult if you have had many social experiences that have lowered your self-esteem. Perhaps you can begin to rebuild your confidence by getting involved. It is often easiest to join in activities that have a specific goal and take lots of workers. That way you will be in a social group with a defined task. Volunteer opportunities in your school or community are a good way to meet people, plus you can feel good about your ability to help others.

For some of you, the pain of social rejection may be keeping you from joining a group. You may be angry from previous experiences where your feelings were hurt. In that case, you may want to find someone to talk to about these problems. Perhaps there is a social worker or psychologist on your cleft team who can help you. There is more to life than your cleft. You owe it to yourself to overcome your problems so that you can learn to enjoy life!

Looking Toward the Future

Even though you may be considering more treatment, you can't put the rest of your life on hold. You may be tempted to put off joining a club or team, or even making a college decision, because you think you have another surgery coming up. Remember that your life doesn't have to stop for you to get the help you need or want.



Your high school counselor can help you make plans about your future career and educational goals. You have lots of choices after high school: getting a job, training for a technical career, joining the military, or attending a community college or four-year college. There are very few college scholarships reserved specifically for people with facial difference, but there may be resources for individuals with learning disabilities. Talk to your counselor for up-to-date information.

One of your dreams for adulthood may be marriage or a significant relationship with another person. Even if you are concerned about your appearance, you shouldn't give up this dream. You have as much chance of finding love as anyone else.

Focus on becoming your own person and feeling good about yourself. Many factors influence your self-esteem – like your personality, your talents and accomplishments, your family and friends – not just your appearance.

Some teenagers worry that they may someday have children born with cleft lip or palate. If you are concerned about this possibility, ask your team about genetic counseling. You can also get the booklet, *Genetics and You* from the Cleft Palate Foundation.

Your teenage years are a time for you to become more independent. Everyone has some “bumps and bruises” on the way to adulthood, and you will, too. They don't have to stand in your way. It may help for you to connect with adults besides your parents who can encourage you. You may especially enjoy meeting adults who were born with clefts. Ask your team or local support group for tips on meeting others. These older friends can help you fit your dreams into the world's realities.

Stories From Other Teens

Being a teenager is hard enough on its own. Being a teenager born with a cleft lip and palate obviously has its own added set of frustrations and concerns. For me, the thing that's been harder than the surgeries, braces, and speech troubles is my outlook on how all this affects who I am and how I feel about myself. Friendships and relationships are a big part of being a teenager, and I often wonder how my cleft lip and palate affect the way people see me. I have learned over time (though it is still sometimes easy to forget) that the effect is actually very little.



Amanda

When I think of myself, I see the gifts that I have been given: my talents for singing and dancing, my patience, the physical features that I like about myself, and the life that I have been blessed with. I also see the not-so-great things about myself, like the less-than-desirable personality traits I sometimes have and the physical traits I really believe I could do without. Somewhere in between the good and the bad things is the fact that I was born with a cleft lip and palate. To be honest, I don't know if I should include it with the good, the bad, or both! It's a part of what defines me...but only a part.

The people most important to me in my life, like my friends and family, are the people I've allowed to know all of me. I have learned how important it is not to worry about what people see and don't see, or even what they think of what they see. This is who I am, and there are obviously people who like me this way!

Being born with a cleft lip and palate has actually been a positive experience in some ways, even though it didn't always seem like it. I like to live by the quote that says, "Life is 10% what happens to you and 90% how you react to it." This attitude has slowly helped me to see the positive qualities I've developed as a result of my experiences. It isn't always easy, wondering what decisions to make and having all sorts of weird dental appliances and facial surgeries that most people don't have to endure. But if you stop to think about the positive things that have come out of it – and you will find some – then the experience becomes a lot easier to accept.

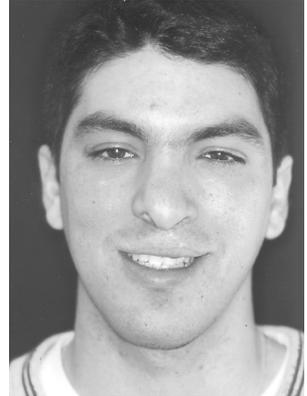
I think one of the biggest things that has helped me is the age-old, simple yet effective method of talking to others about it. I have been very fortunate to know people of many ages who were born with cleft lip and palate. The adults have eased my fears about the future, serving as role models for me. The kids have given me a chance to be a role model myself, which is another positive result of having this condition. Fears and worries and concerns will inevitably creep up, but they can be overcome with a positive outlook and by talking it out.

It's funny how even though doctors fix our clefts before we are even two years old, the effects stay with us for the rest of our lives. I, for one, am always consciously aware of what I was born with. But I think that's OK! I see it as something that has sometimes been a big pain, sometimes isn't so bad, and sometimes is even sort of positive. Like I said, it's a part of me, and that's that!

Amanda

Being born with a cleft lip and palate has played a huge role in my life. It has shaped who I am today and given me strength for the difficult situations that life puts in front of me. I endured more surgeries before age 21 than what most people will have in their whole lives.

Several of the major surgeries were during my teenage years, which was both a blessing and a curse. It was a blessing because of all the love and attention I received from family and friends, making our relationships a lot stronger. I also got to skip many days of school—yeah!! However, it has also been a major source of sorrow and frustration.



Alex

As a teenager, a kid tries to fit into the normal high school life, but that is a little hard to do when you stand out by having a noticeable scar on your lip. People call you names because they are ignorant to what you are going through.

Remember that the same thing happens to any person who is a little different than the rest of the students. Their teasing got worse if they saw me getting angry, so I chose to ignore them. At times it was very frustrating when kids would say the same thing every day. I lost some self-confidence and became very self-conscious about my scar. And my dating life in high school was practically non-existent.

My main regret is that I never talked to anyone at the time about what was bothering me. As I look back, I wish I had talked more to my parents about it instead of pretending things were fine so I would not worry them. I also wish that instead of ignoring the kids who teased me, I could have educated them about what the scar was. There was no reason for me to be so embarrassed about my scar!

My main advice is to value your family and friends very much. They are the most important people in your life, and they will help you get through anything. Talk to them about what is bothering you, no matter if it happened ten years ago or just today. That approach helps me in every aspect of my life.

I think being born with a cleft and having to deal with a scar on my face has

given me character. As I said, it has shaped who I am and how I go about solving issues in my professional and personal life. Everyone goes through tough times, and each person's struggles are a little different. As someone once told me, "God hands each person different challenges. The most difficult ones are left for the special few, so consider yourself lucky."

Alex

In elementary school I was teased quite a bit. It hurt just thinking about getting ready for school sometimes, and it was really hard trying to handle all of this before the age of 12. When it got to be too much, I finally asked my mom what exactly I was born with and why I was "different." She and I talked for a long time, and she made sure that I understood everything about my cleft lip and palate.

I really wanted to know how to make the teasing stop, so this is what she told me. "Every time someone starts to make fun of your cleft lip and palate, ask them if they have a question about it." Well, the next day, the kids made their usual comments, but this time I was ready. I turned around and confronted them, and I asked, "Do you have a question about my lip?" They didn't expect me (quiet and shy as I was) to say anything back to them at all. So, to my surprise, they started to ask questions about what happened and why I looked different. They were not expecting me to be able to answer them, but I did, and gradually the teasing stopped. By the time all of my surgeries were done, no one in high school could even tell that I was born with a defect. I am so thankful for all the amazing doctors and nurses who helped me!



Shawna

People will judge you if they want to, but they are the ones with the problem. If you have a talent for something, people will notice you positively. They will realize that there is no reason to judge or tease at all.

Shawna

For More Information

Las publicaciones de la Fundación del Paladar Hendido también se ofrecen en español. Favor de llamarnos para recibir copias en español.

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To date, the Cleft Palate Foundation has shared over 7,000 Gund Teddy Bears with repaired cleft lips with children and families all over the world. Please visit www.cleftline.org or call the **Cleftline** for more information about our bears.

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