



**American Cleft Palate–  
Craniofacial Association**

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## Information about Treatment for Adults with Cleft Lip and Palate

### **What treatment is available for adults with cleft lip and palate?**

Treatments currently available to infants and children with cleft lip and palate are also available to adults with clefts. Although every attempt is made to complete cleft care by the late teens, some ongoing treatment still may be required or some unmet patient need may become apparent in later years. In addition, new approaches for management of clefts become available as time passes. Finally, adults may desire genetic counseling in order to determine the likelihood of having an infant with a cleft.

### **How can treatment needs be determined?**

Evaluation by a Cleft Palate Team can provide the adult with a cleft with information regarding clefting and its management. A Cleft Palate Team consists of a group of specialists with particular expertise in cleft lip and palate. Specialties represented on the team include plastic surgery, ear-nose and throat, hearing, dentistry, speech, oral surgery, nursing, and psychology among others. You can obtain the names of the Cleft Teams in your area by phoning 1.800.24.CLEFT.

### **What are the most frequent concerns of adults with clefts?**

Adults, like younger individuals with clefts, are most concerned about the appearance of their lip and nose, the ability to speak clearly, the quality of their hearing, and the appearance and function of their teeth.

### **What can be done about the appearance of the lip and nose?**

Although the scar of the repaired cleft lip is permanent, it may be possible to improve the quality of that scar. Surgery also can change the shape of the lip, the deformity of the nose, and the obstruction to nasal breathing. Such cleft revision surgery is usually done on an outpatient basis. Specific questions about changing the appearance of the lip or nose should be directed to the surgeon to determine what is surgically

possible and what such surgery will require in terms of time, discomfort, and expense.

### **Is improvement in speech possible for an adult who has a cleft?**

Although the most dramatic changes in speech are observed in children following the treatment for their clefts, significant improvement also can be achieved in adults with speech problems related to the cleft palate. The speech pathologist and other members of the Cleft Team evaluate speech and advise the individual whether or not improvement is possible. This may require renewed speech therapy, an oral speech appliance or even an additional operation. Adults with cleft may also have some hearing impairment. Hearing loss may reduce speech clarity and often makes communication more difficult. Adults should have their ears and hearing checked routinely by an ear-nose-throat (ENT) specialist and an audiologist so that necessary treatment can be recommended.

### **What treatment is available for adults with abnormalities of teeth and jaws resulting from clefts?**

Adults with clefts may have crooked, poorly shaped, or missing teeth. Crooked teeth can be straightened with “braces.” Poorly shaped and missing teeth can be restored or replaced with dental bridges or jaw implants. In addition, teeth may not meet properly because of an abnormal jaw relationship. Failure of the teeth and jaws to meet together can interfere with chewing, speech, and attractiveness. Surgery can reposition jaws which do not come together properly. The Cleft Team orthodontist, prosthodontist, oral surgeon, and plastic surgeon work together to determine the best treatment plan for each individual patient.

### **Can something be done to help adults with clefts who feel embarrassed and who lack self confidence?**

Psychological counseling, along with the other restorative treatments mentioned above, can

help an individual with a cleft feel better about himself or herself. Concerns about appearance, the ability to get along with others, satisfaction with one's job, goals for the future, and hopes for a loving and happy relationship are concerns that may be discussed with the members of the Cleft Team, particularly the psychologist and social worker. Interaction with other adults with clefts, through a patient-parent group, also can be beneficial.

**Are there sources of financial support for adults when they need and desire treatment?**

Funding through the Children's Special Health Services (formerly Crippled Children's Services) stops between 18 and 21 years of age depending upon the regulations of each state. Some adults obtain funding for cleft services through their state Division of Vocational Rehabilitation (or State Rehabilitation Services) if a structural problem causes significant difficulties in areas such as speech related to employment. Sometimes standard medical insurance will pay for part of the treatment, however, many claims are rejected due to "preexisting condition" clauses. The social worker on the Cleft Team can assist in finding sources of funding for needed treatment.

**Can adults benefit from membership in support groups?**

The American Cleft Palate-Craniofacial Association provides referrals to patient-parent support groups throughout the country. Adults with clefts may wish to join such a group to meet other adults with similar concerns. In addition, adults with clefts can provide valuable assistance as role models for younger individuals with clefts and their families. Membership in the patient-parent support group also can provide an opportunity for the adult with a cleft to advocate for better insurance coverage and state and federal programs for others with similar problems.

**Please contact ACPA Family Services for further information or for a referral to a cleft palate/craniofacial team.**