

# Policy on the Management of Patients with Cleft Lip/Palate and Other Craniofacial Anomalies

## Latest Revision

2019

The American Academy of Pediatric Dentistry (AAPD), in its efforts to promote optimal health for children with cleft lip/palate and other craniofacial anomalies, endorses the current statements of the American Cleft Palate-Craniofacial Association (ACPA).<sup>1</sup>

A child born with cleft lip/palate or other craniofacial anomalies has multiple and complex problems, including early feeding and nutritional concerns, middle ear disease, hearing deficiencies, deviations in speech and resonance, dentofacial and orthodontic abnormalities, and psychosocial adjustment problems.

Reports by the U.S. Surgeon General<sup>2,3</sup> on children with special needs issued in 1987 and 2005 stressed that the care of these children should be comprehensive, coordinated, culturally sensitive, specific to the needs of the individual, and readily accessible. Recognizing that children with clefts and other craniofacial anomalies have special needs, the Maternal and Child Health Bureau in 1991 provided funding to ACPA to develop parameters of care for these patients through a series of consensus conferences among a multidisciplinary group of specialists.<sup>1</sup> In addition, the ACPA joined with the Cleft Palate Foundation to create standards for approval of teams to ensure that care is provided in a coordinated and consistent manner, including an appropriate sequence of evaluations and treatment for the patient's overall developmental, medical, and psychological needs.<sup>4</sup>

As part of the parameters<sup>1</sup> and standards<sup>4</sup>, several fundamental principles were identified as critical to optimal cleft/craniofacial care. These principles are:

1. Management of patients with craniofacial anomalies is best provided by an interdisciplinary team of specialists.<sup>1</sup> These teams are composed of qualified health professionals from medical, surgical, dental, and allied health fields working together in a coordinated system. A designated patient care coordinator should be included in the team to assist in coordinated care for patients and their families/caregivers.<sup>4</sup>
2. Optimal care for patients with craniofacial anomalies is provided by teams that see sufficient numbers of these patients each year to maintain clinical expertise in diagnosis and treatment.
3. The optimal time for the first evaluation is within the first few weeks of life and, whenever possible, within the first few days. However, referral for team evaluation and management is appropriate for patients of any age.<sup>1</sup>
4. From the time of first contact with the child and family, every effort must be made to assist the family in adjusting to the birth of a child with a craniofacial anomaly and the consequent demands and stress placed upon that family.<sup>1</sup>
5. Parents/caregivers must be given information about recommended treatment procedures, options, risk factors, benefits, and costs to assist them in: (1) making informed decisions on the child's behalf, and (2) preparing the child and themselves for all recommended procedures. The team should actively solicit family participation and collaboration in treatment planning.<sup>1,4</sup> When the child is mature enough to do so, he or she should also participate in treatment decisions.<sup>1</sup>
6. Treatment plans should be developed and implemented on the basis of team recommendations.<sup>1</sup>
7. Care should be coordinated by the team, but should be provided at the local level whenever possible; however, complex diagnostic or surgical procedures should be restricted to major centers with appropriate treatment facilities and experienced care providers.
8. It is the responsibility of each team to be sensitive to linguistic, cultural, ethnic, psychosocial, economic, and physical factors that affect the dynamic relationship between the team, the patient, and his/her family.<sup>1</sup>
9. It is the responsibility of the team to monitor both short-term and long-term outcomes. Thus, longitudinal follow up of patients, including appropriate documentation and record-keeping, is essential.<sup>1</sup>
10. Evaluation of treatment outcomes must take into account the satisfaction and psychosocial well-being of the patient, as well as effects on growth, function, and appearance.<sup>1</sup>

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### ABBREVIATIONS

**AAPD:** American Academy Pediatric Dentistry. **ACPA:** American Cleft Palate-Craniofacial Association.

Patients with craniofacial anomalies require dental care throughout life as a direct result of their condition and as an integral part of the treatment process. A dental home should be established within six months of eruption of the first tooth and no later than 12 months of age.<sup>5</sup> It includes oral health examinations, caries control, and preventive, restorative, and prosthetic dental treatment as needed. Patients should be closely monitored for periodontal disease and anomalies in dentition and eruption. The condition of the developing dentition and supporting tissues, with counseling regarding early oral hygiene and prevention of early childhood caries, is essential. Prosthetic appliances such as an obturator may help to close a fistula or aid in speech. Orthodontic treatment is also an integral part of the habilitative process and often takes place in phases. The skeletal and dental components should be regularly evaluated. When indicated, orthodontic treatment prepares a child for alveolar bone grafting of the cleft maxilla, correcting malocclusions, and jaw surgery.<sup>1</sup> As members of the interdisciplinary team of physicians, dentists, speech-language pathologists, and other allied health professionals, pediatric dentists should provide dental services in close cooperation with their orthodontic, oral and maxillofacial surgery, and prosthodontic colleagues.<sup>1,4</sup> All dental specialists should ensure<sup>1</sup>:

1. Consultation with an appropriate dental specialist should be made for cleft lip taping and/or pre-surgical orthopedics including, but not limited to, nasal alveolar molding. A craniofacial orthodontist (or appropriately-trained clinician) who can discuss with the family the types of infant orthopedic services available and the rationale for using infant orthopedics prior to initial cleft lip repair is necessary.
2. Dental radiographs, cephalometric radiographs, and other imaging modalities as indicated should be utilized to evaluate and monitor dental and facial growth and development.
3. Diagnostic records, including properly occluded dental study models, should be collected at appropriate intervals for patients at risk for developing malocclusion or maxillary-mandibular discrepancies.
4. As the primary dentition erupts, the team evaluation should include a dental examination and, if such services are not already being provided, referral to appropriate providers for caries control, preventive measures, restorative care, and space management.
5. Before the primary dentition has completed eruption, the skeletal and dental components should be evaluated to determine if a malocclusion is present or developing.
6. Depending upon the specific goals to be accomplished and also upon the age at which the patient is initially evaluated, orthodontic management of the malocclusion may be performed in the primary, mixed, or permanent dentition. In some cases, orthodontic treatment may be necessary in all three stages.

7. While continuous active orthodontic treatment from early mixed dentition to permanent dentition should be avoided, each stage of orthodontic therapy may be followed by retention and regular observation. Orthodontic retention for the permanent dentition may extend into adulthood.
8. For some patients with craniofacial anomalies, functional orthodontic appliances may be indicated.
9. For patients with craniofacial anomalies, orthodontic treatment may be needed in conjunction with surgical correction (and/or distraction osteogenesis) of the facial deformity.
10. Congenitally missing teeth may be replaced with a removable appliance, fixed restorative bridgework, or osseointegrated implants.
11. Patients should be closely monitored for dental and periodontal disease.
12. Prosthetic obturation of palatal fistulae may be necessary in some patients.
13. A prosthetic speech device may be used to treat velopharyngeal inadequacy in some patients.

## References

1. American Cleft Palate-Craniofacial Association. Parameters for Evaluation and Treatment of Patients with Cleft Lip/Palate or Other Craniofacial Differences. Chapel Hill, N.C.: The Maternal and Child Health Bureau, Health Resources and Services Administration, U.S. Public Health Service, DHHS; January 2018. Grant # MCJ-425074. Available at: "<https://acpa-cpf.org/team-care/standardscat/parameters-of-care/>". Accessed October 11, 2019. (Archived by WebCite® at: "<http://www.webcitation.org/73es0ax0L>")
2. U.S. Department of Health and Human Services. A Report of the Surgeon General: Children with Special Health Care Needs. Rockville, Md.: Office of Maternal and Child Health, U.S. Department of Health and Human Services; 1987.
3. U.S. Department of Health and Human Services. The Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities. Rockville, Md.: U.S. Department of Health and Human Services, Office of the Surgeon General; 2005.
4. American Cleft Palate-Craniofacial Association Commission on Approval of Teams. Standards for Approval of Cleft Palate and Craniofacial Teams. American Cleft Palate-Craniofacial Association; 2016. Available at: "<https://acpa-cpf.org/wp-content/uploads/2017/06/standards.pdf>". Accessed October 11, 2019.
5. American Academy of Pediatric Dentistry. Policy on dental home. *Pediatr Dent* 2018;40(6):29-30.