

# Guidelines for the Care of Children and Adolescents with Cleft Lip and Palate

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## Basic Team

The special care needs of the child with cleft lip and/or palate (CLP) are met best by an interdisciplinary team of specialists who work in collaboration with the child, the child's parents, and the primary care health professional. The craniofacial team coordinator, if desired, can assist in the coordination of special services that these children require.

A CLP team typically consists of a plastic or reconstructive surgeon, an otolaryngologist, a nurse, an orthodontist, a dentist, an oral surgeon, a speech-language pathologist, a medical social worker, and an audiologist. Furthermore, consultation with or ready availability of the following disciplines is desirable: a genetic counselor, a medical geneticist, a developmental pediatrician, a radiologist, a prosthodontist, a dental hygienist, a psychologist, a physical therapist, and an occupational therapist.

## Initial Evaluation

The optimal time for the first evaluation is at or shortly after birth; however, referral for team evaluation and management can be considered for individuals of any age. When the diagnosis has been made prior to delivery, prenatal counseling should be made available. The critical issues for the young infant with CLP are feeding and nutrition, initial surgical correction of the cleft, and pre- and postoperative support of the child and the family. The responsibilities of the primary care physician are to refer to the craniofacial disorders team (the team members initially involved are the plastic or reconstructive surgeon, the feeding specialist, the nurse, and the speech-language pathologist); identify associated defects; closely monitor growth and nutrition; and determine the need for other referrals (e.g., to the medical geneticist).

## Frequency of Visits

The frequency and timing of visits to the specialty team are dependent on the child's needs and overall status. In general, the team evaluates the infant or toddler and the family at least twice yearly, and then yearly or as needed after the toddler years. The timing of the usual surgeries for children with CLP is as follows:

<u>Surgical procedure</u>	<u>Age for completion</u>
Lip adhesion	1–2 days
Initial lip repair	3–10 weeks
Palate repair	6–18 months
Pharyngeal flap and/or pharyngoplasty, if needed	2–7 years
Lip and/or nasal revision	4–6 years
Alveolar bone grafting	8–12 years
Cleft nasoseptal reconstruction	15–16 years
Orthognathic surgery	15 years or older

The primary care office monitors growth and nutrition, developmental and school progress, and middle-ear function; identifies associated medical problems; assists the family with care coordination; and provides ongoing child and family support and education in conjunction with the CLP team. The child's progress is reviewed at least annually (more frequently for younger children), and an office management plan is updated at that time.

# Guidelines for the Care of Children and Adolescents with Cleft Lip and Palate

The following elements are recommended by age group, and the listing is cumulative. Review all items indicated up through the actual age group of a child entering your practice for the first time as part of the initial evaluation.

AGE	KEY CLINICAL ISSUES/CONCERNS	EVALUATIONS/KEY PROCEDURES	SPECIALISTS
Birth– 1 month	Feeding/Nutrition/Risk for Dehydration	Growth parameters, evaluation by feeding specialist as needed	Feeding specialist, nutritionist
	Cause of the Cleft Lip and/or Palate (CLP)	Evaluation for minor anomalies, craniofacial dysmorphology screen	Developmental pediatrician (DPed), medical geneticist as needed
	Evaluation for Associated Congenital Defects	Blood chromosomes, other tests as needed Cranial ultrasonography (US) or computed tomography (CT) scan, echocardiogram, other tests as needed	DPed and/or medical geneticist
	Closure of the Lip	Pre- and postoperative care	Plastic or reconstructive surgeon, CLP team
	Hearing Status/Risk for Middle-Ear Effusion and Infection	Schedule neonatal hearing examination with auditory brainstem screening (ALGO) or otoacoustic emissions (OAEs), prophylactic bilateral myringotomies and ventilation tube placement	Audiologist, otolaryngologist (ENT)
	Risk for Airway Obstruction (e.g., Pierre Robin sequence) or Aspiration (e.g., laryngeal cleft)	Detailed otolaryngologic examination, positioning, other interventions	ENT, plastic or reconstructive surgeon, DPed, nurse
	Need for Intraoral Prosthetic Appliance	Evaluation for bilateral and/or severe clefting	Plastic or reconstructive surgeon, dental specialist
	Parent Education/Anticipatory Guidance Care Coordination/Family Support	Initiate care notebook, provide educational materials and resource list; complete family interview using parent questionnaire (e.g., Family Needs Survey) or CLP psychosocial screening form as needed	Speech-language pathologist (SLP), ENT CLP team coordinator, medical social worker, DPed, referral to community health nurse as needed
1 month– 5 years	Growth/Nutrition Oral motor dysfunction Gastroesophageal reflux (GER)	Growth parameters, diet record, evaluation by feeding specialist, workup for GER as needed	Nutritionist, feeding specialist, DPed as needed
	Initial Palate Repair (6–18 months of age) Pre- or postoperative support	Confirm that family is established with plastic or reconstructive surgeon	Plastic or reconstructive surgeon, nurse, SLP, other team members as needed
	Monitor Hearing Status/Middle-Ear Function	Audiologic testing at least annually or as needed	Audiologist, ENT as needed

## Guidelines for the Care of Children and Adolescents with Cleft Lip and Palate *(continued)*

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AGE	KEY CLINICAL ISSUES/CONCERNS	EVALUATIONS/KEY PROCEDURES	SPECIALISTS
1 month–5 years <i>(continued)</i>	<p><i>Dental Care</i> Prevention of dental caries</p> <p><i>Associated Medical Problems</i> Visual problems or strabismus Seizures Craniosynostosis</p> <p>Associated congenital defects (e.g., heart or renal defects, hand or foot anomalies)</p> <p><i>Speech-Language Progress</i> Language delay Speech disorder (due to dental and anatomic differences) Voice quality and need for pharyngeal flap for velopharyngeal incompetence (2–7 years of age)</p> <p><i>Developmental Progress/Need for Early Intervention (EI) or Early Childhood Special Education (ECSE) Services</i> Speech-language delay Developmental delay</p> <p><i>Family Support Services</i> Respite care Parent group Community health nurse Advocacy Financial services (e.g., Supplemental Security Income [SSI])</p>	<p>Review dental hygiene and potential dental issues (e.g., missing and supernumerary teeth)</p> <p>Vision testing Electroencephalogram (EEG) Skull X rays, cranial computed tomography (CT) scan as needed Additional tests dependent on type and severity of associated problems</p> <p>Monitor language progress</p> <p>Assessment of velopharyngeal incompetence and voice quality</p> <p>Developmental surveillance and screening Refer for eligibility testing for EI services as needed</p> <p>Family interview, parent questionnaires (e.g., Family Needs Survey) Provide resource information (e.g., Cleft Palate Foundation) Care coordination</p>	<p>Dentist</p> <p>Pediatric ophthalmologist Neurologist Neurosurgeon</p> <p>Cardiologist, orthopedist</p> <p>SLP SLP, orthodontist, oral surgeon</p> <p>SLP, ENT, plastic or reconstructive surgeon as needed</p> <p>Referral to child development team as needed</p> <p>Medical social worker, referral to community health nurse, other community services as needed</p>

## Guidelines for the Care of Children and Adolescents with Cleft Lip and Palate *(continued)*

The following elements are recommended by age group, and the listing is cumulative. Review all items indicated up through the actual age group of a child entering your practice for the first time as part of the initial evaluation.

AGE	KEY CLINICAL ISSUES/CONCERNS	EVALUATIONS/KEY PROCEDURES	SPECIALISTS
1 month–5 years <i>(continued)</i>	<p><i>Anticipatory Guidance</i></p> <ul style="list-style-type: none"> <li>Review individualized family service plan (IFSP) with family as needed</li> <li>Transition from preschool to kindergarten</li> <li>Risk for dental, orthognathic, or facial differences and their treatment</li> <li>Risk for behavior problems, low self-esteem</li> <li>Promote self-care and independence</li> </ul> <p><i>Collaboration with Community Services</i></p> <ul style="list-style-type: none"> <li>Community health nurse</li> <li>Educational services</li> </ul>	<ul style="list-style-type: none"> <li>Family interview, educational materials, resource information</li> <li>Teacher interview, school conference as needed</li> </ul>	<ul style="list-style-type: none"> <li>Primary care office in collaboration with CLP team</li> </ul>
6–12 years (school-age)	<p><i>Dental Care</i> (e.g., missing or impacted teeth)</p> <ul style="list-style-type: none"> <li>Full set of dental X rays</li> </ul> <p><i>Facial Differences</i></p> <ul style="list-style-type: none"> <li>Lip or nasal revision (ages 4–6 years)</li> </ul> <p><i>Orthognathic Differences</i></p> <ul style="list-style-type: none"> <li>Alveolar bone grafting (ages 8–12 years)</li> </ul> <p><i>Speech-Language Progress</i></p> <ul style="list-style-type: none"> <li>Increased risk for hypernasality as adenoidal tissue atrophies</li> </ul> <p><i>School Progress</i></p> <ul style="list-style-type: none"> <li>Learning disabilities</li> <li>Mental retardation (if birth defect syndrome is present)</li> </ul> <p><i>Social Skills</i></p> <ul style="list-style-type: none"> <li>Involvement in peer-group activities at school and in the community</li> </ul>	<ul style="list-style-type: none"> <li>Comprehensive care coordination with regular exchange of written information (at least yearly) with other service providers</li> <li>Full set of dental X rays</li> <li>Evaluation of facial aesthetics and function</li> <li>Establish orthodontic care and, if indicated, oral surgical care</li> <li>Evaluation of speech-language skills, voice quality, and assessment of velopharyngeal incompetence as needed</li> <li>Regular exchange of information with school behavioral questionnaires; child, parent, and teacher interviews; school progress report; intellectual and achievement testing as needed</li> <li>Encourage participation in community services, social skills program at school as needed</li> </ul>	<ul style="list-style-type: none"> <li>Primary care office in collaboration with CLP team</li> <li>Dentist, oral surgeon</li> <li>Plastic or reconstructive surgeon</li> <li>Orthodontist, oral surgeon</li> <li>SLP, ENT as needed</li> <li>Referral to child development team or individual psychology appointment as needed</li> <li>Collaborate with school staff</li> <li>Psychologist, behavioral specialist, school counselor as needed</li> </ul>

## Guidelines for the Care of Children and Adolescents with Cleft Lip and Palate *(continued)*

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AGE	KEY CLINICAL ISSUES/CONCERNS	EVALUATIONS/KEY PROCEDURES	SPECIALISTS
6–12 years (school-age) <i>(continued)</i>	<p><i>Anticipatory Guidance</i></p> <ul style="list-style-type: none"> <li>Discuss diagnosis and management with the child</li> <li>Need for cleft nasoseptal reconstruction, orthognathic surgery</li> <li>Transition to middle school</li> <li>Recreation and leisure activities</li> </ul>	<ul style="list-style-type: none"> <li>Child and family interviews, provide educational materials and resource information</li> <li>Encourage participation in community recreation and leisure activities</li> </ul>	Primary care office in collaboration with CLP team and school staff
13–21 years (adolescents and young adults)	<p><i>Cleft Nasoseptal Reconstruction</i> (ages 15–16 years)</p> <p><i>Orthognathic Surgery for Class III Malocclusion</i> (ages 15 years and older)</p> <ul style="list-style-type: none"> <li>Retrusive midface</li> <li>Prognathism</li> </ul> <p><i>Persisting Speech Differences</i></p> <ul style="list-style-type: none"> <li>Risk for velopharyngeal incompetence</li> <li>Continuing articulation difficulties</li> <li>Continuing vocal quality deviations</li> </ul> <p><i>Anticipatory Guidance</i></p> <ul style="list-style-type: none"> <li>Review genetics and recurrence risk with adolescent and family</li> <li>Promote healthy behaviors (e.g., diet, exercise)</li> <li>Sexuality and high-risk behaviors (e.g., substance abuse)</li> <li>Transition to high school</li> <li>Career planning/higher education</li> <li>Transition to adult medical services</li> </ul>	<ul style="list-style-type: none"> <li>Evaluation of airway and appearance of nose</li> <li>Evaluation of dentoskeletal facial balance and function</li> </ul>	<ul style="list-style-type: none"> <li>Plastic or reconstructive surgeon and/or ENT</li> <li>Oral surgeon, orthodontist</li> <li>SLP, ENT as needed</li> </ul>
		<ul style="list-style-type: none"> <li>Adolescent and family interviews</li> <li>Teacher interview, school conference, review individualized education program (IEP) with family as needed</li> <li>Referral to gynecologist, mental health specialist as needed</li> </ul>	Primary care office in collaboration with CLP team



## **Family and Physician Management Plan Summary for Children and Adolescents with Cleft Lip and Palate** *(continued)*

6. Who are your/your child's other community service providers?  
Community health nurse \_\_\_\_\_  
Other \_\_\_\_\_
7. Do you also receive services from a cleft lip and palate team of specialists?  
Contact person \_\_\_\_\_  
Location \_\_\_\_\_
8. Have you/has your child had any blood tests, radiologic (X-ray) examinations, or other procedures since your last visit? If yes, please describe.
9. Have you/has your child been hospitalized or received surgery since your last visit? If yes, describe.
10. Please note your/your child's accomplishments since your last visit. Consider activities at home, in your neighborhood, or at school, as well as success with treatments.
11. What goals (i.e., skills) would you/your child like to accomplish in the next year? Consider activities at home, in your neighborhood, or at school, as well as success with a treatment.
12. What questions or concerns would you like addressed today?

# Family and Physician Management Plan Summary for Children and Adolescents with Cleft Lip and Palate

The Family and Physician Management Plan Summary should be completed at each annual review and more often as needed. It is intended to be used with the Guidelines for Care, which provide a more complete listing of clinical issues at different ages as well as recommended evaluations and treatments.

Child's name \_\_\_\_\_ Person completing form \_\_\_\_\_ Today's date \_\_\_\_\_

Clinical issues	Currently a problem?	Evaluations needed	Treatment recommendations	Referrals made	Date for status check
<i>Family's Questions</i>					
<i>Cause of the Cleft Lip and/or Palate (CLP)</i>					
<i>Growth/Nutrition</i> Feeding problems					
<i>Surgical Checklist</i> Initial lip repair Initial palate repair Lip or nasal revisions Myringotomy/tube placement Alveolar bone grafting Cleft septorhinoplasty Surgical improvement of velopharyngeal closure if indicated Orthognathic surgery Other					
<i>Dental and Orthodontic Care</i>					

## Family and Physician Management Plan Summary for Children and Adolescents with Cleft Lip and Palate (continued)

Child's name \_\_\_\_\_ Person completing form \_\_\_\_\_ Today's date \_\_\_\_\_

Clinical issues	Currently a problem?	Evaluations needed	Treatment recommendations	Referrals made	Date for status check
<i>Hearing Status/Middle-Ear Function</i>					
<i>Risk for Airway Obstruction</i>					
<i>Associated Medical Problems</i> Visual problems or strabismus Seizures Craniosynostosis Other congenital defects					
<i>Speech-Language Progress</i> Need for speech-language therapy Poor speech intelligibility Voice quality (nasality)					
<i>Developmental/School Progress</i> Current school achievement Review individualized family services plan (IFSP) or individualized education program (IEP) with family					

## Family and Physician Management Plan Summary for Children and Adolescents with Cleft Lip and Palate *(continued)*

Child's name \_\_\_\_\_ Person completing form \_\_\_\_\_ Today's date \_\_\_\_\_

Clinical issues	Currently a problem?	Evaluations needed	Treatment recommendations	Referrals made	Date for status check
<i>Social Skills</i> Involvement in peer-group activities at school and in the community					
<i>Self-Care/Independence</i>					
<i>Family Support Services</i>					
<i>Anticipatory Guidance</i> List issues discussed and materials provided					
<i>Collaboration with Community Agencies</i> School Community health nurse					

# Family and Physician Management Plan Summary for Children and Adolescents with Cleft Lip and Palate *(continued)*

Child's name \_\_\_\_\_ Person completing form \_\_\_\_\_ Today's date \_\_\_\_\_

Clinical issues	Currently a problem?	Evaluations needed	Treatment recommendations	Referrals made	Date for status check
Comments					

Next update of the Management Plan Summary \_\_\_\_\_

Signature \_\_\_\_\_ Date \_\_\_\_\_  
(Child and parent)

Signature \_\_\_\_\_ Date \_\_\_\_\_  
(Health professional)

**CRANIOFACIAL DISORDERS PSYCHOSOCIAL SCREENING FORM**

Child's name \_\_\_\_\_ Age \_\_\_\_\_ Date of birth \_\_\_\_\_

Diagnosis \_\_\_\_\_ Today's date \_\_\_\_\_ Examiner \_\_\_\_\_

**Surgical variables**

Motivation for treatment \_\_\_\_\_

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Understanding of risk-to-benefit ratio \_\_\_\_\_

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Expectations of surgery \_\_\_\_\_

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Number of prior surgeries \_\_\_\_\_

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**Psychosocial variables**

Body image \_\_\_\_\_

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Self-concept \_\_\_\_\_

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**CRANIOFACIAL DISORDERS PSYCHOSOCIAL SCREENING FORM (continued)**

Emotional status \_\_\_\_\_

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\_\_\_\_\_

Social skills \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Behavior problems \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**Family and social support**

Parents' motivation for treatment \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Parental relationship \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Family climate \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Family cohesion \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**CRANIOFACIAL DISORDERS PSYCHOSOCIAL SCREENING FORM (continued)**

Available social support \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**Educational variables**

Child's age \_\_\_\_\_ Grade \_\_\_\_\_ School placement \_\_\_\_\_ Special services? Yes \_\_\_\_\_ No \_\_\_\_\_

**CRANIOFACIAL DISORDERS DYSMORPHOLOGY SCREENING FORM**

Child's name \_\_\_\_\_ Age \_\_\_\_\_ Date of birth \_\_\_\_\_

Diagnosis \_\_\_\_\_ Today's date \_\_\_\_\_ Examiner \_\_\_\_\_

**Cranial deviations**

Cranial size \_\_\_\_\_

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Cranial shape \_\_\_\_\_

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Hair growth pattern \_\_\_\_\_

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Other \_\_\_\_\_

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**Craniomaxillofacial deviations**

Craniomaxillofacial deviations \_\_\_\_\_

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Ear structure, size, and position \_\_\_\_\_

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**CRANIOFACIAL DISORDERS DYSMORPHOLOGY SCREENING FORM (continued)**

Presence or absence of skin tags and pits \_\_\_\_\_

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Size, shape, and function of nose, including nasal ala and columella \_\_\_\_\_

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Philtrum \_\_\_\_\_

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Lip intactness, shape, thickness, and function, including potential lip pits \_\_\_\_\_

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Contour and intactness of alveolar process \_\_\_\_\_

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Dentition \_\_\_\_\_

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Dental occlusion \_\_\_\_\_

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**CRANIOFACIAL DISORDERS DYSMORPHOLOGY SCREENING FORM (continued)**

Contour and intactness of hard palate \_\_\_\_\_

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Contour and intactness of soft palate \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Appearance of face (e.g., malar eminences, midface) \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Length, mobility, and symmetry of soft palate \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Depth of oropharynx in relationship to soft palate \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Other \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**Cranioorbital deviations**

Eye structure, position, orientation, and function \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**CRANIOFACIAL DISORDERS DYSMORPHOLOGY SCREENING FORM (continued)**

Other \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Craniomandibular deviations**

Tongue size, structure, and function \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Size and symmetry of mandible \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Other \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Source: American Speech-Language-Hearing Association (1993).