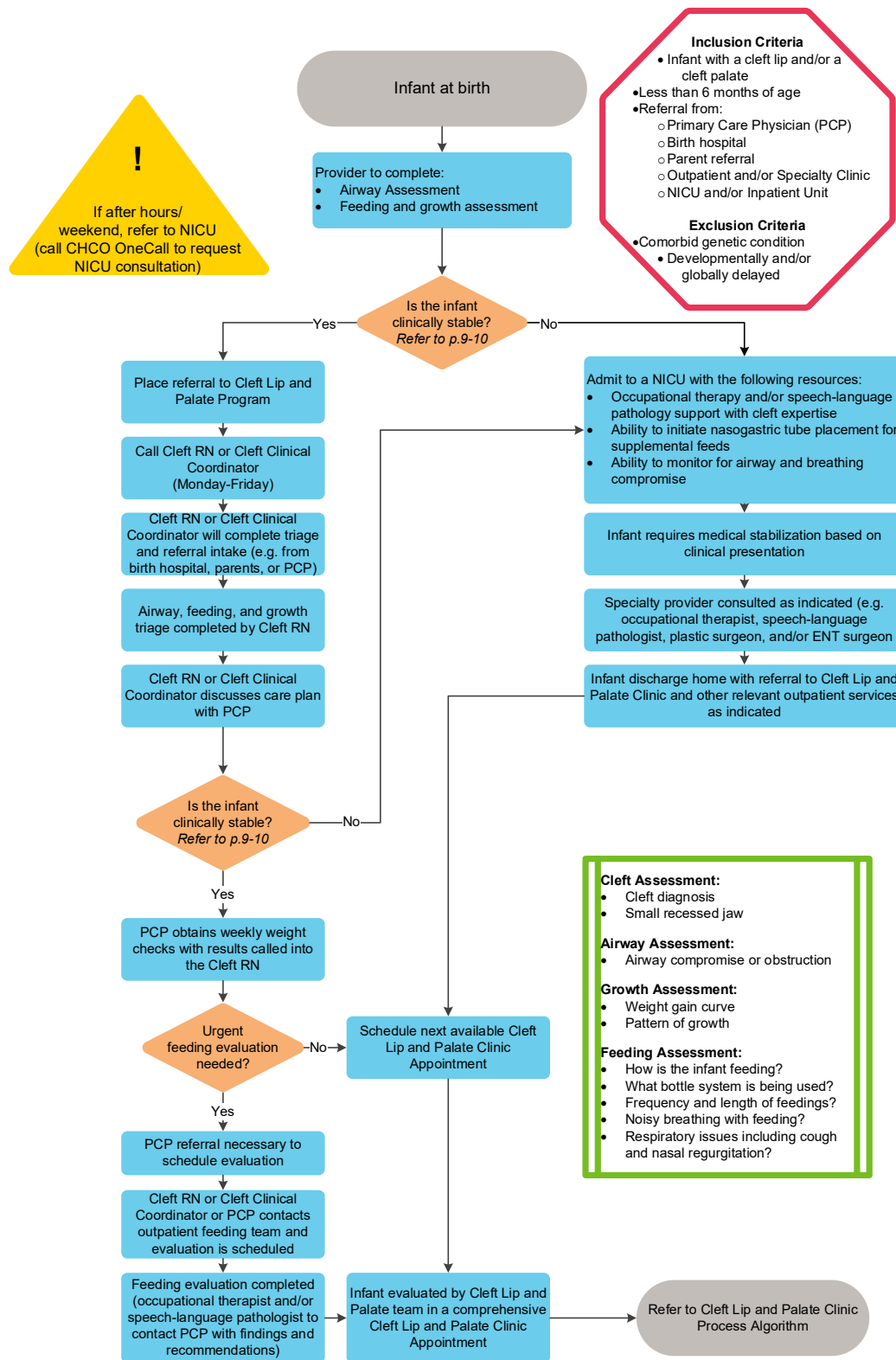


INFANTS WITH A CLEFT LIP AND/OR CLEFT PALATE

ALGORITHM 1. Triage and Treatment Process for the Infant



For contact information, please visit the [Cleft Lip and Palate Program](#) website or contact CHCO One Call at 720-777-8838

ALGORITHM 2. Cleft Lip and Palate Clinic Process for the Infant and Family

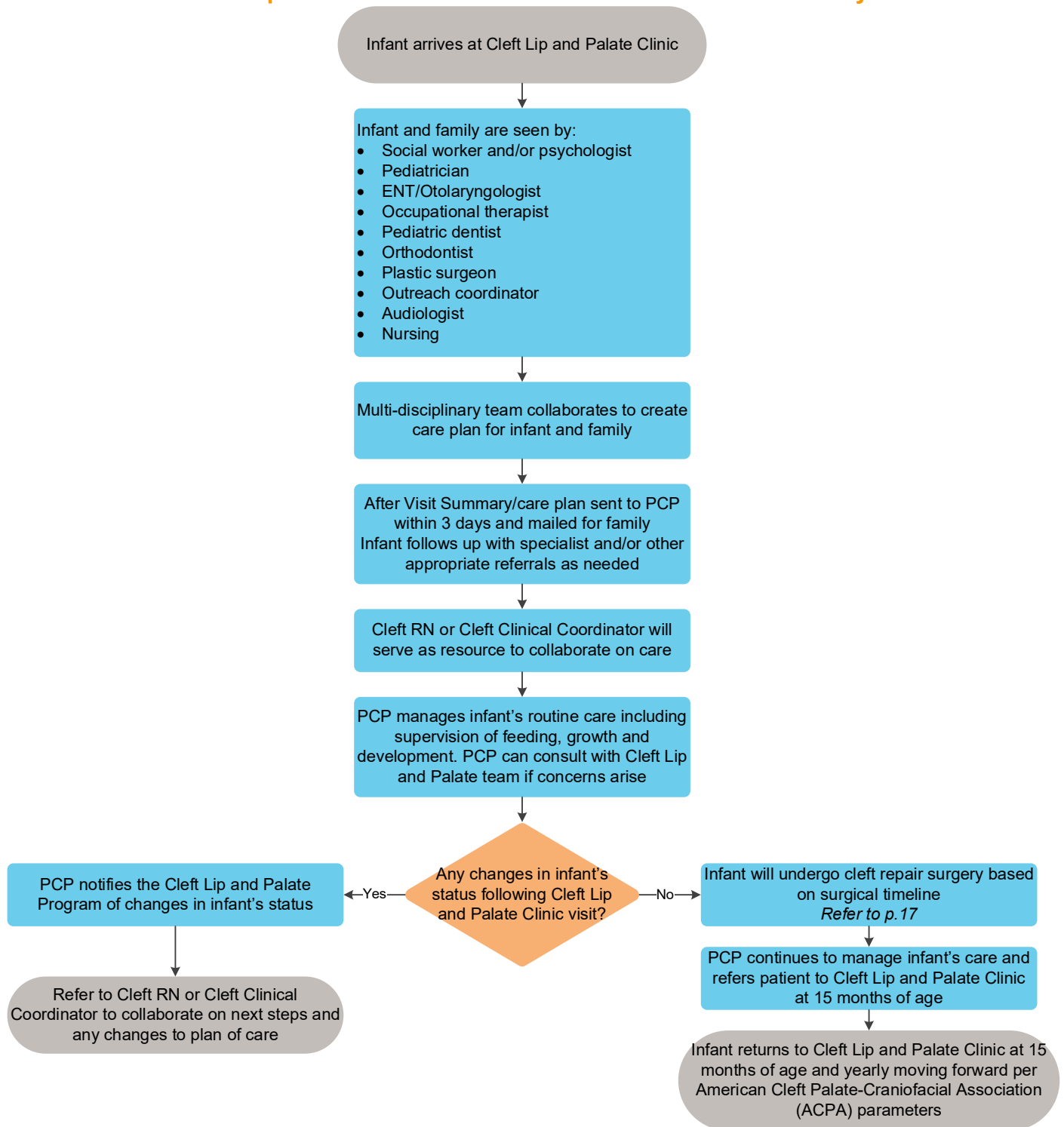


TABLE OF CONTENTS

[Algorithm 1. Triage and Treatment Process for the Infant](#)

[Algorithm 2. Cleft Lip and Palate Clinic Process for the Infant and Family](#)

[Target Population](#)

[Key Points](#)

[Background | Definitions](#)

[Initial Evaluation | Clinical Management](#)

[Infant Requires Urgent Feeding Evaluation](#)

[Clinical Studies | Imaging](#)

[Therapeutic Support Services](#)

[Parent | Caregiver Education](#)

[References](#)

[Appendix A. Example Timeline for Treatment of an Infant with Cleft Lip and/or Palate](#)

[Clinical Improvement Team](#)

TARGET POPULATION

Inclusion Criteria

- Infants with a cleft lip and/or a cleft palate
- Infants less than 6 months of age
- Referral from:
 - Primary Care Physician (PCP)
 - Birth hospital
 - Parent referral
 - Outpatient and/or Specialty Clinic
 - Children's Hospital Colorado Neonatal Intensive Care Unit and/or Inpatient Unit

Exclusion Criteria

- Infants with comorbid genetic condition
- Infants with developmental and/or global delays

KEY POINTS

Key points and recommendations are based on the "Parameters for Evaluation and Treatment of Patients with Cleft Lip/Palate or Other Craniofacial Differences", the official publication of the American Cleft-Palate-Craniofacial Association (Revised 2018).

- There are many types of congenital craniofacial differences, the most common of which is cleft lip and/or palate. In the United States this condition affects approximately 1:700 births each year. The health and wellbeing of this patient population is dependent on the clinical expertise of those who serve them.

- Inadequate or improper care results from diagnostic errors, failure to recognize and treat the full spectrum of associated health problems, as well as unnecessary, inappropriate and poorly timed medical or surgical interventions.
- Complex interdisciplinary management for infants with congenital craniofacial differences (including a cleft lip and/or cleft palate), requires a high level of ongoing coordination of services.
- Within the first week of the infant's life, an airway, feeding and growth assessment should be completed. This assessment is crucial in order to identify areas of need, and address concerns that require urgent intervention by a Cleft Lip and Palate multidisciplinary team.
- A referral for a Cleft Lip and Palate team evaluation should be placed as soon as possible.
- Following the multidisciplinary Cleft Lip and Palate Clinic appointment, the Cleft Lip and Palate team will make recommendations on the plan of care in conjunction with the primary care provider.
- Management of the infant's care is the responsibility of the primary care provider with guidance from the Cleft Lip and Palate team. Infants with a cleft diagnosis require weekly assessments of nutritional intake and weight gain for a minimum of the first month of life by the primary care provider.
- The family of an infant with a cleft lip and/or palate should continue to receive support through telephone calls, office visits and referrals to other specialists and/or for therapy services as indicated.

BACKGROUND

A cleft lip and/or palate is a defect occurring in 1:700 births and may be an irregular occurrence not commonly encountered by community providers. Because of this, there is a challenge with consistent education of medical providers about how to counsel and direct families of patients with cleft lip and/or cleft palate, particularly newborn infants. Specifically, providers may not be aware of the impact of a cleft lip and/or palate on an infant's airway, feeding and growth. Due to this inconsistent education and experience of health care providers, parents may be given inadequate information which can lead to newborn infants with not receiving the specialized support needed.

Infants with an isolated cleft palate, micrognathia and glossoptosis may have Pierre Robin sequence (PRS) and may often present with significant challenges including breathing and feeding difficulties which require specialized evaluations and interventions. The severity of the airway obstruction and feeding difficulty in PRS can also be related to the presence of additional congenital anomalies (Smith & Sender, 2006). Understanding the degree of airway obstruction and the subsequent impact on the infant's feeding and swallowing skills is essential in caring for the infant with Pierre Robin Sequence. Therefore, care needs to be customized to meet the infant's needs. Health care providers must understand the anatomy and mechanisms of airway obstruction to develop an individualized treatment plan to improve breathing during and after delivery. Health care providers must also ensure a safe, functional, and pleasurable feeding plan is in place to promote optimal growth and development.

Feeding and nutritional challenges are usually the first obstacles encountered by families and professionals when an infant is born with a congenital cleft condition. Early establishment of appropriate feeding patterns and adequate nutritional intake are important for any newborn (Kaye, A, et al, 2017). The preceding goals can be extremely challenging for the infant with a cleft lip and/or cleft palate, especially if parents have not received the proper education and support.

Specific to infants with a cleft lip/palate and breastfeeding, the literature shows success rates for infants who breastfeed are lower than for infants without a cleft. Exclusive breastfeeding may not be possible for the infant with a cleft palate or cleft lip/palate and can result in negative consequences including fatigue during feeding, prolonged feeding times, and/or impaired growth and nutrition (Boyce, et, al, 2019).

This Clinical Pathway has been developed to assist clinicians in making appropriate decisions for infants with a cleft lip and/or cleft palate including triage, clinical assessment and appropriate interventions and/or treatment specific to the topic of airway, feeding and growth. There is extensive evidence based literature that supports appropriate timing of airway, feeding and nutritional interventions.

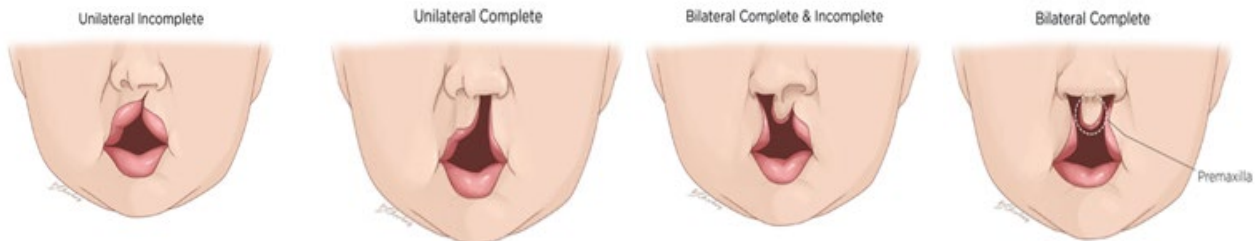
Frequently Used Medical Terms/ Definitions

Cleft lip and/or palate:

- A cleft is an abnormal opening. Infants diagnosed with a cleft lip and/or palate have an opening in the lip, the roof of the mouth (palate) or both. Clefting occurs during the first trimester of pregnancy when the tissue of the lip and palate do not fuse together.

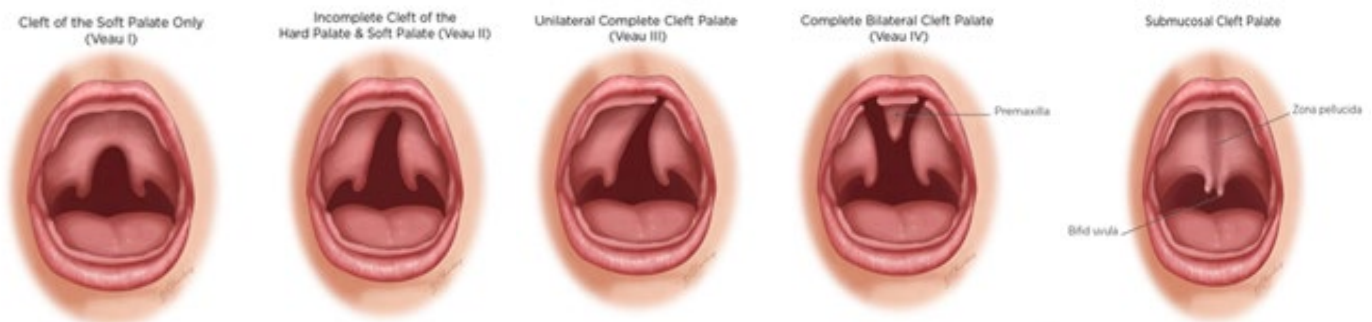
Types of cleft lips:

- Unilateral: involving philtrum on one side
- Bilateral: involving philtrum on both sides
- Complete: extends all the way to the nostril
- Incomplete: does not extend into the nostril
- Isolated: cleft lip without a cleft palate
- There are additional, more rare forms of clefting including lateral clefts that are outside the scope of this Clinical Pathway



Types of cleft palate:

- Alveolar: a cleft in the upper gum line (alveolus) that may or may not extend into the cleft palate
- Submucous: a cleft in the muscles of the soft palate in the posterior roof of the mouth that is covered by a thin layer of mucosa; this type of cleft is often challenging to diagnose because it is not easily seen upon assessment. A submucous cleft sometimes occurs with a bifid uvula.
- Complete: extends from the alveolus (gum line) all the way through the back of the palate
- Incomplete: does not extend all the way through the hard and soft palates
- Isolated: cleft palate without a cleft lip



Pierre Robin sequence:

- Pierre Robin sequence is a craniofacial condition characterized by micrognathia (a smaller than normal lower jaw) and glossoptosis (the tongue falls back and obstructs the airway); can occur with or without a cleft palate.
 - Pierre Robin sequence can be mild to severe. Infants with Pierre Robin sequence can have breathing problems. Different treatment options are available depending on the severity of the infant's breathing difficulties.
 - Infants with Pierre Robin sequence face two main problems: upper airway obstruction and feeding difficulties.
 - Pierre Robin sequence can be associated with other severe congenital abnormalities.

Bifid uvula:

- A uvula that is split into two parts. This can often be associated with a submucous cleft palate.

Stable infant:

- Infant who may be experiencing challenges with feeding and growth necessitating feeding intervention(s) but does not require escalation to a higher level of care

Unstable infant:

- Infant demonstrating physiological compromise or deterioration

Vomer ulceration:

- The vomer is bone that makes up the inferior part of the nasal septum and is exposed in a cleft palate. A vomer ulceration is an ulcer of the mucosal layer at the vomer usually caused by pressure from a bottle or feeding system. The ulcer can often cause pain and discomfort for the newborn and may impact the infant's success in feeding.

Stridor:

- Stridor is a term used to describe noisy breathing in general; refers specifically to a high-pitched crowing sound associated with respiratory infection, and airway obstruction.

Stertor:

- A coarse snorting sound localized to the posterior pharynx

Obstructive sleep apnea:

- A pause in breathing caused by a narrowing or blockage of the airway

Dysphagia:

- Difficulty with eating or swallowing

INITIAL EVALUATION AND CLINICAL MANAGEMENT

Infants born at birth with a diagnosis of a cleft lip and/or cleft palate require a timely and appropriate evaluation to determine the proper clinical management. An infant should first be assessed for any kind of airway compromise or breathing difficulties. If there are no signs or symptoms of airway compromise or breathing difficulties, a medical provider should then proceed with a detailed assessment of the infant's feeding and growth. Of note, an infant with a cleft lip or palate may also have associated congenital anomalies. It is the provider's responsibility to complete a thorough assessment for possible anomalies.

Assessment of Airway and Breathing

History

Clinical evaluation of an infant with possible airway compromise starts with a careful history obtained from the parents and/or primary caregivers. A history of symptoms is completed including asking the parents if they have noticed any of the following signs or symptoms:

- Presence of stridor or stertor
- Increased work of breathing or retractions
- Changes in the infant's color such as cyanosis or a dusky appearance
- Sleep disordered breathing symptoms such as snoring
- Factors that improve symptoms or make them worse such as infant's position, feeding behaviors, and/or infant's activity

Because of the connection between breathing and feeding in infants, a history of the infant's feedings and growth pattern needs to be completed. Depending on the degree of respiratory compromise, the infant's feeding and swallowing skills may be significantly impaired and contribute to aspiration which can subsequently impact an infant's growth.

Examination

The examination starts with overall inspection of the infant, carefully visualizing the infant's head, neck and chest. Ideally the infant should be assessed in different positions and while feeding.

Optimal oral exam is completed and includes:

- Comprehensive assessment of the infant's hard and soft palate by visual inspection. The infant's tongue should be depressed in order to visualize the entire palate.
- Focused head and neck examination.
- Weight and length measurement, and checking infant's vital signs including obtaining oxygen saturation level with infant in different positions.

The infant with upper airway obstruction at the tongue base may present with audible stertor. Monitor for increased work of breathing such as retractions, accessory muscle use and/or head bobbing. These symptoms can indicate respiratory distress. A supine position tends to worsen the airway obstruction. Placing the infant in a prone position can help the tongue move forward which will improve airway patency, and help the infant breathe more comfortably.

- Infants who are demonstrating signs of airway obstruction may need to be hospitalized for monitoring of the airway symptoms, feeding, and weight gain. Surgical intervention may be necessary based on the severity of airway obstruction.
- Infants who do not demonstrate airway obstruction require ongoing close monitoring of breathing, feeding and growth on a weekly outpatient basis because airway obstruction can worsen after the newborn period.

Assessment of Feeding and Growth

The goal of the triage process is to obtain a feeding history and review of the infant's growth pattern to identify areas of concern that help the provider to determine the infant's clinical stability and/or instability.

- Clinical assessment
 - Cleft diagnosis: unilateral versus bilateral, complete versus incomplete, lip and/or palate
 - Small recessed jaw: assess for possible Pierre Robin sequence

- Growth assessment
 - For an infant to grow at an appropriate rate they require adequate calories and essential nutrients. Conversely, poor growth is an important indicator of nutritional inadequacy.
 - Obtain history of weights and plot on growth curve
- Feeding assessment (open ended questions to elicit detailed history)
 - Quality of feeding
 - Positive or negative feeding experience based on parent/caregiver observations
 - Bottle or breast feeding
 - Confirm feeding system being used including nipple type and/or flow rate delivery
 - Dr. Brown's Zero-Resistance Specialty Feeding System with Infant Paced Feeding Valve
 - Level of nipple (Ultra-preemie, Premie, Transitional, Level 1, Level 2, Level 3, Level 4)
 - Medela Standard Special Needs Feeder or Mini Special Needs Feeder (previously known as the Haberman Feeder)
 - Flow rate line being used (short, medium or longest line or in between lines)
 - Parents/caregivers are asked if they are providing additional support to help infant transfer milk (i.e. applying a pulsating squeeze to barrel of the nipple while infant is sucking)
 - Cleft Palate Nurser with Pigeon nipple
 - If infant is breastfeeding, confirm infant's ability to adequately transfer milk (e.g. were before and after breastfeeding weights obtained). Determine whether infant is able to latch and sustain latch at breast via mother's description of breastfeeding.
 - Length and frequency of feeding
 - Volume consumed
 - Infant behaviors with oral feedings
 - Noisy breathing (at rest and during oral feedings)
 - Changes in breathing effort and/or rate
 - Color changes (at rest, during and following oral feedings)
 - Ability of infant to remain alert/awake for feedings
 - Emesis and/or nasal regurgitation during or following feedings
 - Coughing, choking, gagging and/or gulping

Identification of an Infant's Clinical Status

Infant is determined as clinically stable or clinically unstable based on assessment.

Clinically unstable: If infant is exhibiting any of the following signs a clinical evaluation is warranted as infant may likely require hospitalization.

- Infant is below birth weight at 14 days of life per American Academy of Pediatrics (AAP) guidelines. Immediately after birth, an infant may lose approximately 10% of their body weight because of fluid loss and tissue breakdown. Infants will usually regain their birthweight in 7 days.
- Infant is not demonstrating a positive pattern of growth after 14 days of life
 - Of note, an infant is expected to lose weight following birth and should return to birthweight within 2 weeks of delivery. If infant has not regained birthweight after this time frame, this is an indication infant is not feeding effectively or may be clinically unstable.
- Weight deceleration or weight loss that crosses 2 major growth percentile lines on the growth chart with a negative trending growth curve
- Weight gain pattern shows less than 20 to 30 grams per day gain (goal of 30 grams per day) for the infant less than 4 weeks of age
- Any loss 10% or greater of birthweight
- Supplemental oxygen requirement and/or need for increase in oxygen requirement
- Changes in breathing pattern such as increased work of breathing (head bobbing, grunting, flaring nostrils, or shows retraction above the collarbone or between or below the ribs) and/or infant is described as demonstrating an obstructive breathing pattern such as gasping or pausing to breathe
- Any color changes in infant's skin color including face, lips, and/or trunk and extremities during feeding or at rest
- Excessive sleepiness
- Not showing any hunger cues (lack of feeding readiness behaviors such as rooting, coming to an awake state, fussing, sucking on hands/fingers)
- Infant does not arouse for feedings and/or is unable to remain awake to complete a feeding
- Excessive emesis with feedings with weight loss
- Refusal to eat
- Underlying or suspected genetic/other medical diagnosis
- Infant's physical appearance including poor tone, poor color, lethargy and/or presents with little subcutaneous fat

Intervention for clinically unstable infant

- Admission to Neonatal Intensive Care Unit (NICU) with the following resources:
 - Occupational therapy and/or speech-language pathology support with cleft expertise
 - Ability to initiate nasogastric tube placement for supplemental feeds
 - Ability to monitor for airway and breathing compromise
- Children's Hospital Colorado NICU available for consultation
 - If infant is being admitted to CHCO NICU, primary care provider will need to contact One Call at 720-777-8838.
 - Once connected with One Call, the CHCO team will connect with appropriate providers to assist in the admission process.
- Children's Hospital Colorado NICU admission process
 - Once admitted infant is assessed by the NICU medical team and is stabilized.

- Feeding specialist (occupational therapist and/or speech language pathologist) is consulted to formally assess infant's oral motor/feeding skills.
- Feeding plan is created in collaboration with medical team and consultants.
- Family/caregivers are provided education and training regarding feeding plan in anticipation of discharge to home.
- If infant is admitted to CHCO NICU, Cleft Nurse or the Cleft Clinical Coordinator and surgeon are contacted to provide education and support for infant and family/caregiver.
- Prior to discharge from NICU, infant is scheduled for appointment in CHCO Cleft Lip and Palate Clinic for multidisciplinary team evaluation.
- Upon discharge, primary care physician will receive updates regarding infant's NICU course and recommendations post discharge.

Clinically stable: Infant may be experiencing challenges with feeding and growth necessitating intervention(s) although does not require hospitalization. Based on the below criteria, infant may need an urgent feeding evaluation.

- Infant with a cleft lip who is presenting with breastfeeding challenges such as difficulty maintaining latch at mother's breast; infant not satisfied following breastfeeding session, and/or mother reports not feeling empty after breastfeeding infant
- Infant is not using a cleft specific bottle system such as the Dr. Brown's Specialty Feeding System with Infant Paced Feeding Valve (blue disc) or the Medela Special Needs Feeder
- Length of feeding extends past 30 minutes per feeding
- Feeding completed in less than 30 minutes; however, feeding is characterized as effortful and/or infant is taking small amounts (20 mLs or less)
- Infant demonstrates noisy breathing at rest and/or with feeding (gaspings and/or demonstrates a high pitched, squeaking sound)
- Infant demonstrates a clicking sound while feeding (not generating enough suction and/or breaking suction)
- Color changes (pale or dusky)
- Feeding refusal behaviors and/or signs of oral aversion (such as infant pulling away from bottle, not opening mouth with presentation of bottle)
- Signs of reflux such as arching, crying, emesis, and/or discomfort during and following feedings
- Infant is feeding more frequently than every 2 hours (grazing) and still not satisfied
- Infant is audibly gulping, demonstrates gurgling or wet sounds in the throat, and/or exhibits coughing, choking or gagging with feedings
- Infant is losing milk/formula out of corners of mouth during feedings
- Infant has plateaued on the growth chart or infant's weight is no longer following a positive growth curve pattern after one month of life
- Irritability (infant not consolable)
- Easily fatigued
- Lack of molding to parent/caregiver's body
- Lack of age-appropriate engagement in feeding interaction
 - 0-1 month: infant roots and searches for the nipple; sustains non-nutritive suck; demonstrates coordination of suck-swallow-breathe and exhibits symmetrical oral movements
 - 2-3 months: demonstrates excitement when offered breast or bottle

- 4-6 months: brings hands to bottle; holds spoon to wave and bang
- 7-8 months: explores foods with hands; gross grasp on finger foods to bring to mouth
- 9-10 months: improved accuracy with finger feeding
- 10-12 months: beginning to dip spoon and bring to mouth

Intervention for clinically stable infant

- Recommend contacting Children's Hospital Colorado (CHCO) Cleft Nurse phone line at 720-777-5364.
- Cleft Lip and Palate Program nurse will collaborate with the CHCO Outpatient Feeding Program scheduler to schedule an evaluation with an occupational therapist and/or speech-language pathologist experienced in working with an infant with a cleft lip and/or palate.

INFANT REQUIRES URGENT FEEDING EVALUATION

Outpatient evaluation initiated

- Cleft Nurse or the Cleft Clinical Coordinator contacts Cleft Lip and Cleft Palate team member(s) regarding infant's feeding and growth status and works with CHCO Outpatient Feeding Program scheduler to coordinate scheduling a feeding evaluation as soon as possible.
- Feeding evaluation is completed by an occupational therapist and/or speech language pathologist.
 - History is gathered including infant's diagnosis, reason for referral, family concerns, respiratory status, feeding history, and previous therapy support at birth hospital.
 - Observation of infant feeding is completed including assessment of:
 - Position for feedings
 - Behaviors exhibited (positive, negative, maladaptive)
 - Posture and muscle tone
 - Oral structures
 - Current feeding plan including whether infant is breast and/or bottle feeding, type of feeding system, frequency of feedings, length/duration of feeding and volume consumed
 - Level of engagement/participation
 - Hunger/satiety behaviors
 - Sensory processing (e.g. signs of oral aversion)
 - Oral feeding skills
 - Discussion of next steps/feeding progressions including:
 - Timing and introduction of infant cereal/puree textures
 - Transition to solid/finger foods
 - Preparation for cleft palate repair surgery (feeding expectations following surgery; cup suggestions)
- Recommendations are made based on feeding evaluation:
 - Feeding therapy
 - Frequency of therapy services (e.g. weekly; biweekly; monthly) including follow up assessment to ensure feeding plan is supporting positive feeding experiences resulting in growth. Additional visits may be beneficial at time of feeding milestones such as:
 - Introduction of spoon feeding with baby food/purees
 - Introduction of solids
 - Getting ready for surgery/recovery from cleft surgery (cup drinking)

- Self-feeding
- Referral to other specialists and/or agencies may be suggested including, but not limited to:
 - Lactation Counselor
 - Dietitian/Nutritionist
 - Early intervention screening/evaluation

CLINICAL STUDIES | IMAGING

Clinical studies and/or imaging may be recommended based on the assessment of an infant's status including airway feeding, and growth as well as the infant's presenting clinical symptoms.

Polysomnogram (PSG): Sleep Study

Patency of the upper airway is complex and depends on many factors such as tone, neuromuscular control, and collapsibility. The mechanisms that are normally in place to maintain airway patency may fail for an infant with a compromised upper airway space such as in infants with Pierre Robin sequence. Most issues with breathing occur when the infant is asleep. Problems are exacerbated when the infant sleeps on their back because gravity causes the tongue and other tissues to fall back into the airway.

An overnight sleep study (nocturnal laboratory PSG) provides a functional, noninvasive assessment of the severity and quantity of episodes of airway obstruction during sleep. This is the ideal method to diagnose obstructive sleep apnea (OSA). The sleep study will provide information on how many times the infant's oxygen levels decrease during sleep. During this study multiple areas are monitored including the infant's oxygen and carbon dioxide levels, brain waves and heart rate. Videos of the infant's positioning is recorded.

A sleep study can provide additional data to quantify airway obstruction during sleep in infants with Pierre Robin sequence and will capture airflow, apnea/hypopneas*, gas exchanges, sleep stages and architecture. The polysomnogram can be a sensitive tool and is particularly useful when the clinical picture is unclear. The study further helps to gauge the severity of the infant's breathing obstruction and can guide the provider's decision for surgical management.

Indications

Indications for a sleep study include infants with any or all of the following:

- Pierre Robin sequence and/or apnea
- Oxygen desaturations
- Need for supplemental oxygen
- Carbon dioxide retention
- Poor growth despite adequate calorie intake
- Noisy breathing or pauses while sleeping or when supine

Nasal Endoscopy

To establish optimal therapy and treatment for a patient with airway obstruction it is critical to understand the site of the obstruction. A flexible fiberoptic endoscopy airway evaluation allows for visualization of the airway from nasal passage to the level of the vocal folds. This examination is helpful in identifying levels of airway obstruction at or above the vocal folds and is the most reliable method to assess vocal fold ability.

Indications

- Suspected airway obstruction
- Pierre Robin sequence
- Suspected submucous cleft palate

Imaging

A computed tomography scan (CT) can also be obtained to evaluate under developed mandible associated with Pierre Robin sequence. This will help a surgeon or care provider examine the physical relationship of the jaw, tongue and airway. In general, the problem will be worse the farther back the lower jaw is positioned relative to the upper jaw. With this imaging the surgeon or care provider can measure the size of the small mandible and determine if surgery may be needed.

Indications

- If surgical management, such as mandibular distraction, is indicated for an infant with airway compromise.

Evaluating Dysphagia: Instrumental Evaluations (VFSS and FEES)

Instrumental Evaluations of Swallowing

An instrumental evaluation of swallowing involves visualization of the oral and pharyngeal structures and their function during, and after active swallowing. The two most common studies to evaluate swallow function include Videofluoroscopic Swallow Study (VFSS) and Fiberoptic Endoscopic Evaluation of Swallowing (FEES).

The first goal of an instrumental evaluation of swallowing is to evaluate the anatomy and baseline pharyngeal function, including the timeliness of initiation of the swallowing reflex, ability to protect the airway (achieve adequate laryngeal closure and elevation) and ability to completely clear the mouth and pharynx of swallowed food and liquid. The second goal is to determine and recommend a functional feeding plan for the infant based on the findings of the exam. A feeding plan may include recommendations for consistency of food/liquid, patient positioning during feeding and appropriate feeding modalities (cups, nipples, utensils, etc.).

Clinical Indications

Swallowing problems that warrant an instrumental evaluation of swallowing include, but are not limited to:

- Coughing
- Choking
- Red, watery eyes
- Wet vocal quality during/after feedings
- Poor coordination of breathing and swallowing
- Frequent respiratory illnesses
- Growth concerns

Videofluoroscopic Swallow Study (VFSS)

A videofluoroscopic swallow study is conducted in radiology under fluoroscopy. The infant is positioned upright, semi-reclined, or in elevated side-lying and is offered various liquid and food consistencies mixed with barium contrast. Swallowing is evaluated as the infant consumes the barium meal, and as adaptations/interventions (i.e. pacing, positioning) are implemented to optimize infant's airway protection during swallowing. Infants are appropriate candidates for VFSS. It is typically the preferred exam for initial swallowing evaluation as a view of the oral, pharyngeal, and upper esophageal phases of the swallow can be obtained.

Indications for VFSS

- Accepts a bottle
- Able to consume at least 1 ounce of liquid or food by mouth
- Appropriate if infant/child presents with significant oral-sensory issues
- Appropriate if there is a concern for potential negative feeding experience with FEES

Fiberoptic Endoscopic Evaluation of Swallowing (FEES)

A fiberoptic endoscopic evaluation of swallowing is conducted in the otolaryngologist's office or at patient's bedside (inpatients). A pediatric-sized endoscope is passed through the patient's nasal passages to the level of the pharynx, and the structures of the larynx and pharynx are viewed from above at rest and during swallowing. A FEES is most often appropriate for children age 12 months and younger.

Indications for FEES

- Able to assess secretions
- Able to assess breastfeeding
- Concern for limited intake
- Appropriate when radiation exposure is a concern
- Anticipate need for serial swallow evaluations and results in minimizing radiation exposure

ADDITIONAL THERAPEUTIC SUPPORT SERVICES

For infants with a cleft lip and/or palate it is appropriate to make a referral for the following services based on infant's needs:

Home Care/Home Health Services

Home Health Services consist of Skilled Nursing as provided by a Registered Nurse (RN), a Licensed Practical Nurse (LPN), or a Certified Nurse Aide (CNA). CNA services may also be referred to as a Certified Nursing Assistant or a Home Health Aide. Other Home Health Services can include Physical Therapy (PT), Occupational Therapy (OT) and Speech Language Pathology (SLP) services.

Early Intervention

Early intervention is a system of coordinated services that promotes a child's age-appropriate growth and development and supports families during the critical **early** years. Parents and/or providers can request a free early intervention evaluation for children birth up until age 3 if there are questions or concerns with their infant's development in the areas of social, emotional, motor, communication, adaptive, and cognitive skills. If infant lives in Colorado, parents and/or providers can contact Early Intervention Colorado at 1-888-777-4041.

Outpatient Therapy Services

Services provided in an outpatient setting may include, but not be limited to:

- Occupational therapy, physical therapy and/or speech-language therapy

PARENT | CAREGIVER EDUCATION

The following [In Care of Kids](#) handouts are available:

- Feeding Your Baby with a Cleft Lip and/or Palate: [English](#) and [Spanish](#)
- Specialty Feeding System: Dr. Brown's Zero-Resistance Specialty Feeding System with Infant Paced Feeding Valve: [English](#) and [Spanish](#)
- Specialty Feeding System: Medela Special Needs Feeder: [English](#) and [Spanish](#)
- Cleft resource binder is available for parents from the Cleft Team. Please contact 720-777-2574 to obtain a copy if desired

Reference the [Cleft Lip and Palate Clinic](#) website for additional information

REFERENCES

1. Al-Samkari, H.T., Kane, A.A., Molter, D.W. & Vachharajani, A. (2010). Neonatal outcomes of Pierre Robin Sequence: An institutional experience. *Clinical Pediatrics*, 49, (12), 1117-1122.
2. American Academy of Pediatrics. Bright Futures: Nutrition Supervision. <https://brightfutures.aap.org/Bright%20Futures%20Documents/BFNutrition3rdEditionSupervision.pdf>
3. American Cleft Palate-Craniofacial Association. Parameters for evaluation and treatment of patients with cleft lip/palate or other craniofacial differences. January 2018; 137-156.
4. Amstalden-Mendes, L.G., Magna, L.A. & Gil-da-Silva-Lopes, V.L. (2007). Neonatal care of infants with cleft lip and/or palate: Feeding orientation and evolution of weight gain in a nonspecialized Brazilian hospital. *Cleft Palate-Craniofacial Journal*, 44, (3), 329-334.
5. Arvedson, J. & Brodsky, L. (2002). *Pediatric Swallowing and Feeding*. Albany, NY: Singular Publishing Group.
6. Beaumont, D. (2008). A study into weight gain in infants with cleft lip/palate. *Paediatric Nursing*, 20, (6), 20-23.
7. Boyce, J.O., Reilly, S., Skeat, J., Cahir, P. & the Academy of Breastfeeding Medicine. (2019). ABM Clinical Protocol # 17: Guidelines for breastfeeding infants with cleft lip, cleft palate, or cleft lip and palate-Revised 2019. *Breastfeeding Medicine*, 14(7), 437-444.
8. Donovan, K. (2012). Breastfeeding the infant with cleft lip and palate. *Infant, Child, & Adolescent Medicine*, 4(4), 194-198.
9. Garcez, L. & Giugliani, E. (2005). Population-based study on the practice of breastfeeding in children born with cleft lip and palate. *Cleft Palate-Craniofacial Journal*, 42, (6), 687-693.
10. Glenny, A.M., Hooper, L., Shaw, W.C., Reilly, S., Kasem, S. & Reid, J. (2005). Feeding interventions for growth and development in infants with cleft lip, cleft palate or cleft lip and palate. *Cochrane Database Systematic Review*, 1, Article no. CD003315.
11. Kaye, A., Thaete, K., Snell, A., Chesser, C., Goldak, C. & Huff, H. (2017). Kaye, A., Thaete, K., Snell, A., Chesser, C., Goldak, C. & Huff, H. (2017). Initial nutritional assessment of infants with cleft lip and/or palate: Interventions and return to birthweight. *Cleft Palate-Craniofacial Journal* 54(2), 127-136.
12. Lidsky, M.E. Lander, T.A. & Sidman, J.D. (2008 Jan). Resolving feeding difficulties with early airway intervention in Pierre Robin sequence. *Laryngoscope*, 118(1), 120-123.
13. Losee, J., Kirschner, (2016). *Comprehensive Cleft Care Second Edition*. Boca Raton, FL: Taylor and Francis Group LLC.
14. Losee, J., Kirschner, R., Smith, D., Lawrence, C., Straub, A., (2015). *Comprehensive Cleft Care Family Edition*. Boca Raton, FL: Taylor and Francis Group LLC.
15. Masarei, A.G., Sell, D., Habel, A., Mars, M., Sommerlad, B.C. & Wade, A. (2007). The nature of feeding in infants with unrepaired cleft lip and/or palate compared with healthy noncleft infants. *Cleft Palate-Craniofacial Journal*, 44(3), 321-328.
16. Masarei, A.G., Wade, A., Stat, C., Mars, M., Orth, D., Sommerlad, B.C. & Sell, D. 2007). A randomized control trial investigating the effect of presurgical orthopedics on feeding in infants with cleft lip and/or palate. *Cleft Palate-Craniofacial Journal*, 44(2), 182-193.
17. Miller, C.K. (2011). Feeding issues and interventions in infants and children with clefts and craniofacial syndromes. *Seminars in Speech and Language*, 32(2), 115-126.
18. Miller, C.K. & Willging, J.P. (2007). The implications of upper-airway obstruction on successful infant feeding. *Seminars in Speech and Language*, 28(3), 190-203.

19. Reid, J., Kilpatrick, N. & Reilly, S. (2006). A prospective, longitudinal study of feeding skills in a cohort of babies with cleft conditions. *Cleft Palate-Craniofacial Journal*, 43, (6), 702-709.
20. Reilly, S., Reid, J., Skeat, J. & The Academy of Breastfeeding Medicine Clinical Protocol Committee. (2007). ABM Clinical Protocol # 17: Guidelines for Breastfeeding Infants with Cleft Lip, Cleft Palate, or Cleft Lip and Palate. *Breastfeeding Medicine*, 2, (4), 243-250.
21. Reilly, S., Reid, J., Skeat, J., Cahir, P., Mei, C., Bunik, M. & The Academy of Breastfeeding Medicine. (2013). ABM Clinical Protocol # 17: Guidelines for breastfeeding infants with cleft lip, cleft palate, or cleft lip and palate. *Breastfeeding Medicine*, 8(4), 349-353.
22. Royal College of Paediatrics and Child Health. (October 2014). Palate examination: Identification of cleft palate in the newborn-best practice guide. <https://www.rcpch.ac.uk/resources/palate-examination-identification-cleft-palate-newborn-best-practice-guide>
23. Wolf, L., & Glass, R. (1992). *Feeding and Swallowing Disorders in Infancy: Assessment and Management*. Tucson, AZ: Therapy Skill Builders.

APPENDIX A: EXAMPLE TIMELINE FOR TREATMENT OF AN INFANT WITH CLEFT LIP AND/OR PALATE

- All infants are different and therefore plans will vary.
- The below timeline is presented only as an example for an infant with a cleft lip and/or palate. It should never replace the recommendations of the Primary Care Provider (PCP) or the Cleft Lip and Palate Team.
- Regular visits to a Primary Care Provider (PCP) and routine immunizations are critical for ongoing good health of the infant.
- Generally, visits to the Cleft Lip and Palate Clinic are recommended to occur on a yearly basis.
 - Once intake is completed for a new infant, scheduling of the infant is prioritized for next available Cleft Lip and Palate Clinic appointment.
 - Typically, infants are seen within the first month of life.
 - Cleft lip repair surgery is typically between 3-6 months of age with possible ear tube placement if necessary.
 - A behavioral hearing test is completed between 7-9 months of age to assess for any deficits and determine need for possible ear tube placement.
 - Cleft palate repair surgery is typically between 9-15 months of age with possible ear tube placement if necessary.
 - It is recommended that the first speech and dental assessments are completed around 1 year of age.
 - Typically, infants are seen for a follow up evaluation in the Cleft Lip and Palate Clinic at 15 months of age.

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MANUAL/DEPARTMENT	Clinical Care Guidelines/Quality
ORIGINATION DATE	January 14, 2019
LAST DATE OF REVIEW OR REVISION	February 24, 2025
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REVIEW | REVISION SCHEDULE

Scheduled for full review: June 2027

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