

Cleft Lip & Palate: Supporting Feeding Development

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Who Am I?

- SLP on the Craniofacial Team at Riley Hospital for Children
- SLP in the NICU at Riley Hospital for Children
- Experience in outpatient feeding therapy, First Steps, and schools
- Mother to a son born with unilateral cleft lip & palate

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Disclosures

- Financial Disclosures
 - I have no financial disclosures
- Non-financial disclosures
 - I am employed by Riley Hospital for Children at IU Health and a member of the Craniofacial Team

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Objectives

- Participants will be able to identify and describe typical feeding patterns in infants born with cleft lip & cleft palate
- Participants will be able to identify and describe symptoms of feeding dysfunction in babies with cleft lip & cleft palate
- Participants will learn and gain confidence with practical approaches to helping families manage every day feeding demands for a child born with cleft lip and/or cleft palate

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Cleft Statistics

- 1:600 newborns is born with either a cleft lip and/or cleft palate
- 2,651 babies are born each year with a cleft palate
- 4,437 babies are born each year with a cleft lip (+/- cleft palate)

CDC, 2016

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Cleft Statistics

- "Asians and American Indians have higher rates of orofacial clefts" (1:500 births)
- "African-derived populations have lower rates of orofacial clefts" (1:2500 births)
- Males are twice as likely as females to be born with a cleft lip +/- cleft palate.
- Females are twice as likely than males to have a cleft palate without cleft lip.

ASHA, 2018

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Cleft Statistics

- Clefts are associated with more than 300 genetic syndromes
- Syndromes account for about 15% of the total number of cases of cleft lip and/or palate

CPF, 2008

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Cleft Lip

- Lip forms between weeks 4-7 of pregnancy
- A cleft lip is a separation of the two sides of the lip
- +/- cleft of the alveolar ridge
- Complete or incomplete



(picture courtesy of CDC.gov)

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Cleft Palate

- Palate forms between weeks 6-9 of pregnancy
- Cleft palate is an opening in the roof of the mouth in which the two sides of the palate did not fuse
- Cleft of the soft palate disrupts the Levator Palatini muscle



(picture courtesy of CDC.gov)

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American Cleft Palate Association: Parameters of Care

- I. Interdisciplinary team of specialists
- II. Sufficient numbers to maintain clinical expertise in diagnosis & treatment
- III. Optimally evaluate within the first few weeks of life and, whenever possible, within the first few days of life
- IV. Assist the family in adjusting to the birth of a child with a craniofacial difference and the subsequent demands

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American Cleft Palate Association: Parameters of Care

V. Parents must be given information to make informed decisions & prepare the child about recommended treatment procedures

Actively soliciting family participation & collaboration

VI. Treatment plans on the basis of team recommendations

VII. Care coordinated by the team but provided at the local level whenever possible

Complex diagnostic & surgical procedures restricted to centers with appropriate facilities & experience

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American Cleft Palate Association: Parameters of Care

VIII. Sensitive to the linguistic, cultural, ethnic, psychosocial, economic, and physical factors that affect the relationship between team & family

IX. Monitor short-term and long-term outcomes

X. Evaluation of treatment outcomes accounts for satisfaction & psychosocial well-being of the patient, as well as growth, function, and appearance

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American Cleft Palate Association: Parameters of Care

- Interdisciplinary team of specialists
 - Accredited teams must include patient care coordinator, speech pathology, surgery, and orthodontics
 - Access to audiology, psychology, social work, audiology, genetics, general & pediatric dentistry, otolaryngology, and pediatrics/primary care

www.cleft.org

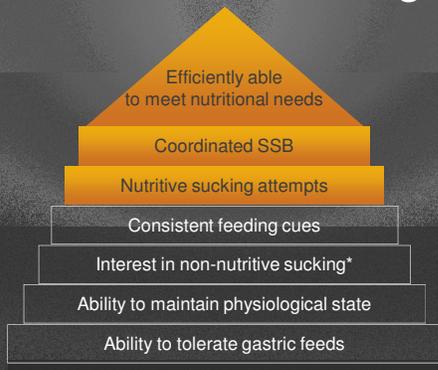
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Know the Basics of Infant Feeding

- A baby with a craniofacial difference is first & foremost a baby
- Successful intervention in feeding babies with craniofacial differences requires a strong foundation in infant feeding
- Many of the feeding strategies that work for babies without clefts also work for babies with clefts

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Foundation of Feedings



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Neonatal Benchmarks

- RR <70 during feedings and otherwise physiologically stable
- Return to birth weight in 10-14 days
- Growth: 25-30 grams per day (after back to birth weight)
- Feedings < 30 minutes
- Maintains respiratory health
- Minimal stress surrounding feedings

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NICU Cleft Feeding

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Nutritive Sucking

- Successful bottle & breast feeding relies on the baby achieving a sufficient and rhythmic pattern of compression (positive pressure) and suction (negative pressure) on the nipple
- Clefting of the lip, alveolar ridge, and palate may negatively impact feedings
 - Compression (positive pressure) requires adequate palatal surface area
 - Suction (negative pressure) requires a closed system

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The Impact of a Cleft

- A cleft palate results in the most significant structural & functional deficits to the feeding mechanism
 - Lack of physical separation of nasal cavity and oral cavity
 - Lack of contraction of the Levator Palatini muscle to elevate the soft palate for separation of the nasopharynx and the oropharynx
- Even "small soft palate clefts" may significantly disrupt feedings

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The Impact of a Cleft

- An alveolar cleft causes a structural deficit to the feeding mechanism that may or may not result in a functional deficit.
- A cleft lip causes a structural deficit to the feeding mechanism, but rarely results in a functional deficit.
 - Occlusion of the cleft lip (structural deficit) is often sufficient to negate any effects to function

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The Impact of a Cleft

- When determining significance of the cleft on feedings, a variety of factors should be considered:
 - Parental feeding goals
 - Feeding efficiency
 - Growth & overall nutrition
 - Baby's response to feedings

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The Impact of a Cleft

- Without appropriate feeding intervention, babies with cleft palate are more likely to experience:
 - Poor feeding efficiency
 - Inadequate volume of oral intake
 - Poor growth
 - Dehydration
 - Nasal regurgitation
 - Excessive air intake

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Quality Matters

- Early nutrition supports rapid brain development and recovery from illness & surgery
- Feeding become voluntary around 2-4 months of age as the rooting & sucking reflexes disappear
- Early feeding times are a valuable bonding opportunity for parent and baby
- Behaviors are the result of repetitive experiences

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Feeding with a Cleft

- Providing quality oral feeding experiences to babies with cleft palate requires maximizing compression
- Optimal feeding systems:
 - Give baby control of expression rate & bolus size
 - Are efficient (<20-30 minutes)
 - Consistent across feedings & caregivers
 - Allow for safe swallow strategies

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Assisted Delivery Bottles

- Caregiver controls the feeding by squeezing the bottle
- Baby can be a passive participant
- Feeding patterns may vary based on the feeder
- Can be difficult for the baby to coordinate an organized pattern with inexperienced/distracted caregivers
 - Squeeze when the baby sucks, rest when the baby rests
 - “Squeeze-2-3, squeeze-2-3, squeeze-2-3...”

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Infant Directed Bottles

- Baby controls the compression depth & sucking frequency
- Most consistent across feedings & feeders
- Can sometimes result in inefficient feedings
- Nipple flow rate can often be increased or decreased
- Thickened liquids can be difficult to express

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Enfamil Cleft Palate Nurser by Mead Johnson

- Assisted delivery system
- Squeezable, soft bottle
- Nipple can be replaced with any other nipple
- Relies on the parent to anticipate the sucking pattern
- \$4 each on walmart.com



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Medela Special Needs Feeder (Haberman)

- Typically used as an assisted delivery system
- Y-cut nipple varies the flow rate based on orientation
 - Short line = no/slow flow
 - Medium line = medium flow
 - Long line = regular/high flow
- Line should be placed under the baby's nose
- Teat must be primed
- \$30+ each on Amazon



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Pigeon Cleft Palate Bottle

- Infant directed with 1-way flow valve
- Y-cut hole
- Two nipple sizes (small, regular)
- The notch is to align with the baby's nose
- Nipple, valve, and collar may be placed on any bottle
- \$24 for entire system or \$10 for nipple + valve on Amazon



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Dr. Brown's Specialty Feeding System

- Infant directed
- No lines to worry about
- Consistent and reliable nipple flow rate (vacuum free)
- Ships with a level 1 nipple
- Compression valves cannot be purchased separately but may be placed in most Dr. Brown's bottles
- \$7 or \$10 on Amazon



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Positioning for Bottle Feedings

- Babies with cleft palate often benefit from being fed in an upright position
- Allows gravity to assist in reducing pharyngonasal reflux
- Observe feeding in the position that is most comfortable for the parent and adjust as needed

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Regulated Pacing

- Regulated/External pacing is most effective when the nipple is removed from the baby's mouth.
- Tilting the bottle down/to the side will result in compression of the nipple and inadvertent expression of the liquid
- Rest the nipple on the baby's lower lip so baby knows it's still there

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Cleft Bottle Tips

- Open cleft bottles over a bowl, cup, or sink if milk remains
- Remind families to keep a tight hold on the 1-way flow valves when washing bottles. They can slip down the drain quickly and make feeding a challenge!
- When families replace worn out nipples, save the valves!
- Bottles with tighter collars will flow slower; to increase the flow rate, loosen the collar.
- If a nipple collapses, loosen the collar. If it still collapses, try cleaning the venting system.

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Cleft Bottle Tips

- Show families how to disassemble the bottle for cleaning. Bottles can become germ havens if not cleaned properly!
- Bottles will only be successful if the parent feels comfortable using it. Provide consistent education, encouragement, and guidance!
- There are lots of recommendations for parent modified bottle systems on the internet - make sure you know what system your child is using.
- If a baby will be going to daycare, encourage the family to do a feeding or two at the daycare before drop off day. This will help daycare workers feel more comfortable with an unfamiliar bottle system.

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Specialty Bottles

- Cleft-specialty bottles may be purchased from:
 - www.amazon.com
 - The manufacturer's website
 - Via customer service with the manufacturer
- There is no retailer that sells cleft bottles locally

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The Palatal Obturator: A Fix for Feeding?

- A palatal obturator will **NOT** create suction
- A palatal obturator CAN make feeding more efficient
- A palatal obturator MAY change SSB coordination

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Feeding & Problem Solving with the MSNF

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Feeding & Problem Solving with the DBSFS

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Breastfeeding with a Cleft

- Similar concerns to typical bottle feeding:
 - Poor contact between soft palate and pharyngeal walls (Reilly et al., 2013)
 - Insufficient separation between nasal and oral cavities during feeding resulting in poor suction (Maserai et al., 2007)
- Lower rates of breast feeding success when compared to non-cleft peers (Miller, 2011)

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Breastfeeding with a Cleft

- Garcez & Guigliani (2005):
 - Infants born with cleft lip only were breast fed for similar lengths of time as their peers born without cleft lip
 - Infants born with cleft lip only were breast fed in greater numbers and for longer durations than infants with CLP or CP
 - Some infants with small soft palate clefts or sub mucous clefts were successful breastfeeders
 - Babies born with CP or CL&P had difficulty latching to the breast, weak suction, nasal regurgitation, choking, and poor weight gain

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Breastfeeding with a Cleft

- Alperovich, M., et al. (2017):
 - Parents who were counseled about feeding were more likely to use breast milk
 - Infants with CL&P had lower rates of breast milk feeding compared to babies with cleft lip only
 - Families of babies with clefts are giving breast milk for longer periods of time and as a larger portion of the baby's diet than they were in previous years
 - Still fall short of their non-cleft peers

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Breastfeeding with a Cleft

- Involve Lactation
 - Take pre & post weights
 - Encourage skin-to-skin contact
 - Encourage non-nutritive time at the breast
 - Supplement time at the breast with bottles of expressed breast milk

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Breastfeeding with a Cleft

- Encourage pumping of mom's breast milk
 - Exclusive pumping can be a burden to many families
- Shift the focus from "how" to "what" the baby is fed
- Believe that **fed is best!**

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Introducing Solids

- For infants born without identified pharyngeal dysphagia, introduction and progression of solids occurs in a developmentally appropriate manner
- Solids may have to be halted for surgeries
 - Do **NOT** wait until after palate repair to begin introducing solids
- Infants with identified pharyngeal dysphagia require individual assessment by a skilled provider prior to introduction of solids

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When to Start Baby Foods

- Usually around 6-months of age
- Pediatrician OK
- Holds head up independently
- Can sit in a supported upright position
- Loss of tongue thrust
- Adequate weight gain
- Curious about foods

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Starting Baby Foods

- Use a flat, soft spoon that is easy for baby to close lips around
- Dip the tip of the spoon in the baby food and present to baby's top lip
- Wait for baby to open mouth and close lips around the spoon
- Try to avoid "scraping" the food into baby's mouth

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Starting Baby Foods

- High chair, booster seat, or feeder seat
 - Adequate trunk and head support
 - Able to secure properly
 - Tray for self-feeding
- If baby doesn't open mouth or seems upset by baby food trial, wait a week and try again
- Wait until baby is done eating to clean up

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Pharyngonasal Reflux

- This is **common** for a baby with a cleft palate and may be more likely to occur with baby foods than with bottle feedings
- Does not mean the baby is choking
- Usually does not increase aspiration risk or respiratory complications
- Babies often sneeze to clear residue
- Often diminishes after palate repair, but may not completely disappear for several months/years

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Advancing Solid Foods

- Breastmilk or formula remains the primary nutrition source until 12 months corrected age
- Discourage families from offering "only purees" until after palate repair
 - There are valuable skills to learn now!
- Advance in a developmentally appropriate manner

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Baby Led Weaning

- Consider the baby's specific developmental milestones
- Follow baby's cues
- Respect family's wishes
- Isolated CP or CL&P should not preclude baby's participation in BLW

HOWEVER...

- Will need to introduce spoon feeding with purees to prepare for post-palate repair restrictions

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Cup Drinking

- Cup drinking is often introduced earlier for babies with cleft palate due to feeding demands after surgery
 - begin practice 2-3 months before surgery
- Rimmed, free-flow cups or open cups work best
- Take out the no-spill valves
- Absent suction will prevent straw or no-spill cup drinking for babies with open cleft palates
- Avoid playing "musical cups"

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Suggestions for Cups

Travel
Coffee
MugsZak!
Toddler
Perfect FloAvent
360 No-spill*

Reflo

Can try an open cup or other rimmed free-flow cup.
AVOID spouted cups, straw cups, or no-spill cups.

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Time for Surgery

- Lip repair ~3-5 months of corrected age
- Palate repair ~9-12 months of corrected age
- Timing may be impacted by a variety of factors
 - Co-morbidities
 - Nutritional status
 - Family demands

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Preparing for Lip Repair

- Have established:
 - Functional feeding system
 - Adequate growth - positive growth trends
 - Stable pulmonary health
 - Good nutrition

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Feeding After Lip Repair

- Restrictions vary by surgeon & center
- The family should discuss specific feeding precautions their surgeon advises after surgery
- Often wear arm restraints or "no-nos" for 3-6 weeks after surgery
- Pacifier?

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Feeding Tips after Lip Repair

- Try to offer nipple on side opposite of cleft (if tolerated)
- May notice increased efficiency after lip repair
 - May need to adjust flow rate or bottle to help baby remain organized
 - Don't make "anticipatory changes"
- Reassess feeding skills 2-3 weeks after repair

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Feeding After Palate Repair

- Craniofacial teams often have specific feeding restrictions that are put in place after palate repair
 - No bottles or pacifiers
 - Liquids and thin, smooth purees only
 - Open or rimmed free-flow cups
- Goal of feeding restrictions is to maintain the integrity of the repair until it is healed
- Make sure the family knows the restrictions from their team & practice in therapy before repair

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Preparing for Palate Repair

- The best way to avoid feeding problems after the palate repair is to adequately prepare before the palate repair
- Begin practice with open cup or free flow sippy cup around 7 months of age (sooner or later depending on surgery timing)
- Practice with formula or EBM in the cup
- Offer cup at the same time as puree feedings, before bottle feedings
- Maintain spoon practice with purees

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Spoon Feeding after Surgery

- Side spoon feeding
 - Flat spoon (Gerber)
 - Prevents baby from "leaning into" the spoon
 - Child relies heavily on parent assistance due to arm restraints

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Tender Care Feeder

- Soft, squeeze bottle with long, soft, flexible tube tip
- Can be used "in a pinch" when having trouble transitioning to cup after palate repair or bottle after lip repair
- Place tip laterally in the mouth
- Let liquid drip or provide a gentle squeeze
- Tip can be trimmed shorter
- Not a long-term solution



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Problem Solving



- Manage pain
- Manage constipation
- Try different temperatures of liquid/purees
- Use distractions during meal times
- Smaller, more frequent meals
- Hold baby during the feeding
- Try adding liquid formula to the baby foods
- Baby foods and Pedialyte assist in hydration but don't provide much nutrition

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Problem Solving



- Still having troubles? The family should call their Craniofacial Team to discuss options.
- SLP can assess for alternate feeding methods
- RD can assess nutritional options
- MD can assess for dehydration concerns and stage of healing

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“All clear!”

- Usually released from feeding precautions 6-weeks after palate repair
- Resume developmentally appropriate solids
- Encourage straw cup drinking (vs. no-spill sippy cup)
- Re-establish desirable meal/snack structure
 - Scheduled family meals
 - In high chair/booster seat
 - Free from distractions

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When it's more than “just a cleft...”

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Non-syndromic Clefts

- Non-syndromic CP or CL&P:
 - Oral dysphagia
 - Degree of clefting often corresponds to the degree of oral dysphagia
 - HOWEVER, even small soft palate clefts can disrupt typical bottle and breast feeding attempts
 - In the absence of neurologic, cardiac, or respiratory co-morbidities, babies with cleft lip and palate should arouse to an alert state and demonstrate typical feeding cues in the neonatal period
- Normal pharyngeal phase

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Syndromes, sequences, and Associations & Feedings

- Clefts occurring with a syndrome, sequence, or association may present both oral and pharyngeal dysphagia
 - Cranial nerve involvement
 - Respiratory compromises
 - Cardiac compromises
 - Neurologic concerns
- More likely to require some tube feeding support (Freitas et al., 2018)
- Identification of persistent pharyngeal dysphagia in babies with clefts may prompt further referral

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Syndromes, sequences, and Associations & Feedings

- Pierre Robin Sequence (respiratory compromises, cleft palate)
- Stickler's syndrome (PRS + cleft palate, significant vision impairments)
- 22q11.2 Deletion Syndrome (cleft palate, VPI, heart defects, hypotonia, laryngotracheal abnormalities)
- CHARGE association (choanal atresia, cranial nerve abnormalities, cardiac defects, cleft lip)
- Goldenhar syndrome (orofacial cleft, facial nerve weakness, limited jaw range, unilateral velar paresis, cleft palate)
- Fetal Alcohol Spectrum Disorder (neurologic involvement, orofacial cleft)

(Miller, 2011)

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Aspiration

- Presence of a cleft lip and palate does not, by its existence, increase the risk of aspiration
- Associated syndromes, sequences, or other conditions resulting in respiratory or neurological concerns may increase risk of aspiration
- VFSS/FEES may be completed if there are concerns for aspiration

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Concerns for Aspiration

- Poor growth despite adequate calorie intake
- Poor feeding cues
- Refusal of feedings
- Persistent distress cues
- Prolonged feeding times
- Wet/gurgly vocal quality
- "Shutting down"
- Cough/sputter
- Stridor or wheezing
- Increased work of breathing
- Desats/apnea/bradycardia
- Increased oxygen needs

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Considerations

- Thickening may be difficult with cleft-specialty bottles
- Slowing flow rate can create efficiency concerns
- Positioning changes and compensatory strategies may be helpful
- Supplemental NG feeds may be beneficial
- Purees may be better tolerated than liquids

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Tube Feedings

- Nasogastric Tubes (NG) or Orogastric Tubes (OG)
- OG/NG-tubes enter the body through the mouth or nose and run down the esophagus into the stomach.
- Non-surgical, most temporary
- Babies may pull tubes out especially as they get older
- May create/worsen feeding aversions in older babies
- Can continue oral feeds if medically appropriate

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Tube Feedings

- G-tube
- Surgically placed through the abdominal wall into the stomach
- More secure than NG/OG placement
- Longer-term supplemental/alternative nutrition needs
- Not permanent - can be removed in clinic or the OR (depending on tube type)
- Can continue oral feeds if medically appropriate

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Helping Families Manage Tube Feedings

- Tube feeding only plans (No PO)
- Pacifier dips if tolerated and developmentally appropriate
- Hang feeding and hold baby during tube feedings
- Place in high chair and play with toys or purees if developmentally & medically appropriate
- Encourage social interaction during tube feedings
- Give tube feedings during family meal times

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Helping Families to Manage Tube Feedings

- PO/tube feeding plans
- Offer PO prior to tube feedings
- If developmentally appropriate, encourage high chair during tube feedings
- Encourage child to engage in family meal times
- Offer a variety of preferred & new/less preferred foods as appropriate

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Weaning from Tube Feedings

- Consider information gained from any instrumental assessments
- Introduce and advance cup drinking skills
- Assess and advance oral motor skills with food-based activities
- Engage in frequent, skilled feeding therapy
- Positive food interactions
- Family involvement

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Weaning from Tube Feedings

- Work with MD and RD to monitor nutrition, weight, and pulmonary health as oral intake increases
- Is the child able to consistently and safely take all nutrition and hydration by mouth over an extended period of time
 - When sick?
 - On the weekends?
 - At daycare?
- Encourage the family to discuss their options with the MD

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Online Support

- Despite clefting being a common condition, many families don't know anyone else affected by a cleft
- Families may turn to the internet for guidance and support
 - The good, the bad, and the outrageous
- Encourage families to discuss ideas they find on support groups with you before making changes
- Steer families to credible sources
 - www.cleftline.org
 - Their Craniofacial team!

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Take Home Points

- Feeding with cleft lip may proceed without concern, but babies should be monitored closely in the first weeks of life
- Feeding is often the biggest challenge for a baby born with a cleft palate due to poor suction strength
- Breast feeding can be difficult for babies born with a cleft palate, but be creative in thinking of other ways to encourage that bonding between mom and baby

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Take Home Points

- Specialty bottles can be invaluable in developing a functional infant feeding plan
- Babies should still meet the typical neonatal feeding benchmarks of efficient and sufficient feedings
- Babies with syndromic CL&P may have additional feeding concerns 2/2 neurologic, respiratory, or cardiac concerns
- In the absence of pharyngeal dysphagia, solids may be introduced in a developmentally appropriate way

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Take Home Points

- Nasal regurgitation is common and most often not a reason to discontinue oral feedings
- Families should contact their craniofacial team to clarify any questions regarding feeding precautions that may be in place after surgeries. There are often significant restrictions following cleft palate repairs. **It is always better to ask than to be sorry!**
- Consistent practice with cup drinking before palate repair is the best way to ensure sufficient feeding after surgery.

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Concerns? Questions?

- Email is the easiest way to get in touch with me
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- Phone works too, but kindly follow-up with me if you don't hear back!
 - 317-948-2755

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