National Pediatric Cardiology
Quality Improvement Collaborative

Promoting Positive Oral Eating/Mealtime Experiences
For Providers

Key Points:

- Discussions related to feeding between caregivers and medical providers is recommended as early as possible (e.g., at time of CHD diagnosis, even if this is prenatal). Explore parents' hopes and expectations along with providing parents with education around common feeding pathways for babies with complex CHD.
- Promotion of Positive Oral Experiences begins at birth and can help to reduce tube dependency.
- Provide caregivers with very clear signs to look for in their child that indicate the child is uncomfortable with the oral experience and stop oral exposure when those signs are displayed.
- Throughout this document we will reference Readiness/Not Ready Cues (see below).
- Provide caregivers with specific methods for providing positive oral experiences at all stages of the CHD feeding journey both before and after a feeding tube is placed.

FEEDING READINESS CUES: baby is in a quiet/alert state, appropriate color, good tone/flexion, able to make eye contact, bringing hands to mouth and/or hands to midline, rooting behaviors, good suck on pacifier or ability to latch and suck on a clean finger, not showing aversive responses to oral stimulation. The older baby will look at the bottle or spoon as it is presented and not avert their gaze or turn away.

FEEDING NOT READY CUES: baby is sleeping or crying, inappropriate coloring, poor tone/flexion, averted gaze, splayed hands, no rooting responses, hiccoughs, sneezing, yawning, or 'shutting down' behaviors. The older baby will turn away or avert their gaze when the bottle or spoon are presented.

Newborn/Presurgical -

- Discuss your feeding goals with parents before their baby is born. Offer prenatal lactation support/education before birth if possible when their desire is to provide human milk.
- If the goal is to breastfeed and/or provide human milk, support moms to start pumping as soon as possible after the baby is born.
    - Schedule meeting with a lactation consultant or lactation counselor as soon as possible.
    - Goal is to pump 8-10x per day to establish milk supply.
    - A lactation consultant can help get a pump for the hospital room and possibly an additional pump for home. Generally, hospital-grade, double electric pumps are recommended to establish a good milk supply for the hospitalized baby.
    - Families should keep a pumping log to closely monitor progress.
    - Additionally, placing baby skin to skin (e.g., Kangaroo Care) and breastfeeding if deemed safe by the cardiology team, especially during the first few days before the mother's milk fully comes in, can help with milk production.
    - If the baby is safe for oral trials but intake volume is a concern, the baby can also be encouraged to latch after the mother has finished pumping.
- The use of a pacifier at the time of birth is recommended and commonly utilized to help establish sucking skills. Babies with complex CHD may not have the endurance to fully breast or bottle feed early on, and the pacifier can help strengthen sucking skills and provide comfort.
    - The choice of pacifier and bottle nipple will be individualized for each baby pending their unique oral-motor needs. A feeding therapist should be consulted.
    - Additionally, parents can be encouraged not to purchase bottles prior to birth because the hospital team will engage in continued evaluation for the best consumption device.
- If the baby is stable and approved by the medical team, support parents to hold their baby skin to skin. Provide oral stimulation with a pacifier when the baby is alert and showing any feeding readiness cues. Use fresh colostrum for oral cares and stimulation by placing drops on the pacifier or a swab.

- If the baby is stable and approved by the medical team, offer small feedings (mother's own milk or donor milk is recommended). This practice will vary across institutions.
    - Preoperative feeding can be done through breastfeeding or using a bottle. Slow flowing bottle nipples are recommended (e.g., Dr. Brown's Ultra Preemie or Preemie).
    - If the baby is only allowed very limited amounts, support mom to bring her to the breast after pumping.

Post first stage palliation -

- Educate the family to provide positive oral stimulation opportunities while their baby is weaning from respiratory support. Again, this can vary between institutions. If nasally intubated, the pacifier can be used if the baby is demonstrating readiness.
- Once stable and approved by the medical team, encourage parents to hold their baby frequently. Provide positive oral stimulation while holding the baby.
- Offer further lactation support if the family's goal is to breastfeed or provide breast milk.
- If the baby is not yet ready for oral feeding, continue to provide positive oral stimulation when they are awake and showing readiness. The pacifier can be dipped in breastmilk or formula to offer small tastes.
- Once the baby is ready for oral feeding, ask for a feeding therapist evaluation if they are not already part of the care team.
- Discuss with the family plans for feeding advancement and what to expect (e.g., will they have a nasogastric feeding tube, how will volume be given, can they try to orally feed their baby before the tube feeding is given, how often will oral feedings be offered).
- Consider the possible complications that could hinder feeding advancement (e.g., vocal cord paresis, feeding intolerance, reflux). Make sure that a feeding therapist is consulted as early as possible in the child's feeding journey so that input related to possible complications can be offered readily.
- If the child is experiencing a high level of discomfort around tube feedings (e.g., vomiting, gagging, retching), consider the impact that the tube is having and ways to adjust the tube feeding. Techniques such as position adjustments, reduced

speed of feedings, feeding schedule adjustments, pauses in feedings (e.g., to encourage burps), as well as volume reductions may be helpful.

Discharge with a feeding tube and beyond-

- Ensure that the family has a plan to continue to provide positive oral experiences and normalize tube feedings as much as possible.
    - A typical newborn will eat every 2-3 hours in the first couple of months of life. They then progress to larger volume feeds every 3-4 hours by 2-3 months of age. Volume of feedings and time between feedings vary significantly and the baby can tell their caregiver when they are ready to eat by their hunger cues.
        - For infants with complex congenital heart disease, tube feedings can take away normal feelings of hunger. Based on how the baby tolerates their tube feedings, nutrition can be given by bolus or continuous (or a combination) feedings.
    - If on continuous feedings or bolus feedings and <u>not</u> safe to orally feed (i.e., aspiration concerns), continue to provide oral stimulation several times per day.
    - It is important to 'ask' the baby if it is a good time. This can be done by providing touch to the baby's face, and slowly moving toward their mouth. Watch their facial expressions and 'feel' what their bodies are telling you.
    - Do they feel safe or do they seem stressed by this touch? If they feel safe, progress to touch their lips, rub their gums, and stroke their tongue to elicit sucking on the pacifier or a clean finger. Dip the pacifier or clean finger in milk/formula to offer small tastes. If they seem stressed by this touch and/or are showing 'not ready' cues, help them to bring their own hands to their mouth for exploration.
        - If they are comfortable with their own hands, you can place drops of milk on their fingers to allow for small tastes. Work toward offering frequent opportunities for sucking and getting tastes of milk.
    - If on continuous feeds and safe for some oral feeding, consider letting the baby have a couple of hours per day with the tube feedings off to potentially promote some hunger.

        - One example would be to run the continuous feeds 20 hours per day, but have 2 hours off during the morning, and 2 hours off in the evening.
        - Watch the baby for hunger/feeding cues while the feeds are off and offer the breast or bottle according to their behaviors. Goal of these feeds are for pleasure and practice versus volume.
        - If the baby is not able to have time off of their continuous feedings, watch for any hunger cues and provide oral stimulation or small oral feedings on top of the continuous feedings. Consider pausing the continuous feedings briefly when the baby is showing feeding readiness for oral intake.
    - If on bolus feeds and safe for some oral feeding, the family can offer the breast or bottle prior to bolus feedings. The volume taken orally can often then be deducted from the bolus volume. Again, always follow the infant's cues and do not 'push' them to accept oral feeding if they are telling you they are not ready. If the baby is not able to accept oral feeding prior to the bolus, encourage the family to continue to hold their baby and offer oral stimulation as tolerated during the bolus feeding.
        - Signs that the baby is not ready for oral feeding attempts include visually avoiding (turning away from) the bottle or breast, crying/whining, coughing, gagging, arm flailing or hand splaying, color changes, hiccups, sneezing, respiration/breathing, sleepiness, and vomiting. If the baby gets to the point of gagging and/or vomiting, or needing to fall asleep to finally accept the nipple, they have been pushed too much.
        - The key is to make the baby feel safe around eating and any oral experiences. If they are fed by a tube, there is a good chance that they will not feel hunger and may refuse attempts to offer oral eating. The primary goal is for all feeding experiences to be safe and pleasurable.
        - If the baby shows any of the 'not ready' signs noted above, make sure to stop offering the breast, bottle or spoon. While the child is still receiving nutrition from a feeding tube, it is very important that they are not 'pressured' to eat orally in any way. When the child is ready for

tube weaning, it will be an easier process if they have already felt pleasure and safety with oral eating.

For the older baby with a feeding tube -

- Educate the family to bring the baby to the family table for meals. Let them be present to experience all of the sounds, sights, smells and social interactions that accompany a family meal. If safe, let them have some food on a highchair tray to touch and explore. Offer tastes of age appropriate foods if safe.
- Try to coordinate the child's bolus feeding with the time that the family is eating or having a snack. Help the child connect any feelings of hunger with a positive oral experience. As the bolus feeding is running, the child will move from feeling hungry to feeling full. They will associate positive oral experiences and their observation of family eating with their overall experience of being fed.
- Continue to provide non-feeding positive oral stimulation several times per day. Offer a variety of teething toys to explore. Provide hands-on touch to the child's cheeks, lips, and inside their mouth. There are a variety of textured tools that can be used for this (nuk brush, infadent, Z-Vibe). The feeding therapist can provide an oral stimulation program specifically designed for the child.
- Oral care or toothbrushing can also be a wonderful opportunity for oral stimulation. When the baby's mouth is still a gummy smile, the family can use a wet soft cloth or finger brush with water to gently rub their gums. This can help remove bacteria and will get them used to having their mouth brushed. As soon as teeth begin appearing above the gum line, it is recommended that parents brush their child's teeth at least twice per day.
- Because of the negative sensory experiences that are often a part of an intensive care environment (pain, unexpected cares while sleeping, intubation and suctioning needs, tube placement/replacement, etc.), the child may have an aversion to touch to their face and mouth. Look at what they are comfortable with and then slowly progress from there. For example, if they take a pacifier and put their hands in their mouth but are upset with other touch to their face, try to offer small tastes of milk or puree foods from their own fingers. As they are holding onto toys, slowly help them to bring the toy to their mouths in order to accept a wider variety of touch and texture. With any of these oral stimulation experiences, it is important to

help them to expand their acceptance, but ‘pushing’ them will often result in more aversion.

- Continue to provide supportive feeding therapy so that bolus or continuous feedings can be adjusted appropriately if the child starts accepting more liquids and solids orally.
- Always follow safe feeding, developmentally appropriate guidelines for advancing oral feeding skills.