National Pediatric Cardiology
Quality Improvement Collaborative

Promoting Positive Oral Eating/Mealtime Experiences For Parents

Key Points:

- Talk to your cardiology team as early as possible (e.g., at time of CHD diagnosis, even if this is prenatal). Discuss your hopes and expectations, and ask for education around common feeding practices for babies with complex CHD.
- Providing Positive Oral Experiences begins at birth and can help to reduce feeding tube dependency.
- Your baby can communicate a lot through their behavior. Learn about infant Ready/Not Ready behaviors that can tell you when your child is comfortable or uncomfortable with oral experiences. Throughout this handout we will reference Readiness/Not Ready Cues (see below).
- Learn about 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, able to make eye contact, bringing hands to mouth and/or hands together, turning their head and opening mouth when their cheek or the corner of their mouth is touched (rooting), and good suck on pacifier. The older baby will look at the bottle or spoon as it is presented.

FEEDING NOT READY CUES: baby is sleeping or crying, turning their eyes away, widely opened or 'stop sign' hands, no rooting responses, hiccoughs, sneezing, yawning, or 'shutting down' behaviors (closing their eyes, falling asleep). The older baby may push back or turn away when the bottle or spoon are presented.

Newborn/Presurgical -

- Discuss your feeding goals with your partner and cardiology team before your baby is born.
- If your goal is to breastfeed and/or provide human milk-
    - start pumping as soon as possible after your baby is born.
    - Request to meet with a lactation consultant or lactation counselor.
    - Goal to pump 8-10x per day to help your milk come in and build your milk supply.

    - Additionally, placing baby skin to skin (e.g., Kangaroo Care) and breastfeeding if the cardiology team says it is ok, especially during the first few days before the mother's milk fully comes in, can help with milk production.
    - If your baby is safe to try breastfeeding but the cardiology team needs to limit the amount they can drink, you may be able to bring them to breast right after you have pumped.
- Use a pacifier to help with your baby's sucking skills. Babies with complex CHD may not have the energy to fully breast or bottle feed early on, and the pacifier can help your baby with their sucking skills.
    - The choice of pacifier and bottle nipple will be individualized for each baby based on their unique oral-motor needs. A feeding therapist should be consulted.
    - Additionally, parents do not need to purchase bottles prior to birth because the hospital team will help you decide what works best for your baby before you leave the hospital.
    - If your baby is stable and approved by your medical team, hold your baby skin to skin.
    - Provide oral stimulation with a pacifier or your clean finger when your baby is showing feeding readiness cues. Use your fresh colostrum for oral cares and stimulation by placing drops on the pacifier or a swab.

- If your baby is stable and approved by your medical team, offer small feedings (mother's own milk or donor milk is recommended).
    - Slow flowing bottle nipples are recommended (e.g., Dr. Brown's Ultra Preemie or Preemie).
    - If your baby is only allowed very limited amounts, ask your team if you can help bring them to the breast after pumping.

Post first stage palliation -

- Talk to your bedside nurses about how you can provide positive oral stimulation opportunities while your baby is still needing breathing support.
    - If nasally intubated, the pacifier can be used if your baby is showing readiness behaviors.
- Once stable and approved by the medical team, hold your baby frequently.
    - Ask often and daily if skin to skin holding can be done. Provide positive oral stimulation while holding your baby.

- If your baby is not yet ready for oral feeding, continue to provide positive oral stimulation when they are awake and showing readiness. The pacifier or your clean finger can be dipped in breastmilk or formula to offer small tastes.
- Once your baby is ready for oral feeding, ask for a feeding therapist evaluation if they are not already working with you.
- Talk to your medical team about plans for feeding advancement and what to expect (e.g., will they have a nasogastric feeding tube, how will the milk be given, can you try to orally feed your baby before the tube feeding is given, how often will oral feedings be offered).
- Consider the possible complications that could make feeding difficult (e.g., vocal cord paresis, feeding intolerance, reflux). Make sure that a feeding therapist is consulted as early as possible in your child's feeding journey to help support you and your baby if there are any complications.
- If your baby is having a lot of discomfort around tube feedings (e.g., vomiting, gagging), talk to your medical team about 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 decreasing the volume may be helpful.

Going home with a feeding tube and beyond-

- Work with your team to make 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 bigger feeds every 3-4 hours by 2-3 months of age. The size of feedings and time between feedings can be different for every baby and can be different at different times per day.
    - Normally, 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 your baby tolerates their tube feedings, nutrition can be given by bolus (a tube feeding that is given like a meal several times per day) or continuous (feeding is slowly given over an extended period of time), or a combination of bolus and continuous 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' your baby if it is a good time. This can be done by

providing touch to your 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, ask your team if your baby can have a couple of hours per day with the tube feedings off to help them feel hungry. 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 your 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 your 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. Ask your team if the continuous feedings can be paused briefly when your baby is showing readiness behaviors for small oral feeding experiences.
- If on bolus feeds and safe for some oral feedings, offer the breast or bottle prior to bolus feedings. The amount taken orally can often then be subtracted from the bolus volume. *Again, always follow your infant's cues and do not 'push' them to accept oral feeding if they are telling you they are not ready.*
- If your baby is not able to accept oral feeding prior to the bolus, continue to hold your baby and offer oral stimulation as tolerated during the bolus feeding.
- Signs that your baby is not ready for oral feeding:
    - attempts include visually avoiding (turning away from) the bottle or breast, crying/whining, coughing, gagging, hiccups, sneezing, sleepiness, and vomiting. If your 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 your 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 your attempts to offer oral eating. The primary goal is for all feeding experiences to be safe and pleasurable.
- If your baby shows any of the 'not ready' signs noted above, make sure that you stop offering the breast, bottle or spoon. While your child is still receiving nutrition from a feeding tube, it is very important that you do not 'pressure' them to eat orally in any way. When your child is ready for tube weaning, it will be an easier process if your child has already felt pleasure and safety with oral eating.

For the older baby with a feeding tube -

- Bring your 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 your child's bolus feeding with the time that the family is eating or having a snack. Help your child connect any feelings of hunger with a positive oral experience. As the bolus feeding is running, your 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 your 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). Ask your feeding therapist for an oral stimulation program specifically designed for your child.
- Oral care or toothbrushing can also be a wonderful opportunity for oral stimulation. When your baby's mouth is still a gummy smile, you 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 you brush your child's teeth at least twice per day.

- Because of the negative oral experiences that are often a part of an hospital environment (pain, unexpected cares while sleeping, intubation and suctioning needs, tube placement/replacement, etc.), your child may have an aversion to touch to their face and mouth. Look at what your child is 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.
- Work closely with your feeding team so that bolus or continuous feedings can be adjusted appropriately if your child starts accepting more liquids and solids orally.
- Always follow safe feeding, developmentally appropriate guidelines for advancing oral feeding skills.