Section 3: Parent Engagement and Collaboration

Parent Frequently Asked Questions

Which medical professionals can I expect to be working with in regards to feeding, and what are their roles?

Usually, the team involved with feedings consists of the following people:

- **Dietitians**: Will help your baby's growth through all the stages of the surgeries.
- **Lactation consultant**: Will work with mom to establish and improve milk supply, provide education with pumping, and help with direct breastfeeding.
- **Feeding therapist**: Will usually assess your baby's oral skills to be sure they are swallowing safely. They will assess your baby's latch to the breast or help bottle-feed. *This could be an occupational therapist, speech-language pathologist or physical therapist depending on your hospital staff.*
- **Bedside nurse:** Will help assess feeding cues and assist with feeding as needed.
- **Cardiologist, ICU physician, nurse practitioner or surgeon**: Will decide if baby is medically stable for oral feeding.

What are some reasons my child might not be allowed to eat before surgery? How will medical staff determine if my child can safely eat?

Babies with cardiac conditions such as HLHS may be at **heightened** risk of developing necrotizing enterocolitis (NEC - see below), possibly due in part to the low gut perfusion they may experience *(meaning that their bodies are often not able to allocate enough oxygen to gut function)*. However, this does not appear to be directly related to oral feeding. The multidisciplinary team taking care of your baby will assess your baby daily and will decide whether feeding is safe. Some cardiac conditions have higher risk for developing NEC than others. NEC is a complex condition, the exact causes of which are not fully understood. Even so, some babies may be permitted to orally eat by breast or bottle, allowing them to regulate themselves, eating if they feel well or refusing if they don't feel well.

Hospital staff may utilize a guide such as this one in order to determine if your baby is ready to eat:

Resource:https://cchmc.sharepoint.com/:b:/r/sites/OralFeedingToolkit/Shared%20Documents/General/KDD%20Intervention%20Strategies/NPC%20QIC%20Feeding%20Flyer%20(5).pdf?csf=1&web=1&e=KehXMm

Hospital staff will watch your baby carefully to determine if they are showing signs of distress, indicating a greater severity of illness. Staff will also evaluate additional risk factors and barriers to feeding. Some of these things include:

- Unstable heart rhythm (arrhythmia)
- Inadequate blood flow (cardiac output)
- Seizures
- If baby does not exhibit signs of feeding readiness
- Differences in baby's digestive system (gastrointestinal abnormalities like a narrowing in the esophagus or duodenum), differences in facial formation (ex. cleft palate)
- Increasing measurements around baby's stomach
- Excessive vomiting or diarrhea
- Blood in baby's stool
- Signs of necrotizing enterocolitis (NEC)
- Too much lactic acid in the blood (determined by blood test)
- Signs that your baby is not swallowing effectively – such as if milk is entering their lungs (aspiration)
- If milk is spilling out the sides of your baby's mouth during feeding
- If your baby is coughing/choking/sneezing or has red/watery eyes

Each hospital has different protocols with regard to feeding. Please ask your care team what feeding pathway they follow.

Parent Experience: In our case, we were told at our prenatal appointments that we wouldn't be able to feed because of the risk of NEC (necrotizing enterocolitis). It seemed to be a matter of hospital policy, though later I was told that wasn't the case. After my son was born, I was too scared to even ask about feeding him. - Rachael

Parent experience: We thought we couldn't feed but it was a matter of asking and getting approved by the team. - Sara

What if I cannot be at the hospital constantly with my baby? Who will handle feeding opportunities, and how? Aside from being at the hospital as much as possible, how can I improve the chances that I'll have an opportunity to help with feeding?

The cardiac/cardiovascular intensive care unit (CICU or CVICU) team and specifically the dietitian and feeding therapist will advocate for your baby's feeding opportunities during "rounds" – the daily morning meeting where all members of your care team discuss your baby's current needs and goals and formulate a plan for the day's treatment – since there are so many benefits associated with oral feeding prior to and after surgery. Parents are encouraged to advocate for feeding opportunities during rounds too! The CICU/CVICU team will be in touch with parents daily if they are not able to be present in rounds to work together regarding a feeding plan.

Parents should not be afraid to be proactive in approaching the care team in order to create a plan where they can be involved. Parents can also usually call the hospital for an update, to check on rounds and the goals for the day, and to discuss when they might be able to be present for a feeding opportunity.

Many facilities will have standing orders for the feeding therapist (OT, SLP, or PT) to assess your baby shortly after they are born to determine safety for oral feeding, help you to feel comfortable holding or providing positive touch, and educate you on your baby's "I'm ready" or "I'm stressed" behavioral cues. Your care team should work with you on an oral feeding plan and developmental needs in the cardiac/cardiovascular intensive care unit. Your oral feeding goals are important: your care team should ask you about them, but if not, you should feel free to approach them and communicate your wishes. It is best if the first oral feeding in particular can be with mom or dad. Many times, your baby can go to breast and/or take milk from a bottle even in the preoperative period if showing oral feeding readiness cues (and as long as they are hemodynamically stable).

What is NEC and why do people talk about it so much?

NEC is an abbreviation for Necrotizing Enterocolitis. NEC is a serious intestinal disease that is caused by many factors. Many babies born with congenital heart defects are particularly at risk for this, one being that they have altered "gut perfusion", meaning they often have less blood distribution to the gut. This can cause the mucosal barrier of the gut to be damaged, which can then be breached by bacteria leading to intestinal injury. In severe cases this can in turn lead to bowel necrosis, sepsis, and even death. You can read more about it here: Necrotizing Enterocolitis (cincinnatichildrens.org) and in the resources below.

Parent experience: We dealt with a lot of NEC issues post-operatively but it was never brought up before his Norwood surgery. The doctors deemed he was stable enough to feed but was monitored closely after he ate. - Sara

How confident can I be that preoperative feeding does not correlate significantly with the risk of NEC?

Below is a list of resources that medical professionals cite and refer to regarding the safety of feeding. They present an overwhelming body of research showing that feeding preoperatively is in most cases safe. There are a lot of factors that are evaluated in each individual decision to allow feeding or not (see above), and unfortunately some babies still suffer from NEC. However, it is not as common as previously believed, and there is not a clear connection between feeding preoperatively and NEC.

In a study (Sagiv et al 2022; Kataria-Hale et al 2019; Scahill et al 2017) of 1,740 infants with different preoperative feeding courses and completion of their first surgery, there was no statistically significant difference in NEC among babies who were fed versus those who were not. Rather, NEC was associated with the level of severity of illness and what happened to them after surgery. Medical professionals believe that the benefits of feeding outweigh the risks of developing NEC.

Resources:

Preoperative Trophic Feeds in Neonates with Hypoplastic Left Heart Syndrome
Preoperative Feeding Neonates with Cardiac Disease
Preoperative Feeds in Ductal-Dependent Cardiac Disease: A Systematic Review and Meta-Analysis
Human Milk Use in the Preoperative Period is Associated with a Lower Risk for Necrotizing Enterocolitis in Neonates with Complex Congenital Heart Disease
The Relationship between Preoperative Feeding Exposures and Postoperative Outcomes in Infants with Congenital Heart Disease
Necrotizing Enterocolitis and Associated Mortality in Neonates with Congenital Heart Disease: A Multi-Institutional Study
A Preoperative Standardized Feeding Protocol Improves Human Milk Use in Infants with Complex Congenital Heart Disease
Necrotising Enterocolitis in Infants with Congenital Heart Disease: the Role of Enteral Feeds
Enteral Feeding in Neonates with Prostaglandin-Dependent Congenital Cardiac Disease: International Survey on Current Trends and Variations in Practice
Reducing the Incidence of Necrotizing Enterocolitis in Neonates with Hypoplastic Left Heart Syndrome with the Introduction of an Enteral Feed Protocol

Low Risk of Necrotising Enterocolitis in Enterally Fed Neonates with Critical Heart Disease: an Observational Study
Nutrition Considerations in the Pediatric Cardiac Intensive Care Unit
Randomized Clinical Trial of Preoperative Feeding to Evaluate Intestinal Barrier Function in Neonates Requiring Cardiac Surgery
Factors Associated with Delayed Transition to Oral Feeding in Infants with Single Ventricle Physiology
Enteral Feeding in Prostaglandin-Dependent Neonates: Is it a Safe Practice?
Preoperative Feeds in Ductal-Dependent Cardiac Disease: A Systematic Review and Meta-Analysis

Are there resources on how to feed a baby with single-ventricle anatomy that my care center might be referencing?
Resources:
https://cchmc.sharepoint.com/:w:/r/sites/OralFeedingToolkit/Shared%20Documents/General/KDD%20Intervention%20Strategies/References%20Oral%20Feeds%20Protocol%20.docx?d=wbe967d6403d34277b5465a7f198037ef&csf=1&web=1&e=UEnyZt

How will it be determined if breastfeeding, bottle feeding, or tube-feeding is the best method for feeding my child preoperatively?

Breast- or bottle-feeding are the best, and if your baby is eligible and interested in eating, how you feed your baby is primarily up to you. However, it has been observed that breastfeeding is actually easier on your baby's system (see AHA article below). Breastfeeding also promotes long-term medical and neurodevelopmental advantages. These advantages include a lower risk for NEC, higher performance IQ/reading/math scores, and fewer ADHD symptoms at 7 years old (studies by Davis and Spatz, 2019; Cognata et al 2019; Elgersma et al 2022; Belfort 2022). When it is not possible to breastfeed, human milk provides at least some of those benefits.

If your baby is not interested in either breast or bottle, those cues should be respected, rather than placing a naso-gastric (NG) tube.

1. **Resource for breastfeeding from a parent's perspective**:
Breastfeeding the HLHS Baby - the Parent Perspective — Sisters by Heart
2. **Resources for breastfeeding from a medical professional's perspective**:
Breastfeeding the HLHS Baby - the Practitioner Perspective — Sisters by Heart
Breastfeeding a Baby with Congenital Heart Disease | Children's Hospital of Philadelphia (chop.edu)
Feeding Tips For Your Baby with CHD | American Heart Association
Breastfeeding your baby with congenital heart disease | Australian Breastfeeding Association

If your baby is not ready to eat, what other positive feeding/oral experiences can I expect, ask about, and help with to promote bonding and healthier neurodevelopment?

Holding during oral feeding is an important component of development for your baby – and even if your baby can't eat now, holding remains very important. Ask your providers what the holding policy is at your hospital. Many facilities have specific policies and procedures in place to protect the lines (such as IV/IJ lines, arterial line, pulse oximeter cord, patient monitoring cords, etc.) for parents to hold their baby. Ask specifically about skin-to-skin holding (a specific form of holding in which the parent holds their unclothed, diapered infant directly to their bare chest). There are many researched benefits to skin-to-skin holding, including decreased pain and calmer behavior in the infant, improved sleep and vital signs, improved growth, decreased length of stay, and decreased risk of hospital-acquired infection. Benefits to mothers include decreased postpartum depression, increased milk production, and improved parent/child bonding.

Sometimes your baby is not medically stable enough to have any real volume of milk, but can be offered tastes of colostrum and breastmilk from a pacifier or cotton swab. Some facilities allow baby to go to breast right after mom has pumped her milk, so they can get a taste and practice skills without taking in too much volume.

All interactions should be 'infant-driven', meaning we watch the baby for their behaviors to indicate they are ready. For example, if your baby is bringing their hands to their mouth or turning toward a touch on their cheek (rooting), they are likely ready for positive oral stimulation.

How will feeding my baby orally preoperatively benefit them after surgery?

Early feeding promotes a variety of health benefits, including:

- Parent/family bonding and attachment; good for mom's mental health too

- Practicing coordinating suck/swallow while baby's in-born instincts are strong (these instincts fade with time)
- Neurodevelopmental stimulation
- Best for nutrition and immune system development (colostrum); also promotes better tolerance to feeds post-operatively
- Better post-operative blood flow/pressure (hemodynamics)
- Improved post-operative healing
- Less time on breathing support
- Able to take full-calorie feeds sooner
- Shorter hospital stay

Parent experience: We were told feeding before surgery was crucial to ensure his stomach gets the nutrients from colostrum right away. - Sara

Parent experience: My team shared that feeding preoperatively would give my daughter suck/swallow experiences and the opportunity to build those skills which would hopefully transfer to making postoperative eating smoother. - Adrian

What are some differences between feeding a baby with a single-ventricle diagnosis versus a child with typical heart anatomy?

Your baby's feeding cues should be followed. The focus should be on positive feeding experiences, not on a particular volume of milk consumed.
Then again, sometimes your baby may be too sick or tired to eat effectively, and another source of nutrition is needed. Babies with single-ventricle heart disease often have an excessive blood flow to the lungs, causing a cascade of events that leads to fluid retention. This often causes a faster breathing rate, making it harder to achieve suck-swallow-breathe coordination. Babies who breathe faster may utilize more calories as well, making it difficult to gain weight properly (your feeding therapist can have very helpful hints for effective oral feeding, and your medical team may add medications that aid in reducing symptoms).
It is important to evaluate your baby's condition carefully as feeding attempts progress to make sure your baby is still comfortable and not in distress. Signs of distress that parents can watch for include:

- Refusal to engage (turning head away)
- Sweating
- Turning "dusky" or "blue"
- Problems swallowing/milk leaking out the sides of their mouth
- Audible Swallowing
- Oxygen levels dipping down too low ("desatting")
- Coughing/gagging/hiccuping/sneezing/vomiting
- Arm flailing
- Watery eyes

Parent Experience: My heart baby was not my first child. It was hard for me to understand how something as basic as feeding could be too tiring for my heart baby to handle, but I had to accept that there are real differences, and that I would have to watch out for things like heavy breathing, trouble swallowing, or looking purple. - Rachael

Parent Experience: As we prepared for my daughter's first surgery, the team did not want to "overwork" her heart, as eating can be considered exercise for a newborn. Because of this, eating was scheduled and monitored in order to ensure her safety. Each center may have their own protocols, but I was able to feed my daughter every 3 hours. It was limited to the amount of time breastfeeding or a designated amount in a bottle. It was a big adjustment mentally as mothers typically feed as needed for a newborn, but I had to learn that these preoperative feeding experiences are more to learn skills rather than purely for nutrition. These feeds were centered around giving my daughter positive, safe experiences in order to practice her oral skills. While feeding, we had to watch for her cues to see if she had the energy and stamina to be able to handle eating given her fragile state before surgery. - Adrian

How do I find a source for donor milk in my area?

Donor breast milk is an option most hospitals offer. Keep in mind that babies do not need much in the first few days of life: they

typically take a very small volume of colostrum until mom's milk comes in (usually a few days after birth). You can start by speaking to your feeding therapist, dietician, or nutritionist regarding finding a source for donor milk.
Resources for learning about and finding breastmilk through donations include:
Home | Welcome to Human Milk CIC (human-milk.com)
Human Milk Banking Association of North America (hmbana.org)
Milk Donation and Sharing - La Leche League International (llli.org)

If I use formula, will I need to use the same one postoperatively? Are there specialty formulas that need to be used? Will the hospital provide formula? If not, who can I talk to in order to find out where to get what I need?
Most of the time breastmilk and/or donor breastmilk is recommended before surgery because of all the benefits that breastmilk provides to newborns. If formula is recommended and your baby tolerates that well, usually your baby will continue with the same formula after surgery. In some cases, a different formula may be used depending on the baby's medical condition after surgery. Some formulas are better tolerated than others; this depends on your baby's medical and cardiac condition. Some formulas are "elemental" or "hydrolyzed", which means the macronutrients (carbohydrate, proteins and fat) are already broken down and easy to digest.
Your dietician or nutritionist is a good person to ask any questions regarding formula.

If I cannot (or do not wish to) directly breastfeed, but still want to provide breastmilk for my baby, how often should I pump?
It is recommended that you pump the same amount of time as your baby will breastfeed to improve milk supply. Pumping should be initiated as soon as possible after the baby is born. If you wait, it may be harder to develop your supply. During the first two weeks, pump every 2-3 hours during the day and at least once during the night. This is as often as your baby would breastfeed, about 8-10 times per day. It is also important to know that moms typically are only able to pump drops of colostrum or only a very small amount of milk in the first couple of days. This is completely normal and those small amounts can still be collected in either a small syringe or even absorbed from your breast pump via a cotton swab to be given to your baby. Ask for lactation support!

Parent Experience: I was told I should pump every three hours for 10-20 minutes (each side), even through the night, if possible, especially for the first couple of weeks. When I started having trouble waking in order to pump, I was advised to space nighttime pumping sessions out to four hours in between. My pumping schedule was 6am, 9am, 12pm, 3pm, 6pm, 10pm, 2am. - Rachael

Should I start pumping before my baby arrives? What if I have never used a breast pump before?

There are lactation consultants available at most hospitals. If this service is not automatically provided, ask if you can see them. At other facilities, your nurse or feeding therapist may be able to assist you with using the hospital pump. If you have your own breast pump, read the manual and practice setting it up before your baby is born. Many brands have videos online that can show you step by stop how to use the pump. Consider purchasing a hands-free pumping bra, lanolin or coconut oil, and microwave steam clean bags. Some hospitals will provide you with these things, so check with your cardiology team before your baby is born. It is not usually recommended to pump before your baby is born. Although a mother's body can produce small amounts of milk or colostrum at that time, milk production only really gets going when the placenta is delivered and hormones change to cue that process.

Parent Experience: I did not need to pump before my son was born. I did, however, benefit from taking apart and reassembling the pump parts for my home pump a few times so I would be familiar with how to put it together (especially in preparation for the middle-of-the-night pumping sessions!) and take it apart to clean everything. It also helped to try and remember the names of the parts, so that when I was talking to Lactation I was able to let them know specifically that I needed a replacement membrane and a different size flange/shield. Three other indispensable items to support pumping are lanolin, sanitizer bags, and a hands-free resizable pumping bra. - Rachael

Parent experience: I did not pump before he was born but I did right away postpartum. It took a couple days to start producing milk but I was able to start freezing my milk for feeds postoperatively. - Sara

Will the hospital provide a pump or do I need to get one? If the hospital does provide a pump, will they provide one only for hospital use, or at-home use as well? If the hospital does NOT provide a pump, how can I get one?
Most hospitals will have a breast pump available to use, but you will want to have one for home also. Ask your lactation consultant or care team about loaner or rental pumps. Double electric pumps are the best for establishing a milk supply for a hospitalized baby.

Parent Experience: I was provided with a hospital-grade pump both at the hospital where my son was born and at the hospital to which my son was transferred shortly after birth. I did also need to procure a pump for home through my insurance company. I should have started that process sooner. I used the home pump not only when I was at home, but in the car (a plug for use in the car was really helpful!). - Rachael

Parent Experience: The hospital provided me with a hospital grade pump that I used while in the NICU and the CICU. I had purchased a breast pump prior to my daughter being born through my insurance. This was extremely helpful because I used it while at the Ronald McDonald House and then once she was discharged home. Having one just at the hospital and one stationed at the RMH made it so I did not need to transport my own back and forth. - Adrian

Is there any milk storage available at the hospital or will I have to store it at home and bring a supply? Will the hospital store this for use after surgery?

Milk storage is available at the hospital. Most of the time the milk will be stored in the milk lab or in another designated area (separate from your hospital room).
Hospitals have specific policies for storing breastmilk that may be more stringent than the CDC or AAP. Generally, freshly expressed milk can be stored at room temperature for up to 4 hours, in the refrigerator for 4 days, or in the freezer for 6-12 months.

Link for more information - Storing Human Milk - La Leche League USA (lllusa.org)

Parent Experience: There was storage at the hospital both in our CICU room (a small refrigerator, for short-term) and elsewhere (for freezing) in the hospital. They would bring milk from storage as needed. Any milk that wasn't used was kept for whenever we needed it, and was sent home with us when we were discharged. - Rachael

What is an "oral aversion"? How can we help avoid it?

For most babies, oral feeding and having things (their hands, toys, etc.) in their mouths is pleasurable and feels safe. Babies learn about their world through oral exploration. When a baby has been subjected to the many negative sensory and oral experiences that are often necessary in a cardiac ICU (intubation and suctioning, NG tube, etc.), they may develop hypersensitivity about how their mouth feels when being fed or touched. Babies who are pushed to feed when they are not showing feeding readiness behaviors are also at heightened risk for developing an oral aversion. A baby with an oral aversion may refuse the breast and/or bottle by turning their head away, getting upset with feeding attempts, or more subtly shutting down and falling asleep when you try to feed them. Sometimes oral aversions present with gagging, vomiting, or other distressing behaviors.

The best way to prevent oral aversion is to limit negative oral experiences and provide positive ones. Some simple things parents can do is learn how to read your baby's behavioral cues about when they are 'ready' to engage in oral activities (calm and alert, bringing hands to mouth, rooting toward a touch on their cheek or lips) and their 'not ready' or stress cues that indicate they need a break and some support to feel better (arching or pulling away, facial grimace, avoiding your gaze or turning their gaze away from you, or other visceral signs such as gagging, hiccoughing, or yawning).

I have heard that feeding a baby with a CHD can be hard. Is that true? What encouragement is there?

Feeding a baby with CHD can be a challenge, but it is by no means impossible. Be sure to talk daily with the CICU team and the dietitian: they can help to resolve your specific concerns.

Parent Experience: It IS harder than with a heart-healthy baby, especially if you want to breastfeed (though in my experience all the work I put into breastfeeding was absolutely worth it). Kids with CHD face many hurdles and obstacles with feeding that "normal" people don't even think about. Fortunately, there are lots of different ways to get babies fed, and lots of people to help with those obstacles! You will adjust to your child's needs, and though everything may feel very overwhelming at first, after a while, everyone finds their new "normal". - Rachael

Parent experience: If you talk to other heart moms, you will hear that the biggest struggle is feeding. Most babies, if not all, go home on some form of feeding tube and it will be up to your team and you to decide which one works best for your little one. Don't feel discouraged by this, it is only temporary. As your little one starts recuperating, it will become easier to wean off the tubes. Work closely

with your team to set up a goal. - Sara

Parent Experience: Many babies born with CHDs struggle with feeding and that is one of the biggest stressors for parents on this journey. My best advice is to join social media groups to meet other people who are experiencing similar struggles. It's a great place to ask questions, get tips and tricks, give and receive encouragement, and just connect to others who can understand the feeding struggles. Between other heart parents and your hospital team, you will get great guidance to help your child! - Adrian