

## The Heart of the Matter – Jennifer Fogel

### Q and A

#### How/when do you promote direct breastfeeding?

Our lactation educators (IBCLC's) work with mothers right after birth by providing information / education regarding pumping and ways to build their milk supply. We always support mothers who want to bring baby to breast. Most mothers do not have a large milk supply during the first few days prior to surgery. Therefore, we use donor milk for the trophic bottle trials until mother's milk comes in. Due to placement of umbilical lines, the mother may need to bring baby to breast by standing near the bed and positioning the baby toward the breast with support of another caregiver. Another option is to secure the lines and position baby in mother's arms. Check with your hospital's protocol for holding with lines. Children's Hospital of Philadelphia has a nice clinical pathway on holding, and Boston Children's Hospital is working on standardizing holding infants with lines, intubation tubes, and/or ECMO cannulization. If mother's milk is "in", the lactation educator will evaluate the baby for ability to extract, and the SLP will be present to assess safety. Once the evaluation is complete, we develop a plan of care for bottle and breast feeding. If there are swallowing safety concerns, part of the plan may be 5 min of non-nutritive breast feeding, which is bringing baby to a breast that has been pumped. Most of our infants will go to surgery within the first week of life. Trophic feedings are for GI stimulation and not for nutrition as the baby is receiving fluids. If the infant is hemodynamically stable, we recommend that baby receives a few feedings by bottle with the mother or father and a couple times at the breast. There is regular collaboration with the medical team when determining when and how often the baby can receive a breast or bottle trial. We often use the First Feeder with the ultra-preemie nipple when introducing trials pre-operatively, as this is the bottle we will have baby start with following surgical repair and extubation. As mentioned, we also provide education and support for mothers of infants who have a pre-natal diagnosis of CHD. If there is a pre-natal diagnosis, some mothers are interested in lactation courses before baby comes.

We continue to work with collaboratives such as the National Pediatric Cardiology Quality Improvement Collaborative (NPCQIC) on safe feeding practices. And our recent publication listed in the references also references breast feeding opportunities.

Jones, C., Desai, H., Fogel, J., Negrin, K., Torzone, A., Willette, S., Fridgen, J., Doody, L., Morris, K., Engstler, K., Slater, N., Medoff-Cooper, B., Smith, J., Harris, B., Butler, S., Disruptions in the development of feeding for infants with congenital heart disease. *Cardio. in the Young* Nov. 2020

**How closely do you work with your dietitians? We often end up with very calorie dense nutrition which is frequently not well tolerated.**

We work very closely with our dietitians, as well as our cardiology and surgical teams. We have established feeding protocols, realizing that there will always be clinical variability re: how each newborn tolerates the diet. Many newborns, especially those with Hypoplastic Left Heart Syndrome (HLHS) and other comorbidities (malrotation, GERD, poor heart function, and prematurity, etc.) have trouble tolerating caloric dense nutrition. Some are on continuous feeding longer than others. While other infants need a special diet for management of chylothorax. We have a dedicated dietitian to our PCICU and High-Risk Clinics, as well as a dedicated outpatient dietitian to help with tube weaning. This support fosters consistency with plans. If you would like to collaborate, I could connect our dietitian with yours...just email me.

Do you work with NIDCAP program?

I do not work directly with NIDCAP. But my co-partner with the Cardiac Newborn Neuroprotective Network, Samantha Butler from Boston Children's Hospital, is very involved and presents with NIDCAP. She is also a NIDCAP trainer. This is a wonderful organization, and I hope to collaborate more with them regarding the individual care approach and applications for the High-Risk CHD population. I am a member of NANT and hope to present and collaborate at this conference. One of my goals is to collaborate more with these groups and work towards standardized care for infants with CHD across our globe!

Do you follow your babies' feeding outcomes on a long-term basis? Do you have data that you can share?

Currently we are collecting data through both NPCQIC, Cardiac Neurodevelopmental Outcome Collaborative (CNO), and our own center. I do not have data to share at this time, but these collaboratives will have information out soon. I am a co-lead for developing NPCQIC's pre-operative feeding goals for HLHS, and we are designing more specific measures. In the past it was a simple "yes/ no"... "Do you provide pre-operative oral feedings?". That appears to no longer be the case. Through CNO, we are starting to measure tube weaning outcomes; this is led by another group. I hope that in the next year or so, we will have more information and data to share specific to feeding outcomes.

My colleague, Lisa Doody, and I are completing a study which looks at the pre- and post-operative oral feeding skills of infants with CHD and comparing their oral feeding skills to those of normal/typical newborns.

My experience has been that because technology has improved over the past 10 years and the survival rate for infants with CHD has greatly improved, we can now collect more data and really look at quality of life issues, especially feeding, with infants born with CHD. At my own center we collect information within our Cardiac Neurodevelopmental Clinic...this is similar to a NICU Follow Up Clinic...we see patients at 6, 12, 18, 24, 36 months. During these visits, we address feeding and make sure our infants are receiving Early Intervention or Feeding Therapy services. We also follow them in ENT (if they have vocal cord paresis) and cardiology clinics.

How can I get my unit to buy in on 'The Three Strikes you're out?'

Providing education and asking your teams to become more involved in specific cardiac collaboratives would be a great first step. Explain that "slow and steady wins the race". Provide a positive, nurturing oral experience; and educate staff and families regarding cues, identifying that the baby will be the driver. It is worth explaining that you need to get your feet wet before swimming. Or use the example of how physical therapy brings a patient to the side of the bed before standing. I can provide a copy of our "Three Strikes You're Out". It has been a nice simple way to explain oral feeding readiness.

At your center, are your therapists only dedicated to the cardiac unit or other units as well?

All our inpatient therapists serve the cardiac units and other units. We have therapists that focus on quality improvement efforts and collaborate with specific units for improved relations and updates for the whole team. Our PT/OT/ST go to the PICU, NICU, PCICU, and other floors. I attend many conferences and work on specific cardiac collaboratives to share the information with my team but will also service the NICU, PICU, and other floors. We have assigned NICU and PICU therapists that provide QI and attend specific conferences so no one gets overwhelmed with it all.

We have standing orders for PT/OT/ST once the CHD infant is born and again the day of surgery.

Do you think offering small amounts of PO while a patient is still on high respiratory support creates more negative experiences vs positive experiences? If there's still a risk of aspiration with that PO introduction isn't that creating more negative experiences?

This is a great question! During my 25 years of experience and after reading the literature, I have found that lack of appropriate, nurturing care for our fragile babies and negative experiences cause the most aversion. When individuals do not measure and control FLOW, VOLUME, POSITION, PACING, WATCHING, and not being PRESENT...this can impose the highest risk. I have read the research of the high risk of aspiration with high respiratory support and there is nothing conclusive.

Through my clinical experience I have not had my patients develop oral aversion from slow introduction of oral trials following the infant's cues, but rather from repeated suctioning, pushing a pacifier when baby not latching, feeding intolerance, and other noxious stimulation. Research that shows systematic approaches such as the "Infant Driven Feeding Scale" or the "Safe Individualized Nipple Feeding Competence" are the safest and most effective to getting fragile infants to feeding safely. Early "individualized experiences" that are provided with the parent in a gentle manner get the best results to weaning from respiratory support to oral feeding trials. This is NOT FOR ALL INFANTS. Again, look at individual factors. It was becoming frustrating when we were asked to consult when the patients were on our step-down unit and then we had 1-2 days to come up with a discharge feeding plan. If we can become involved earlier and provide "pre-feeding" experiences and education to parents, the discharge plan is better, more infant-focused and more readily followed by parents. Rather than waiting on numbers to determine when pre-feeding experiences start. Ask these questions before considering high respiratory trials:

1) Why is the patient on such high respiratory support? 2) Is the patient demonstrating awake calm state after nursing assessment? 3) What types of feeding readiness is the patient demonstrating? 4) How strong is the patient's base of tongue retraction and how are they handling oral secretions? 5) What is the parents' understanding of the oral feeding journey. Therapeutic oral feeding trials on respiratory support depend on all these factors. This is not a plan of care that would be recommended every day or at every opportunity. This might be done with the feeding therapist only with the parent and using the ultra-preemie nipple (i.e., 3-5 ml with strict pacing every 3-4 sucks and following the infant's cues). It is more harmful to try to feed an infant on high flow for nutritional goals and tube weaning goals rather than providing safe nurturing oral experiences. This should be done with an experienced therapist that feels comfortable working with these infants and is working fully collaborative with the team.

This is an area our Cardiac Newborn SIG is going to look at and research further with other Level 4 centers. Further research needs to be completed in this area, especially with this specialized population of newborn with CHD. Most of the current literature contains subjects that are premature we need more research in feeding and outcomes for infants with CHD. If you are interested in joining and collaborating, we would love to have you. This could be another talk and discussion for sure.

What pacifier do you use when intubated? The purple wee soothie or the smaller wee thumbie? Are most of these patients orally or nasally intubated and is there evidence of better feeding outcomes between the two?

We use the wee thumbie at our institution and recently I have a 3 month old patient that has been intubated since birth, she is now sucking on the purple wee soothie. It was so interesting... after she was orally intubated for a long time, once nasally intubated she latched onto the green pacifier and had suck cycle bursts of 10-12 which was impressive, as I thought she would have a poor latch and be too weak to sustain sucking. But mother was educated early when patient was receiving milk swabs. We educated mother how to provide lingual stimulation specifically to the body of the tongue under the tube with the milk swab and then we transitioned to the wee soothie until then, she had been taking the purple pacifier under the tube. She had cysts in her nares and after they were removed, she had to be orally intubated again.

I do not have evidence regarding oral intubation vs. nasal intubation with feeding outcomes. Unfortunately, most of our infants are orally intubated with the hope they will be extubated soon. Our medical team determines the best respiratory support. We do use NIV NVAVA so that has been very helpful with providing early positive oral experiences.

Can you go over how you fluoro in side lying? What positioners do you use? We've had push back from our radiologists.

We place our infants 6 months and younger on the radiology table with a slight elevation. We place them side lying for the best lateral view. We have tried them in the small red tumble form but especially for infants 4 months and less they have better postural stability and breathing in side lying.

With the 3 strikes you're out, is that 3 occurrences during one feeding or three separate feedings?

Three strikes is for 1 feeding occurrence watching for up to 3 signs of stress then we stop for that feeding opportunity then try again later if the patient is showing feeding readiness cues. This is an aspiration prevention education that we use with nurses and parents when deciding if a patient should have a trial feeding. This is also used in our NICU and PICU.

We have found that lowering O2 via HFNC "just" for feeding trials can still place the infant at high risk for aspiration to po. What are the objectives you use to justify using this approach vs continuing paci dips until they can show physiological stability on 2L HFNC?

We are using this approach with cardiac patients only and not with premature infants. These are different scenarios. The cardiac infant has respiratory issues that are not the same as the premature infant with bronchopulmonary dysplasia and lungs that are not fully developed. The CHD infant has full term lungs with cardiopulmonary circulation differences. The objective of providing early, safe, protective oral trials helps to start the process. In addition, infants with CHD can often be weaned rather quickly such as 2-3 days after surgery, which is different from infants born prematurely. There is also a difference between recommending "feeding trials" as a plan of care and therapeutic feedings of 3-5 mL to help connect synapses for sucking and swallowing. Therapeutic trials can be completed with the infant 1-2 times per day with the therapist and parent. As the patient weans from respiratory support, oral intake can be adjusted, while evaluating the flow, volume, strength, position, and safety of the infant. Further research and information need to be collected specifically for infants with CHD, but I have seen good pro-

gression for the infants I have worked with post-operatively. There will be more comes from the collaboratives I am working with. If the clinician is not comfortable providing therapeutic trials, then he/she should not implement these techniques with CHD newborns.

**Do you have an apnea or cardiac follow up clinic after NICU discharge in addition to early intervention?**

We have a high risk interstage clinic where we follow patients with Hypoplastic Left Heart Syndrome or Single Ventricle defect. In this clinic we follow patients for ongoing feeding challenges until they have their other surgeries. Collaboratives are currently working on tube weaning practices following multiple surgeries as well. We have a 0-3 Cardiac Neurodevelopmental Clinic, a Heart Failure Clinic and a Cardiac School Age Clinic. In addition, we follow up with any infant that has an ng tube after surgery at their 2 week surgical follow up . If patients still have an ng tube in place at this visit, we help them follow up with a dietitian and outpatient speech therapist. Many centers have outpatient feeding clinics as well.

**Can you share the studies (maybe via email to participants) about the studies of aspiration on HFNC?**

Please see list of references in handouts. There are many studies that have been completed with premature infants. There are currently no studies that examine infants with CHD that I am aware of currently. I hope our special interest group will be able to examine this more in the future.

**What studies are available that have investigated swallow safety while PO feeding specifically on HFNC?**

There are many studies in reference to oral feeding with premature infants requiring increased respiratory support. There are some that state it increases aspiraton risk and some that report inconclusive evidence. Searching through the literature I have found that each infant with CHD needs to be evaluated as an individual not by their numbers. Often clinicians will not meet the infant or work with the infant and family until their level of respiratory support is at a certain number. There are gentle sensory oral motor experiences we can provide until they are ready for milk in a bottle or trial at the breast. I would encourage you to work with your CHD infants before they have the “right” numbers. Watch their behavior, look at their responses, provide and protect when working on feeding. There are no definite guidelines except to evaluate based on the individual and his/her family dynamics. Further research needs to be completed with infants born with CHD, both before and after surgical repair. I have adapted some of the methods from the “SINC” feeding method for our CHD infants and found success. Dagleish, Stacey. Eating in “SINC”: Safe Individualized Nipple-Feeding Competence, a Quality Improvement Project to Explore Infant-Driven Oral Feeding for Very Premature Infants Requiring Non-invasive Respiratory Support. Neonatal New. 2016;35(4):217-27.

**Can we find the facebook group?**

Our facebook page and twitter is Cardiac Newborn Neuroprotective Network. If you have trouble finding it or joining please contact me : [jennifer.fogel@aah.org](mailto:jennifer.fogel@aah.org)

I hope you will join us!! We are excited as we now have clinicians from all over the world joining us and sharing their experiences.