National Pediatric Cardiology
Quality Improvement Collaborative

Addressing Parent and Provider Tube Weaning Fears

Thank you for your interest in beginning a tube weaning program at your center. We recognize and acknowledge that implementing tube weaning procedures can feel like a daunting task and scary undertaking. Offering this service line will make your program better and family-centered because parents are seeking and requesting this support. In addition, if tube feeding is a part of your center's practice, we strongly encourage that the ability to tube wean is also offered. The removal of feeding tubes has the potential to greatly impact the child and family's quality of life, the child's developmental progress, and help more interstage graduates achieve the goal of orally eating their first birthday cake.

Providers and parents alike express similar fears when the idea of a tube wean is mentioned, although it is notable that providers commonly cite worries that the child might somehow be harmed while parents commonly note fear of the wean failing. All fears are valid, but acknowledging and addressing them is critical for forward progress. Both parents and providers have dealt with fears previously in the care of children with CHDs, and tube weaning will not be an exception. We can assure you that this is effective and empirically supported, adverse events are rare, and there are experienced centers implementing this intervention. However, the number of centers offering this service is still far too low, making the need for tube weaning programs a health equity issue.

In the table below, we offer a list of the fears commonly noted by both providers and parents, along with important considerations related to these fears. The technique of identifying fears and then considering evidence and alternative perspectives to alleviate those fears is derived from Cognitive-Behavior Therapy, a psychological intervention with extensive empirical support. The considerations are derived from both numerous research papers as well as input from experienced tube weaning clinicians. We hope this information will allow you to bypass fears and move forward in the very important work of tube weaning eligible children. Our team will be available for ongoing support.

CHILD READINESS, BEHAVIOR, AND DEVELOPMENT	
FEAR/CONCERN	**ALLEVIATE FEARS**
Parents and Providers: What if the child has never taken anything by mouth? Is my baby's swallow really safe?	1. Literature review shows that the majority of children begin weaning with taking 0% orally, and they often begin oral intake within 1 week or less 2. The child very well may not be taking anything by mouth *because* of tube dependency, so tube weaning is likely what is needed to see oral intake begin. 3. One parent's reflection: My son did not take anything orally, and our team used the fact that he could manage his own secretions as a sign that we could move forward. 4. Babies must learn to coordinate sucking and swallowing from birth. The tube may have interrupted this normal development. Remain persistent and patience with each other and the child as oral skills are built and learned.

	5. Rely on information provided by any medical evaluations (e.g., video swallow study), when available. 6. It is often true in medical care that 'You don't know until you try'. We know tube weaning works and is worth the investment of parent and providers if a child is medically stable.
<u>Parents</u>: Are we ready? We just got through interstage and don't know if we can add tube weaning into our busy family life where we are trying to establish some sort of 'new normal'. Am I a terrible parent for weaning before my baby seems ready?	1. A parent/caregiver has directly experienced both the positive and negative impacts of tube feeding for their family. 2. Timely tube weaning is best for a child's overall development as well as a family's quality of life. 3. Families must be honest with the medical team if feeling like they are not ready to begin weaning because honesty between families and the medical team is critical to success. 4. Together, the child's medical team and family will assess readiness for tube weaning because we know that when children are ready, literature shows that tube weaning can occur more quickly than anticipated.

SUPPORT, GUIDANCE, AND EXPERIENCE WITH TUBE WEAN

FEAR/CONCERN	ALLEVIATE FEARS
<u>Providers:</u> What if my institution doesn't have a well-established multidisciplinary outpatient structure to help follow children through tube weaning? Who will lead and be a resource for providers and parents?	1. Despite the various professionals noted in the literature (medical/cardiology, GI, nutrition/dietetics, feeding therapy (ST/OT/PT), psychology, and child life), there are NPCQIC centers who have been successfully implementing tube weaning programs with two clinicians for a very long time. 2. Per the literature and clinical expertise, we advise that the three key professionals to include are medical, nutrition, and feeding therapy. Whenever possible, the addition of psychology/mental health is strongly recommended. 3. Experience with a tube wean is not essential. A critical key component is an engaged family that feels supported with open, honest, and transparent communication between parents and providers. 4. For motivation, consider learning from other teams or departments who have been practical and successful despite limited team member resources.

Providers: What if adding this intervention takes too much time from my already extremely busy clinical schedule? What if I don't have the time to focus on oral feeding skills before every feed and the tube is easier to deliver the nutrition?	1. Children need this tube wean intervention, and it is empirically supported. Providing tube weaning support is a responsibility of each center who places tubes, and it is a health equity issue. 2. A trusting relationship between parents and providers as a result of recent graduation from Interstage Home Monitoring (IHM) places the child's medical team in the best position to offer tube weaning. 3. Direct guidance and "hands on" by the primary IHM team who knows the child and family best, has fostered growth and nutrition care, and has impacted feeding plans makes the most sense to owning the tube weaning plan. Focusing on the child's feeding cues, not a fixed timeline for tube feeding delivery is a more positive feeding experience for all involved. 4. Tube weaning is currently in its infancy across centers so hospital administration might not support the intervention quite yet. If a team can demonstrate and prove the effectiveness, support can come in time. 5. While the reality is that this is a labor-intensive intervention, an experienced clinician describes their center's undertaking of tube weaning as a "labor of love", noting that "the positive outcomes are HUGE for both provider and family and so essential for family's quality of life".
Providers: What if this child needs a different approach compared to most other children?	1. Advice from an experienced tube weaning team: Every child and family is unique as they begin the journey. Some flew faster because of the pre-wean education that we became more aware needed to happen much earlier in the journey, even as soon as prenatally. Some did not eat orally until we found that "magical" consumption device and/or fluid choice. Reducing the volume of tube feedings is paramount for allowing the child to demonstrate true hunger derived eating. 2. Advice from an experienced tube weaning team: Any substantial reduction in tube-fed volume will lead to improved oral eating, which tends to be 20% at a minimum with 25-30% more common. Note that cutting too few calories will not yield the hunger needed for oral eating to come on board. 3. Individualization is highly encouraged. Once a team gains more experience with weaning a wide range of children, they will become knowledgeable with how to individualize appropriately. As with all new skills, it takes some 'trial and error'/building of experience to gain comfort and skill. 4. Advice from an experienced clinician: Having an easy-to-access mentor is extremely helpful when facing unfamiliar situations and can give newer clinicians confidence. With increased tube weaning experience, confidence grows to explore more complex patients who also need your support.
Providers and Parents: Can you do a wean 100% virtually if the child lives geographically far from the center?	1. Yes…there are various research articles demonstrating the effectiveness of virtual programs. 2. Also, private companies are providing tube weaning services on a solely virtual platform (obtaining local medical support is recommended).
Providers and Parents: Who is going to help the family after-hours?	1. Dedicated personnel will need to be available at all hours for families to feel supported, but It is very rare for critical issues to arise, and typically concerns can wait until the next day. 2. This level of support is no different from that offered during IHM.

	3. Providing families with guidelines on what constitutes an emergency can be helpful (e.g., minimum volume goals, goals for weight gain during a wean, and wellness signs).
<u>Parents</u>: Why won't anyone on the medical team help me wean my baby? When will the medical team think my baby is ready to wean?	1. Tube weaning is a developing but very needed intervention for cardiac centers. Some prefer to shift this to feeding clinics, but that is not always appropriate or feasible. We are creating this intervention package so that medical oversight and expertise will be readily available for all children. 2. Our intervention package contains a Readiness to Wean Checklist, which helps providers identify key signs of readiness (e.g., evaluation of cardiac stability, swallowing, nutrition status).
<u>Parents:</u> How do I know if my child's team has enough experience/that they can see my child through a wean?	1. Even if providers have never done a tube wean, there are numerous research articles as well as experienced clinicians/centers for any provider to reference. Tube weaning is often not complicated. If a provider has determined that a child is ready to wean, research demonstrates that 90% plus are successful at reaching tube freedom. 2. Tube weaning is similar to IHM in that paying attention to details of feeding and nutrition will help parents and the medical team assess and guide the tube weaning plan.
EFFECTIVENESS AND OUTCOMES	
FEAR/CONCERN	**ALLEVIATE FEARS**
<u>Providers and Parents:</u> What if the wean doesn't work (the child still needs the tube, the tube must be reinserted, the wean has to be delayed, etc.)?	1. *It is the greatest of all mistakes to do nothing because you can only do a little. Do what you can.* -*Syndey Smith*...Life with a feeding tube is very difficult, and when children reach medical stability, they are typically appropriate for weaning and thrive off the tube, living a better life without it. 2. While it is scary to try something when there is no true guarantee it will work, the odds are in your favor because 90%+ of kids are able to be weaned. 3. If the child doesn't fully wean after the first attempt, this does not mean that future attempts will fail! For example, children may encounter routine illnesses during a wean and may need to pause or restart a wean once back to baseline wellness. This is not considered a failure. 4. Children who cannot fully wean often need much less from the tube compared to before their wean.
SAFETY, POTENTIAL FOR HARM, & MEDICAL COMORBIDITIES	
FEAR/CONCERN	**ALLEVIATE FEARS**

Providers and Parents: What if they lose too much weight and the wean must be stopped, neurodevelopment is adversely impacted, the immune system is weakened, damage to the heart occurs, etc.?	1. Weight loss is expected and accepted. Numerous studies note acceptable weight loss of up to 10%. 2. Across studies, a minority of patients reach this 10% threshold. 3. Consider all indicators of wellness (e.g., energy level, wet diapers, developmental progress, quality of feedings). 4. Think about “strength” alongside evaluation of “growth”. 5. Across the literature, cardiac problems were not cited as a reason children could not wean. 6. Other research notes the developmental *gains* children experience after weaning.
Providers: Can you wean patients with ongoing cardiac issues? • Residual heart failure • Reduced ventricle function • Valve regurgitation • Anti-arrhythmic	1. Some children feel more ‘high risk’ than others. Advice from an experienced center: We have now been doing this for over 3 years and we still sometimes doubt ourselves with complex patients. We have found that we CAN do it, even in these more fragile kids. Not always, but MUCH more often than we would have ever imagined. 2. Advice from an experienced clinician: Although difficult, there will always be that patient, that undesired outcome that gives pause. On the whole, weaning is the right thing and the best thing. Multidisciplinary communication and monitoring is important for complex patients. 3. The research discusses reasons for inability to tube wean, and cardiac status is not cited. 4. Please consider reviewing our case study examples of challenging tube weaning successes (available in Intervention section).
Providers: Can a child with a history of feeding complications (e.g., aspiration, vocal cord paresis) be weaned safely?	1. Utilize the Readiness to Wean Checklist to help guide decisions. Some issues, like aspiration, are often presented as a barrier to tube weaning in the literature. 2. Notably, some children can still be weaned if the appropriate consistency of liquids is provided and there is close collaboration with developmental specialists regarding the details about the best consumption device as well as next steps to providing safe feeding skills based on feeding cues.
Providers and Parents: What if the child becomes dehydrated?	1. Children are typically more stable after their Glenn surgery, and the risk of dehydration is not as significant as it was during interstage. Constipation is common and should be addressed early (naturally with foods or medications) to minimize impact in oral feeding success. 2. Make sure to track various indicators of wellness along with numerous signs of a problem to make the best clinical decision. For example, avoid assessing hydration solely by what ‘goes in’, making sure to consider other indicators like production of tears, wet diapers, overall energy level, etc.

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