



National Pediatric Cardiology Quality Improvement Collaborative

Back to Basics: Tube Weaning Frequently Asked Questions

Tube feeding is often necessary after surgery in children with complex congenital heart defects (CHD). As a child remains on tube feedings, TUBE DEPENDENCY can develop. A plan for preventing tube dependency should exist with the family and caregiver team to set goals to achieve oral independence. Tube weaning will alleviate tube dependency and can lead to increased quality of life and mental health for children and families.

Why is tube feeding often necessary?

- The causes of oral feeding challenges in children with complex congenital heart disease include the following:
 - Medical complications- ex. prolonged intubation, vocal cord paresis, dysphagia/aspiration
 - Decreased cardiorespiratory endurance
 - Feeding intolerance- ex. reflux, gastritis, delayed gastric emptying
- Some children enjoy and are safe for oral feeding but may struggle with growth due to the heart needing to pump faster to meet the body's needs. Often a child may need extra calories to maintain weight and growth.

What is tube dependency?

- Children who initially require supplemental tube feeding are at risk of becoming *tube dependent*. This is a condition in which children with stable health statuses and safe swallow ability remain dependent on feeding tubes for all or most of their nutritional and fluid needs due to food refusal and food aversion.
 - A related issue for tube dependent children is often that they are unable to connect feelings of hunger with fullness through oral eating.
 - Tube dependency is often characterized by overt disinterest in eating, food avoidance and active refusal, gagging, vomiting, oversensitivity, and other oppositional and aversive behaviors.
- Symptoms of tube dependency greatly impact the child and family's quality of life as well as caregiver mental health. Tube feeding can feel unnatural to parents and serve as an ongoing reminder of the child's medical fragility and continued connection to the medical system. If parents are unable to breast- or bottle-feed their child, they can experience significant grief and guilt.

What is tube weaning?

- *Tube weaning* has been defined as all the processes required to transition a child from dependency on tube feedings to eating by mouth and meet all nutrition needs without affecting development, social environment, and family.
- Tube weaning enhances quality of life to have normal meal time experiences in varied settings

When can you start a tube wean?

- Tube weaning preparation can and should start before the tube is placed. Focus on positive oral stimulation and partial oral feeding opportunities while the child is requiring tube feeding.
- Early intervention from a skilled feeding therapist to normalize oral motor and oral sensory skills in addition to evaluation of swallow safety is recommended during the time when the child is dependent on their feeding tube.
- Children are ready to begin weaning from their feeding tube when their medical issues have stabilized (e.g., post Glenn), nutritional status is stable, oral-motor skills are adequate, swallowing is observed as safe, and caregivers are ready.

Who initiates/owns a tube wean?

- From the time that the tube is placed, families should be provided with information on all aspects of tube feeding including practical, social, and emotional management.
- A plan for tube weaning should be discussed at that time, and that plan can then be added to the medical chart and given to the family.
- Having *multidisciplinary team* involvement to guide tube weaning is a gold standard. A comprehensive team offers the insight and clinical guidance necessary to address the developmental, nutritional, behavioral, oral motor/swallow function needs, and sensory concerns that may be present when children have been fed by tube.
- At a minimum, it is recommended that a medical provider (cardiologist, nurse practitioner, etc.), dietitian and/or nutrition support, and feeding therapist (OT, SLP, PT) be involved in the tube weaning process.

What settings can tube weaning be done in?

- Tube weaning can be done in a variety of settings including inpatient hospitalization, day treatment or intensive outpatient, outpatient, home-based, or telehealth.
- Many published studies report high success rates that are not dependent on the setting or type of feeding tube.

How long does tube weaning take?

- Once the child is medically stable and has been approved for tube weaning by their cardiology and primary medical provider, the process of moving to all oral feedings can be relatively brief.
 - *In a review of published tube weaning program literature, the time reported for children to move from tube dependency to full oral feeding varied significantly between programs, but often was accomplished within weeks to months.*
- Success will be greatly impacted by all of the preparatory measures that happened while the child was dependent on their feeding tube.