Setting the Table for Tube Weaning: Development of Early Pre-Tube Weaning Recommendations

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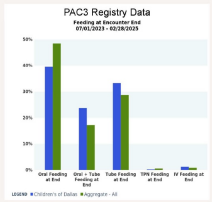
Background

Approximately 60% of patients are discharged from Children's Health's Acute Care Cardiology Unit with supplemental tube feeds.

Outpatient tube weaning and feeding therapy resources are limited, leaving patients tube fed longer than medically necessary and leading some parents to attempt tube weaning on their own or to turn to expensive private feeding programs.

In response, the Cardiology Tube Wean Program at Children's Health was established in January 2022.



Purpose

To evaluate outcomes of the Children's Health Cardiology Tube Wean Program and apply key learnings to improve weaning strategies and support early, proactive preparation for tube weaning beginning at initial tube placement.

Methods

Cardiology Tube Wean Program volume and wean outcomes were measured by:

- Number of evaluations conducted
- Number of weans conducted
- Duration of wean
- Weaned to all oral feeding or not
- Duration of post-wean follow-up

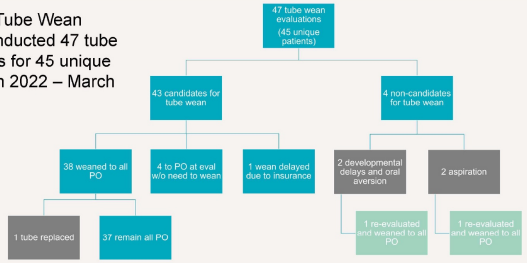
The tube wean team tracked the incidence of behavioral and developmental oral feeding barriers that prolonged tube wean follow-up.

PediEat and Feeding Impact parent surveys were conducted at the pre-wean evaluation and at the end of program follow-up.

- PediEAT survey measures parental report of problematic feeding in young children.
- Feeding Impact survey measures parental report of the impact of child's feeding challenges on the family and parent.

Program Volume & Wean Outcomes

The Cardiology Tube Wean Program has conducted 47 tube wean evaluations for 45 unique patients from Jan 2022 – March 2026.



Average time to wean off tube feeds decreased from 28 days in 2022 to 20 days in 2025 and 10 days so far in 2026, but duration of total tube wean follow-up has not decreased at an average of 119 days.

	Number of patients evaluated	Number of patients weaned	Time to all PO (days)			Time to follow-up conclusion (days)		
			Mean*	Median*	Range	Mean*	Median*	Range
2022	8	7	28	22	10-56	124	125	70-174
2023	11	7	24	25	15-39	93	88	69-146
2024	12	12	19	19	7-34	128	111	55-246
2025	13	9	20	20	9-30	130	125	76-201
2026	3	3	10	11	0-20	Remain in follow-up		
Program Total	47	38	21	20	0-56	119	118	69-246

*4 patients came to evaluation taking all PO and evaluation confirmed good oral feeding status.
*4 patients not candidates to wean; 2 received targeted treatment and later weaned.
*1 patient's wean initiation is delayed due to insurance.

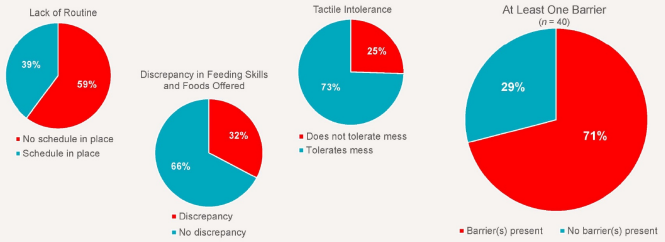
Behavioral, Developmental, & Psychosocial Results

Behavioral & Developmental Feeding Barriers

Common behavioral and developmental oral feeding barriers that prolonged tube wean follow-up were:

- Lack of routine - present 59% of the time
- Tactile intolerance - present 25% of the time
- Discrepancy between feeding skills and foods offered - present 32% of the time

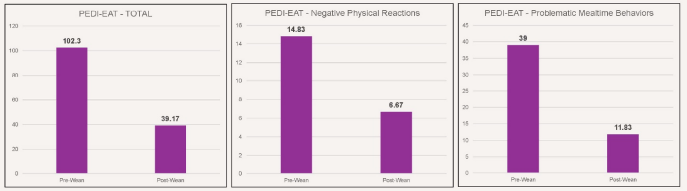
Patients had at least one of these oral feeding barriers 71% of the time.



PediEat Survey

PediEat pre- to post-wean survey results demonstrate statistically significant declines in:

- Overall problematic oral feeding behaviors
- Negative physical reactions during feeding (choking, gagging, etc)
- Problematic mealtime behaviors (food avoidance, refusal, stress, etc)



$t(11) = 6.51$, $p = <.001$ $t(11) = 4.52$, $p = <.001$ $t(11) = 3.85$, $p = .003$

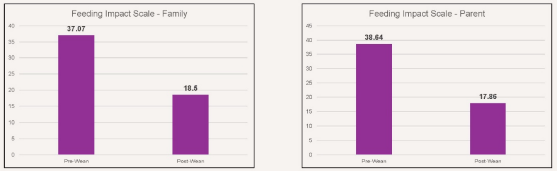
Pedi-EAT Selective and Restrictive Eating subscale (aka narrow food choices) decreased over the course of the wean and approached significance.

Oral Processing subscale (like chewing difficulties) decreased over the course of the wean but, was not statistically significant.

Feeding Impact Survey

Feeding Impact pre- to post-wean survey results demonstrate statistically significant declines in:

- Overall impact of child's feeding challenges on the family
- Overall impact of child's feeding challenges on the parent



$t(13) = 5.99$, $p = <.001$ $t(13) = 6.34$, $p = <.001$

Conclusions

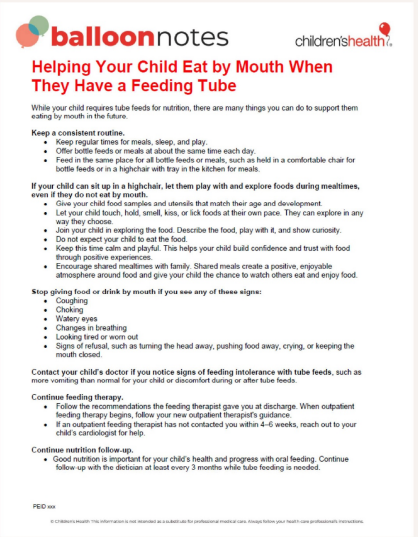
Tube wean duration decreased from a mean of 28 days in 2022 to a mean of 20 days in 2025, but the duration of post-tube wean follow-up has not changed.

Three major categories of oral feeding barriers that prolong tube wean follow-up were identified: lack of routine, tactile intolerance, and discrepancy between feeding skills and foods offered.

PediEAT and Feeding Impact parent survey results demonstrate statistically significant, positive impacts of participation in the Cardiology Tube Wean Program on oral feeding behaviors and feeding challenges for the family.

Future Direction

Identification of oral feeding barriers and the benefits of tube weaning have informed development of standardized recommendations to support safe, positive oral feeding experiences while tube feeding remains medically necessary.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Helping Your Child Eat by Mouth When They Have a Feeding Tube

While your child requires tube feeds for nutrition, there are many things you can do to support them eating by mouth in the future.

Keep a consistent routine.
- Keep regular times for meals, sleep, and play.
- Offer bottle feeds or meals at about the same time each day.
- Feed in the same place for all bottle feeds or meals, such as held in a comfortable chair for bottle feeds or in a highchair with tray in the kitchen for meals.

If your child can sit up in a highchair, let them play with and explore foods during mealtimes, even if they do not eat by mouth.
- Give your child food samples and utensils that match their age and development.
- Let your child touch, hold, smell, kiss, or lick foods at their own pace. They can explore in any way they choose.
- Join your child in exploring the food. Describe the food, play with it, and show curiosity.
- Do not expect your child to eat the food.
- Keep this time calm and playful. This helps your child build confidence and trust with food through positive experiences.
- Encourage shared mealtimes with family. Shared meals create a positive, enjoyable atmosphere around food and give your child the chance to watch others eat and enjoy food.

Stop giving food or drink by mouth if you see any of these signs:
- Coughing
- Choking
- Watery eyes
- Changes in breathing
- Looking tired or worn out
- Signs of refusal, such as turning the head away, pushing food away, crying, or keeping the mouth closed.

Contact your child's doctor if you notice signs of feeding intolerance with tube feeds, such as more vomiting than normal for your child or discomfort during or after tube feeds.

Continue feeding therapy.
- Follow the recommendations the feeding therapist gave you at discharge. When outpatient feeding therapy begins, follow your new outpatient therapist's guidance.
- If an outpatient feeding therapist has not contacted you within 4–6 weeks, reach out to your child's cardiologist for help.

Continue nutrition follow-up.
- Good nutrition is important for your child's health and progress with oral feeding. Continue follow-up with the dietician at least every 3 months while tube feeding is needed.

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We aim to implement these recommendations at the time of initial feeding tube placement and reinforce them at subsequent encounters.

The intentions of implementing these recommendations are to:

- Better prepare patients and families to tube wean once medically appropriate
- Decrease the duration of post-wean follow-up

We are collaborating with inpatient speech therapy and nutrition to identify patients and initiate caregiver education earlier in the process. This has sparked a concurrent initiative to incorporate speech therapy recommendations into the discharge After Visit Summary.

When assessing impact of implementing these recommendations, it is important to consider that follow-up duration may be influenced by expanding the program to include more medically and behaviorally complex patients as team experience grows.