Follow Up/Post Wean

Nicole Coolidge, Nurse Practitioner

Megan Horsley, Dietitian

Lacie Patterson, Parent

National Pediatric Cardiology
Quality Improvement Collaborative

Objectives

- Define what it means to be a feeding tube “graduate”
- Discuss how to de-intensify from the tube weaning program
- Empower families & reduce feeding related stress and anxieties
- Support families with developmentally appropriate feeding resources
- Transition the care of the tube weaned child

Defining graduating from the feeding tube

What is happening when a child has officially graduated?

- Child is demonstrating adequate oral intake (calories) determined by team during wean
- Child is demonstrating adequate fluid intake determined by team during wean
- Child is taking all medications by mouth without concern

Creating a Customized Plan for Families

How to de-intensify data collection following a wean

Monitoring of weight and intake after tube wean

Goal: **Decrease Frequency**

- Weight recommendation*:
  - obtain weight 1-2x/week for one-two weeks;
  - then monthly x1-2 months or until next cardiac visit;
  - Routinely per PMD checks and cardiac visits
- Intake recording recommendation:
  - Strongly suggest discontinuation on day of last tube feed
  - May monitor in conjunction with weight frequency post wean if team desires

*After weaning is complete, weight will stabilize and gradually start gaining in the course of 2-3 months depending on incidence of greater motor skill development which could cause weight stagnation to last longer[1]

[1] *Dunitz-Scheer 2009*

Cincinnati Case Study Example - *continued from Intervention Module*

4 months of age, HLHS s/p Glenn, “BM”

Baseline:

- Weight= 5.68kg
- Weight z score -1.63
- WFL z score -0.05

1 month post-wean:

- Weight = 6.2kg
- Weight z score -1.4

1 year post-wean:

- Weight 10.1kg
- Weight z score -0.24
- WFL z score 1.09

Duration of Wean lasted 12 days

Weight gain: baseline -1 month = 520 grams (17 g/day)

Weight gain: baseline -1 year = 4.42 kg, (12 g/day)

Feeding tube removal

- Long term complications of feeding tubes can include; infection, perforation, dislocation, chronic skin eczema, dumping syndrome, and most commonly, recurrent daily vomiting.[2]

- Time parameters vary child to child but the feeding tube should be removed as soon as possible depending on the type of tube in place.

- NG Tubes - should be removed once child has proven adequacy of intake (calories and fluid) defined as (>70-85% PO) and able to tolerate all medications by mouth.

- Surgically placed tubes:
  - Removal is recommended within 1-3 months post last tube use.
  - Centers are encouraged to have a plan in place identifying the GT removal provider.
  - Continue cleaning and maintenance care until removed.
  - No current literature available that supports keeping feeding tubes through cold/flu season or until all planned surgical repairs are completed.

[2] *Mittal 1992, Nelson 1998, Puntis 1990, Sleigh 2004, Strauss 1997*

Medication reminders

- Oral feeding oftentimes improves gastroesophageal reflux symptoms, as the process of digestion starts in the mouth with chewing, salivating, and swallowing!
- NG tube removal can also improve reflux symptoms as well
- Review the need for reflux medications (H2 blockers, PPIs, motility agents) and consider weaning or discontinuing once tolerating all oral feeds
- The focus on oral medications should come at the end of the tube weaning process

Evaluating Growth & Development

Post Tube Wean

What defines long term success?

- Enjoying normalized, tube-free mealtimes
- A child who is excited about bottles/food
- A child whose oral intake is sufficient for developmental growth (gross motor, fine motor, emotional/social)
- A child having the ability to find their own true growth curve
- A child who is happy, energetic and enjoys the pleasure of food

Developmentally appropriate feeding

- A newly tube weaned child is a fragile but capable emerging eater
- Families will need support, resources, and direction to foster and encourage appropriate feeding and family mealtime development
- Centers should follow standard age appropriate food guidance and provide resources to families accordingly
- Consider additional developmental feeding resources such as;
    - Baby Led Weaning, http://wwwbabyledweaning.com
    - Division of Responsibility (*Ellyn Satter*), https://www.ellynsatterinstitute.org
    - The Feeding Doctor (*Katja Rowell*), http://thefeedingdoctor.com

Transition of Care

Ensuring a smooth transition of care

- Refer to Customized Plan Module for suggested reduction in weight and intake monitoring
- In general, children are considered to “transition” from the tube weaning program at 1 month post last tube feed if they are meeting their goals for growth and development
- There is no structured transition model as it varies by patient and center but generally a formalized handover to PCP and referring Cardiologist (including sharing of accomplishments and goals) is necessary.
- Communication is essential - set realistic goals and establish a follow-up plan with the family (see handout for families)
- Consider additional medical team members as needed (for example: SLP/OT/PT follow-up for any underlying motor issues and/or Nutrition for diet quality check-ins)

Long term follow up

- Continue to work on developing oral eating skills
  - Depending on age at time of tube weaning or challenges with introduction of new foods/textures/solids, assess need for continued speech/feeding therapy and outpatient nutritional support. **Therapy does not equal failure!** Use resources available through this intervention to help gain and maintain oral feeding success.
- Literature supports that most patients who successfully complete tube weaning continue to be successful long term unless significant changes in clinical status emerge (i.e. new onset heart failure)
- Refer patient to dental care to follow general Pediatric recommendations for oral healthcare maintenance