Spectrum Pediatrics Tube – Weaning Program
Treatment Progression for children who are tube dependent

Feeding Tube Dependence

1. Stop harmful activities
2. Neutral play
3. Normalize family mealtimes without eating expectations
4. Make food meaningful – food experiences without hunger leads food to be experienced as objects. It can be playful or fearful, but not nourishing. They may eat for social reasons, acceptance, fear, taste, but not for satisfaction or sustenance, which is the main purpose of food.
5. Competence emerges – Children learn to eat BY EATING. Learning to eat using discrete non-nutritive skills is like learning to swim by standing on the dock. You may be flapping your arms or moving your jaw, but you are not swimming, and you are not eating.
6. Gaining and growth – Self-regulation of eating is refined to allow for appropriate growth for their body.

The Family Table - they need the same developmentally appropriate expectations for behaviors, skills, manners as peers or other family members. They should be allowed to like or dislike foods, and try foods in a way that is consistent with their temperament, taste and physical abilities. Because it is consistent with the child and with the culture of the family, it is sustainable, and can develop as the child matures.

Areas addressed during treatment include:

1. Mealtime communication, including cues of hunger and refusal
2. Mealtime stressors, particularly parent behavior at meals that inadvertently increases stress and refusals
3. Family stress
4. Parents are also coached regarding appropriate food choices for skill level and interest of the child

Families were coached to avoid or replace adult behaviors that increased mealtime stress or created negative associations around food, including:

- Excessive praise for eating
- Food only mealtime conversations
- Restricting preferred foods
- Frequent cues or reminders to eat
- Frequent offering of food
- Describing, “selling,” or praising food throughout the meal
- Ignoring or minimizing child’s cues of “all done,” “no,” or “slow down”
- Bribing or rewarding for eating
- Distractions to eat, such as TV, computer, or book reading

Mealtime schedules were modified to allow hunger to develop. Overall volume was decreased to allow hunger to develop. The goal for oral intake was 5-6 small meals, including drinks. All day snacking or juice/milk between meals was eliminated.

Weight was monitored by the child's pediatrician at follow up health visits. Slow or absent weight gain resulted in individual treatment planning to address the appropriate mealtime behaviors. None of the children required resumption of tube feeding to address weight gain.

Outcomes include all children enrolled in an intensive home-based tube-weaning program from 2011-2014. Tube dependency was judged by percentage of nutrition and hydration that were provided by tube. Child was judged to be tube-free when able to sustain themselves with $\leq$ 10% by tube. Results were obtained through medical record review and parent interview conducted by a therapist who was not involved in the actual tube-weaning program.

At the beginning of treatment:

- 74.29% were 100% tube dependent
- 6% were 75-100% tube dependent.

At the end of treatment

- 66% of children were tube-free after the intensive 10-day treatment portion,
- 88.57% were tube-free after 6 months
- 91.43% were tube free one year post intensive wean.
- All children who were weaned from the tube remained tube-free at subsequent dates.
- Caregivers reported improvements in oral motor skills, vomiting and overall development. Results of parent survey informs us of additional indicators of success in children who are able to successfully wean from the feeding tube.

In order to obtain qualitative outcome data, parents participated in a parent phone survey, including one parent whose child remained tube-dependent at the end of treatment. Calls were conducted at least 6 months after the intensive period of treatment. Parents were asked to rate their child's behavior as occurring **Never, Seldom, Often** or **Always.** Some surprising outcomes had been noted during treatment and were added to the interview, although there is not a direct comparison pre-treatment in all cases. Because these children were tube-dependent with a failure to progress orally, the findings on these data points are positive enough to be addressed in future research.

My child gags:

Pre-Treatment	0%	Never	28.57%	Seldom	51.43%	Often	2.86% Always	2.86% ND
Post-Treatment	40%	Never	50%	Seldom				

My child signals hunger:

Pre-Treatment	60%	Never	20%	Seldom	20%	ND	
Post-Treatment			6.7%	Seldom	46.7%	Often	46.7%Always

My child eats enough on their own:

Pre-treatment	77.14% Never	22.6% Missing Data
Post-treatment	40% Often	40% Always

Out mealtimes at home are relaxed:

Post-treatment	40% Often	46.7% Always

My child likes to eat:

Post-treatment	40% Often	53.3% Always

*ND = No Data

Parent stress plays a significant role in mealtime stress, particularly fears or concerns regarding weight gain or in response to a traumatic medical event in the past. In fact, the NCTSN (National Childhood Traumatic Stress Network) estimates that about 20% of families of children who have had a life-threatening illness or injury will demonstrate stress responses that are significant enough to impact their child's treatment. In addition to questions from the Impact of Events Scale-Revised, which is used to assess Traumatic Stress, families are asked to rate themselves on a scale of 1-5 on the items below. Items that scored as high the most frequently are in bold.

I feel isolated
I have disagreements with or between medical professions
I worry about the long-term impact of my child's difficulties
I feel uncertain about the future
I have little time to take care of my own needs
I have trouble dealing with the needs of other family members
I feel misunderstood about the severity of my child's condition
I feel uncertain about disciplining my child
I have noticed a change in my relationship with my partner
I have help with attending to my child's daily needs
I feel confident when making choices regarding my child's condition and needs
I feel supported when making choices regarding my child's condition and needs

Family coaching during treatment includes discussions with family members on how to navigate disagreements between family members regarding weight and mealtime discipline. Care was taken to attempt to facilitate cooperation with the child's existing medical team, and avoid disagreements that place the family in the middle. Mental health services for traumatic stress are provided or recommended as appropriate.