



Tube Wean Program

Multidisciplinary Team Member Roles/Responsibilities

Prospective programs should have most if not all of the following domains/components, in addition to an actively involved caregiver/family-member:

Medical Lead:

- Responsibilities include:
 - medical clearance of patients prior to tube wean initiation
 - medication adjustments/additions if needed during the program
 - ongoing medical assessment to determine need to suspend tube weaning
 - assist in educating the family to the program and explaining the process
 - assist in answering questions from families during the tube wean

Nutrition:

- Responsibilities include:
 - nutrition clearance of patients prior to tube wean initiation
 - creating the intervention/nutritional wean during the tube wean
 - determining readiness to complete the wean/discontinue tube feeds and remove the tube
 - assist in educating the family to the program and explaining the process and components
 - primarily answering questions from families regarding nutritional next steps during the tube wean

Feeding Therapy (Speech, Occupational, and/or Physical Therapy):

- Responsibilities include:
 - swallowing/safety assessment of patients prior to tube wean initiation
 - performing ongoing feeding assessments as needed
 - developing appropriate interventions to increase oral-motor skills, progress in texture, ensure positive oral experiences, determine appropriate consumption device, etc.
 - primarily answering questions from families re: ideas or concerns with feeding during the tube wean

Mental Health (Psychologist, Counselor, or Social Worker; include whenever possible):

- Responsibilities include:
 - acknowledging the distress that tube feeding can cause for the family
 - discussing family's expectations for the program
 - learning about family structure/resources/strengths/psychosocial challenges
 - ensuring that family can maintain the feeding schedule
 - Problem-solving with family around scheduling issues

- preparing family for emotional portion of weaning
- working with caregivers to change their communicative and behavioral approaches with the child
- behavioral psychologist may be needed if there are active feeding refusal behaviors

Nurse/NP Coordinator (recommended, if roles not filled by another team member):

- Responsibilities include:
 - Identifying new patients and assessing patient/family resource readiness for tube wean
 - assist in orienting families to the program and explaining the process and components
 - serving as a point of contact for questions and issues that arise
 - assist in answering questions from families during the tube wean

Parent Mentor/Advocate:

- Primary role: support the tube weaning family
- Responsibilities include:
 - Has directly experienced tube weaning
 - Facilitates communication between family and medical team
- Helpful when:
 - Tube weaning family would like to speak with experienced family
 - Tube weaning family is experiencing significant stress
 - Tube weaning stalled
 - There is benefit of speaking to someone outside medical team