



Parent Mentor/Advocate

Family members/parents are an essential part of the tube wean team, and tube weaning progresses more readily when the family and providers trust one another so that the family is able to honestly report what is occurring at home during the wean. However, voicing concerns and asking questions can feel scary for the family, especially when emotions are high around tube weaning (e.g., parents often have significant fear that the wean will not work). The family may, therefore, feel more comfortable speaking with a parent advocate. Additionally, parent advocates can help the medical team by providing insight into certain daily aspects of the tube wean process that the team might not see/realize. Advocates have the benefit of life experience to know how information may be perceived by the family and to act as a support person outside the medical field during a stressful time.

Centers offering tube weaning programs have found that parent advocates can be an essential part of the tube weaning process. Families enrolling in the tube wean program should be notified in advance of the option of speaking with a family/parent advocate, and should feel empowered to ask questions and voice their concerns. A parent advocate can work with the family on how to voice the family's concerns during the wean if the family is feeling uncomfortable doing so.

A family/parent advocate should:

- Be selected by the tube wean team as a partner who has knowledge of the tube wean team and process, but has a primary role to support the family
- Be a parent of a child with a history of cardiac diagnosis and NG/G tube feeding, who has already successfully completed tube weaning
- Ideally, the parent advocate should have experience of tube weaning as an active (rather than passive) process in their child's life
- Agree in advance to make themselves available to speak with families by phone when needed

Use of family/parent advocate:

- This resource is available for any family that could benefit from speaking with a parent who has experienced NG/G tube feeding and the emotions that come with weaning
- Parent advocate is connected with the family *only after consent is granted* by the family of a tube wean patient. The family is informed that the medical team may discuss the child's medical information that is crucial to the tube wean process with the advocate and that the advocate may similarly share information with the medical team

Responsibilities include consulting in cases where:

- The tube wean family would like to speak with someone who has already been through this process before and can listen supportively to concerns the family has
- There is significant amount of parental stress regarding starting the tube wean process

- There is stalled progress during the wean, causing increased stress to the family or need for additional ideas to try at home
- There would be benefit to speaking with a party outside the immediate care team