

A Parent's Guide to: Tube Feeding

For some children with Congenital Heart Defects (CHD), total or supplemental nutrition by a feeding tube may be necessary. Navigating this new way of feeding your child can feel overwhelming and intimidating. This bulletin was designed by parents of tube fed children with CHD, in collaboration with mental health and healthcare professionals, in order to provide information and resources that may be helpful as you begin your journey with a feeding tube.

Feelings

Many parents of tube fed children experience a roller coaster of emotions. Parents may feel relief and comfort knowing their child is safely receiving the nourishment they need, it is also natural to feel frustrated, defeated and unprepared.

Parents experience feelings of uncertainty about their child's future with a feeding tube and anxiety regarding feeding schedules, weight gain, and managing new medical equipment and supplies. Also, some parents report that they often feel alone and isolated. These feelings are normal and you are not alone. Here are some things that other parents of tube fed children have found helpful:

- Connect with other families of tube fed children through your medical center, local support groups, or online resources
- Discuss expectations with your child's care team—it's never too early to discuss your child's tube weaning plan
- Be easy on yourself; a feeding tube does not mean you or your child have failed
- Take time to acknowledge the positive progress in your journey
- Identify a trusted caregiver that can help to give you the much needed breaks

Stress

It is natural for parents to have stress regarding their child's nutritional needs, and parents with a tube fed child have unique hurdles. Knowing what to expect can help you prepare yourself and your child better. Parents often identify some of these things as stressors as they adjust to life with a feeding tube:

- Experiencing tube feeding side effects such as vomiting, retching, food refusal, oral aversion, reflux, and/or difficulty with weight gain
- Unsolicited advice from family or friends on how to "get your child to eat"



Looks like a mess, but this was a happy eating success!

- Pressure and expectations from providers regarding caloric intake or weight gain
- Frustration caused by lacking a sufficient support network
- Difficulty in identifying the provider that is your go-to for feeding tube issues and concerns
- Additional responsibilities, feeling more like a medical provider than a parent
- Uncertainty of the future and/or lacking a detailed plan
- Learning how to use new equipment and adjust to it in everyday life

You may not be able to alleviate all of these stressors, but you can learn how to best manage them and be aware of how you react to them moving forward. Engage your child's care team in discussions regarding your concerns. Remember that you are all on the same team and one team member's input is just as valuable as another. As the parent you know your child best.

Bonding & Mealtime Relationships

Bonding with your baby may be difficult when you feel you are unable to feed your baby the way you may have planned. It is normal to wonder when and how your child will develop their feeding and drinking skills and no longer need a feeding tube. Remember that a feeding tube is only a tool, just like a spoon or a bottle. As a parent, your role is still a meaningful and important one. There are ample opportunities for bonding and developing healthy food and meal time relationships at any age, no matter how your child is being fed:

- A foundation of trust and support between you and your child is important
- Promote regular, positive, and fun opportunities around food and eating
- Manage your expectations—it is common that a tube fed child will not show interest in oral eating right now
- Celebrate all successes, none is too small
- Remember that sometimes, less is more—pushing or being forceful can prevent rather than promote progress
- Oral defensiveness is not uncommon, however encouraging safe oral stimulation through exploration or play can allow your child this important connection
- Tube feeding can still be ‘normal’ feeding and is not a ‘medical’ event—holding your baby while they are tube fed and having your child be a part of the family mealtime is still possible

Self-Doubt & Empowerment

Feeling disconnected or doubting yourself can be common as a parent with a tube fed child. This is especially true if you are also preparing for another heart surgery. The stakes feel high and this new world of feeding your baby can be intimidating and/or overwhelming. As a parent you are the expert on your child, and therefore the most important part of their feeding/nutrition plan:

- Trust your instincts
- Do not hesitate to ask questions and be a strong advocate for your child
- You are enough! Align your resources at your medical center and revisit your child's age appropriate development plan frequently
- Don't be afraid to think outside of the box, discuss new ideas, explore all options
- Give yourself credit for all that you've learned



First birthday cake is tasting great!

Support

There are many supports available for families with tube fed children with CHD.

Clinical Resources

Resources may vary by medical center. It is important to understand your therapists and their role in the present and long term care for your child's nutrition, feeding tube management and weaning. Here are some of the therapy resources parents have utilized:

- Speech Language Pathology (SLP)
- Physical therapy & occupational therapy
- Early Intervention or Baby Net Services—services vary by state. Seek referral prior to discharge.
- Formal tube weaning programs

Community Support

Finding online forums and support groups that allow you to connect with other families going through the same challenges can be greatly helpful. Check out:

- Local and national congenital heart disease parent support groups like Mended *Little* Hearts, Conquering CHD, etc.
- Feeding Tube Awareness Foundation: feedingtubeawareness.org
- National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC): npcqic.org
- Inside Out Care: insideoutcare.com



National Pediatric Cardiology
Quality Improvement Collaborative



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