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HOW TO SUPPORT YOUR CHILD LEARNING TO EAT BY MOUTH

By DR. KAY TOOMEY

The decision to have a G-tube (or NG tube) placed for your child is not one that you have made without a great deal of thought and consideration. Many of the parents we work with talk alot about their fear that their child will either stop eating by mouth, or may never learn to eat by mouth. The good news is that there are many things you can do as a parent from the very first day the G-tube is placed to help support your child's oral feeding skills and to best insure that he or she will someday be able to eat without a tube. This handout has been designed to help you carry out a program that will give your child the best chance of eliminating their need for their tube at some point in the future.

THE MOST IMPORTANT THING THAT WE NEED TO DO AS PARENTS FOR OUR G-TUBE FED CHILDREN IS TO MAKE SURE THAT THERE CONTINUES TO BE A CONNECTION BETWEEN THEIR MOUTHS BEING USED AND THEIR STOMACHS GETTING FULL. In our Pediatric Feeding Center, we see many children who have been G-tube fed from the start while lying flat on their backs in a bed with nothing happening in their mouths. These children learn very quickly that they do not need to do anything to get their tummy's full. Instead they learn that the food appears "magically" out of the sky and goes into this little tube on their stomach. These children also DO NOT learn that feeding and eating are social experiences that occur in kitchens or dining rooms while we are sitting up (semi-reclined as young infants) while interacting with others. Most of us do not eat lying down in our beds without anyone else around (not since we had kids anyway).

If your child maintains this connection, it will be much easier to either teach them to eat or to get them to continue eating by mouth - even when they need to get many or most of their calories through the tube. Without this connection, it is very difficult to undo the dependence on the tube which these children can develop.

RECOMMENDATIONS:

1. Begin use of the G-tube when given the Okay from your surgeon.

2. There are two ways to feed children through their G-tubes, either through a syringe and a gravity controlled bolus or via a pump controlled bolus. Using a **G-tube pump to administer bolus feedings is our preferred Method** for several reasons.
   A. When using a pump, an adult's hands can be freed of equipment so that the adult can interact with the child and model how to eat.
   B. The pump can also be placed behind the child while they are eating so the pump is "out of sight, out of mind." This allows the child to focus on learning to eat by mouth rather than focusing on the G-tube feeding. Children on a syringe feeding system learn more quickly that the tube feeds them versus them needing to work their mouths in order to eat.
   C. In addition, pump feedings allow the child to have a consistent, slow stretch on the stomach in order to decrease discomfort and reduce possibility of gagging/ wretching being associated with feedings.

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3. Begin adding calories to your child's diet by the tube in a somewhat **slow** fashion. When we increase a child's calories dramatically by the tube in a short amount of time, their bodies often times think they are being overfed and their appetite drops out. Their eating by mouth also drops out with their appetite.

For Example: You have a child who is only taking 500 calories a day by mouth when he needs 1000 calories a day. If we double this child's calories in 1-2 days by giving those extra 500 (or more) calories through the tube, this child's body will have no appetite what-so-ever. It will feel like we all do after we've eaten way too much at Thanksgiving dinner. We would recommend instead, advancing the child's calorie intake for the day by only about **150 to 200 calories at a time.** After the child has had about **5-7 days** to get used to this calorie increase and re-adjust it's appetite, you can then increase by another 150-200 calories every 5-7 days or so until the ideal number of calories have been reached.

4. The **Rate** at which you bolus or drip feed your child is also important - that is - how fast does the food go into their tummy through the tube? Especially for children who have had a Nisson fundoplication procedure, the bolus and drip feedings need to be started at a **slow rate** in order to avoid setting in a gagging and wretching habit with every tube feeding. However, we would recommend that ANY child with a G-tube placement be started at a slow rate of drip or bolus feeding.

5. In addition, the**Volume** of food going into your child's stomach at any one time is also important We do NOT want to over-fill the child's stomach. This creates an unpleasant sensation which becomes connected to feeding, food and satiation (fullness). Think again about how you feel after you've eaten too much at Thanksgiving dinner. We recommend that you begin drip and bolus feedings with small volumes and gradually increase the volumes every 3-5 days to give the child's stomach time to stretch out to accomodate larger and larger amounts.

How to figure what Rate and Volume is appropriate for your child depends on their age, body size, stomach size and sensory tolerance (IE. how well do they handle physical sensations). **For ANY child, if they are gagging and wretching during a tube feeding they are indicating that they are not handling the rate and/or volume of the feeding.**

We would recommend first slowing down the rate of the feeding. If this does not work, or if the child continues to gag and wretch at a certain volume of food, we would recommend decreasing the size of the tube feeding (and increasing the number of feedings as needed to make up the calories).

Your surgeon will help you determine what those initial rates and volumes to try will be. It may take a while however, to find the ideal rate and volume for your child. Be patient and be willing to try different strategies.

6. Your child's **Position** during a tube feeding is also quite important. As noted before, we want the tube feedings to look as much like a normal feeding for a child your child's, age as possible. Normally infants are fed initially while in a semi-reclining position on a

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parent's lap while looking at a parent. Infants taking baby foods and older children eating table foods are normally fed while sitting upright in a chair while facing a parent.

Position for a young Infant = tube feed while child is being held in the arms of an adult, facing the adult who holds the child in a semi-reclining position. It is preferred to not have the child fed completely horizontally as this frequently leads to more gagging, wretching and/or vomiting.

Position for a spoon-fed aged Infant, Toddlers and older children = these children all need to be tube fed while sitting upright (or semi-upright) in a high chair type of seat (e.g.. bouncey seats, still swing seat, seats which attach to the table, booster seats, high chairs). Car seats are not generally recommended because they tend to put too much pressure on the stomach and do not hold the child in a good position consistently for feeding.

7. **Keeping the Food Connection** means that your child must have some type of food and/or drink in front of them to interact with throughout the tube feeding. We would recommend that at every feeding time, you first offer the child some form of a feeding by mouth. When they begin to show disinterest in the mouth feeding, start the tube feeding BUT also continue gently attempting the mouth feeding. We want to give the children the chance to do what they can on their own, but also we want to keep that connection of my mouth needs to work and/or there needs to be food present in order for my tummy to get full. (This does means having the tube feeding all hooked up and ready to go before you sit down with your child to feed them by mouth).

DO NOT FORCE FEED YOUR CHILD BY MOUTH. This leads to further rejection of eating by mouth. If all they can handle doing is playing with the bottle or spoon, touching the nipple or touching the spoon to their mouth, or taking small tastes - THIS IS OKAY. **The goal is to create a positive situation** that is as close to a normal feeding during a tube feeding as your child can handle. If you are gentle and model for them what the next step would be in taking that food into their mouths or swallowing it etc., they will eventually imitate you and do more and more by mouth. (Your modeling of eating is why it is so important to make sure your child can see your face during a feeding).

For children who are on a Continuous Drip feeding, we would recommend that you identify what are normal times for a child of a similar age to be eating by mouth. These would then be the times that you put your child in a normal feeding position and present them with food and/or a drink. For example, a young infant should be held for a bottle/breast feeding with a bottle/breast presented every 2-4 hours (potentially throughout the night too) depending on their age. A table food fed infant or toddler would be eating in a chair every 2 1/2 to 3 hours during the day.

WE HOPE THAT YOU WILL FIND THIS INFORMATION TO BE HELPFUL TO YOU AND YOUR CHILD. We also recognize that we are giving you alot to do and think about. Please feel free to call us as suggested by your surgeon, gastroenterologist or pediatrician.

Best Wishes

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