

FEEDING TUBES AND GASTROESOPHAGEAL REFLUX

Many of our families have questions about “feeding tubes” for sole or supplemental nutrition for their children. If one looks at individuals affected by Ectodermal Dysplasia, he will note that a substantial percentage of individuals are long and lean (aren't a lot of us jealous!) It is possible, then, that a child affected by ED may appear to be too thin to others, including the doctor, but actually be the appropriate weight for the child. The difficulties associated with absent, decreased number or misshapen teeth generally will not cause a child to “fail to thrive”. Dieticians with expertise in working with children will be able to work with families to assure adequate caloric intake while dental issues are being resolved.

Another concern raised by ED members is the frequency of diagnosis of Gastroesophageal Reflux Disease (GERD). This may be manifested by frequent spitting up or vomiting, choking, “heartburn” or a combination of these symptoms. It has not been determined that there is a higher incidence of GERD in children affected by the ED's. GERD is extremely common in the general population of infants and children. The majority of children with GERD require no special medication or intervention, but some may benefit from medication to decrease acid in the stomach or to speed up the flow of food from the stomach to the intestines. On rare occasion, reflux will be refractory to conservative medical management and may require surgery to tighten the muscle at the top of the stomach to prevent vomiting.

Gastrostomy tube feeding has been available for over 100 years for nutritional support for children with many types of medical problems, including gastroesophageal problems, neurological and developmental problems and head injury. Initial insertion of the g-tube requires surgery, which will be done under general anesthesia. The gastrostomy tube is essentially a soft hollow tube that is placed through the skin of the abdomen and directly through the wall of the stomach. It is held in place by an air-filled balloon that is blown up inside the stomach. Many varieties of gastrostomy tubes are available, including skin level feeding devices that close off with a “button” or cap, rather than being connected to a tube emerging from the abdomen.

Usually a feeding delivery system that allows the infant to receive the feeding over 20 to 30 minutes is used, relying on gravity to cause the feeding to flow into the stomach. This stimulates a normal eating pattern and stomach-filling process. For some children, feedings are given by a continuous drip regulated by a mechanical pump. Your child's doctor will make the recommendation most appropriate for your child.

The mouth may be the most sensitive part of the body for the infant and it needs to be associated with pleasant sensations. The infant's need for sucking is threefold: for food, for pleasure and for the continued development of a coordinated suck/swallow. “Warm fuzzy calories” are provided during the interaction between caregiver and child. Whether during a real or simulated feeding, these warm fuzzy calories are delivered by the dynamics of the feeding: the closeness, face to face positioning, verbal cues and response to touch. Therefore, even if the infant cannot be fed by mouth, oral stimulation to simulate feedings should be given to the child while the gastrostomy feeding is being given. This will allow the infant to associate oral gratification and a feeling of fullness. The child will often benefit from continued work with an occupational therapist and a speech therapist to enhance sucking and swallowing.

There is not enough space in this article to discuss the specifics or home care of the gastrostomy tube. Be assured that the majority of gastrostomy tube insertion surgeries are fully healed within two to three weeks. You will receive detailed instructions on how to care for the g-tube, prepare feedings, and give feedings and medicines, etc. before discharge from the hospital. Parents do become comfortable with the g-tube in a short period of time! Community home nurses are likely to be involved to help you with the transition from hospital to home.

REMEMBER—a child's requirement for a gastrostomy tube is NOT an indication of failure of parenting! Parents should not be frustrated, angered or feel worthless. It is important to view the gastrostomy tube as a “bridge” – a way to provide nutritional support for your child's growth until the child develops more interest in oral feeding or develops the required oral-motor coordination.

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If you have any questions or concerns related to your child's nutritional needs, gastrostomy tubes, gastroesophageal reflux or other issues, be sure to speak with your child's doctor. Most areas of the country are within easy reach of a paediatric department with expertise in gastroenterology, nutrition, occupational therapy, speech therapy and other services that might benefit your child. Feel free to call the ED Society to discuss these issues or to obtain further information for yourself or your child's doctor.

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