



## TUBE FEEDING

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“Tube feeding” is the method used to feed children and adults when they cannot receive adequate nutrition by mouth. It is also called enteral (by way of the intestine or gastrointestinal tract) nutrition. Many individuals with MPS and related diseases have severe neurological problems resulting in increasing problems with feeding. As chewing and swallowing become more of a problem, the time required by the caregiver for feeding can become very prolonged. Enteral nutrition can allow adequate nutrition to prevent weight loss and to improve the quality of life for the individual with MPS and for the caregivers.

The decision to change to enteral nutrition is a difficult one and should be made only after consultation with the pediatrician, geneticist, gastroenterologist and nutritionist. Monitoring the individual’s intake of food, weight gain or loss, choking and gagging, episodes of pneumonia, and time required for feedings provides important information to the professionals assessing the need for enteral nutrition. Choking and gagging can cause the individual to aspirate or silently aspirate liquids and food into the lungs, resulting in pneumonia, which can be life threatening.

Enteral nutrition can be obtained through either a gastrostomy tube (G-tube) or a jejunostomy tube (J-tube). A G-tube goes into the stomach through a surgical opening in the abdominal wall. A special kind of G-tube tube may be inserted by means of an endoscopic procedure and is called a percutaneous endoscopic gastrostomy (PEG) tube. A J-tube is usually surgically placed through the abdominal wall into the part of the small intestine called the jejunum. Each tube is a flexible (usually silicone) catheter that remains in place at all times and is clamped between feedings to prevent leakage of stomach contents. G-tube feeding can be done at regular mealtimes, called “bolus feeding”, or given slowly over a period of several hours using the “gravity or drip method” or “pump controlled method.” There are advantages and disadvantages to both methods of feeding, and many factors need to be considered in deciding which schedule to use. Feedings done through J-tubes are continuously infused because the small intestine is pressure sensitive.

The surgical opening for the G-tube or J-tube is called a stoma. The stoma can be slow to heal after surgery. Proper care of the stoma site is very important to avoid infection or irritation from gastrointestinal secretions. The area should be kept covered with a dressing and changed as often as needed to keep dry. The skin around the stoma should stay snug around the tube. Swimming in lakes or ponds should be prohibited because of the possible bacterial contamination from such an environment.

A G-tube is anchored inside the stomach by a small balloon at the tip of the tube. The balloon can deteriorate and deflate and the tube can fall out. Your doctor will provide you with a replacement tube and instructions on how to insert it. The J-tube can only be reinserted by a physician, so an immediate call to the individual’s doctor is necessary if the J-tube falls out. Also, these tubes can become clogged.

Prepare for this by discussing with your doctor appropriate methods to unclog them in advance. The Mic-key low-profile gastrostomy feeding tube/kit is a skin level device to replace the gastrostomy tube. Because this device is level with the skin it is less likely to be pulled out and can easily be covered by your child's clothes. A special connector allows the G-tube to be removed between feedings.

After deciding to insert a feeding tube, the doctor will perform X-rays of the gastrointestinal tract to help determine if a standard G-tube or PEG tube is indicated. An individual being considered for tube feeding should be evaluated for gastroesophageal reflux disease (GERD) because tube placement may worsen existing GERD and a J-tube may be a better choice. A J-tube may also be an option if there is very poor motility (spontaneous movement) of the stomach. Because of special concerns regarding anesthesia in MPS patients, prior consultation with an anesthesiologist is essential.

The optimal tube feeding schedule will enable the individual to maintain adequate weight, tolerate the tube feedings comfortably, and be fed at convenient times. Caregivers should have contact with a nutritionist to regularly discuss the individual's feeding needs. For most individuals, regular enteral solutions such as PediaSure, Resource, or Kindercal are sufficient to fill their needs. The addition of fiber to their formula may help with the chronic diarrhea that is common in MPS. The formulas are generally tolerated with little difficulty.

Good positioning during feedings is critical in successful enteral nutrition. If the individual is not positioned well, he or she may have trouble receiving food through the tube or trouble breathing properly. The individual should not be sitting slumped over, as this can put too much pressure on the stomach. If the individual has difficulty in maintaining an upright position, specialized equipment and supports are available to assist in maintaining support positions.

When feeding difficulties begin in the individual with MPS, it is important to begin monitoring his/her food intake and weight. This will help to determine if another method of feeding needs to be considered. The decision to switch to enteral nutrition is not an easy one to make, but many individuals will thrive after the placement of their G-tube or J-tube. Difficulties that may be encountered are best dealt with by the medical team in charge of the individual's medical care. Continued contact with them is essential for successful enteral feeding.

*This fact sheet is not intended to replace medical advice or care. The contents of and opinions expressed in the fact sheet do not necessarily reflect the views of the National MPS Society or its membership.*