This information is provided to you as background to pass along to patients who may be recommended for enteral tube feedings such as a G-tube for someone with dysphagia. This information represents medical and common knowledge that is generally included in patient information when a dialogue takes place related to dysphagia and safe eating alternatives. We would like to provide you with a context from which you may wish to inform the patient, his/her family and/or guardian when they approach you with questions on this particular issues. We acknowledge that every person is an individual and that circumstances can be very specific and trust that if you do not find sufficient information on the following pages that you may seek additional information from your preferred data resources.

First some definitions:

Dysphagia: Difficulty with swallowing resulting in risk for choking, aspiration and/or not meeting nutritional needs.

Dysphagia is a common problematic condition found in people with intellectual and developmental disabilities. One of the common underlying pathological mechanisms is swallowing incoordination that is the result of abnormal muscle tone of the chewing muscles and poor muscle control because of injuries or damage to their central nervous system. There are degrees and or severity in dysphagia: some people with dysphagia only have difficulty with thin fluids, others can safely swallow fluids when thickened; some can only tolerate certain food or drink consistencies and textures. When this is the case people can get their nutritional needs based on a carefully designed meal plan by eating and feeding specialists such as speech pathologist, occupational therapist, nutritionist and medical providers. When the degree of dysphagia is severe and occurs with all types of liquids and food consistencies then eating by mouth is no longer considered safe for the person; this is when the recommendation for a feeding tube may be made by the medical provider.

Some people may be able to have something by mouth while still have a feeding tube. Other times the feeding tube is used primarily for fluids and medication delivery while the person can still enjoy eating.

Feeding Tubes: Generally feeding tubes are flexible rubbery devices that are used to bypass the mouth to deliver fluids, nutrients and or medicines to the gastrointestinal tract. Feeding tubes are generally used when oral eating is not safe or possible. Feeding tubes are indicated after careful assessment and evaluation by the medical provider and with the aid of diagnostic tests and consultation with feeding specialists. Most of the times when

indicated feeding tubes can be a scheduled procedure and are only rarely an emergency. Tube feedings is an option that can offer an alternative to eating by mouth but it is not without health risks and emotional implications. Nutritional and hydration needs can be accomplished via a feeding tube when a person is no longer able to eat or drink by mouth.

There are various types of tubes and of diverse materials: rubber, silicone or other synthetic material. Tubes are selected depending on the problem and purpose.

The NG or "NASO-GASTRIC" tubes are inserted through the nose and gradually passed into the stomach by a nurse, physician assistant, doctor or other medical provider who has received training in this procedure. Certain precautions are taken to ensure that the placement is correct. Depending on the clinical setting an x-ray may be indicated; however, placement is frequently determined by placing a stethoscope over the abdomen while flushing air with a syringe through the tube and listening for "air sound" over the stomach area AND by obtaining stomach secretions by suctioning with a syringe. If no secretions are obtained and the patient is experiencing coughing or respiratory discomfort the tube may have gone through the breathing pipe and needs to be pulled back PRIOR to flushing down any substance through the tube. In general NG tubes are considered "temporary", not for long term purposes. They are usually secured to the face with tape. No sutures are needed. People report that NG tubes can be uncomfortable. It can be used for bolus or continuous feedings. They need frequent replacement (can be weekly) and can be done at home by someone other than a health professional who is trained in the technique.

"G-Tubes" or GASTRIC TUBES are tubes that are first inserted by a specialist: surgeon or gastroenterologist directly into the stomach. The surgeon will commonly do it in the operating room under anesthesia. This implies cutting through the abdominal wall and tying the tube to the stomach. There are usually a few stitches on the skin. A tract is formed through the muscles and skin. The risks and potential complications are those of cutting through the skin and into the abdominal cavity: initially bleeding and later on a wound infection may occur. Over several weeks this tract is healed and called stoma. People who have these tubes do not complain of pain once it is healed from the initial placement. Usually ONLY the specialist should replace the tube for the first time and or if it is accidentally removed or pulled out. If the latter happens, the specialist should be contacted immediately and the patient transferred to the emergency room or where the specialist's preference may be. There is a SIGNIFICANT risk of creating a false pass way into a cavity other than the stomach. ONLY when the specialist tells you specifically that it is safe to replace the tube can you do so without going into the emergency room or urgent care facility; and when appropriate training has been provided.

Another procedure done usually by a gastroenterologist but also used by surgeons is via an endoscopy. This is known as percutaneous endoscopic gastrostomy tube (PEG tube). This procedure can be done at the specialist office or in a setting where the patient can be monitored closely through the procedure and until fully awake. Endoscopy involves the use of a tube with a camera on the tip that is introduced through the mouth or nose into the stomach while the patient is sedated –different from general anesthesia. The camera allows the specialist to look at the stomach from the inside; while directing a bright light towards the skin the doctor makes a small cut through the skin and then inserts the tube from the outside; this also includes placing several sutures to prevent the tube from leaking and or slipping out. As in the other procedures it is important that the first time this tube needs to be replaced it is done by the specialist, typically the one who inserted it the first time. G-Tubes can be used for bolus or continuous feedings. They usually need to be changed every 3-6 months.

J-Tubes or JEJUNAL TUBES are tubes that have their tip in the small intestine past the stomach and duodenum. They are only inserted by specialist and are recommended only for specific conditions. These tubes have different implications for their use and are associated with higher risk for complications, reasons why they are not frequently used. Initial care is similar to the other tube types. J-tubes are only recommended with continuous feedings. Only specialists should attempt to change these tubes and a t the intervals they recommend.

Feeding tubes can be temporary while the condition that makes it risky to eat by mouth gets resolved. When the condition like severe dysphagia is unlikely to change then it can be recommended as a permanent option. Tubes can be taken out when no longer desired or indicated. This is usually done without surgical intervention.

Immediate and Long-term Risks & Complications: Complications can be common; immediately after the procedure there can be bleeding and later on infections. In the long run one of the most serious complications is bowel obstruction and or perforation. If this happens it becomes a surgical emergency and usually means a prolonged hospitalization and significant discomfort and pain. It also means that for a time medications, fluid and nutrition requirements will be provided intravenously. Once the bowel heals, the feeding tube use can be restarted. Creating a false pass way into the intraabdominal cavity s another complication with similar outcomes as the ones mentioned above.

The most common "complication" is that the tube is accidently pulled out. This can happen because it is hanging outside of the body and not secure to the skin and while transferring or getting dressed this can happen. In most cases once there is a "well-formed stoma", the

tube can be re-inserted with minimal effort. At times the stoma can close very rapidly and then the specialist needs to be notified so that the tube can be replaced and fluid, nutrition and medications can be delivered safely again.

While the risks for conscious sedation and general anesthesia for these procedures are very low, they are not insignificant; usually less risk than riding in a car every day.

Sometimes tubes leak stomach contents that are acidic and can irritate the skin and this can create discomfort. Other times there is "skin overgrowth" at the stoma site that looks like flesh and is wet. The medical provider can use a chemical and/or creams to keep it under control or make it go away. If there is too much leakage there may be a need to replace the tube of different size to achieve a better seal.

Bolus Feedings: This refers to feedings given over a prescribed time with intervals when no formula is given. The purpose of this approach is to emulate how we usually eat: as in the form of meals and not continuously eating. This technique is used with NG and G-tubes but not with J-tubes. Nutrition is usually accomplished via formulas and only in specific circumstances may food be processed through a blender. Formulas can be delivered by gravity or with a pump. Pumps offer the advantage that they deliver the amount intended during a specific time whereas the flow of formula via gravity is not as predictable.

Continuous Feedings: as it implies, these feedings run continuously over several hours at a slower rate. This approach is preferred when there is concern about the volume that may accumulate in the stomach. For this method a pump is recommended. Sometimes this method is chosen to deliver nutrition at night to minimize the time the person is "attached to the pump". Being "attached to the pump" is a common complaint by users that limits their mobility and ability to participate in other activities.

Tube Care: After the initial period of healing –past 6 weeks- following the insertion of the tube, care can be very simple and done at home by trained staff or family. Most of the time the focus is placed on keeping the opening (stoma) clean and dry and ensuring that there are minimal chances for the tube to be pulled out accidently. Creams of different types can be used to create a protective skin barrier and minimize irritation of the skin around the stoma.

Oral Care and oral Hygiene: Eating and drinking when normal swallowing is present assist in keeping the mouth clean. Of course brushing the teeth and typical oral hygiene contribute to good health as well. When the patient is no longer eating by mouth and a feeding tube is in place oral health continues to be of utmost importance. Most cases

of aspiration are due to saliva that under normal circumstances already contains hundreds of thousands of bacteria; in the presence of poor oral hygiene as in chronic gingivitis the bacterial content in saliva is much more significant. The continuous or frequent trickling of contaminated saliva into the airway leads to pulmonary infections and other potential complications. Therefore, oral hygiene becomes even more important when tube feedings are in place.

It is unusual for the tubes to be clogged when only giving liquids however, medications are sometimes crushed and given through the tube and this can lead to clogging. The specialists have a variety of" tried and true" methods to unclog them and only rarely does the tube needs to be replaced for this reason. Be sure to ask the specialist for their recommendations.

Long Term Implications: Much of this is determined by the initial and ongoing indication for a feeding tube. Studies show that when there is evidence that the person is aspirating due to gastro-esophageal reflux disease then a feeding tube can decrease the chances for aspiration. However, it is also well known that most aspirations on people with dysphagia occur when the saliva trickles down into their trachea and lungs; feeding tubes do not help in preventing this cause of aspiration. Often feeding tubes are recommended after many years of dysphagia and aspiration when the person already is debilitated by their primary condition and from recurrent and chronic pulmonary problems. Under these circumstances the placement of a feeding tube does little to prolong the person's life. Consideration should be given to the limited benefit when compared to the potential complications and implications to the quality of life of the person and family.