

## Summary – Home Nutrition Support

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#### Who Needs Nutritional Support?

The guidelines for children and adults are somewhat similar. For children we are concerned with weight loss and lack of growth. Growth charts are used and children below the 10th percentile are identified early. For adults weight loss again is a consideration, especially persistent and unabated weight loss. We can use protein markers (specifically blood levels of albumin) to help identify those at risk for malnutrition. Adults whose condition prevents them from an appropriate intake of calories would be identified as appropriate for supplements. In patients with mitochondrial disease, tube feeding may be implemented for several reasons: the mainstay of a patient's nutrition; supplemental nutrition in addition to eating by mouth; and hydration - alone or with caloric nutritional supplements.

#### Enteral versus Parenteral Nutrition

Both enteral (g-tube, g/j, PEG, or j-tube) and parenteral (via a central line, IV, or PIC line) nutrition are considered sources of nutritional support. In 1995 it was estimated that about 40,000 persons used home parenteral nutrition and about 150,000 used home enteral nutrition. Today the number of people using enteral support is probably 2-3 times greater; parenteral support use is probably about the same. The goal of these nutritional programs is to allow a people to be on nutritional support systems while living their life as normally as possible. Despite the medical myth several years ago that a person could not "live long-term" on parenteral nutrition, today there are many patients doing exactly that! ThriveRx's goal is to help every patient have enough support so that their home nutrition program gives the patient and family the best quality of life and ease of use as possible.

**Enteral** nutrition (also called tube feeding) involves the use of a feeding tube placed somewhere into the gastrointestinal track. Since it is through the GI tract that we normally eat, this method of support is more physiologically "normal" than the parenteral (intravenous) route.

By placing the tube in the GI tract and by adding nutrition here, we are taking advantage of the enzymes produced by both the stomach and intestines. This method is the first choice whenever possible. The enteral route also has less risk for infection.

The accompanying slides list some common diagnoses which might require the use of home tube feedings; for example, mitochondrial disease, cancer, malnutrition, & Parkinson's Disease.

**Location or Site for Enteral Tube** An enteral tube can be passed through the nose and into the stomach or it may be placed directly into the stomach or intestine through a small opening or stoma which is made for it. The term for a tube that passes through the nose and on into the gastric system is called a **Nasogastric Tube (an NG Tube)**. A tube that is placed directly into the stomach is called a **g-tube** whereas one that goes directly into the intestine (usually the jejunum, a portion of the small intestine) is called a **j-tube**.

In general NG tubes are used for short term nutritional support and often are used with children to get them started with nutritional support before transitioning to a g-tube when longer support is needed. Infants frequently require an NG tube first before moving to the g-tube. Hospitalized adults may also use NG tubes, but if they go home and still need support, only about 1% will continue to use the NG tube - most all are moved to the g-tube. Long term use of NG tubes can irritate the nares and for that reason they are not used for any length of time. The use of a g-tube also allows people to lead a more normal life since the tube can be hidden under clothing. Occasionally, when tube feedings are used to supplement normal food a person can pass the NG tube at home (say an adolescent who does this when they get home from school once a day) and provide additional nutrition in this way.

**Long Term Feedings PEGS** are tubes that are used for long term nutritional support and can be placed directly into the stomach or intestine by using a scope or X-Ray - no surgery is required. These can be placed in the endoscopy suite as an out patient/day surgery procedure, and the feeding tube can be used that very day. The alternative, the surgically placed tubes, require the use of an OR. Generally this method of placement is used when the person is undergoing surgery for other reasons and while they are there, the tube is also placed. A surgical procedure might also need to be used if the PEG-tube is not working well for some reason.

**Gastrostomy tubes (g-tubes)** are made by many different companies and are good for long term nutritional support. They, however, require that the stomach be working properly. If the issue is gastric paresis, then a j-tube will be needed (into the intestine). Often there is a clear disc or "bumper" at the place on the skin where the tube enters the body; this prevents the tube from slipping inside, keeping it appropriately placed on the outside of the body. You may also see several "ports" which allow different places where the tube feeding can be attached - one for nutritional supplements, one for water and/or medications.

**Jejunostomy tubes (j-tubes)** are used for a number of reasons: aspiration problems, GERDS, poor gastric emptying, etc. There is a valve between the stomach and the intestines which in theory prevents the back flow from intestine to stomach. The theory is to feed below that valve - directly into the small intestine. The intestine, however, has no pouch and cannot store food, so these feedings must be done very slowly and in small amounts. In 99% of the cases j-tube feedings use a pump which can insure slow feedings.

**Terminology** When a g-tube or j-tube is placed and after the area heals, a "button" may be placed right on the skin around the opening through which the feeding will go. The term "button" is actually a trade name (Bard); the generic term is "skin level feeding device". A balloon or button is on the inside of the stoma (opening) and the flat area is on the outside. The tubing for feeding connects to this device. When one is not feeding, a cap can be placed over the opening. The benefit to this is that no long tubing is hanging out, and for active people this allows them as normal a lifestyle as possible. Also, with children, it provides a degree of safety for children who would be pulling at the tube. Physicians who care for adult patients may not be as familiar with these

devices, but patients can advocate for themselves and find support from the experienced nurses at ThriveRx.

When a tube is left "hanging out" it may be of varying lengths. Standard g-tube length is about 5-7 inches outside the body. TEG tubes can be very long (as much as 12 inches) and are problematic under clothes. Again, patients should advocate for themselves and work with their physician to find equipment that suits their lifestyle.

**DEHP** is a chemical used in the plastics industry which may or may not be found in tubing and other devices. There has been animal research demonstrating long term use causes liver damage. Because children are more susceptible to such damage and because there are no human trials yet, it is recommended that materials used for tube feedings be **DEHP free**.

**Care of Skin** The skin area around the site of an enteral feeding may get irritated especially if there is leakage at the site. This build up of granulation tissue can be difficult to deal with. It is important that the tube be stabilized at the site and not move around too much. With the use of buttons, stabilization of tubes has improved a lot. There are also some devices which use Velcro to help keep the tubes in place. Silver nitrate and other creams are available to help with skin irritation if it should occur.

## **Parenteral (Intravenous) Feedings**

**Parenteral** nutrition (also called hyperalimentation, **Total Parenteral Nutrition**, **Total Nutrition**, or **Home Parenteral Nutrition**) provide nutritional support through an intravenous catheter; this can be a peripheral line like an IV which is inserted into a vein in the arm or a central line which is inserted into a vein close to the heart. This method is less physiological than enteral nutrition because it by passes the GI tract. It does, however, give the GI tract a rest and for that reason is necessary in certain situations. Great strides have been made in recent years to make the administration of parenteral nutrition easier. The risk for infection is greater for this kind of feeding and it can be more costly.

This type of nutritional support may be used for those with various diagnoses such as intestinal malfunction, malabsorption disorders, short bowel syndrome, Crohn's Disease, Scleroderma, or any disorders which cause decreased intestinal motility (like mitochondrial disease). **TPN**, **TN** or **HPN** is warranted if someone needs IV nutrition for more than 10 days, because regular IV fluids alone cannot provide adequate nutrition or calories. It must be noted that the higher the number of calories delivered, the higher the sugar content, and therefore, the higher risk for infection.

A **Central Line** is a line which is placed into the vena cava right near the heart. There are other venous access options, such as near the wrist for short term use. Usually for home use TPN is used with an implanted port. A **PIC** line is a long line which is placed at or above the elbow and then threaded through the blood vessels to the heart. These

are usually used for shorter durations (but can be used for up to a year or so). **Tunnel catheters** are catheters that are placed into the chest, tunneled under the skin and then down into a vein near the heart. This space or distance from the heart which the skin gives decreases the risk for infection and is meant for longer term therapy. One brand name for these catheters is a Hickman catheter/line.

### **Length of Time**

Neither parenteral or enteral nutrition is meant to be a permanent method of feeding; both are used to supplement nutrition for either short or longer durations. When they are no longer needed, they can be stopped and removed fairly easily. The goal is always to get the person back to eating in a more normal manner. Can people eat while a feeding tube is in place? Yes! It is very common for people to eat while receiving supplemental nutrition. Sometimes a feeding tube is placed a little before the need is there and then is left in place until they don't need it, trying to make the transition as easy as possible.

### **Mitochondrial Disease & Nutrition**

Most patients with other diseases use enteral or parenteral nutrition to provide specific needed nutrients. Those with Mitochondrial Disease may use a g-tube just for additional hydration and occasional supplementation, while others may rely on home nutrition support in order to give the body the best metabolic support via nutrition. This provides a good mechanism for dealing with nutrition and hydration issues, electrolyte supplements and even medications. For all patients, care must be taken that tubes do not become clogged when using them to administer medications, so always check with physicians and pharmacists about this. Remember, some meds given by mouth are done so because they rely on gastric or intestinal enzymes; if meds bypass either stomach or intestine or both, then this may change their effectiveness.

Some patients with Mitochondrial Disease may start receiving nutritional supplements through a g-tube then years later progress to a j-tube, then TPN or PIC after many years. For others, they may use a supplemental form once and this gets them through a crisis and they rebound and do well.

### **Support**

ThriveRx provides support for families in many ways. Services are usually paid for by Medicare, Medicaid, or private insurance. In some small cases, individuals pay out of pocket as well. They can be contacted at 1-888-684-7483. Lori is the customer service representative and she will direct your call and questions to the appropriate person. Deborah Pfister can also be reached via email: [DPfister@thrivervx.net](mailto:DPfister@thrivervx.net).