



**PINNT**

A SUPPORT GROUP FOR PEOPLE  
RECEIVING ARTIFICIAL NUTRITION

# Enteral Feeding: Your Questions Answered.

Adults

Questions frequently asked by new patients requiring Enteral  
Nutritional Therapy with Answers supplied by fellow patients.

**Steven Brown**  
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What is Enteral nutrition?

Enteral nutrition is the method of providing an individual with nutrients through a tube directly into a part of the Gastrointestinal Tract. Commonly the nutrition is supplied directly into the stomach, the duodenum or the jejunum (both parts of the small intestine).

Why is tube feeding necessary?

People are tube-fed because they cannot eat enough ordinary food to get the nutrition and fluids they need.

How is the tube placed? & where does the feed go?

The placement is dependent upon your condition and the expected duration of your needs for enteral feeding results. For individuals with a fully functioning stomach, it may be possible to administer the feed directly into the stomach, otherwise the stomach can be bypassed completely and the feed delivered directly into a part of the small intestine. For short term use a tube is passed up the nose and fed down into the stomach or jejunum, these are known as Naso-gastric (NG), Naso-duodenal (ND) or Naso jejunal (NJ). For longer term treatment a surgically implanted tube is placed through the abdominal wall, known as a Gastrostomy (into the stomach) or jejunostomy (into the jejunostomy).

Will the tube hurt?

Many patients who have a naso-enteric tube (NG, ND, NJ) inserted say that there is a little sharp pain when the tube reached the top of the nasal cavity and turn around, but following this it is only really a slight discomfort or irritation and once the tube has been in place for a few hours the irritation settles down. Depending upon your health care team, you may be given some mild sedation and/or pain killers to help you, but often this is not needed.

For placement of enterostomy tubes (PEG, PEG-J, JEJ), sedation and pain killers and prescribes as these involve a small surgical procedure and often an endoscopy to aid in the selection of the best site for the tube to be placed. Due to the formation of a stoma in the abdominal wall, there will be some pain for a few days following the procedure whilst the stoma forms and the muscles in the area heal.

After the initial placement, there is unlikely to be much pain associated with the areas unless they get infected. This can be minimized by following the aftercare advice given by your health care team.

Will the tube fall out?

Displacement of the tube is more likely with the naso-enteric tubes, but you will be instructed how to minimize this from happening and given a method to follow to ensure that the internal end of the tube is in the correct place before you initiate the feeding. (cont...)

Will the tube fall out? (cont...)

Enterostomy tubes are difficult to dislodge, as they are held in place by an internal fixation device and often there is less tubing on the outside of the body when not feeding to become tangled up and accidentally dislodged or removed.

What is the “feed”?

The artificial nutrition is not simply a liquid form of the foods you find in the supermarket, it is a sterile and specifically designed nutritionally complete liquid. There are a number of variations to the type of feed that is used for Enteral Nutrition and the exact preparation is dependent upon your individual needs. Your dietitian and nutrition team will have reviewed your specific needs regarding your energy and nutrient needs and will prescribe a solution to fit those needs and with your underlying condition in consideration.

You may hear talk of **Standard enteral feeds:** which contain all of the carbohydrate, protein, fat, water, electrolytes, micronutrients (vitamins & trace elements) and fiber in the proportions you need.

Another type is **Pre-digested Feeds:** these contain nitrogen as short peptides or free amino acids instead of the normal protein complexes and this improves the absorption of the nutrients in some conditions, such as **inflammatory bowel disease.**

A third type is **Polymeric feeds:** these contain the nitrogen as the whole protein, but it is the carbohydrate that is partially digested (hydrolysed) and the fat is modified to simplify the absorption.

The content of fiber with each type of feed is negligible and many commercially used feeds have versions with and without fiber added.

Will I be able to taste the feed?

Although the feed bypasses the mouth and therefore the taste buds by being administered directly into your digestive system, either the stomach or small intestine, some patients do report that they can taste the feed if they burp or if they have fed a large volume overnight. This is far more likely to be the case if the feed is administered into the stomach than into the small intestine, but often it is described more as a “shadow taste” that does not stay in the mouth as it would if you had drank the feed.

If you do find that you experience a lot of reflux and frequently taste the feed, try using a mouth wash more frequently which should help remove the taste. If that does not help, speak to your nutrition team for advice.

My friend has the same problem as myself and they are on a different feed?

The feed that you are prescribed is chosen by your nutrition team on the basis of your specific needs and underlying health condition. In the same way that there are a number of different brands of everyday food products there are also different brands when it comes to enteral feeds and just because the name on the bottle is different or the shape of the bottle is different, does not imply that one is superior to the other. Often the branding of the feeds is based upon which nutritional company supplies your local hospital and each company makes a full range of feeds that are matched by a similar product from another company.

When will I be fed?

Different people have different needs for enteral feeding. Some patients feed themselves continuously usually – overnight and are therefore unencumbered throughout the day. Others feed themselves at intervals throughout the day, similar to ordinary meal times, this can be via a pump or using the bolus method and some people use a combination of both methods, doing the majority of the feeding with the pump overnight and then a couple of bolus throughout the day. Combining the two methods can be beneficially for some people, especially if you are in employment and do not want to spend 10-14 hours attached to a pump.

What is continuous and Bolus feeding exactly?

As the name suggests Continuous feeding involved the administering of the feed over a specific duration of time, often at a specific rate, regulated by a feed pump. The patient attaches a specifically designed tubing (giving set) to the feed bottle (or reservoir). The giving set is then fed through a pump, which is programmed to run at a specific rate (which you will be advised about by your nutrition team) before connecting it to the external end of the feeding tube. Once the connection is established you are free to get on with your normal activities or often go to sleep without worrying about it. Should a problem be encountered such as a blocked tube or a finished bottle the machine will alert you to this also, meaning you do not have to think about the feed at all. Bolus Feeding involves administering a specific volume of feed at a specific time of the day. This is often in 200ml units (although smaller volumes may be advised, especially when administered into the small intestine) and is done via use of a gravity drip (where the feed is placed in a reservoir above you and gravity allows it to flow through a giving set to your tube. Alternatively the feed can be placed into a large syringe, which is connected to your feeding tube and slowly dispensed through the tube.

If I use a pump, do I have to stay in bed for the duration?

NO, people on enteral feeding have the advantage of being able to pause and disconnect their feeds once it is started. Although this is not advised and should be kept to a minimum it is safe to do so, if necessary, such as getting ready in the morning, before the feed is completed. With advances in medical equipment this is not often required as many of the feeding pumps and equipment are small and portable and therefore you can continue to get on with normal activities during feeding.

Can I increase the rate of the pump so that I get it over with quickly?

The rate of administering the feed is changeable, but it is not advisable to change this rate without consulting your nutrition team. They will have advised the rate that they believe is most appropriate for you. It would not be their intention to make the feed last too long, as the ultimate goal is for you to get on with life as much as possible, but it is known that delivering the feed too fast can cause complications, such as bloating, cramps, nausea and vomiting and in extreme cases Dumping Syndrome.

What is Dumping Syndrome?

A condition caused by the rapid entry of nutrition into the small intestine, which results in a large amount of water entering as well causing distension and discomfort.

There are 2 types “early” and “late”. “Early” occurs immediately and the symptoms include nausea, vomiting, bloating, cramping and diarrhoea, often with dizziness and fatigue. “Late” dumping which occurs within 1 to 3 hours after feed administration see symptoms such as weakness, sweating and dizziness.

In addition to this and regardless of the type of dumping syndrome the rapid loading of the small intestine with hypertonic solution can cause the Pancreas to secrete large amounts of insulin; resulting in a dramatic drop in blood sugar, leading to hypoglycaemia. This is referred to as “alimentary hypoglycaemia”.

In patients on Enteral feeding, particular where the feed is administered directly into the intestine (NJ or PEJ), it is important that the rate of administration is carefully selected to reduce the likelihood of Dumping Syndrome occurring.

When the feed is administered will I feel hungry and full?

Enteral feeds are supplied into the digestive tract (stomach or jejunum) and therefore the normal mechanisms that are triggered within the tract when eating will also occur in during feeding. The feeling of satiety is the result of distension in the stomach and intestine, due to the presence of food and therefore this mechanism remains in place and results in a “full feeling”

Will I be able to eat and drink?

Due to the by-passing of the mouth and therefore the chewing action, specific hormones that are released during mastication are also by-passed and this can slow down the speed at which things move through the digestive tract. This slowing can result in feelings of bloating, diarrhoea, nausea and cramping. Should you encounter these sensations, talk to your nutrition team as there are medications and techniques which can improve things.

This will depend on your condition and the advice given by your hospital. You may be able to eat whilst receiving enteral feeds and the tube is designed so that eating and drinking is comfortable even with the tube in place.

How will people react to me?

If you are unable to eat and drink you may want to take your tube feeds at the same time your family is eating. Eating is a social experience. If you miss the taste of certain foods and are able to chew, but not swallow, you may be able to chew them and then spit them out. Sugar-free chewing gum may be helping in satisfying the urge to chew. If you are not allowed to eat or drink then it is important to clean your teeth at frequent intervals and to take regular mouthwashes. This avoids the build up of plaque and stops your mouth feeling dry.

If you have a naso-gastric tube it will be noticeable and you may have to explain why you need this tube in your nose. Some people prefer to remove the tube when they are not feeding. If you have a gastrostomy or jejunostomy tube this will not be seen when you are dressed.

How will it affect my family and friends?

By the time you leave hospital, your family and friends would have had time to adapt to your new lifestyle. Once you are at home it is up to you how much or how little you want to tell people about your illness. Most people are quite relieved to know that your new treatment is doing you good. Support from your family and friends can make all the difference to your acceptance of the therapy. Make time to discuss your feelings. Sometimes family members may feel guilty about eating and drinking in front of you.

Will I be able to cope?

Your ability to cope with your treatment should have been carefully assessed by your nutrition team, dietician or nurse prior to your discharge from hospital. You will only have been allowed home because the doctors and nurses have confidence in either you or your carer being able to provide the treatment you need. The procedures are relatively simple and repetitious and another family member will normally be taught the procedures to help you if necessary. It is important that if you feel unable to cope, you relay your fears to your hospital or GP who can provide support. Nearly all patients feel anxious and frightened when first discharged home.

Can I lead an active/normal life?

If you feel well enough it is important to continue with social activities. You may find the time taken up with feeding is a little restricting – but you can stop and start your feeding around your social activities as long as you are sensible. **IT IS IMPORTANT THAT YOU ARE MASTER OF YOUR TREATMENT AND NOT IT OF YOU.** Remember that your underlying illness may cause some limitations which have nothing to do with nutrition.

Can I drive?

If your doctor believes that you are well enough to drive then there should be no problem with it, although you may have to inform the DVLA of your current medical status and they may request written confirmation from your doctor to state that he declares you fit to drive, but in general many people on enteral feeding can drive.

Can I play sports?

If you feel well enough then there are many sporting activities you can enjoy. Very physical contact sports may be best avoided if you have a gastrostomy or jejunostomy tube in place in case it gets dislodged. If you are undertaking any strenuous activity you may need some extra water to prevent dehydration

Can I go on holiday?

Everyone needs a holiday and your treatment should not prevent you from travelling. Holidays at home or abroad may need some special organisation but this should not defer you. Supplies can be arranged from home. Speak to your hospital, home care provider or PINNT who may be able to help you with the necessary arrangements.

Can I get the tube wet?

If you have a naso-gastric tube this is not a problem. If you have a gastrostomy or jejunostomy tube there is also nothing to prevent you enjoying showering, swimming or water sports, once the stoma is fully healed. Indeed it is a good form of exercise as long as the exit site is well healed, your skin is in good condition and your tube is clamped or capped off.

How can I like my body when it has a tube sticking out of it?

Body image issues are a frequently encountered issue, but need not be a problem. It is normal to find it difficult to adjust to your body when you have a tube in place. After all it is something that you are not accustomed to. It is advisable to talk about your feelings with your nutrition team and your family or friends who will help and support you to accept yourself. You certainly would not be the first to have a period of low body image, but with time and support you can overcome it.

Does my needing enteral nutrition mean that I will never be in a relationship?

NO, there is no reason at all why you will not be able to be involved in a committed relationship with someone. It is a misconception that people will not understand and they will turn away from you because of your medical condition and extra needs.

Many patients with NG, NJ, PEG or PEJ have found themselves involved in serious committed relationships and often report that it is when they accept themselves and the facts of their nutritional requirements that people begin to take an interest in them.

Can I lead a normal sex life?

A normal sex life can be maintained. You should try to minimise the presence of tube and not let it inhibit you. Discuss your feelings about your treatment with your partner and any anxieties you may have. As mentioned above adjusting to your body image is something which takes time and the level of time is different for everyone. It can be take even longer to find that you are comfortable with showing your body to your partner (either a new partner, or someone with whom you are in a long-standing relationship), it is therefore advisable to discuss these feelings with your partner and that should allow for a deeper understanding between the two of you, avoiding any misinterpretation of the situations and they can support you. Remember you are not the only one involved in this situation, so you don't have to deal with it alone. In some cases you may find that your medical condition affects your energy levels and your interest in sex may not be as great as the average person, but remember that this is something that is perfectly normal in people who are fit and healthy. There is no typical level of sexual interest, so do not be hard on yourself for you lack of interest. Talk about this with your partner. It can be helpful to talk to a third partner about such matters and if you or your partner have views or emotions that you wish to discuss with people in similar situations, PINNT is there to help.

Can I have Children?

If you are a woman on enteral nutrition and would like to have children it is important to discuss this with your hospital doctor. It is not impossible for people on artificial nutrition to have well nourished babies but it does require some planning and consultation to make sure you receive all the necessary nutrients needed for the baby to develop normally. It will be essentially to ensure you are nutritionally well.

Will I be able to work?

Once you have settled into a routine and have adjusted to your feeding then there is no reason why you should not return why you would not return to work if you feel able to. You may feel better than you have done for some time now that you are well nourished. With the portable pumps now available you should also be able to feed while on the move. If you are unable to cope with work then it is important to accept this as part of your illness and you should not to feel a failure.

If I can't work, how will I afford to live?

There are a number of benefits that people on enteral nutrition who are unable to work are entitled to and these include incapacity benefit and disability living allowance, or attendants allowance and tax credits. It is important to remember that these benefits are not awarded because you are dependent on enteral nutrition, but are given because of your underlying health condition makes you unable to work. For this reason these benefits are not given automatically to people on artificial nutrition.

It is worth speaking to your health care team and social services to see what benefits are available to you.

My feeds are all on prescription, but there is so many that it is very expensive, what can I do to make it affordable?

For patients who are fed via a gastrostomy or jejunostomy then you are medically exempt from prescription charges and if you are not informed of this, discuss this with your nutrition team and your GP. Unfortunately, despite the cost being the same for patients who are fed via a naso-gastric or naso-jejunal tubes, they are not exempt. This is because the nasal tubes are certified as “temporary”, whilst the gastrostomy and jejunostomy are a “permanent fistula”. If you are not exempt it is recommended that you purchase a Prescription Pre-Payment Certificate (PPC). These are available for 3 month and 12 months and cost approximately £29.10 and £104 respectively (May 2011).

Can I get food poisoning?

Good hygiene is essential during tube feeding, because any contamination with bacteria could cause food poisoning. Your hospital will teach you how to prevent this happening.

Will I be closely monitored for complications when I am at home?

Yes, you will not be allowed home until the team are sure that you are fully able to cope and aware of everything that you need to know and are confident that you can do it without incident. Often those you live with, or care for you are trained in the same way and therefore you have someone to back up the procedures at home.

I am told I will need to have regular blood test, Why is this?

You will be monitored in the community often by a multi-disciplinary team, including a dietitian, district nurse (often a specialist in enteral nutrition) and your GP. Each will have a specific role involving your care and you will be made aware of these and given information on who to contact when and how.

It is important that you are receiving the best feed for your needs and you may find that as your treatment continues your requirements may change. It is important to ensure that you are getting the appropriate mix of nutrients and therefore regular blood test will help to determine whether your needs are being met and provide an indication as to how your body is maintaining its internal balance. Anyone on Enteral nutrition, particularly if you are very underweight or malnourished are at risk of “refeeding syndrome” and regular blood tests can pick up on this in its early stages, before serious complications arise.

What is “refeeding Syndrome”?

As the name suggests it is a set on conditions that arise when a malnourished person begins to receive regular nutrition and this is of a greater risk when the nutrition is given via parenteral or enteral methods. This is because as the refeeding occurs there is a high demand for particular nutrients and chemicals, which typical feeds are not able to meet. This failure to meet demand can result in swelling of the ankles, legs and around the heart muscle; increasing the effort required to maintain a regular blood pressure. Furthermore, the potential for severe hypoglycaemia is far greater, which if untreated can result in coma or death.

What is Buried Bumper?

This is a rare condition of PEG tubes where the internal fixation device around the tube migrates between the stomach wall and the skin. The result is that new cells grow around the end of the tube and a fistula (cavity) which is mucus filled grows outside the stomach.

This fistula can leak or even burst resulting in the contents entering the body and causing sepsis. This is a serious condition and requires urgent medical intervention, but it is extremely rare that it gets to this stage.

What is Buried Bumper?

With regular check-ups your nutrition team will ensure that the risk of buried bumper syndrome is minimal, but in the event it does, it is likely to be recognized early and can be corrected endoscopically, without the removal of the tube.

How will I get all of my feed and accessories?

The evidence suggests that when the tube is fixed by a saline inflated balloon, the risk of Buried Bumper Syndrome is further reduced as the surface area of the fixation device is far greater, preventing burying.

When you leave hospital you will be told about the “Homecare” company that your local health authority uses. These will take over the responsibility for ensuring that you have everything that you need to be able to administer the feed and do so in a safe manner. Typically you will receive a phone call from the company about 7 days prior to your scheduled delivery date, to check on what stock you have left and what you require. After the stock check and order is processed you are given the opportunity to discuss any issues with deliveries, such as alternate address if you are not going to be at home.

What if the pump breaks down?

It is important to remember that it is your responsibility to ensure that you are able to collect the delivery; after all it is your medication that you are receiving. You cannot expect the courier to wait around for you or make repeat visits to your home to see if you are in to take the delivery, so it is recommended that you have someone wait in for the courier or arrange for an alternate delivery address before hand.

This is a common worry to which the first step is to ensure that the pump is adequately charged or plugged in to the wall socket. Some pump leads need to be pushed in firmly to ensure they are charging and it is easy to think it is plugged in when in fact it is not.

If it definitely is broken, the first port of call should be your homecare company. Technically the pump belongs to them and you are only loaning the item, therefore they are responsible to ensure that it is serviced regularly and working correctly. They will try to ensure that you get a replacement pump as soon as is possible, but occasionally holidays and geography can make things difficult.

Depending on your particular circumstances it may be possible for you to use the bolus or gravity method until your new pump arrives, but they will try to make sure that it is with you as quickly as possible.

What do I do if the Feed bag leaks?

Although in general the material used to make the bags which contain the feed are sturdy, there is always a chance that it will leak, especially at the point where the giving set attaches to it. With so many different types of feed available, all supplied in different types of packaging, there is no specific advice to be given.

In general the safest and easiest thing to do is to stop the pump and check all of the tubing, particularly the reservoir end of the giving set. If you find that the giving set is at fault, replace it with a new one.

If it is not the tubing then it is safer to discard the feed bag and the giving set and start again with a fresh bag and giving set. There is a possibility that the bag of feed was not sealed correctly in the first place and therefore not aseptic, which could lead to food poisoning.

## Glossary of Common Terms.

**This is not an exhaustive list! If you hear any term that you don't understand, please ask someone to explain it to you.**

<b>AMINO ACIDS</b>	The building blocks of proteins, sometimes referred to as Pre-digested or Hydrolysed proteins.
<b>ASPIRATION</b>	A procedure used to determine the position of the end of the tube. It is also a term to mean removing feed from the lungs by suction.
<b>BOLUS FEEDING</b>	A prescribed volume of feed given slowly via a syringe at a specific time.
<b>BURIED BUMPER SYNDROME</b>	A rare complication which occurs when the PEG tube migrates between the stomach wall and the skin.
<b>CONTINUOUS FEEDING</b>	A method of administering feed from the reservoir into the gastrointestinal tract over a continuous length of time. A pump is usually used.
<b>DEHYDRATION</b>	The loss of water and salts essential for normal body functions.
<b>DIETARY FIBER</b>	Indigestible carbohydrate can be either soluble or insoluble. Insoluble fiber increases bulk to the content of the large intestine facilitating bowel function and excretion.
<b>DUMPING SYNDROME</b>	A set of symptoms caused by the rapid delivery of food/feed into the GI tract.
<b>DYSPHAGIA</b>	Difficulty swallowing.
<b>ELECTROLYTE</b>	A chemical that conducts electricity when dissolved and maintains the homeostasis (balance) of the body, regulating cardiac and nerve functions, fluid balance and oxygen transport.
<b>FLUSH</b>	Administering a small volume of water through the tube to clean it after you have used it to deliver your feed or drugs.
<b>FISTULA</b>	An abnormal opening between 2 organs or 1 organ and the skin.
<b>GASTROSTOMY TUBE</b>	A tube inserted directly into the stomach through the abdominal wall.

## Glossary of Common Terms.

**This is not an exhaustive list! If you hear any term that you don't understand, please ask someone to explain it to you.**

<b>GIVING SET</b>	Plastic tubing used to connect the container to your tube. (Sometimes called the delivery or administration set)
<b>GUIDEWIRE</b>	A removable, fine wire which runs through the lumen of the feeding tube to assist in its placement. It is removed once the position of the tube has been verified.
<b>JEJUNOSTOMY TUBE</b>	A tube going directly into the jejunum (part of the small intestine)
<b>LITMUS PAPER</b>	Used to confirm correct tube placement.
<b>NASO-DUODENAL</b>	A tube passed through the nose and down to the duodenum (part of the small intestine) to enable feeding to bypass the stomach.
<b>NASO-GASTRIC</b>	A tube passed through the nose and down into the stomach
<b>NASO-JEJUNAL</b>	A tube passed through the nose and down into the Jejunum (the second part of the small intestine), bypassing the stomach and duodenum.
<b>OSTOMY</b>	A surgically created opening.
<b>REFLUX</b>	'Burp-back'
<b>RESERVOIR</b>	Glass or plastic container used for the feeding solution
<b>REFEEDING SYNDROME</b>	A condition which can occur during feeding after illness, caused by shift in metabolic activity. Requires medical treatment.