



PINNT

A SUPPORT GROUP FOR PEOPLE
RECEIVING ARTIFICIAL NUTRITION

Enteral Feeding: Your Questions Answered.

Paediatrics.

Questions frequently asked by parents/carers of children
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 the condition and the expected duration of your child needing enteral feeding. For children 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 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).

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 the needs of the individual. Your child’s nutrition team will have reviewed these needs accounting for the energy and nutrient requirements and will prescribe a solution to fit those specific needs.

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

What is the “feed”?
(cont..)

In simple terms, the feed mixture is essentially a nutritional milkshake that contains all of the nutrients that your child needs. It is something that will be reviewed on a frequent basis as children are constantly in a state of growth and development, therefore it is likely that you may find the amount and types of feed that is prescribed to your child is altered. Despite the underlying health conditions which facilitated in the need for enteral feeding it is important that your child is able to grow and develop at a rate consistent with their peers.

Why can I not just puree food and syringe it through their tube?

It is tempting to think that as the feed is essentially liquid food that it is ok to syringe pureed foods through the tube, but this is not advisable at all. The feeding tubes are not designed to accommodate this and you are likely to find that they become blocked more frequently, even if you ensure that all lumps are removed before you syringe the pureed foods through, the texture is different to that of the feed and will form a layer on the inside of the tube, which overtime will result in blockages.

It is also worth remembering that whilst the feed is essentially liquid food, it is far more specific than that. A great deal of time and expense has gone in to the manufacture of these feeds to facilitate that the nutrients are delivered in a form that is easy and affectively digested. There is a lot of evidence to show that the processing of pureeing foods, can for some foods reduce the number of vitamins and minerals available for absorption, meaning he/she does not get everything that you think you are giving them and that they need.

If you still believe that you want to do this, then it is advisable to discuss this further with your doctor and/or dietitian.

Will my child ever be able to eat real food?

You doctor will tell you what is happening and what you can and cannot do at regular appointments. If he/she believes that they can manage to eat food, then he/she will encourage you to encourage and enable them to do so. You will probably be advised to start slowly and will be given information on how to do this.

Some children will not be able to eat anything at all, some will be able to eat a little and some may be able to eat normally and no longer need the tube and many will spend periods in each of the three situations depending on their state of health.

When will my child be fed?

There are a number of different factors involved in deciding when it is best to feed your child and your child's nutritional team will decide what the best method is accounting for your child's needs and the practical issues around the actual feeding method and duration. Some children are fed continuously usually – overnight and are therefore unencumbered throughout the day. Others are fed at intervals throughout the day, similar to ordinary meal times, this can be via a pump or using the bolus method and some child 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 child and their parents depending on the family situation and the needs of the child.

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. A giving set is used to connect your child's feeding tube at one end to the feed bottle (or reservoir) at the other end. 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). Should a problem be encountered such as a blocked tube or a finished bottle the machine will alert you to this, 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 your child and gravity allows it to flow through a giving set to the feeding tube. Alternatively the feed can be placed into a large syringe, which is connected to the feeding tube and slowly dispensed through the tube.

If my child uses a pump, then do they 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 your child can continue to get on with normal activities during feeding.

Can the rate be increased to get it through quicker?

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 your child. It would not be their intention to make the feed last too long, especially in children, 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.

How will it affect my family and friends?

By the time your child leaves hospital, your family and friends would have had time to adapt to this new situation. Once at home it is up to you how much or how little you want to tell people about your child’s illness. Most people are quite relieved to know that the new treatment is improving the situation and accept that no matter how unusual they may find it, if it helps then it is fine with them. Siblings, depending on their age may find the situation a little confusing at the beginning, but explaining to them what the new situation is and why it is needed is likely to help them understand and adjust.

Will I be able to cope?

Your ability to cope with your child's treatment should have been carefully assessed by your child's nutrition team, dietitian or nurse prior to your child being discharged from hospital. Your child will only have been discharged because the doctors and nurses have confidence in your ability to provide the care and treatment your child needs.

The procedures are relatively simple and repetitive and if it is possible another family member or close friend will have been taught the procedure and can provide you with support when necessary. Being a parent is always a challenge, but when your child is on enteral feeding it can be a little more challenging at times, but with support from your family, friends and health care team life can be made easier emotionally and practically.

Will my child be able to go to school?

There is every chance that your child will be able to attend school and the doctor will inform you of when they believe that it is appropriate for them to do so. You will be included in this decision and your care team will help yourself, your child and the school establish a safe and effective environment.

My child has to be fed during the day, can he still attend school?

Yes, generally speaking there are no medical or physical reasons why your child can not attend school and to do so on a full-time basis. There will of course have to be specific arrangements made with the school and the level of intensity will depend on the age of the child, their personal care needs, and their own level of independence and the facilities of the school.

If your child has never been to school before, then there will need to be a meeting with the school to explain the situation and organise for extra support if needed. The school nurse may not be formally trained to deal with enteral feeding and/or may not be confident in doing so. Arrangements will need to be in place to ensure that there is someone on site who is able to provide assistance to your child, especially in an emergency. This responsibility may fall to you to begin with, but it may be possible for the school nurse to be trained either formally or even by yourself (after all you are an expert!), or the school may be willing to recruit a Special Education Needs Support (SENS) worker.

The same type of meeting and arrangements will need to be made even if your child has been to school prior to starting treating. You may find in this instance that the doctor suggests that the return to school be staggered, to allow both your child and the school to familiarise with the new situation and ensure that everything is in place for your child and their safety.

Can my child play sports at school?

Again, this will depend on your child's state of health, level of mobility and the school policies. Your doctor will provide you with information regarding what sports he/she are able to participate in and which should be avoided. In general exercise is beneficial to the growth and development of your child, so it will only be advised against for a good reason.

You may find that he/she is advised against contact sports, as there is a potential risk of displacement of the feeding tube, which could be very dangerous.

You will also need to discuss this with the individual school as there may be additional requirements for supervision or support for your child during sports, due to insurance and health and safety policies.

Can my child go swimming?

Yes, even with a Nasoenteric tube (a tube fed from the nose) you are allowed to go swimming. You may have to wait a little while if you have been in hospital for anything or you have had a tube inserted into your stomach or intestine through your abdominal wall.

Can my child play outside?

Yes, there is no reason why you will not be allowed outside to play in the fresh air. You may need to have an adult with you to make sure that you are safe, but as you get older you may be allowed to do more things for yourself.

Will my child be able to make friends?

Yes, there is no reason why they cannot make friends just like everyone else. Even if the tube is in your nose, it generally does not make it any more problematic to make friends, especially when they are younger. They may even find that other children will want to talk to them based on curiosity about the tube.

There may be more issues when he/she gets older and become body conscious, but there will be support offered to help them to deal with this.

Will my child accept their body with a tube sticking out of it?

There is always a worry about how feeding tubes will affect body image and in children there is often more concern that if they require a feeding tube during puberty and adolescence that this can be a more difficult issue and could have physiological issues which continue into adulthood. Every child is likely to deal with this differently and in children who have had a feeding tube in place since birth or from a very young age that they may be more accepting of its presence and able to overcome the body image issues easier than children who find they require a feeding tube for the first time later in their childhood.

Will my child accept their body with a tube sticking out of it?(cont...)

No matter how comfortable your child may be with their feeding tube and their specific requirements, puberty especially is difficult for almost everyone when it comes to body image. It is important to remember that there is support available from your child's health care team and it is likely that the team will be aware of the increased potential for body image issues in child with feeding tubes in situ.

Can we go on holiday as a family?

Yes, your doctor will make sure that he/she are safe to travel and will discuss with you some of the practical issues that you will need to consider before you travel. They will be able to provide documentation to allow you to obtain travel insurance and supply fitness to fly certificates (if applicable) and give you practical advice on managing away from home.

Will my child be closely monitored for complications when they are at home?

One of the big issues will be ensuring that there is sufficient enteral feeds and equipment available for you to take and this will be done by your homecare company. Depending on the length of the holiday they supplies will be delivered to you direct, for you to take with you or for longer holidays they may transport the supplies directly for you. You will need to make arrangements with the airline and airport to ensure they are aware of your requirements and you will be asked for a medical note from your doctor to confirm the need.

Why does my child need to have regular blood tests?

Yes, your child 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. If your child is old enough they too will be instructed on the correct procedures..

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

It is important that your child is receiving the best feed for your needs and you may find that as their treatment continues and they get older that their requirements may change.

It is essential to ensure that they are getting the appropriate mix of nutrients and therefore regular blood test will help to determine whether their needs are being met. Anyone on Enteral nutrition, particularly if they are just beginning treatment and/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 of 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 Syndrome?

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.

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.

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.

Can my child get food poisoning if they don't eat?

YES, it may seem strange to think that your child can still get food poisoning when they do not eat food, but essentially food poisoning is when unfriendly and harmful bacteria are able to enter the gastrointestinal tract (GI). Because these bacteria need a supply of nutrients we find them on foods and when we eat such foods we allow them to enter the GI tract. The feed is basically a liquid form of all these nutrients providing a perfect medium for bacterial growth. Without good hygiene during tube feeding, contamination with bacteria could cause food poisoning. Your hospital will teach you how to prevent this happening.

How do I explain to my child why they have their food this way?

It is important to explain the reason for needing this type of nutritional therapy in a way that is appropriate for your child. No one knows your child better than you do and you will know how to explain things to him/her. It is therefore recommended that you make sure that you are fully informed with the situation, with how things stand at the moment and the reasons for the treatment being given and how things are likely to progress in the future.

When you are more informed with things then you will find a way to explain them to your child. How you go about telling them is something that cannot be planned, child are unpredictable and naturally curious and question things around them. Use your instincts as a parent to know when and how to inform them.

With so many reasons behind the need for enteral nutrition it can be confusing to explain the entire condition and the mechanics behind nutritional requirements. It may therefore be useful to remember that despite the physiological reasons behind the need for enteral feeding, it comes down to the basic necessities for all life. In order to grow and develop we need to give our bodies the ingredients to do the job. Whether the ingredients come from food or from the feed, the body will get what it needs to grow big and strong.

Will my child still 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”

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.

How will I get all of the feeds and equipment that my child needs?

When your child leaves hospital you will be told about the “Homecare” company that your local health authority uses. These will take over the responsibility for ensuring that your child has 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 your child has left and what they will require to cover the next period. 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.

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 child’s 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, if you know that you will not be available to collect the delivery.

What if the pump breaks down?

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?

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.

ASPIRATION	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.
BOLUS FEEDING	A prescribed volume of feed given slowly via a syringe at a specific time.
CONTINUOUS FEEDING	A method of administering feed from the reservoir into the gastrointestinal tract over a continuous length of time. A pump is usually used.
DUMPING SYNDROME	A set of symptoms caused by the rapid delivery of food/feed into the GI tract.
FLUSH	Administering a small volume of water through the tube to clean it after you have used it to deliver your feed or drugs.
GASTROSTOMY TUBE	A tube going directly into the stomach through the abdominal wall.
GIVING SET	Plastic tubing used to connect the container to your tube. (Sometimes called the delivery or administration set)
GUIDEWIRE	A thin wire used to strengthen a feeding tube while it is being placed.
JEJUNOSTOMY TUBE	A tube going directly into the jejunum (part of the small intestine)
LITMUS PAPER	Used to confirm correct tube placement.
NASO-DUODENAL	A tube passed through the nose and down to the duodenum (part of the small intestine) to enable feeding to bypass the stomach.
NASO-GASTRIC	A tube passed through the nose and down into the stomach
REFLUX	'burp-back'

Glossary of Common Terms.

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RESERVOIR

Glass or plastic container used for the feeding solution

REFEEDING SYNDROME

A condition which can occur during feeding after illness, caused by shift in metabolic activity. Requires medical treatment.