



PINNT

A SUPPORT GROUP FOR PEOPLE
RECEIVING ARTIFICIAL NUTRITION

Parenteral Feeding: Your Questions Answered.

Adults

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

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What is Parenteral Nutrition?

Parenteral Nutrition (PN) is a means of supplying your body with nutrients and water which bypasses the digestive system. This is achieved through the insertion of a catheter directly into the bloodstream, through which a feed that is specific to your needs is administered. This is commonly referred to as Total Parenteral Nutrition (TPN).

What do the letters TPN mean?

TPN is a common abbreviation for TOTAL PARENTERAL NUTRITION. This literally means to eat (-enteral) through the vein (par-). However the terms PN (Parenteral Nutrition), HPN (Home Parenteral Nutrition) and TPN are often used interchangeably.

How will the nutrition enter my veins?

A very fine soft tube known as a 'catheter' is inserted under the skin of your chest wall into a large vein that leads to your heart. A local anesthetic is given beforehand to minimise any discomfort. A mild sedative may also be given while your catheter is being inserted. Once the correct position of the tip of the catheter is confirmed it can be connected to a container of PN fluid using a giving set.

Will PN contain everything I need?

Your doctor and the nutrition team will have calculated the amount of nutrients you require in your PN to keep your body well nourished. This is done by making measurements of your weight, height and by blood tests and urine collections. Changes may be made to your feed to meet your on-going needs. Due to PN being prescribed on an individual basis, some people may make additions to their PN, if this is necessary they are taught how and when to do this.

When will I be fed?

Most people on PN feed whilst they are asleep however it is well documented that the infusion time often extends beyond time spent asleep. You will determine how best to fit in the time you require in order to complete your infusion time with your lifestyle. During the night sleep patterns may be disturbed due to necessary visits to the toilet. Many people find they adjust to this over time but people reported sometimes feeling tired depending on the number of times they need to get up. Feeding as much overnight allows freedom during the day, evening or morning. Each person's infusion time will be agreed in line with your personal needs. New patients may be given a set time with this being reduced over time.

Will I be confined to bed or at home?

HPN should not be restricted to lying in bed or staying at home unless that is your choice or is necessary for your individual needs. Portable feeding pumps have made it easier to be mobile whilst receiving your feed. Not all patients want to use a portable pump but improved mobility can be achieved with smaller drip stands for use around the home.

How long will I need to be on PN?

Some patients will require PN for only a short time, such as to permit the digestive system to rest following surgery or illness or for a variety of reasons. For others they will require PN for the rest of their lives. If a specific condition improves then PN can be reduced or in some cases patients may be switched to enteral feeding depending on their specific medical needs.

Will I be able to eat and drink?

This will vary according to your condition. Your doctor may suggest that you eat and drink as well as receiving HPN. In fact you may wish to continue eating and drinking on a social basis, which even if your digestive system is unable to absorb the nutrition may help you to feel included in social activities. Your doctor will advise you whether you are able to do this. This is one aspect that may change from time to time depending on your personal needs. If you are constantly thirsty you should contact your doctor or nurse and oral fluids will not replenish the thirst and may actually be detrimental to you. There are some oral mixtures for patients who want and need to drink which contain sugars and salts; these may be suggested on an individual basis.

How will PN affect me on a day to day basis?

This will depend on the symptoms of your underlying illness. However many patients say that they feel stronger than they have for some time due to being well nourished and hydrated and therefore more able to cope with life.

Will I have to brush my teeth?

Even if you are unable to eat or drink anything, it is very important that you maintain good oral and dental hygiene. Continuing to brush your teeth at regular intervals and to routinely use mouthwashes are important as plaque can quickly build up, especially if your mouth is dry.

Will a line/stoma, affect what I can wear?

Most people tend to carry on wearing exactly the same clothes as they did before all of the surgery, including jeans. It is important that whatever you wear you feel comfortable in and there is no reason why you cannot be fashionable and wear the latest trends because you have a line/stoma.

Will I be able to cope?

Your ability to cope will have been carefully assessed by your nutrition team prior to you leaving hospital, and you will only have been allowed home because the doctors and nurses have confidence in your ability to look after yourself.

If you have been trained at home you will still have access to all the usual support networks and should let people know if you do not feel you are coping or if things change.

It is important that any fears you may have are relayed to your nutrition team who will provide support whenever you need it. If you have nurses coming to your home then you can chat to them if anything worries or concerns you.

Nearly all patients feel anxious and frightened when they are discharged home and the hospital staff are used to patients contacting them after discharge. You may receive the support of a homecare nurse who can be especially supportive to new patients. Your ability to cope may also change depending on how your underlying condition affects you on a day to day basis. It is not unusual for people to have mixed emotions even after a long time on HPN.

How will it affect my family and friends?

The feeding is organised to cause as little disruption as possible to the lives of both you and your family. By the time you leave hospital, your family and friends will have had some time to adapt to your new lifestyle. Once at home you can decide how much or how little you want to tell people about your therapy. It is advisable that at least one relative or friends should be familiar with the practicalities of HPN. It is natural for people close to you to want to care for you and protect you, but it is far more beneficial to receive encouragement and support rather than sympathy to help you regain your independence to the best of your ability.

How will people react to me?

When disconnected from your feed it will not be obvious to anyone that you require artificial nutrition as the catheter will be concealed underneath clothing. If for any reason you need to infuse their PN in the company of other people it is entirely your decision as to how much information they share. Some people share the basic information as to what it is and why, others are happy to go into greater detail. The key factor is to tell people as much as is needed in order to ensure you are comfortable being in their presence. Depending where and why, if there is a need to consider safety, then it is best to tell others around you so you remain safe.

Will I be able to have a cat or dog?

Lots of patients on PN have pets and they are perfectly safe to do so. There are obvious precautions if you do own pets and have a central line, etc. but they are really about being sensible and protecting your line and always washing your hands after you are in contact with them.

If you have a guinea pig, hamster, or other little animal that like to nibble on anything and everything, then it is advisable to ensure that they never get close to the central line or giving sets.

Can I lead a normal social life?

Normal life and social activities should not be restricted by your feeding regimen. You may wish to fit your feeding around your activities but be sensible. **IT IS IMPORTANT THAT YOU ARE THE MASTER OF YOUR TREATMENT AND NOT IT OF YOU!** Remember that your underlying illness may cause limitations which have nothing to do with your HPN. Social interaction is important if this causes you any concerns then discuss your fears with a friend or family members so they can assist you to overcome any issues.

Will I be able to work?

There is no reason why being on PN will prevent you from working. Working will very much be dependent upon other factors such as why you are being fed and how your underlying condition affects you. Once you have settled into a routine and have adjusted to your feeding you may be ready to return or start seeking employment. You may feel better able to cope with work than you have for some time. Portable equipment makes it possible to feed whilst you are working although this will depend on your occupation and personal ability. If you are unable to return to work it may be difficult to accept so consider retraining or voluntary work within your means.

Can I play sports?

If you feel well enough then there are many sporting activities you can enjoy. Common sense should prevail at all times. Avoid discomfort or harm occurring to yourself and your catheter. You should talk to your nutrition team before undertaking water sports or any activity which is very strenuous.

Can I get my dressing wet?

Central line dressing should be kept dry at all times although each individual unit or hospital will have their own guidelines for water activities, e.g. bathing, showering and swimming.

Can I lead a normal sex life?

If you want to - yes. It is advisable that your line should be securely taped in place to avoid displacement. Discuss any feelings or anxieties you may have with your partner, a period of adjustment may be necessary for both parties. Adjustments to altered body image may take time to come to terms with. There is no set time limit because each person is an individual and will therefore respond differently. Underlying medical conditions may affect energy levels therefore interest in sex will vary just like a normal person. If you or your partner have views or emotions that you wish to discuss with people in similar situation PINNT is there to help.

Many women find that irregular or absent menstrual periods are restored to a regular monthly cycle when on PN. It is also important to remember that women with absorption problem should not rely on oral contraception as a method of birth control.

Can we have children?

If you are a women on home PN and would like to have children, please discuss it with your hospital doctor first. It is possible for women on PN to have normal well nourished children. It will be important to ensure you are nutritionally well and all aspects of your medical condition have been considered.

What will my children think about my line and feeds?

Children generally seem to adapt well to anything that they encounter and it is often best to keep them informed and let them know what's happening. The amount you tell them will be dependent upon their age and ability to understand, but by including them you are helping to dispel the worries that they will be experiencing.

Am I going to experience a lot of complications being fed by PN?

With careful management and following the hygienic protocols described by your hospital nutrition team, you should find that you experience very few problems, but it is unrealistic to pretend that nothing can go wrong and therefore you will be given information about the types of things that can occur and more importantly the initial signs and symptoms to be aware that something may not be right.

What are the common complications that can arise when on PN?

The most common complication to arise from PN is INFECTION and recognizing the early signs are extremely important. You will be given comprehensive information to recognize the signs and instructions on what you will need to do. If this does not happen ensure you ask prior to discharge. Always make sure you know how to contact your medics outside of normal working hours.....(cont)

What are the common complications that can arise when on PN? *(continued)*

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Never ignore obvious signs of infection or complications.

All hospitals when discharging patients home on PN should provide written information on procedures, complications, contact details along with any other information they feel appropriate.

Not all line infections result in the removal of the line, they should be preserved for as long as is possible in situ. A decision will be made depending on the type of infection as to whether a treatment plan can be instigated and successfully save the line. This will vary but removing the line should not be seen as the only option. If you find yourself in a hospital other than your treating hospital it may be advisable for the consultant caring for you makes contact with your own consultant so they can discuss treatment options.

How will I know that my line is infected?

If you have a temperature soon after your have started to feed then you should seek advice immediately or follow the instructions you have been given. You may also experience shaking, 'rigors'. Not all infection start soon after feed has been set up. If you find yourself having cold or flu like symptoms and just don't feel right contact your unit or follow the instructions you have been given. If you suspect that the line is infected seek medical advice immediately. The sooner the infection is diagnosed, or ruled out, the better it is for you and your line.

The only way of knowing for sure whether your line is infected or not, is by having a blood cultures taken which will be monitored by your unit to see what grows. Watching for early indications of an infection are key to your personal welling being - these include redness, pain and /or discharge from the entry site, and you may experience systemic symptoms such as fever, headaches, lethargy. If in doubt, ask, it is better to be safe than sorry.

What would happen if I damaged the line or pulled it out by accident?

Seek medical attention at once. Depending on type of damage to the line you will be given appropriate advice from your unit. Always clamp off the line if there is damage to the external segment of the catheter. It may advisable to ensure you have a pair of plastic clamps at home in the event that the clamp breaks, these can be requested from your unit or home care provider.

I'm told how very important my aseptic procedure is, but some medical staff do not seem to be as aware of how important it is, should I tell them?

YES, always tell them! If anyone tries to attempt anything with your line that you are not fully happy with always say something. If you are not at your usual hospital then ask them to speak to your own team for advice. There are variations in protocols but at no time should you feel your safety is being compromised. If you feel good practice is not being carried out ask to speak to the ward sister or the consultant currently looking after you and get your point across. This is where written literature from your own unit or hospital is important to demonstrate the standards of care you use. Unfortunately there are still medical staff out there that are unaware of how important the lines are and remember not all staff are trained in Parenteral Nutrition and you will probably find that your own knowledge is far more extensive than theirs. Try to work with people to ensure you are comfortable in their care; being in a hostile situation is non productive for all concerned.

Never be afraid to speak up, it is your life line, you have a voice, use it!!

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 special arrangements but this should not deter you. Speak to your hospital, homecare provider or to PINNT who may be able to help you consider your options and talk you through what preparations and planning is advisable. The PINNT Holiday Guidelines are a good place to start. It is recommended that people aspire to their own goals and not be influenced into travelling just because they know other have and do. Always focus on what you want to do and try to achieve this.

What if I am on holiday and I show signs of complications?

What to do in the event of a complication while on holiday should be something considered well before departure or when it happens. Whether holidaying abroad or at home, you should have a plan. Consider who you would contact based on where you are going or how you would get back home. If travelling abroad it is essential that you have appropriate travel insurance to cover any medical care and medication you may require. Medication and hospital costs can be expensive in some countries. When travelling to Europe ensure you take your EHIC card. Always check prior to departure that your EHIC card is valid. If applying via the internet for a EHIC card do not pay for it – these are free.

It is essential that if you feel unwell or suspect anything is not right you **SEEK MEDICAL ATTENTION IMMEDIATELY**, if only to reassure yourself that everything is ok.

What if I am on holiday and I show signs of complications?
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If you are travelling abroad do consider that there could be a language barrier where English is not widely spoken or understood. If this is the case then you should consider ensuring that any relevant medical information supplied by your hospital is translated so you are able to convey key message to people who may be caring for you.

If the question above do not cover what you were looking for them please email PINNT at: info@pinnt.com with questions and we will seek answers and add them to the list.

While this list of Q&A's has been answered to the best of our ability this does not replace individual medical advice that is provided directly to you. You should never accept anything you read as suitable for you without clearing it with your own healthcare professionals.

Each PN patient is an individual, while there are commonalities there are also huge variations even with PN, underlying conditions and personal expectations.

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.

AMINO ACIDS	The building blocks of proteins, sometimes referred to as Pre-digested or Hydrolysed proteins.
CATHETER	A fine hollow tube used to introduce fluid into a vein. They are referred to by the manufacturer's name, e.g. Broviac or Hickman.
CATHETER HUB	The part of the catheter which connects to the giving set or catheter cap.
ELECTROLYTE	Mineral which conducts chemical energy when dissolved in water, particularly important in maintaining water balance and cardiac output. e.g. Sodium, Potassium.
EMULSIFICATION	The mixing of two substances that are not normally mixable with the use of a substance that can mix with each of them.
ENTRY SITE	The place where your catheter is inserted into the vein.
EXIT SITE	The place where the catheter comes through the skin (and is covered by a dressing) NB. Some catheters are implanted and the exit site is under the skin.
FISTULA	An abnormal opening between 2 organs, or between 1 organ and the skin. Some are the result of deliberate surgical intervention.
GIVING SET	Specifically designed tubing to connect the feed container to your catheter.
HAEMATOCRIT	The volume of the blood that is composed of red blood cells. This level can be used to detect early signs of Anaemia (low levels) and dehydration (high levels)
HYPERGLYCAEMIA	A high blood sugar level which if left untreated can lead to complications with eye sight, infections and ulcers.
HYPOGLYCAEMIA	A low blood sugar level (sometimes called a hypo), which left untreated can develop into a diabetic coma and death.
ILEUS	Paralysis of at least part of the Gastrointestinal Tract
INFUSION	The process whereby fluid is delivered into a vein.

Glossary of Common Terms.

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INTRAVENOUS	Going directly into the vein.
PARENTERAL	“to eat via the vein” (literal translation)
REFEEDING SYNDROME	A condition which can occur during feeding after illness, caused by shift in metabolic activity. Requires medical treatment.
SALINE	Salt solution.
SHORT BOWEL SYNDROME	Resulting from the removal of a portion of the small intestine, with characteristic symptoms including impaired digestion & absorption.
SEPTICAEMIA	A widespread infection carried in the bloodstream.
TOLERANCE	The degree to which symptoms arise from an infusion of formula
PN/TPN	Parenteral nutrition/Total Parenteral Nutrition – when all the nutrients needed are delivered directly into the bloodstream