

Home Parenteral Nutrition (HPN) Information for Patients and Carers

Introduction

This leaflet gives you information to help you understand what home parenteral nutrition (HPN) or home intravenous (IV) fluids are and why you may need them. If you still have questions after reading it, please speak to a member of the Intestinal Failure Nutrition Support Team who will be able to explain more.

Important points:

- It is generally only beneficial to give HPN/home IV fluids if you need it for at least three months.
- You will be registered with a private home care company who will provide you with all the necessary equipment to have your HPN/IV fluids at home.
- Your details will be added to the national Intestinal Failure Registry.
- **You or a relative/carer will need to be trained to administer the HPN/IV fluids.** Training may take place in the hospital or rarely at home depending on availability of services.
- While you are receiving HPN/IV fluids you will be under the care of the Intestinal Failure nutrition support team at the Queen Elizabeth Hospital Birmingham. All your HPN/IV fluid follow up appointments will take place here.

What is Parenteral Nutrition?

Normally when you eat, food is broken down and digested in your gut. The nutrients are then absorbed through your gut and into your blood stream. Parenteral Nutrition (PN) also known as Total Parenteral Nutrition (TPN) is a special nutritional formulation in a bag that can be given directly into your blood stream without the need to go into your gut first. It is a way of providing nutrients when you are unable to be fed into your gut or if you cannot absorb the nutrients, you need through your gut.

What are intravenous (IV) fluids?

Normally when you drink, fluid and electrolytes are absorbed through your gut and into your blood stream. Like PN, IV fluids are a way of giving you fluids and electrolytes to hydrate you without the need to go into your gut first. You may have had IV fluids, also called 'a drip', if you have been in hospital for other reasons.

What is Home Parenteral Nutrition/Home IV Fluids?

For most people, PN or IV fluids will only be given as a short-term treatment while they are in hospital. However, there are a small number of people who need this type of nutrition/hydration for a longer period. So, in some cases, it is possible to give these therapies at home. HPN is where the same special nutrition given in hospital is provided in your home environment. Home IV fluids is where the IV fluids you may receive in hospital can be given in your home.

Why do I need to be fed/hydrated like this?

You will have been diagnosed with intestinal failure. PN provides the nutrients that your body needs by avoiding the gut and the way nutrients are normally digested. IV fluids may be used if you are able to absorb nutrients but need help with hydration. HPN or home IV fluids mean that

you do not have to remain in hospital to receive this treatment.

How long will I need HPN/Home IV fluids?

This will depend on your individual circumstances. Some people will need it for a number of months while others may need this lifelong. Once the decision has been made for you to have HPN/home IV fluids and your medical or surgical condition is stable, you will need to be in hospital for about a further two to three weeks to ensure we have the correct parenteral nutrition formulation or IV fluid plan for you.

What kind of HPN/IV fluids will I have?

If you need HPN, bags and formulations are usually chosen according to your individual needs. Sometimes, the parenteral nutrition bags will contain all the fluid, calories, protein (nitrogen), and sometimes vitamins and minerals that you need. This will be calculated for you by the nutrition support team. Some people have a mixture of bags. This is often because we remove the fat (lipid) from parenteral nutrition on some days of the week. This is noticeable as bags that are white in colour contain fat (lipid) and those that are clearer or straw coloured have no fat (lipid) in them. If you have HPN you may also need to have additional IV fluids and separate IV vitamins and minerals depending on your individual circumstances.

We provide the home care company with a 'contingency' prescription for every patient's PN/IV fluid. This means that if there is ever a supply problem with your usual bags at home, the home care company have a suitable alternative to send you in the short term.

Can I eat or drink while I am having HPN?

This depends on your individual circumstances, but this may be possible. Because of their medical condition, people receiving HPN are often not able to eat or drink. This may not be permanent, but it can be very difficult when you are at home and see people around you eating and drinking normally. If you have been advised not to eat or drink, we will explain the reasons for this to you fully. Sometimes the nutrition support team may recommend a restricted food or fluid intake to you. This will be fully explained if it is relevant to you.

How will the parenteral nutrition be given into my blood stream?

Because the parenteral nutrition can irritate small veins, we cannot use a cannula as you might have seen with a normal IV drip. If you are having home IV fluids a cannula is generally not suitable as it can fall out easily and needs to be changed in hospital regularly. It is also very difficult to manage your own therapy at home if you are restricted by a cannula.

For these reasons you will need to have a central venous catheter inserted. This is a catheter that is inserted into one of your large veins that sit just above your heart. There are normally two ways to insert the central venous catheter:

- Peripherally Inserted Central Catheter (PICC) – this is where the catheter is inserted into the large veins via your arm. This is mostly for shorter term use and, if necessary, before you are fitted with a Tunnelled Central Venous Catheter
- Tunnelled Central Venous Catheter – this is where the catheter is inserted more directly via the veins in your chest. This is intended for patients with longer term needs.

You may hear your PICC or Tunnelled Central Venous Catheter referred to in several different ways. Sometimes the 'catheter' is referred to as a 'line'. Some of the terms you may hear include 'central line', 'Hickman line' or just your 'line'.

Are there any risks?

Yes.

There are risks when either the PICC or the central venous catheter is being inserted. These risks will be explained to you in full at the time but include the risk of infection and bleeding. Whilst unusual, blood clots can sometimes form in the veins, and this can be serious. This is one of the reasons we use central veins for the parenteral nutrition. There is no need to routinely take treatment to prevent clots.

When you are having HPN/IV fluids the main risk to you is developing an infection in your blood (septicaemia) from your PICC or central venous catheter. Although this type of infection is rare, it can be very dangerous for you. So, you will be given information and essential contact numbers before you are discharged home.

Sometimes, people who need HPN long term experience changes to the way their liver works. There are many reasons for this but if it is likely to be a problem for you, we will discuss this in more detail with you. We routinely check how your liver is working in the blood tests we carry out in hospital and in clinic.

Before you are sent home with your HPN or IV fluids you should be receiving the correct parenteral nutrition formulation or fluid regimen for you. However, sometimes there might be changes in your medical condition, weight, blood sugars or blood salts that require us to change your prescription. These changes will normally be picked up when we see you in clinic following discharge. You will be given contact telephone numbers in case of any queries when you are at home.

Are there any alternatives?

There is no other way of giving nutrients or fluids into your blood stream. Before deciding to offer you HPN or home IV fluids we will have explored every option to allow you to be fed and hydrated into your gut first. Using your gut for nutrition and fluids is always preferable as this method carries fewer risks and complications than HPN/IV fluids.

HPN/IV fluids will only be given if there is a definite medical reason for it, if your condition is within NHS England criteria for HPN/home IV fluids and if the nutrition support team looking after you believe it will be of benefit to you.

Will I feel hungry if I have HPN?

Even though you are being provided with all the nutrients that your body needs you will often have no food going into your stomach, therefore, there may still be periods when you feel hungry.

Planning for home

While you are in hospital, we will register you with a suitable home care company that specialises in HPN and home IV fluids. We will plan your discharge with them. Please be aware that if anything changes with your medical condition this can sometimes delay your discharge home.

Training to administer parenteral nutrition/IV fluids.

The nutrition nurses in hospital will train you to administer your own parenteral nutrition/IV fluids and some medications if needed and to look after your central venous catheter. There are many advantages for you in being able to manage your infusions yourself at home. These include:

- Being in control of your care.
- The freedom to take your HPN or IV fluids at a time to suit your routine at home.

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- Being able to give yourself extra fluids if needed, sometimes avoiding the need to return to hospital.
 - Being able to travel and take holidays.

If you are unable to manage this yourself, we will request to train a relative or carer to support you with this. They will need to visit the hospital during normal working hours for training with us. Our aim is for you/your carer to be completely independent with your HPN/IV fluids before discharge.

Please do not worry about this – the nurses will take time to teach you in small steps and will only allow you to do any step on your own once they are confident you can manage.

If you need support with dressing changes then we may ask your district nurse/practice nurse to help with this if they are able to. Alternatively, you may visit the hospital each week for dressing changes.

Will I have to stay at home all the time?

No.

Once we have the correct parenteral nutrition formulation or IV fluid plan for you, you will usually be having this for 12-14 hours overnight. With IV fluids you may have them over an even shorter period of just a few hours. This means that you are free to go out or do other activities during the day if you wish. In some cases, you will need to have the parenteral nutrition or IV fluids every night. However, we review this regularly and will alter the number of nights you have the nutrition if your condition allows for this.

When you are having your parenteral nutrition/IV fluids at home, this will be via a portable pump that can fit into a special rucksack and be carried. This means that even when you are having your parenteral nutrition/IV fluids you are free to mobilise and go out if you wish.

It is important to note that with your parenteral nutrition/IV fluids running over night you are likely to have disturbed sleep due to the need to pass urine.

At home

HPN/home IV fluids are a significant undertaking for both you and the people close to you. Many people find that HPN/home IV fluid restricts their daily activities, but when you are at home our aim is for you to be independent and lead life as normally as possible. This section explains how your HPN/home IV fluid will be organised. If you still have questions after reading it, please speak to a member of the Nutrition Support Team who will be able to explain more.

What is a HPN home care company?

There are a few commercial companies approved by NHS England to provide HPN/home IV fluids. The Nutrition Support Team will contact a suitable company and register you with them. The company will need some details about you including: your name, address, telephone numbers, date of birth, any allergies, general practitioner information and the main reason that you need HPN. The HPN, homecare company, will provide all the equipment you need for your HPN/home IV fluids. The Nutrition Support Team liaise closely with your home care company throughout the time you are on HPN/home IV fluids.

What equipment will I need?

There is a variety of parenteral nutrition and IV fluid bags. A type of parenteral nutrition called 'compounded parenteral nutrition' needs to be stored in a refrigerator. If you are receiving compounded parenteral nutrition, the HPN home care company will supply a large refrigerator that

will hold two weeks' worth. Please be aware that for safety reasons, maintaining temperature control and reducing risks of infections/contamination, only your parenteral nutrition can be stored in this. It is essential that ordinary food stuffs are not put in your parenteral nutrition refrigerator. You must also monitor the temperature of the refrigerator carefully. If your compounded parenteral nutrition is not stored at the correct temperature, you cannot use it. Other types of parenteral nutrition called off the shelf parenteral nutrition or multi-chamber bags (MCB), and normal IV fluids do not usually need to be stored in a refrigerator.

The HPN home care company supplies the pump, rucksack and administration sets that you receive your PN/IV fluids through. You may also receive equipment such as a drip stand, dressing trolley/plastic tray, dressing packs, gloves, dressings and cleaning solutions. There is quite a lot of equipment to store so it is useful to think about where you are likely to have room for the refrigerator (if needed) and equipment. It may be a spare room, dining room, bedroom etc.

Pump

Your infusion pump can send information to the hospital team regarding your HPN or IV fluid infusions. We may access this information remotely from time to time. You do not need to do anything regarding this.

What about my pets?

Many people on HPN/home IV fluids have pets. For cleanliness, it is important that pets are not allowed in the room where you store your HPN/home IV fluid equipment or the room where you attach yourself to your PN/IV fluids. You should not sleep with pets in your room when your PN/IV fluids are running.

Can I still bathe, shower or go swimming?

You can have a bath, but you must not let bath water get on to your dressing. If you have a shower you should try to keep your dressing dry. However, if your dressing gets wet, it will need to be changed.

Swimming – it is recommended that you only swim in chlorinated swimming pools as the chlorine will reduce the number of germs in the water. You should avoid swimming in the sea or other open water as this increases the risk of germs contaminating your central line. If you wish to go swimming, please discuss this with the nutrition nurses. There are waterproof dressings you may be able to purchase to protect your central line and keep it dry.

Will I have nurses at home?

Not usually but you are able to contact the nutrition nurse team at the hospital.

Rarely patients may need support from the home care company nurses. The nurse can arrive with you at any point during a two-hour slot, so you must be home for the times given to you by the company. We do not have any control over the timing of the slots. It is important to understand that reliance on nursing input can be highly restrictive in terms of preventing you going out or away, or in terms of reducing the amount of time you are disconnected from your HPN/IV fluids. If you have a nursing visit planned but are not going to be home, **you must cancel the appointment with the home care company giving them at least 24 hours' notice.**

Important note:

There can be disruptions to the nursing service provided by home care companies and their ability to visit you at home. This may be due to bad weather or in times of severe staff shortages. In these cases, the home care company may need to reduce the number of nursing visits they offer

you as part of a short term 'contingency' plan. They will always aim to ensure your safety within the contingency plan.

We aim to avoid admission to hospital for all our patients on HPN/home IV fluids. However, for some vulnerable patients, admission to hospital may be the only option if contingency plans cannot meet your individual needs in your home. In this case you may be advised to attend your local emergency department for admission.

How often will I be seen when I am discharged?

The Nutrition Support Team will see you in a specialist HPN and Intestinal Failure clinic within a few weeks of your discharge. At these clinics, you will see a consultant gastroenterologist, a nutrition nurse, dietitian and sometimes a pharmacist and clinical psychologist. At these clinics, we will check your weight, carry out blood tests, check your central venous catheter and talk through your medications with you. This is a good opportunity for you to ask questions so please make a list of things you are not sure of before attending.

We see most patients every three to six months in this clinic once their condition is stable. It may be different depending on your individual circumstances. You will have the telephone number for the nutrition nurse team in case you have any problems or questions between these appointments. The nutrition nurses at Queen Elizabeth Hospital Birmingham will be your main contact for HPN/home IV fluid queries.

Your other medical teams are also likely to arrange to see you in their own clinics for any reviews that they need to carry out with you.

Can I still go on holiday?

If you are independent with your PN/IV fluids, then you can still go on holiday and travel. If you are dependent on nurses then, unfortunately, this is unlikely to be possible.

If you are receiving compounded parenteral nutrition, you will need to ensure that there is a refrigerator at your destination that you can store your parenteral nutrition in. For the purposes of a holiday this can be a normal domestic fridge but again you must only store your parenteral nutrition in this. You also need to take a refrigerator thermometer to ensure the correct temperature is maintained.

You will need to speak to your HPN home care company well in advance and they can advise on how best to transport your parenteral nutrition /IV fluids to your holiday destination.

For some patients on compounded parenteral nutrition, we can consider short term off-the-shelf parenteral nutrition that does not need to be stored in a refrigerator to make travelling easier. These bags do not contain vitamins or minerals, and they will probably have different amounts of protein and calories to your normal bag. So, you will need to discuss this with us to see if it is suitable for you.

Will my HPN or IV fluids ever be stopped?

There are specific incidences when we may stop your HPN or IV fluids, either temporarily or completely. This includes:

- If your condition has improved and you no longer need them
- If you develop a suspected infection in your central venous catheter (we would pause your HPN/IV fluids for several days if you have an infection like this)
- If your condition or circumstances change and we feel that HPN/IV fluids no longer offer any benefit to you.

Any changes will always be discussed with you before they take place.

What is the Nutrition Support Team?

The Nutrition Support Team is a multi-disciplinary team with experience and specialist knowledge of looking after patients with intestinal failure who need HPN/home IV fluids. Although other hospitals may have patients who receive parenteral nutrition and IV fluids in hospital, only a few specialist Intestinal Failure Centres are able to provide and manage this treatment for people at home.

The Nutrition Support Team consists of consultant gastroenterologists, nutrition nurses, specialist dietitians, specialist pharmacists and a clinical psychologist. When doctors think their patient may need HPN/home IV fluids they refer them to the Nutrition Support Team to be assessed. The Nutrition Support Team will decide exactly what formulation the parenteral nutrition needs to be for individual patients and look at blood results and other tests. When we know that the parenteral nutrition is right for that person, we will contact a specialist HPN home care company to start planning for your discharge.

HELP AND SUPPORT

Clinical psychology

We understand that starting on HPN/home IV fluids can be a significant worry to you and a burden at home. The circumstances that have led to you needing HPN/IV fluids are sometimes an area of worry and anxiety in themselves. We have a clinical psychologist who works within the Nutrition Support Team to help our patients with intestinal failure. We will routinely invite patients to see a psychologist as this is a routine part of care. This may be in hospital and/or as an outpatient.

Patient support group

PINNT is a support group for people receiving parenteral nutrition or enteral nutrition (liquid nutrition given into the gut). The website is particularly helpful for people who need HPN/home IV fluids, where there is more information and access to patient forums that provide valuable support. You may wish to pay a small fee to join the group, but this is optional. Many of our patients have found PINNT to be very helpful.

Website: www.pinnt.com

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Contacts

Nutrition Nurse Team telephone 0121 371 4561 (Mon-Fri 0800-1600 excluding Bank Holidays)

Accessibility

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