

Nutrition and Dietetics

Nutrition Team: Home Parenteral Nutrition or Fluids and Electrolytes

This information is for people who have intestinal failure where home parenteral nutrition or home parenteral fluids and electrolytes is being considered. It must only be given to patients by the nutrition team.

This information has been produced to help you understand how Home Parenteral Nutrition (HPN) or Home Parenteral Fluid and Electrolytes (HPFE) works and aims to answer some of your questions. If you have further questions after reading this leaflet, or still feel you need further information, please discuss this with your Nutrition Team.

What is Home Parenteral Nutrition or Home Parenteral Fluids and Electrolytes?

Parenteral Nutrition (PN), sometimes referred to as Total Parenteral Nutrition (TPN) or Home Parenteral Nutrition (HPN) is a way of giving nutrition into the bloodstream directly. This means the nutrition does not go through your digestive system.

Parenteral nutrition is given to:

· people who cannot eat and drink



 people who cannot have liquid nutrition through a tube directly into their digestive tract.

People may have parenteral nutrition for different reasons such as:

- a blockage in the digestive system
- food cannot move through the gut properly
- the gut cannot absorb nutrients properly
- a leak in the gut

What parenteral nutrition is made of

Parenteral nutrition contains all of the nutrients your body needs – including calories (from sugars and fats), proteins, vitamins, minerals and fluid.

You may be able to absorb enough calories and nutrients and only need fluids and electrolytes when you leave hospital.

Your nutrition team dietitian will decide if you need home parenteral nutrition (HPN), home parenteral fluid and electrolytes (HPFE), or both.

Home parenteral nutrition may be temporary or permanent. This will depend on your situation.

How parenteral nutrition is given

Parenteral nutrition is given through a special line. The end of the line is in a large vein near your heart. This allows your heart to pump the feed around your body.

If you received parenteral nutrition in hospital, this may have been through:

- a line into your neck (central venous catheter)
- your arm (peripherally inserted central catheter)

Most people have a Hickman line put in to have parenteral nutrition at home. But you may be discharged with a peripherally inserted central catheter line for your parenteral nutrition.

Your nutrition team will tell you what type of line you will have and when this will be put in.

What is in the parenteral nutrition bags

The bag of PN contains a sterile mixture of:

- glucose
- protein (nitrogen)
- fat
- fluid
- electrolytes (salts)
- vitamins
- minerals

Your bag is prescribed by the nutrition team to meet your specific needs. You may receive bags that are made bespoke to your exact requirements.

You may have:

- A white bag that contains fat. This is usually given 2 or 3 days a week
- A clear bag which does not contain fat This is given on the other days

You may be on home parenteral fluid and electrolytes. Your prescription will not give you protein, fat or glucose, as you are able to consume enough calories through eating to maintain your weight, but you still need support with hydration and electrolytes.

Measuring your response to parenteral nutrition

Your response to parenteral nutrition is checked by measuring your weight, strength, muscle mass and through blood tests.

A prescription will be prepared for you by the nutrition team. You will be monitored closely and told if you need any changes to your feeding regimen.

When you're discharged from hospital, you will have regular clinic appointments with the Nutrition Team to monitor you. You will have contact numbers in case you have any questions between appointments.

Having parenteral nutrition at home

The Nutrition Team consultant will tell you the process of going home and what your individual plan will look like. You will have plenty of opportunities to ask questions and discuss any concerns you may have. Your nutrition team are also happy to discuss with your

The Homecare nurses who connect your home parenteral nutrition will contact you to find out more about you. This is to provide you, and any family members, plenty of opportunity to ask questions and to be given the information you need to be discharged. You will have plenty of opportunity to ask questions.

We will register you with a Homecare company. They will provide the home parenteral nutrition solution and deliver it to your home. They also provide the items to care for the Hickman line and connection of the feed.

The Homecare nurses will help you plan where and how to store the necessary equipment in your home. The equipment you require will vary depending on your HPN prescription. Storage requirements for the PN bags can vary between products, if you are on specially compounded bags then you will require a fridge to be delivered, this will be provided free of charge by the Homecare company and we will inform you of this. The team will discuss with you the space you need to accommodate this. If you have limited space, the team can arrange a smaller fridge to be delivered. But you'll need to have deliveries of parenteral nutrition more often.

The Homecare team will organise delivering and installing all the equipment you need.

Nursing visits

When you first go home on home parenteral nutrition, the nurses will visit you twice a day:

 The Homecare nurses will connect your home parenteral nutrition in the evening.

They will visit again the next morning to disconnect it.

The nurses usually visit within a 2-hour allocated slot. We will tell you when your allocated slot is before you leave hospital..

Caring for your home parenteral nutrition

The homecare nurses will train you, or a family member, on how to care for the connections and disconnections of your home parenteral nutrition once you are at home.

Sometimes we cannot train you. If we cannot train you, you'll need long-term nursing. Your Nutrition Team will discuss your nursing needs prior to discharge.

When you can go home

Setting up your home parenteral nutrition can take a few weeks. We need to make sure your prescription is stable by monitoring your weight and bloods.

If you have a complex prescription, we may need to request a compounding slot to make bespoke compounded home parenteral nutrition. This is because we are unable to match your requirements to our standard parenteral nutrition bags. This process can take a bit longer because all compounding slot requests are discussed once per week nationally.

We need to contact a Homecare company to supply your home parenteral nutrition and arrange nursing visits to connect and disconnect it. Once this is organised, we will give you a date for you to go home. This will be the same day that your Homecare nursing visits start.

A nurse from your Homecare company will contact you before discharge. They may arrange a home visit to get more information about your home environment, such as checking the supply of hot running water.

Risks of having parenteral nutrition

The risk of developing complications with home parenteral nutrition is low.

The main risk is getting an infected Hickman or PICC line. To help reduce the risk of infection:

- there are strict sterile processes the Homecare nurses follow when setting up and disconnecting the parenteral nutrition bags.
- tape the Hickman line out of the way of any stoma appliances.

Other complications will include line blockages or fracture.

Your prescription may need amending if it no longer meets your needs.

We will give you information on what to do and who to contact if a complication happens at home.

Can I eat and drink when I go home on parenteral nutrition?

Your dietitian will give you with individualised advice on what if and what you can eat and drink depending on the reason for your intestinal failure.

If you cannot eat and drink, your dietitian can give you advice on how to cope with this.

How long you're connected to the parenteral nutrition

You are usually connected to your home parenteral nutrition for 12 hours overnight. But this could be longer depending on your needs.

We will aim for a night off home parenteral nutrition per week. But this will also depend on your individual needs.

Your Nutrition Team will discuss the frequency and length of your home parenteral nutrition with you.

The Nutrition Team

The Nutrition Team are a specialist team who support patients that need parenteral nutrition.

There are several team members offering different areas of expertise in your HPN care:

- Dr Nicola Burch, Dr Mike McFarlane, Dr Dana Ismail and Dr Lauren O'Flynn - Consultant Gastroenterologist
- Teri Kilbane, Manuel Maniu and Barbara Ayarkwa Nutrition Specialist Nurses
- Dr Nicky Wyer, Laura Helm and Laura Woodend Specialist Dietitians
- Ruth Bates and Amir Ghajar Gastroenterology & Nutrition Pharmacist

We will send you an appointment after you leave hospital This is so we can review you and continue to monitor you.

Who to contact if you have problems at home

Before you are leave hospital, we will give you a folder of information. This will include:

- details of your Homecare company
- your PN prescription
- how to contact the Nutrition Team during working hours

There is also a guide of what to do during evenings and weekends. Your Homecare company will have a 24-hour phone number you can ring if you have any problems outside of working hours.

Going on holiday

You can go on holiday on home parenteral nutrition once you or a family member is trained.

You need to plan and discuss your holiday with your Nutrition team before you book it. Depending on your holiday destination, we may need to:

- amend your prescription
- order you more items
- provide you with certain documents

You must get comprehensive travel insurance if you are travelling abroad. This is in case of any intestinal failure or home parenteral nutrition issues that may happen.

If you no longer need parenteral nutrition

Your nutrition team will tell you if you can stop parenteral nutrition.

Your line will usually stay in for a few weeks after you stop parenteral nutrition. This is in case you need to restart on parenteral nutrition.

The hospital will arrange to remove your line. Your Homecare company will arrange to collect any equipment you no longer need.

More information

If you have any questions or would like more information, ask your Nutrition Team.

PINNT (Patients on Intravenous or Nasogastric Nutrition Therapy) www.pinnt.com

Contacts

Nutrition Nurses: 024 7696 6074

Nutrition Team Dietitians: 024 7696 7177

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