NHS
Leicester Intestinal Failure Team

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University Hospitals of Leicester
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# Palliative home parenteral nutrition (HPN)

Digestive Diseases Centre

Information for Patients

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## What is home parenteral nutrition?

- Parenteral nutrition (PN), or being fed through a vein (intravenous), is a way for you to get all the nutrition that you need when your gut is not working.
- It has the water, energy, vitamins and minerals that you would normally get from your food.
- PN when it is made up looks like a milky fluid. It comes in a large drip bag.
- It is given via a fine tube put into your vein known as a line. You may hear people refer to this as a PN line, PICC line or Hickman line.
- Some people need PN for a short period of time while in hospital. Others need to be fed this way for the long term and it is given at home. This is called home parenteral nutrition (HPN).

## What is palliative home parenteral nutrition?

Palliative HPN is used in patients with cancer whose bowel is not working properly. This is usually due to the bowel being blocked as a result of cancer.

We call it palliative HPN because it is used as part of managing bowel obstruction rather than treating the cancer itself.

Having HPN will not alter your cancer outlook. It is used to improve your nutrition and hydration when your bowel is not working.

Palliative HPN will not improve your appetite, and is not the right treatment for everyone.

Weight loss is often seen in advanced cancer. It may be due to the cancer rather than because the bowel is not working properly. This means that careful assessment with your cancer doctor (oncologist) and the team caring for you is needed before thinking about it as a treatment.

Sadly, some cancers progress too quickly for patients to improve with HPN. If this is case the team caring for you will talk about how nutrition and hydration can be supported in a different way.

## How do I know if palliative PN is the right thing for me?

Your oncologist, surgeon or palliative care doctor will have talked to you about this. If you agree they will refer you to see us.

- If you are an inpatient, we will come and see you on the ward.
- If you are at home, we will see you in our outpatient clinic.

This first meeting can sometimes feel a bit overwhelming as you will meet a few members of the team and there is a lot of information to take in. We hope this leaflet helps with this. During this first meeting we will talk to you about

- HPN
- what the aim of it is
- how it is given
- what limits it brings
- work out together if it is the right treatment for you

If you are not already seeing one of the palliative care doctors regularly, we will ask them to see you as part of our assessment process. People sometimes worry about being seen by the palliative care team, but this is a standard part of our assessment for palliative HPN. It is common for patients to have symptoms such as pain and being sick from their bowel obstruction. The palliative care team will help manage these.

The aim of palliative HPN is to make sure you are getting enough fluid and nutrition so you can keep doing your normal activities. It is a very personal decision balancing the benefits of HPN versus the burdens it comes with. It is important to know that when we come to see you it is an assessment. It does not mean that we will always think it is the right treatment for you, and it also does not mean that you have to go ahead if you feel that it is not the right treatment for you.

Sometimes people are referred to us before they reach the point of needing HPN. We can find out together if it would be the right thing for you at a later point.

## Who will be looking after me?

The Leicester Intestinal Failure Team or LIFT team is made up of doctors, dietitians, nurses and pharmacists who specialise in nutrition support. We work with the other teams involved in your care, and with the home-care nurses who support you having PN at home. We will monitor your treatment.

We will give you our contact details so that you can get in touch if you have any questions when you are at home.

## How is HPN given?

If we all agree that HPN is the right treatment for you we will arrange

- for a line to be inserted as an outpatient
- admit you to our ward (the Intestinal Failure Unit) to start the PN

We aim for this stay to be as short as possible. It is for around a week, but may sometimes be longer.

When you go home the PN will usually be given overnight so that you are not connected to it during the day.

Specialist home- care nurses come to you home 2 times a day. They will connect and disconnect the bags.

If you or your family members wish to learn how to do this yourself we will arrange training with the home-care nurses.

For many people learning to do it themselves decreases the burden of being on HPN. You do not have to plan your days around the nurse visits, but not everyone wants to take on this extra responsibility and this is ok.

## What are the risks of PN?

An infection in your PN line is the most common problem.

It will show as a fever while the PN is running.

Only people trained in how to use the PN line should hang or disconnect the bags of PN. This lowers the risk of infection.

If you get an infection you will need to be admitted to hospital for treatment.  It is important that you get help if you feel unwell or have any concerns about your PN.

## Will I be on HPN forever?

At your first meeting with the LIFT we will talk to you about

- why you have been referred for palliative PN,
- the difference that it could make to you
- some of the common problems that people have
- what you are hoping for from treatment

We do not always know how long you will need PN for. You may decide that you do not want to go ahead with it.  Some patients may need it long term. Others may be able to stop it in the future if it is expected that their bowel obstruction will improve with further cancer treatment.  Your views on HPN may change over time. We know that there are some points when it is important for us to check that it is still the right treatment for you.  Common examples of these are :

1. if you start to need regular help from other people for your personal care and daily activities,
2. If you are feeling more tired and are regularly resting for more than half of the day,
3. If there are signs that your cancer is getting worse,
4. If HPN is no longer helping you do the things you want to do day to day.

## Can I eat as well as being on PN?

In palliative PN the HPN usually gives you all the nourishment that you need. Most people do not need to eat on top of it. We know that not being able to eat and drink can be unpleasant or distressing. We will talk to you to see if small amounts of oral intake is possible alongside the PN. Where this is possible the LIFT specialist dietitians will give you personalised advice.

## What if I decide PN is not for me?

Sometimes people decide that PN is not right for them, and this is a very personal decision. The team will support you in making your decision. If you decide that you do not want PN we will make sure that your normal medical team know this and that they support you with control of your symptoms.

## Contact details

Leicester Intestinal Failure Team 0116 258 6988 (Monday to Friday 9am to 4pm)