The ROYAL MARSDEN
NHS Foundation Trust

Home Parenteral Nutrition

Patient Information

NHS

Introduction

This leaflet provides information on how to get nutrition if you cannot eat or drink. You will continue to have discussions about this with your healthcare team. You may have lost a part of your digestive tract due to your cancer treatment, or your cancer means the digestive tract cannot work properly. When this happens for five or more days, or is likely to continue without improvement, the body may not absorb enough nutrients to meet its needs.

There are various ways of providing nutrition either by mouth, through a feeding tube into the digestive tract, or by the delivery of nutrients directly into the bloodstream (Parenteral Nutrition or PN). Parenteral Nutrition is used when it is not possible to use the digestive tract to provide nourishment. This method of feeding can be used in hospital, but it requires special management if it is used for nutrition at home.

Home PN is a complex and specialist treatment, requiring 24-hour access to advice and support. Whilst it can be started by The Royal Marsden, ongoing monitoring and management take place through the Intestinal Failure team at another hospital more local to you.

What is Parenteral Nutrition?

Parenteral Nutrition (PN) is the delivery of liquid nutrition directly into a vein. You will require a central venous access device such as a PICC. The mixture of nutrients is tailored to your individual nutritional needs. It is delivered daily over a number of hours through a pump. Sometimes it is delivered through the night for convenience.

Home PN must be planned over a number of weeks (at least 4 to 6 weeks), and is never carried out in an emergency. It involves careful assessment from a range of specialist services, to decide if the benefits of PN outweigh the potential risks. The multidisciplinary team who will be involved in your care include:

- Medical doctors and surgeons
- Dietetics Team
- Symptom Control and Palliative Care Team
- Complex discharge coordinators
- Intestinal Failure Team
- A commercial homecare company providing PN equipment and support
- Local community support services
- Your GP

What are the potential benefits?

If your gut is functioning, there is no advantage to PN over usual eating and drinking or providing food straight into your stomach via a feeding tube (also known as a nasogastric [NG] tube). PN is needed if you are not able to maintain your nutrition and/or hydration status because the digestive tract cannot absorb enough to meet your needs. This condition is known as intestinal failure and is caused by disease or damage to the bowel. This can lead to problems such as diarrhoea, weight loss, malnutrition and dehydration.

Home PN can improve quality of life in some people with advanced cancer (cancer that has spread to more than one part of the body) and may help support activity levels day to day. This can improve life expectancy as long as patients meet the following criteria:

- You spend less than half of the day sedentary/resting in bed or a chair
- You have a long enough prognosis, usually many months, to gain benefit.

When the criteria above cannot be met, for example, by patients with rapidly growing (over weeks) cancer, or very advanced cancer, home PN may not prevent a general deterioration in quality of life and life expectancy. In the final stages of illness there is no scientific evidence that continuing home PN makes a significant enough improvement to patients' wellbeing. This is why the continuous, regular assessment of home PN benefits and burdens is so important in deciding whether it should continue once started.

Does PN give me all the nutrition I need?

When Parenteral Nutrition is started, your nutritional requirements are estimated and matched to a suitable bag.

There are some conditions, such as bowel obstruction, or high stoma outputs, where it is difficult to provide sufficient fluid or electrolytes (body salts) by home PN alone. In these cases, additional bags of fluid or vitamins and minerals may need to be taken alongside the feed. Therefore, home PN itself is not always a complete solution to your nutritional problems.

Also there may be occasions, such as when the cancer is progressing, in which PN is not able to prevent deterioration in your weight, muscles and overall strength. In these circumstances giving more PN is not always the solution as there can be risks associated with providing higher amounts of nutrients.

Are there any complications or risks with PN?

Once PN is started, you will need to remain in hospital for a period of time until your blood tests and PN prescription are stable.

When you are in hospital, your bloods are taken regularly and your fluid balance recorded. These measurements allow the nutrition team to adjust your feed accordingly with protein, glucose, fats, electrolytes, vitamins, trace elements and water. At home, you will continue to need regular monitoring whilst you are on PN.

You may need to attend another hospital or your GP for blood tests. This will depend on where you live and the arrangements made before discharge.

How is Parenteral Nutrition given?

PN must be delivered straight into the blood via a large vein. You will need a Central Venous Access Device (CVAD) to reach the vein. This is a type of long thin plastic tube, and there are different types. One is a PICC (Peripherally Inserted Central Catheter) line and is usually placed in your arm. Another suitable device would be a Hickman line that is placed on the upper part of the chest.

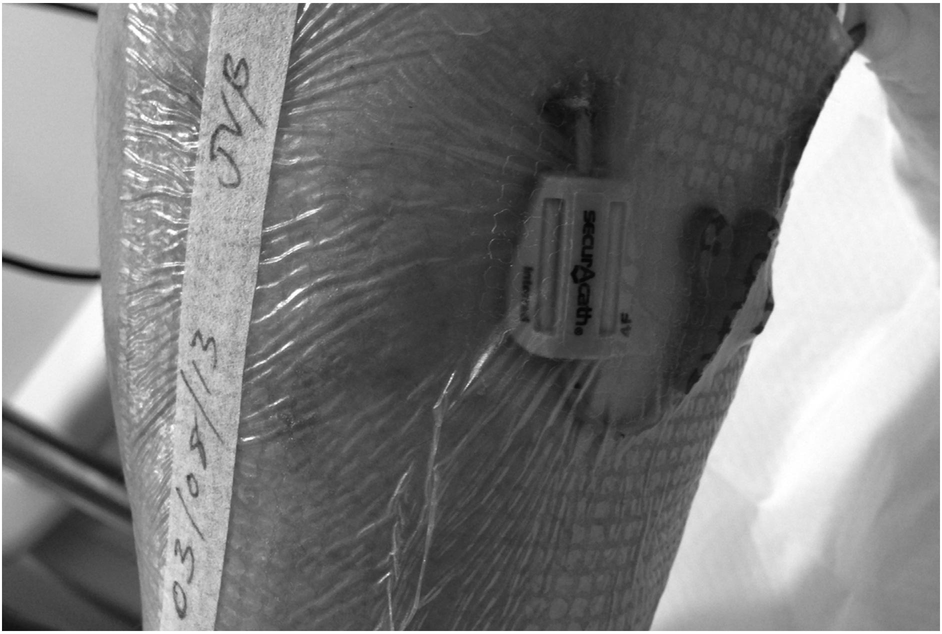

Photo of a PICC

Issues with Central Venous Access Devices include:

- Infection – Either locally around the insertion site to the body, or more serious bloodstream infections that can make you very unwell. This can be significantly reduced if strict cleanliness regimes are followed – we will provide special training. Some severe infections may require admission to hospital and removal of the central venous catheter.

- Moisture – You will need to try and keep your CVAD as dry as possible. Swimming is not allowed. You can shower or bathe only if you are careful to cover your CVAD.
- Air in the catheter – This can be prevented by clamping the line and using the sterile end clamp. All of these safety precautions will be covered in the training provided.
- Line blockage – With the right training, patients can often unblock their PICC lines themselves with simple procedures.
- Line fracture – This is splitting the line due to internal pressure, and you will be trained in how to deal with this.
- Central venous thrombosis – If you experience symptoms of arm/face or neck vein swelling or chest pain, you must attend your nearest Accident and Emergency department (A+E) for assessment. There is a risk that you will require additional visits or admissions to hospital to manage the Parenteral Nutrition.
- Line falling out – Do not panic. Contact the Nutrition Nurse at the Intestinal Failure Centre and they will arrange for you to be admitted to hospital for a new line insertion.

Are there any alternatives to PN?

There are some alternatives to PN that you are welcome to enquire about, but these are likely to need careful planning. Alternatives include:

- Intravenous (IV) fluids – these can be provided by the same commercial homecare company. This can provide hydration, increase comfort and requires less monitoring than home PN. However, fluids alone are not nutritionally complete.
- Risk feeding – this is done when people have difficulty swallowing but want to have the taste and flavour of food, and agree to swallow it at their own risk. This is a serious decision, given the potential life-threatening risks of choking or regurgitating food. This must be discussed with your

medical/surgical team, the dietitians, and the speech and language team (SALT). While the consistency of foods can be altered to minimise risks, there is no guarantee that total nutritional requirements can be met in the long-term.

How is PN organised at home?

All the necessary equipment to perform sterile procedures and administer the PN at home is provided by the homecare company. A dedicated fridge may be delivered to you to store the PN in.

You will receive a PN delivery schedule every 1 to 2 weeks depending on how often you need blood tests and how stable your prescription is.

To start with, specialist homecare nurses will come to your home every day to assist you with connection and disconnection from the PN bag. District nurses from your GP surgery will not be able to assist as this is specialist equipment. You will need to set aside a two-hour window for each nurse visit. They will also change the dressing for your CVAD line weekly.

Where possible, you will be taught, over a period of weeks, to care for your line and to administer your own nutrition. In some circumstances, it may be possible to train a designated carer for this task.

On a practical level, you will need to be well enough manage with all that is involved with home PN, or have a relative or carer at home who can help.

When can I go home?

The referral process is complex and affects when you can go home.

Step 1: The process starts when the doctors looking after you agree that you require assessment for home PN, because you fulfil the eligibility criteria.

Step 2: They will discuss this with the Parenteral Nutrition team and the ward dietitian team, who further assess whether home PN is appropriate after discussion with you and the referring team. If you are not already receiving PN they will carefully estimate your nutritional requirements, arrange for insertion of the central venous catheter, and begin the regimen in hospital under close monitoring.

Step 3: You will then be referred to a hospital-based intestinal failure team depending on your postcode. The London teams are based in:

- University College London Hospital, Central London
- St George's Hospital, Tooting
- St Mark's Hospital, Northwick Park

The case will be discussed between teams across hospitals. You may then be transferred to a ward at any of the above hospitals under the care of the Intestinal Failure Team prior to you being safe for discharge to continue the process at home. In total this process may take 4 to 6 weeks, but it may be longer. Occasionally you may remain at The Royal Marsden for these weeks if it is agreed that you are suitable for a remote set up. This involves visiting the Intestinal Failure Team as an outpatient. The Royal Marsden and the Intestinal Failure Team will link up closely. The Royal Marsden does not have the specialist services to offer ongoing management and care to patients at home on PN.

What needs to be in place before discharge?

You can go home providing:

- You are clinically stable
- The equipment is in place
- The delivery schedule of supplies is confirmed.

You will require a follow up schedule with your local intestinal failure team hospital, including regular blood monitoring and ongoing review.

What if things change?

Home PN as a treatment requires continued, regular review of its suitability. Discussion of continuation of PN may take place if:

- You establish an adequate oral or enteral diet (such as via a device from the skin to the gut directly, for example a gastrostomy such as a gastrostomy [PEG/RIG] or jejunostomy feeding tube)
- You no longer feel the benefits of continuing PN outweigh the burdens of this treatment for you or your family
- Your cancer gets to its final stages and you need to spend more time in bed resting
- The PN is causing problems such as fluid overload or electrolyte imbalances.

Your teams at The Royal Marsden are well prepared to have these discussions with you as and when they arise, and to answer any questions you may have.

Useful contacts

Please do not hesitate to contact us about any of the issues discussed in this leaflet:

PINNT: Support Group for patients on Parenteral
Nutrition and their families
PO Box 3126, Christchurch, Dorset, BH23 2XS

Website: *www.pinnt.com*

Tel: 020 3004 6193

Email: *comms@pinnt.com*

The Royal Marsden Macmillan Hotline: 020 8915 6899

You can ring the hotline 24 hours a day, 7 days a week.

Call us straight away if you are feeling unwell or are worried about the side effects of cancer treatments.

This service provides specialist advice and support to all Royal Marsden patients, as well as to their carers, and both hospital and community-based doctors and nurses caring for Royal Marsden patients.

References

This booklet is evidence based wherever the appropriate evidence is available, and represents an accumulation of expert opinion and professional interpretation.

Details of the references used in writing this booklet are available on request from:

The Royal Marsden Help Centre

Telephone:	Chelsea	020 7811 8438 / 020 7808 2083
	Sutton	020 8661 3759 / 3951
Email:	patientcentre@rmh.nhs.uk	

No conflicts of interest were declared in the production of this booklet.

Should you require information in an alternative format, please contact The Royal Marsden Help Centre.

The patient information service is generously
supported by The Royal Marsden Charity.

royalmarsden.org

Registered Charity No.1095197

Revised August 2023. Planned review August 2026

PC-1740-03

Radiotherapy and
Chemotherapy Services
F538021 & F538022