

Adult Home Parenteral Nutrition Discharge Booklet

Information for patients



Introduction

Now that you are going home on parenteral nutrition, we need to share some important information. Like all treatments parenteral nutrition (PN) can cause side effects, some of these can be kept to a minimum with good line care and regular monitoring.

The regular observations you need to do are:

Temperature

You need to record your temperature every day, especially if you are feeling unwell. This is because having a permanent Central Venous Catheter (sometimes also known as a central line) (PICC, Hickman, Broviac or Port) makes you more at risk of infections. If you develop a high temperature (more than 38°C), or flu like symptoms, contact the Nutrition Team for advice.

Weight

Keep a record of your weight every fortnight. This helps us to see if you are gaining, losing weight, or retaining fluid.

If you are continuously losing weight or gaining weight too quickly, please contact the Nutrition Team as we can discuss changes in your feed.

Observe Central Venous Catheter entry site daily

This can either be a Hickman, Broviac, PICC or Port. Observing around the entry site of the line can help identify signs of infection early.

Observe for swelling, oozing of fluid, redness, the area being hot to touch, or skin irritation. Contact the Nutrition Team if you have any of these symptoms.

General health

Observe closely for changes in your general condition, such as vomiting, diarrhoea, or increased stoma output (if applicable). Look out for signs of fluid overload, such as swollen feet or legs.

These symptoms may indicate that you need an urgent blood test and possibly a change to your IV (Intravenous) fluids/nutrition prescription subsequently.

Let the Nutrition Team know if you are suffering from any of the above.

Arriving at home following your discharge

Homecare

A homecare company will provide your IV equipment, and ensure that it is delivered safely to your home. They will receive the prescription from the pharmacist at the hospital, and supply you with the bags you need. You will get to know the homecare team, who will be at the end of the telephone to give you advice regarding supplies and delivery times etc.

When you first go home, the homecare company will organise a convenient date and time for you to take your first delivery of fluids or nutrition bags. A nurse from the company will usually meet you at home on the day of your first delivery to help you with the equipment & storage of the equipment.

After your first delivery, the company office staff will phone you on an agreed day and time, for you to re-order any items you will need in the following weeks. Most deliveries of fluids or nutrition bags are every fortnight. In a few cases, they may be weekly or monthly.

On your first delivery you will receive:

- Fridge (Compounded nutrition bags only)
Multi-chamber nutrition bags do not require a fridge.
- Pump & equipment.
- Drip stand & trolley.
- Giving sets.
- Pre-filled syringes.
- Chlorhexidine wipes.
- Gloves, Tape & Paper towels.
- Clamps.
- Needle free devices & Curoc caps.
- Dressings.

Collecton of clinical waste

Clinical waste will include your sharp-bins, all the waste used for connections and disconnections of feed/fluids (including empty bags).

Ring your local council to see what they will and won't accept in a standard bin. They may need to provide you with a clinical waste bin.

Potential problems and what to do about them

Infection

- Hot/cold/flu like feelings.
- General feeling of being unwell.
- Signs of discharge, redness, heat, swelling, inflammation, or oozing around line site.

What to do?

Measure your temperature if above 38°C, stop the infusion and contact the nutrition team straight away. If in office hours, if out of office hours contact J91.

Stoma Issues

- Contact local stoma nurse.

Dehydration

- Rapid weight loss.
- Feeling unusually thirsty.
- Dry skin and tongue.
- Passing less urine than normal.

What to do?

- Contact the Nutrition Team.
- Give yourself extra fluids intravenously (IV) as per your home prescription.

Hypoglycaemia (Low blood sugar levels)

- Dizziness, irritability, palpitations.
- Excessive sweating.

What to do?

Have something high in sugar straight away. Ensure the feed is infusing at the correct rate. The timing or rate of feed may need to be altered. Contact GP or Nutrition Team.

Hyperglycaemia (High blood sugar levels)

- Drowsiness.

What to do?

Contact GP or Nutrition Team.

Pump and stock issues

- Contact your homecare company.

Line blocked or damaged

- Unable to flush the line.
- Leakage around the line or around the line site.
- Resistance when flushing line.
- Frequent pump alarming high pressure.

What to do?

Stop the feed/fluids straight away. If line is damaged please clamp above damaged area with blue clamps. Contact the Nutrition Team.

Air in line

- Sudden onset of breathlessness.
- Fainting.

What to do?

Clamp the line straight away. If symptoms are severe, phone the emergency services (999) as you may need emergency treatment. Lie down on your left side. Elevate your feet. If symptoms are less severe, call your GP, or the Nutrition Team.

What to do when you want to go on holiday

It may be possible for you to travel abroad whilst receiving home nutrition therapy. If you are going to a hot country, you may need extra fluids to stop you becoming dehydrated.

You will have to think carefully about holiday insurance. Insurance companies must be told about your nutritional therapy, and may require a letter from the nutrition team. The team will be happy to write such a letter.

If you are going on holiday, please contact the Nutrition Team for advice with the information below, and we will be able to help you make arrangements:

Please give a minimum of eight weeks notice for all holidays.

- Mode of travel.
- Departure date (specific port for departure/ arrival).
- Return date (specific port for departure/ arrival).
- Flight number (if applicable).
- If you use a fridge for your PN, whether this is available whilst on holiday.
- Are you able to 'roll' a multi-chamber nutrition bag (MCB), we sometimes use these as holiday bags as they don't require a fridge.
- If you use pre filled syringes, are you able to break and draw up from glass ampoules.
- If you use Taurolock glass ampoules, will you require extra sharps bin.
- Do you require a medical letter for your travel company from a nutrition point of view only?

Clinic

When you are discharged you will be seen in the nutrition clinic, usually within 6-8 weeks.

You will come to clinic and have your bloods taken by the phlebotomy team, you will also be seen by the dietetic assistant to check your weight and measurements.

When attending clinic please can you wear shoes that are easy to slip off when being weighed. It is useful to wear loose clothing so that we can access the top of your arm to take your measurements. Short sleeves or a stretchy jumper is ideal.

You will be seen by one of the doctors and the wider MDT team, this may include nurses, dietitians and pharmacists.

You may be asked to come for bloods, weight check and measurements two weeks prior to your appointment. You will receive a letter regarding clinic appointments.

Other important information

- Wash all bedding at 60 degrees.
- Tattoo/Microblading/Permanent makeup - Please ensure you wash with antibacterial wash following any of these procedures.
- Please note, all independent patients who are trained on accessing central lines will have assessment/refresher training annually.

Useful website

PINTT Charity:

- Website: <https://pinnt.com/Home.aspx>

Our team

Intestinal Failure Lead:

- Joanne Orford

Consultants:

- Dr Donnellan (Gastroenterologist)
- Dr Mooney (Gastroenterologist)
- Mr Burke (Colorectal Surgeon)
- Dr Grant Zhou (Colorectal Surgeon)
- Dr Ian Botterill (Colorectal Surgeon)
- Dr McKay (Speciality doctor)

Nutrition Team Coordinator:

- Janice Penny

Nutrition Pharmacists

Nutrition Fellow

Nutrition Nurse Specialists

Advanced Clinical Practitioner

Nutrition Team Dietitians

Essential Contact Numbers

Please contact us with any specific concerns you may have regarding your home parenteral nutrition therapy.

Nutrition Team

J91, Level 4 Bexley Wing
St. James's University Hospital
Beckett Street
Leeds
LS9 7TF

Tel: 0113 206 8649 (Monday - Friday 08:00-16:00)

Email address: leedsth-tr.adultsifpatientenquiries@nhs.net

Please note the mailbox will be monitored between 08:00 -16:00 Monday - Friday. For queries or concerns out of these hours, please contact J91.

Remember if you are acutely unwell and not sure of the cause please seek advice from your GP/111. If it is an emergency please contact 999.

Out of hours: Contact Ward J91:

Tel: 0113 206 9191

(Monday - Friday 16:00-08:00, All day Saturday & Sunday & bank holidays)

St James's University Hospital Switchboard: 0113 243 3144



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Your views matter



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