Intestinal failure and home parenteral nutrition

This leaflet explains more about coming to St George’s for an assessment of whether home parenteral nutrition is appropriate for you. It includes details of why you have been referred to St George’s, what you can expect from your inpatient stay, and how we can support you at home. If you have any further questions, please speak to a doctor or nurse caring for you.

What is intestinal failure and parenteral nutrition?

Intestinal failure
Intestinal failure occurs when your intestines cannot digest food or absorb the fluids, electrolytes and nutrients essential to live. It is usually caused by obstruction, abnormal motility (inability to propel food along the digestive tract), or major surgical resection (removal of part of the digestive system). It may also be congenital (a birth defect) or caused by a disease that prevents absorption in the gut.

Patients with intestinal failure are often unable to retain energy, water and mineral balance, particularly when there has been a major loss of length of the small bowel, and this can cause malnutrition and/or dehydration. If this persists for more than a few days, nutrients and water will need to be given intravenously (via a needle in your vein). This is called parenteral nutrition.

Parenteral nutrition
The feed used for parenteral nutrition is specially prepared in the pharmacy department for each patient, and is a synthetic mixture of all the nutrients that the human body needs – water, glucose, lipids, sodium, potassium, chloride, magnesium, calcium, phosphate, fat and water-soluble vitamins. It may also contain trace elements such as zinc, copper and iron.

The feed is often given via a catheter (thin plastic tube) inserted into the vein on the chest wall. The catheter is capped when not in use to prevent air being sucked into the heart and is flushed from time to time with sterile sodium chloride solution to prevent infection.

What is home parenteral nutrition (HPN)?
If you have ongoing problems with your gut, you may need to receive parenteral nutrition at home. This will be arranged by a home care company who will deliver the feed to your home, along with all the necessary equipment, and provide nursing care and support (as well as emergency support, if needed). Although the home care team will provide this additional support, you will remain under the care of St George’s intestinal failure team, who specialise in caring for patients on HPN and will review your needs regularly in the outpatient clinic. Receiving parenteral nutrition at home can be quite complex, so it is important that you attend your outpatient appointments.
Why do I need to come to St George’s if I am considering HPN?
Home intravenous feeding is a very complex intervention to make. The intestinal failure team at St George’s specialises in caring for patients on HPN. Initial assessments regarding whether HPN is appropriate are made at the hospital by this team. The aim is for a stay in St George’s that is as brief as possible but ensures that you are ready to be sent home safely. This process means that you will only need to return to hospital for outpatient follow-up appointments or if you feel unwell.

How can I prepare for my stay at St George’s?
There is nothing in particular that you need to do to prepare for your stay, but you may wish to pack a bag containing the following items:

- Clothes and footwear (loose clothes are often more comfortable)
- Any medicines you are taking
- Toiletries (toothbrush, toothpaste and soap, sponge/flannel, dry shampoo)
- Your hospital passport / “All about me” folder (if you have one)
- Contact details for your next of kin and GP

We recommend that you do not bring any valuable items or large amounts of cash into hospital with you; however, small change can be useful for the vending machine, phone or television cards.

If you have special dietary requirements please inform the nurse upon admission.

What will happen when I am admitted to hospital?
When you arrive on the ward, the nurse will show you around and complete some forms with you. He/she will also check your height, weight, temperature, pulse and blood pressure, and provide you with a wristband displaying your hospital identification number.

During your stay in hospital you will be assessed by the various specialist members of the intestinal failure team. This may include:

- **gastroenterology doctors** – a team consisting of a consultant gastroenterologist, registrars and junior doctors, who will manage aspects of your day-to-day care.
- **nurses** – a team of staff highly trained in all aspects of intestinal failure care and accredited to safely administer parenteral nutrition.
- **gastrointestinal surgeons** – the intestinal team includes a number of highly experienced gastrointestinal surgeons, who will consider any possible surgical options that can be offered.
- **stoma therapists** – this team provides help and advice for patients adjusting to living with a stoma or fistula.
- **intestinal failure nurses** – these specialist nurses will ensure you have an appropriate line for delivery of your nutrition. They will also liaise with the home care nurses to ensure a smooth transition and that all the equipment you need will be ready and available for when you go home.
- **intestinal failure dietitians** – the specialist dietitians will undertake a full nutritional assessment and calculate your nutritional requirements to tailor the most appropriate intravenous nutrition regimen for you. He/she will also optimise your oral nutrition plan if
appropriate and will consider whether enteral nutrition (which uses your bowel and not a vein) is more appropriate.

- **intestinal failure pharmacist** – you will be frequently reviewed by the specialist pharmacist who will work alongside the intestinal failure dietitians to ensure you are on the most suitable intravenous feeding regimen. He/she will also provide advice on any medications you may need for the management of your condition, and will suggest alternatives if there is a problem taking the medication by mouth.
- **discharge coordinator** – the discharge coordinator will ensure that everything is in place for when you are ready to leave hospital.

**How long will I need to stay in hospital?**
The expected length of stay for assessment is in the region of seven to ten days, however this may be prolonged in complex cases. The length of your stay will depend on many variables, including **venous access** and **your intravenous nutrition prescription**. The team will try to minimise the length of stay as far as possible.

**Venous access**
It is very important that you have an appropriate line before being discharged for HPN. Intravenous feeding lines placed in other hospitals may not be suitable for long-term use, and if this is the case, a new line may need to be placed during your stay at St George’s.

**Prescription**
Long-term intravenous feeding is a complex treatment. Whilst you are in hospital under the care of the intestinal failure team, your prescription will be altered and fine-tuned, sometimes on a daily basis, until the prescription is stable and optimal for you. The team from the hospital that referred you will ensure that you are as stable as possible before you are transferred to the intestinal failure team at St George’s, but we may change the calories, fluid content and the levels of minerals in your feed if necessary. Only once your feed prescription is stable will we consider discharging you from hospital, and passing your prescription on to the home care service.

**Useful information about your stay**

**Same sex accommodation**
Every patient has the right to receive high quality care that is safe, effective and respects their privacy and dignity. Patients should not normally have to share sleeping accommodation or washing and toilet facilities with members of the opposite sex, however, in some circumstances, we might need to make an exception (for example, for emergency admissions and in critical care). The Department of Health has very clear guidelines that we follow closely. To find out more about these guidelines, visit [www.dh.gov.uk](http://www.dh.gov.uk).

**Visiting, telephone calls and letters**
Friends and relatives are welcome to visit you whilst you are in hospital, but it is very important for your health and recovery that you also have time to rest. Therefore, we ask that friends and family take note of the visiting times and adhere to them. Visiting hours are usually between 3pm and 8pm, although this can vary between wards. Most wards also have a rest period from 1pm to 3pm, as well as protected mealtimes to allow patients to eat their meals without disruption. Please speak to the ward manager if your visitors have difficulty with these times.

Due to limited space, most wards ask that a patient has only two visitors at any one time.
You can receive telephone calls as an inpatient. Your relatives and friends can either:

- call the switchboard on **020 8672 1255** and ask for the name of the ward you are on
- call the ward once you know the direct dial number (please ask the ward staff for information on the best time to ring)
- call your bedside terminal, which includes a telephone (please note this will show on their phone bill as a premium rate number).

Please note that flowers and plants may not be allowed on some wards for infection control or general housekeeping reasons.

**Car parking**
There is a pay and display car park in the hospital grounds, which can be entered via Blackshaw Road. This costs £2 for the first hour with half hourly rates after that.

**Cash machines**
There are cash machines located in the main entrance of Grosvenor Wing and the reception area of Jenner Wing.

**Chaplaincy service**
There is a chapel in St James Wing, and the hospital chaplain is available for you to speak to. Faith leaders from other religions and belief-systems visit the wards, and arrangements can be made for you to see them if you wish. Please ask a nurse if you would like more information.

**Retail outlets**
There are a number of retail outlets within the hospital, including:

- Marks & Spencer Simply Food
- Whistlestop newsagents and convenience store
- Friends of St. George’s Shop
- M&S Cafeteria
- Peabody’s coffee shop

**Telephones**
Pay telephones and mini-cab free phones are available in all of the main entrances.

Mobile phones can interfere with sensitive equipment in some areas of the hospital, so please look out for the signs and switch your mobile phone off if necessary. For the consideration of other patients, mobile phones should also be switched off or on silent while you are on the ward. Please do not use camera phones in the hospital.

**Infection control**
We all carry bacteria (germs) on our skin or in our bodies. These bacteria can be passed from person to person. There is a higher chance of cross-infection in hospital because of close contact between patients and staff.

The best way to prevent infection from spreading is by practising good hand hygiene. All staff, patients and visitors should wash their hands thoroughly before and after touching food, touching another person or using the toilet.
You can help us to stay clean and prevent infections by:
- following instructions to clean your hands with alcohol gel before you enter and leave the ward
- asking your visitors to do the same
- asking your visitors to follow any special instructions, such as wearing aprons or gloves
- understanding that we may need to isolate some patients for infection control purposes, which might mean moving them to a side room
- cleaning your hands before eating and after using the toilet or commode
- avoiding touching any wounds or lines you may have
- asking any staff attending to you whether they have cleaned their hands
- asking visitors not to visit if they have any infections (including diarrhoea and colds)
- putting your litter in the bin
- telling the nurse in charge if you see dirt, dust or rubbish.

What happens when I’m ready to go home?
Once we are confident that HPN is safe and appropriate for you, you will be discharged from hospital with the support of a team of highly trained nutrition nurses. Before you are discharged from the hospital a member of the home care nursing team will come to visit you to discuss your care at home and answer any questions you may have. They will help you to care for your intravenous line and will administer your nutrition. They can also provide training for you if you wish to learn how to administer your nutrition for yourself.

When you are discharged from hospital, you will be provided with a range of contact details for the intestinal failure team. You will also receive contact details for a 24-hour helpline provided by our chosen home care team. The home care company works very closely with the team at St George’s to ensure effective management of your care at home.

The hospital team referring you for HPN will try as best they can to stabilise you before you are transferred over to St George’s. This will include making sure that all other aspects of care needed for home life have been arranged, such as support from district nurses, any adaptation of the home as assessed by the occupational therapy team and any other support from the community teams.

Can I get help with travel costs?
If you are on a low income or benefits you may be entitled to reclaim your public transport costs to and from the hospital under the Healthcare Travel Cost Scheme. Please call the hospital cashier on 020 8725 1632 or call 0845 850 1166 and ask for a copy of The Department of Health’s HC12 leaflet.

Contact us
If you have any questions or concerns, please speak to the nurse in charge on the ward you are staying on. You can also contact the intestinal failure team on stghtr.ifsstgeorges@nhs.net.

The nutrition nurses can be contacted on 020 8725 2280 and the dietitian on 020 8725 3049.
Additional services

For more information on living with intestinal failure, please visit the Patients on Intravenous and Naso-gastric Nutrition Treatment website via www.pinnt.com

Patient Advice and Liaison Service (PALS)
PALS can offer you on-the-spot advice and information when you have comments or concerns about our services or the care you have received. You can visit the PALS office between 9am and 5pm, Monday to Friday in the main corridor between Grosvenor and Lanesborough Wing (near the lift foyer). Tel: 020 8725 2453  Email: pals@stgeorges.nhs.uk

NHS Choices
NHS Choices provides online information and guidance on all aspects of health and healthcare, to help you make decisions about your health.
Web: www.nhs.uk

NHS 111
You can call 111 when you need medical help fast but it’s not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year. Calls are free from landlines and mobile phones. Tel: 111