

# Top Tips for Discharging a Patient on Home Parenteral Support in England

Kirstine Farrer, Cathy Cawley, Angela Page, Michael Taylor and the BIFA Committee

Home parenteral support (HPS) (includes home parenteral nutrition [HPN] and/or fluid) is the treatment for patients with Type 3 intestinal failure (IF) requiring long-term support. Since its introduction in the second half of the 20th century, HPS provision has improved the prognosis of patients with severe IF. Unfortunately, HPS provision can be associated with a range of complications, notably catheter-related blood stream infection (CRBSI) and intestinal failure-associated liver disease (IFALD), as well as complications relating to the patient's vascular access and underlying condition.

The National Framework Agreement for the Supply of Home Parenteral Nutrition for England covers all aspects of HPN, including the compounding and delivery of the feed and ancillaries (equipment and consumables) via 'homecare companies', and the provision of nursing for those requiring training or who are not able to administer the infusions or care for their vascular access device themselves. The aim is to provide equity of access to HPS services and for patients to receive consistently high-quality products and care.

Aspects of these Top Tips (e.g. Key points 1-3, 6 & 10) are relevant in Scotland, Wales and Northern Ireland.

## Key steps

1. All patients who are considered for entry into an HPS programme should have documented prolonged IF which, if untreated, would lead to deteriorating nutritional and/or fluid status and should, if appropriate, have undergone an adequate trial of enteral nutrition.
2. The patient/carer/parent/guardian needs to understand their condition and the reasons for this type of feeding and the challenges (including complications) that it brings. They should be given a short medical summary that includes the contact details of their HPN centre. They need to agree to the treatment.
3. Any information transferred between the patient/carer/parent/guardian, HPN centre and homecare company must be kept confidential at all times.
4. A homecare company from the HPN Framework/contract will be allocated by the HPN centre to the patient/carer/parent/guardian to meet all the standards required to provide safe and effective HPS. They will provide the parenteral solution, ancillaries (equipment and consumables) and nursing where clinically indicated and available.
5. A Blueteq® number must be obtained by a member of the multi-professional team at the HPN centre before the patient is discharged. The Blueteq® number is attached to the HPN centre so a new number must be obtained if a patient changes HPN centre. Numbers are valid for 12 months, so yearly update is required. All HPS patients should be registered on the IF Registry (formerly known as e-BANS). The registry needs to be maintained for all patients, including details of any admissions, surgery, outpatient visit outcomes and any HPS-related complications.
6. All new HPS patients must be haemodynamically, biochemically and nutritionally stable prior to discharge home. Physical and psychological co-morbidities must be taken into account. The nutrition support team will formulate the HPS regimen, date and sign the formulation request. It takes 5 working days to process and arrange a home installation.
7. All new HPS patients require a Home Assessment and Patient Needs Assessment Form before the pre discharge assessment (PDA) meeting. This may be completed with the patient/carer/parent/guardian after a discussion or an actual home visit by the nursing team at the HPN centre. There are standard documents which have been produced by the national HPN stakeholders group.

Continued over page...

8. The patient/carer/parents/guardian will meet with a homecare representative to discuss the PDA and provide the patient with all the information about the homecare service and contact details for a named coordinator.
9. The patient/carer/parent/guardian needs to make provision for storage of ancillaries. Prior to discharge the homecare company will arrange dates for a home visit, installation, HPN delivery and if needed nurses to start.
10. HPS patients will be regularly reviewed in an outpatient clinic with regard to nutrition status, clinical health and their homecare service (including the need for home nursing). We suggest an annual review of patient/carer/parent/guardian and nursing staff in relation to connection and disconnection of HPS and their compliance to national protocols.
11. Homecare companies should submit a weekly nursing report for nursed patients and send to each HPN centre. Monthly stock checks are recommended. The need for home nursing care needs to be reviewed. Ideally, all long-term patients or their carer/parents/guardian should be trained to set up/take down the feed themselves. Any urgent issues/concerns must be escalated to the HPN centre immediately, including the lead clinician for the patient and the chief pharmacist who has board level responsibility for all homecare.
12. The patients/carer/parents/guardian can request changes to aspects of the homecare service after consultation with their HPN centre (from 2020 a standard form will be available). Any transfer of care between homecare companies should be seamless by email/phone. If a patient needs medical supplies and medications over and above completely standard HPS, careful consideration is needed as to what can be provided as part of the HPS 'package' and what will need to be provided by another means (e.g. GP, district nursing, etc.).
13. Each HPN centre must demonstrate evidence that the patient, carer or nurse undergo annual peer review of their practice in relation to HPS administration and intravenous access management.

## Explanations to selected key recommendations

- **Consider other treatments (Key point 1):** Given the complications associated with HPS, e.g. catheter-related sepsis, metabolic complications and impact on quality of life it is imperative to consider other treatments and avoid parenteral support if a patient has a functioning gut.
- **Initial consultation with family (Key point 2):** There should be a clear agreement in relation to roles. It is essential that the patient complies with the HPN centre in relation to clinic appointments and blood monitoring. The patient/carer must accept responsibility to being compliant with visit

windows and not demand a precise time. Any planned holidays must be discussed 6 weeks in advance of their proposed holiday and agreed with the HPN centre and the homecare provider. Any changes to their visit schedule must be communicated to the HPN centre and homecare provider.

- **General Data Protection Regulation (GDPR) (Key point 3):** General Data Protection Regulation (GDPR) came into force in May 2018 and reshapes the way sectors manage personal data and redefines the roles for key leaders in businesses and healthcare. It applies to all companies processing the personal data of subjects residing in the European Union, regardless of the company's location. Organisations in breach of GDPR can be fined up to 4% of annual global turnover. The request for consent must be given in an intelligible and easily accessible form, with the purpose for data processing attached to that consent. This consent must be clear and distinguishable from other matters and provided in an intelligible and easily accessible form, using clear and plain language.
- **HPN Patient's Charter and HPN Framework (Key points 2, 4, 5, 9-12):** See further reading; HPN Patient's Charter and HPN Framework document copies can be found via the NHS Network for NHS purchasers of HPN. Information on this site is confidential to the NHS and must not be shared outside the NHS.
- **Prevention of electrolyte disturbances & unnecessary re-admissions (Key point 6):** The HPN Framework highlights the importance in prevention of electrolyte disturbances and unnecessary re-admissions to hospital due to the complications associated with HPS. An HPS programme must include provision of evidence-based therapy, prevention of HPS-related complications, such as CRBSIs and metabolic complications, whilst ensuring quality of life is maximised. Regular audit of therapy and outcomes are required by the HPN centre.
- **Patient Needs Assessment Form (Key point 7):** The HPN Framework outlines the importance of completing a home assessment to ensure that the patient is being discharged to a suitable home environment. The Patient Needs Assessment Form should ensure a suitable environment that meets the standards for health and safety.
- **Meeting with homecare representative for PDA (Key point 8):** This is in line with NHS England HPN Framework to ensure that the patient/carer/parent/guardian feels confident, competent and supported prior to discharge home in order to avoid unnecessary deterioration in clinical status and re-admissions to hospital.
- **Changes (Key point 12):** HPN centres and homecare providers must ensure any changes to the ancillaries delivered to the patient or change in protocol, are clearly communicated verbally and in writing as failure to do this can cause confusion and anxiety.

### Further reading

- Home Parenteral Nutrition Services in England Patients Charter 2016.
- The National Framework Agreement for the Supply of Home Parenteral Nutrition for England.
- Pironi L *et al.* ESPEN guidelines on chronic intestinal failure in adults. *Clin Nutr.* 2016; 35(2): 247-307.
- British Intestinal Failure Alliance (BIFA). BIFA Position Statement 2016: Home Parenteral Nutrition; BIFA 2016: [www.bapen.org.uk/images/pdfs/news/bifa-position-statement-about-hpn.pdf](http://www.bapen.org.uk/images/pdfs/news/bifa-position-statement-about-hpn.pdf)
- Cawley C, Lal S, Nightingale J, Small M. British Intestinal Failure Alliance (BIFA). Guidance: Standardised Parenteral Support Catheter Guidelines; BIFA 2018: [www.bapen.org.uk/pdfs/bifa/standardised-parenteral-support-catheter-guidelines.pdf](http://www.bapen.org.uk/pdfs/bifa/standardised-parenteral-support-catheter-guidelines.pdf)