

British Intestinal Failure Alliance (BIFA) Position Statement Home Parenteral Support (HPS)

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Home parenteral support (HPS) includes those having home parenteral nutrition (HPN) and those having home parenteral fluid usually saline with magnesium (HPF). HPS is needed for patients with acute or chronic intestinal failure (IF) in whom nutritional and / or water and electrolyte balance cannot be corrected by oral or enteral feeding and in whom parenteral support is feasible at home (Messing B et al in Intestinal Failure 2001). While HPS was first described in 1970 (via an arterio-venous fistula), it has been used as a treatment via a central catheter in the UK since the 1980s and the number of patients have been increasing so that the total number (point prevalence) exceeded 1000 in 2013 (British Artificial Nutrition Survey) and was 1144 in 2015.

The reasons for starting HPS include a short, leaking (perforated), obstructed or dysfunctional gut or extensive small intestinal mucosal disease. Occasionally it is due to no enteral access or after unsuccessful enteral nutrition. Consideration for stopping HPS may be when oral / enteral intake is resumed, a problem has resolved (e.g. obstruction or entero-cutaneous fistula), or the gut has adapted (e.g. after colon continuity has been restored) or it is no longer in the patients' best interest.

The aims of HPS include preventing or treating undernutrition, inanition and/or dehydration, helping a patient become fit for surgery, reducing diarrhoea/vomiting, reducing abdominal pain caused by oral/enteral feeding and improving the quality of life.

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A patient or his/her family, carers or guardian have much to learn before and while having HPS. They need to learn about the principles of asepsis, basic gut and vascular anatomy and the complications of PS, and about their underlying illness. They have to learn the skills of hand washing, sterile techniques, connecting and disconnecting a feed, changing a dressing, flushing a catheter and managing a pump. To do this personally, they need to be physically fit enough to lift an IV pump and bags, with sufficient manual dexterity and vision. They need to be psychologically motivated and manage the HPS in an appropriate home environment. They may need to learn how to adjust to lifestyle events such as bathing, showering, swimming, partaking of sports and travel. In addition to the HPS they may also have to cope with wound/stoma management, chronic pain and much medication (e.g. analgesics, proton pump inhibitors, anti-diarrhoeal and anti-emetic drugs).

This document was first requested by Michael Stroud when Chairman of the British Association of Parenteral and Enteral Nutrition (BAPEN) in 2015. It aims to help Nutrition Support Teams (NST) setting up IF/HPS/HPN centres and/or managing patients receiving HPS. It addresses the key practicalities relating to the facilities and quality of care expected in the UK at an IF/HPS/HPN centre for infants, children, young people and adults. While not directed at commissioners, it may be referenced by them.

It has been written for guidance in the United Kingdom hence many statements are generic. In some points the specific policies/practices in England, Scotland, Wales and Northern Ireland are mentioned. It can be read in conjunction with the Healthcare Improvement Scotland Document on Complex Nutritional Care Standards (December 2015). This BIFA position statement does cover 5 of the 6 standards quoted in the Scottish document; however it does not address the enteral nutrition one. It was drafted by the BIFA Committee and widely distributed via BAPEN. The first document was produced in 2016. This final version (2019) has been modified by BIFA after comments from BAPEN council and members, and from the British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN) and IF Working Group, and by NHS England. It will be reviewed again in July 2021.

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BIFA Position Statement Home Parenteral Nutrition

Unit

1. Patients receiving home parenteral support (HPS) should be cared for by a Severe IF or HPS/HPN designated unit with a multidisciplinary nutrition support team (NST).
2. HPS should only be practiced in centres that are commissioned and where there is a governance framework (with Trust Board support) including finance in place for caring for these patients.
3. Units should have at least 30 adult patients (or ideally 10 paediatric patients) receiving HPS of which at least 10 adults have been receiving it for more than 5 years. New units may develop under the guidance of an established unit meeting the criteria in this document.
4. In England, all patients starting HPS must be registered via the prior approval form (currently Blueteq) high cost drugs system and their Blueteq number should be added to all prescriptions and invoices (in NHS England only).
5. HPS/HPN units should work together to standardise practice.

Team

6. The adult team should consist of a minimum of 2 consultants (with dedicated sessions), 2 or more nutrition nurse specialists, a specialist dietitian (with dedicated sessions) and a specialist pharmacist (with dedicated sessions). Children's teams should have a paediatric gastroenterologist, paediatric trained nurses, a dietitian and a pharmacist.
7. There should be arrangements for cross cover with skilled staff of appropriate expertise when any member of the team is away.
8. Within the team there should be dedicated staff (nutrition nurse, dietitian, pharmacist or IF/HPS co-ordinator/administrator) to liaise directly with the home care companies.
9. There should be a member of the team or another specified expert available for 24 hours emergency specialist advice (with access to an intensive therapy or a high dependency unit when required).
10. There should be on site expertise in stoma care/tissue viability that may include managing a dehiscid abdominal wound and when appropriate giving distal enteral feeding.

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Practice

11. There must be a central venous catheter insertion service that can insert tunnelled central catheters, peripherally inserted central catheters (PICCs) and implantable ports. It should be possible to achieve HPS access within 24 hours for a short term central venous catheter and within 3 working days for a long term central venous catheter (except an implantable port).
12. There must be a clear pathway to admit a patient if an emergency (e.g. superior vena cava occlusion, catheter fracture or sepsis).
13. There must be written protocols with pathways, agreed by teams involved with central venous catheter care, for the management of complications (see 12 above). Information leaflets that outline procedures, complications and actions to take including contact telephone numbers/emails should be given to patients/carers.
14. Units must have agreed pathways and the expertise to repair unblock or replace a central venous catheter.
15. Staff (includes medical) must have access to a training program (includes both knowledge and skills) in complex nutritional care as relevant to IF/HPS patients.
16. Once a decision for HPS is made the patient /parents or carers should be assessed for their ability to perform HPS procedures. This assessment will have to be repeated when situations change.
17. The team should have the specialist skills, when appropriate, to train a patient, carer, friend or family member to do all the procedures or facilitate training by a home care company.
18. When a patient is medically stable and a home care HPN company has an agreed contract, the patient should be able to go home within 5 working days of the formulation request (final script) submission to the home care company (as specified in the NHS National Framework for the Supply of HPN in England or the National Procurement HPN Contract in Scotland).
19. Patients with cancer and/or needing palliative care have their individual needs/circumstances considered quickly and are fast tracked home or to a hospice within 14 days of the decision for HPS, providing they are medically and psychologically stable and all relevant information has been received from the referring unit A remote discharge, arranged by the IF/HPS/HPN centre, from another unit may be appropriate.
20. Wherever possible scripts for adults should aim to have the least amounts of additions to licensed standard bags. This may reduce both the compounding time and costs. It is inevitable that some patients will need significantly higher amounts of fluid and electrolytes than standard bags provide.

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21. HPS is only supplied by an accredited NHS HPS national framework supplier in England, via the Scottish HPN contract in Scotland, via the Welsh managed clinical network for HPN in Wales and via the Commissioned Intestinal Failure Service, Belfast Trust, in Northern Ireland. However, the Trust and the prescriber are still overall responsible for the patient's Care and they need to monitor the performance of the home care companies.
22. Patients should be reviewed by a dedicated multidisciplinary team (at least nutrition doctor, specialist nurse and dietitian) usually in a specialist outpatient department (or sometimes by telephone or video link) at an interval not longer than 6 months. The frequency is determined by the patients' underlying medical problems, their nutritional/fluid status and complexity of the regimen/medical treatments /psychosocial issues.

Relationships

Internal

23. Good links and established pathways with an onsite interventional radiology service for patients with difficult venous access or for re-establishing patency if a central vein becomes occluded.
24. Good relationship with microbiology service and regular/when appropriate meetings to discuss patients (especially for central venous catheter sepsis, discitis etc).
25. Have good relationships and links with an aseptic unit.
26. Have access to a psychological medicine department and for children/young adults to have access to children and adolescent mental health services (CAMHS) both of which should have experience in managing patients with intestinal failure.
27. Have easy (ideally on site) links to urology, gynaecology, vascular surgery, plastic surgery, upper and lower GI surgery, nephrology (haemodialysis unit), a hepato-biliary team, hepatology, biochemistry, ophthalmology, dental care, occupational therapy, physiotherapy, social care and speech and language therapy (SALT). In addition for children and young people paediatric surgery, young people play/youth workers and paediatric physiotherapy.

External

28. Good links, networking and established pathways with at least one centre doing intestinal failure surgery (e.g. enterocutaneous fistula repairs and re-establishing bowel continuity) and that can pre-assess patients considered for intestinal transplantation and make timely referrals and other HPS/HPN centres and non-specialised services.

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29. Good relationship with commercial HPN service providers (as per NHS HPN National Framework in England) and have regular meetings.
30. Services for young people should provide an adolescent and transition service with pathways and a dedicated transition process held with the adult provider including joint meetings between the patients, the parents or carers and NSTs from both the paediatric and adult centres.
31. A discharge planning service which engages with community services (e.g. community nurses and dietitians, health visitors, stoma care/tissue viability, pain team etc).
32. If a patient is not suitable for homecare or an approved homecare provider cannot be found there should be an escalation process to relevant NHS personnel.

Outcomes

33. The team must conduct regular audits of their outcomes. Units should be aspiring to an adult/young people inpatient catheter-related blood stream infection (CRBSI) rate of less than 1/1000 catheter days on a specialised/dedicated IF/HPS/HPN ward (less than 3/1000 on all other wards within the organisation) and an outpatient CRBSI rate of less than 1/1000 catheter days. Infants on parenteral nutrition have higher rates of CRBSI.
34. Clear evidence of participation in relevant audits and clinical governance. These may include waiting times, length of stay, readmission rates, central vein thrombosis, central venous catheter occlusion, abnormal liver function tests and numbers weaned from HPS.
35. The views and quality of life of HPS patients, carers and families and the views of staff should be regularly audited.
36. Effective networking with nearby hospitals to where a patient may be admitted (e.g. with sepsis or CVC occlusion) and dissemination of shared care guidelines (e.g. catheter related sepsis or CVC occlusion) to the nearby hospitals.
37. 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.

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Reading/References:

Complex Nutritional Care Standards. Healthcare Improvement Scotland. December 2015.
Consultation Guide: Proposed changes to specialised severe intestinal failure services for adults.
NHS England. August 2018.

https://www.engage.england.nhs.uk/consultation/severe-intestinal-failure-services-for-adults/user_uploads/if-service-review-consultation-guide.pdf

Service specification (no: 170077S) for severe intestinal failure (adults). To be used for procurement during 2019/20.

<https://www.england.nhs.uk/wp-content/uploads/2019/07/170077S-Intestinal-Failure-Service-Specification.pdf>

Cathy Cawley, Simon Lal, Jeremy Nightingale, Mia Small. British Intestinal Failure Alliance (BIFA) Guidance Standardised Parenteral Support Catheter Guidelines.
www.bapen.org.uk/pdfs/bifa/standardised-parenteral-support-catheter-guidelines.pdf

Simon Lal, Paul Chadwick, Jeremy Nightingale and the BIFA Committee. British Intestinal Failure Alliance (BIFA) Recommendations for Catheter Related Blood Stream Infections (CRBSI) Diagnosis. April 2018. www.bapen.org.uk/pdfs/bifa/recommendations-for-crbsi-diagnosis.pdf

Simon Lal, Paul Chadwick, Jeremy Nightingale and the BIFA Committee. British Intestinal Failure Alliance (BIFA) Recommendation Management of Catheter Related Blood Stream Infections (CRBSIs). January 2019. www.bapen.org.uk/pdfs/bifa/recommendations-on-management-of-crbsi.pdf

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