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Position Statement

The British Intestinal Failure Alliance (BIFA) Position Statement

Palliative home parenteral nutrition (HPN) for patients with advanced malignancy

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Introduction

Terms such as ‘palliative’ or ‘incurable’ cancer or ‘advanced’ malignancy are used interchangeably in medical literature and in clinical practice and have varying definitions. For this position statement we use the term ‘advanced malignancy’ for patients with malignancy, where cure is no longer possible, or where treatment has been declined by the patient or is not viable due to co-morbidities.

Intestinal failure (IF) in patients with malignancy is most often caused by bowel obstruction, which may be partial, intermittent or complete. It can also be due to an enterocutaneous fistula, short bowel resulting from surgery, dysmotility or severe mucosal disease (often following chemotherapy or radiotherapy).

Home Parenteral Nutrition (HPN) can improve nutritional status even in advanced malignancy, with potential to the benefit quality of life (including improved hydration, general wellbeing and better energy levels) and increased life expectancy. The extra time gained as a result of receiving PN may allow a patient to achieve some personal goals. These include spending time with their family, putting their affairs in order, achieving a personal ambition or attending an event.

There are potential burdens associated with HPN and these include disrupted sleep, equipment and ancillaries in the home, regular nursing visits (if not independently doing the procedures) and the risks of complications especially catheter-related sepsis.

The British Artificial Nutrition Survey (BANS) report of adult HPN in the UK, shows that the percentage of new HPN registrations with 'malignancy' as the underlying diagnosis has risen from 12% in 2005 to 27% in 2015 and accounts for approximately one in 4 new HPN registrations (1). This increasing prevalence has been noted in every European country with published national HPN data (Spain, Poland, Italy, France, Belgium and Denmark) (1).

Patients who are considered for PN in the palliative setting can be classified into three palliative (P) groups:

'P1' IF – those who require HPN with an expected short survival (less than 12 weeks) but with a good performance status (2) and low inflammatory markers. These patients include young individuals with tumours that are usually rapidly growing – for example bowel obstruction due to metastatic or locally advanced bowel, bladder, ovarian, cervical or diffuse gastric cancer. The priority for these patients is rapid discharge home with objective measurable goals.

'P2' IF – those who require HPN whilst receiving ongoing oncological treatment – such as chemotherapy for ovarian cancer or debulking surgery. The P2 state will regress to P1 if treatment is ineffective or to P3 if the tumour is very slow growing. These patients are often metabolically unstable (e.g. due to fluid balance, renal or hepatic impairment) and may require more intensive monitoring and modification of their HPN scripts. They may require management from multiple specialities and require an individualised care plan.

'P3' IF – patients who require HPN, usually due to slow growing tumours such as some ovarian cancer, neuro-endocrine tumours, some sarcomas or pseudomyxoma peritonei and who may survive a long time, often several years, with HPN. In terms of general medical management and follow up they are managed in the same way as other patients receiving HPN. There is likely to come a time when the disease has progressed and discussions about the withdrawal of treatment needs to take place.

The first edition of this document was written following the BIFA annual meeting on 10 November 2015 entitled "Palliative HPN – benefits and burdens". The first position statement was published on BAPEN website in 2017 and this was updated in 2020 and 2026. Palliative HPN is less commonly needed in children and young people less than 18 years of age, but the same standards and recommendations apply.

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When to consider HPN or Home IV fluids in patients with advanced abdominal malignancy

1. Patients concomitant advanced malignancy and IF from bowel obstruction (partial, intermittent or complete), enterocutaneous fistula(s), a short bowel, dysmotility or severe mucosal disease (often following chemotherapy or radiotherapy).

2. When there is an absence of IF in patients with advanced malignancy (i.e. accessible and functional gastrointestinal tract), the quality of life and life expectation is higher when parenteral nutrition is not used. All effort must be made to avoid the use of PN where possible and favour oral/enteral routes (3).

3. Evidence suggests that where intravenous support is needed for advanced malignancy with IF, the use of nutrition in the form of PN is superior to IV fluids alone, but this decision should be made on an individual basis, while favouring HPN over home IV fluids (4). We note that the provision of IV fluids at home is not nationally commissioned and may require the support of local hospital or hospice.

Which patients with advanced malignancy will have the best survival and quality of life (QOL) on HPN?

4. Those patients with higher performance status, i.e. Karnofsky performance scale index (2) above 50 (ideally 70) or an Eastern Cooperative Oncology Group (ECOG)/World Health Organisation (WHO) performance status (5) ≤2 (table 1).

5. In addition, those patients with low serum markers of inflammation (C-reactive protein<10 mg/L and Albumin >32 dg/L) are more likely to survive longer (6-8), but the sensitivity and specificity of objective inflammatory markers are low and cannot be solely relied upon.

6. Existing guidelines (e.g. ESPEN (9,10)) select patients with an expected prognosis of 2-3 months or greater as those who are most likely to benefit from HPN, but a number of studies have shown that, despite variable selection criteria and guidelines, mortality at 3 months is approximately 50%.

7. It remains extremely challenging to predict the length of survival and QOL and there may be palliative benefits in providing HPN to patients with a shorter prognosis but with a good performance status.

The decision to start HPN in patients with advanced malignancy

8. Patients, who meet the above criteria, and their relatives, should be informed about HPN as a potential treatment, including preliminary discussions of the potential benefits, practical implications and risks of HPN treatment.

9. All patients who may be considered for HPN should have an early multidisciplinary team (MDT) review by the nutrition team, oncologists and palliative care teams. The desired aim(s) of starting PN and the plans for withdrawal (either at the end of life, or any time after commencing) should be discussed.

10. If the patient is based at a centre without HPN set-up provisions, early liaison with a commissioned HPN centre is necessary to discuss the patient's suitability (including home circumstances) and their goals of therapy, and for the prescription to be established (a Blueteq number is needed in England). This includes palliative care involvement, before or during the patient selection process. Remote prescribing, to avoid the need for patient transfer, should be considered where there is an established service already in place.

Other considerations at time of starting HPN

11. When IF is due to bowel obstruction, a surgical assessment to consider an operative resolution should be explored. This is most likely to be successful where there is a single discrete cause for the obstruction.

Unfortunately, obstruction is most commonly due to peritoneal disease, adhesions or previous radiotherapy causing multi-level obstruction, with a high chance of recurrence after surgery.

12. Patients who require HPN support for bowel obstruction should also be considered for a venting gastrostomy placement (20F or larger) in order to palliate vomiting and, if wanted, to allow eating and drinking of a limited diet.

13. It should be noted that abdominal interventions risk the tumour growing along any medically or surgically created tract, with a consequent chance of poor healing of the exit site/stoma and possible leakage, especially in the case of ascites developing.

14. When planning HPN the timing and routes of administering other medications needs to be taken into account, especially if they are given intravenously. For this reason a multi-lumen catheter may be appropriate. We advise the use of dedicated lumen and separating infusions of PN and other treatments such as IV chemotherapy.

15. Where there is limited capacity for compounding HPN, efforts should be made to match nutrition requirements to multi-chambered bags (MCB) to avoid delayed discharge. Intravenous and/or oral micronutrients may be given.

Discharge process

16. Early advance care planning, with patient and family, should include discussion regarding options for withdrawing HPN towards the end of life. If in the last few days of life continuing PN is causing more discomfort and intrusion than benefit it should be discontinued, but in the absence of morbidity caused by PN, the treatment may continue. There should be a clear plan around monitoring, frequency of blood tests and the need for physical observations matching the requirement of the patient with a pragmatic approach to holistic treatment. As with all HPN discharges there should be details of whom to contact in a medical emergency or if equipment fails.

17. If the patient is based in a hospital without the facilities to start HPN, priority should be given, by the commissioned HPN centre, to transfer the patient to expedite home discharge, or for the commissioned HPN centre to facilitate a remote discharge of the patient from the original referring hospital, where facilities already exist.

18. If networks already exist for ‘remote discharge’ from a local hospital, with links to a commissioned HPN centre, this should be utilised to expedite discharge. The coordination of remote discharge can be facilitated by phone, video or teleconferencing with the commissioned HPN centre (who will be writing the HPN prescriptions and monitoring the patient as per local agreed protocols with the linked hospital).

19. Patients and family will be encouraged to learn connections and disconnections, but discharge should not be delayed for training. It is envisaged that most advanced malignancy HPN patients will be supported with home community nursing care (except in Northern Ireland and Scotland where no homecare nursing provision is available and district nurse training may be required).

20. There should be a discharge plan with, when appropriate, a record of a discussion around advance care planning and about resuscitation as in the documents Recommended Summary Plan for Emergency Care and Treatment (ReSPECT), Preferred Priorities of Care and Deciding Right. This will include a statement of where the patient wishes to die. This should be shared with appropriate out of hours care providers in the locality. This may be recorded by the Electronic Palliative Care Coordination System (EPaCCS) in England.

21. Clear lines of responsibility should be stated in advance for all aspects of the patient’s care after leaving the hospital. This may include the GP, hospice, palliative care, or nutrition support team. This should be documented

and copies of correspondence sent to all members of the team including the patient.

22. Patient must have a point of contact after discharge. The clinic follow-ups, if necessary, should be arranged before discharge. They may include the local hospital/oncology centre.

23. Community support for stoma, fistulas, gastrostomy site care and medications should ideally be provided and will often involve training the patient or family members.

24. Patients needing palliative care should have their individual needs and circumstances considered quickly by commissioned HPN centre and be fast tracked home or to a hospice within 14 days of the decision for HPN, providing they are reasonably medically and psychologically stable. (9).

What type of PN is given?

25. All reasonable efforts should be made to reduce the burden and costs of HPN therapy by using the lowest frequency, volume and complexity of the HPN solution and keeping the ancillaries (i.e. pump) user friendly. In addition the number of blood tests and time away from home for review should be kept to a minimum.

26. Fluid/electrolyte/nutrition prescriptions may not be ideal for P1 and P2 IF patients at discharge but a quick discharge is most important. Consider multi-chamber bags, standard bags, part infusion of bags and less meticulous stabilisation to aid faster discharge into the community. The feed composition, if required, can be adjusted when the patient is at home after review.

27. Lipid is well tolerated in malignancy (11-15) and there is no need to limit it to prevent PN associated liver disease in P1 and P2 IF patients as this is unlikely to occur if the prognosis is less than 18 months. A lipid source containing fish oil (W3) may be beneficial but not essential (8).

Follow up/monitoring

28. A comprehensive action plan should be in place before discharge that includes clear individualised objective and measurable outcomes and goals. A copy should be given to the patient.

29. Follow up should be arranged on a case-by-case basis, but it is envisaged that for patients discharged home an out-patient appointment is made within 2-4 weeks. For those patients discharged to a hospice, liaison with the palliative care team is likely to be sufficient to meet patients ongoing follow up needs. Note should be made that NHS England will not fund Home Care company nurses to attend patients in NHS funded hospices.

30. In the case of longer surviving patients (>3 months) follow up should be made based upon the patient's condition and clinical requirements. HPN monitoring tests are recommended as advised by the HPN centre.

31. All the relevant teams involved (patient and family/carers, oncology, palliative care, regional and local nutrition teams and community nursing, palliative care and primary care) should share contact details, in order to best communicate with each other about any issues arising.

32. Follow up planning requires clear communication between the oncology, palliative care and HPN providing teams regarding roles and responsibilities. For example responsibility for management of the central access device, IV medications, blood monitoring and how episodes of suspected catheter-related sepsis would be managed. Close follow up and communication between teams may be required to assess response and determine if the patient's classification has changed.

Stopping HPN

33. Advance care planning with the patients/family and palliative care team should be made in order to determine the patient's wishes with regard to the preferred place of care and dying; and the situations when PN would be stopped. Power of attorney is recommended.

34. The criteria for stopping HPN may include the patient's wish to stop, the HPN no longer being able to meet the physiological goal for which it was intended and/or where the complications and burdens of HPN outweigh the benefits. Where a patient no longer has the mental capacity to make this decision and no advanced decision to refuse treatment exists a best interests approach is required. While HPN may be stopped IV fluids and medication necessary for best symptomatic palliative care may be continued.

35. Home care companies must have good communication with the multidisciplinary team/nutrition support team and must be informed when a patient is stopping HPN. They will need to collect all HPN related equipment at an agreed time.

36. If not used the parenteral nutrition catheter may be removed or flushed, using an aseptic technique, at least weekly with saline.

37. Clear pathways and lines of communication should be in place, should the patient need to be admitted to another hospital (approximately 40% of such patients will require this).

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Table 1 – Conversion of Karnofsky score to ECOG/WHO performance status (3) (Eastern Cooperative Oncology Group/World Health Organisation)

Karnofsky Status	Karnofsky Grade	ECOG/ WHO Grade	ECOG/ WHO Status
Normal, no complaints	100	0	Fully active, able to carry on all pre-disease performance without restriction
Able to carry on normal activities. Minor signs or symptoms of disease	90	1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work
Normal activity with effort	80	1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work
Care for self. Unable to carry on normal activity or to do active work	70	2	Ambulatory and capable of all self-care but unable to carry out any work activities. Up and about more than 50% of waking hours
Requires occasional assistance, but able to care for most of his needs	60	2	Ambulatory and capable of all self-care but unable to carry out any work activities. Up and about more than 50% of waking hours
Requires considerable assistance and frequent medical care	50	3	Capable of only limited self-care, confined to bed or chair more than 50% of waking hours
Disabled. Requires special care and assistance	40	3	Capable of only limited self-care, confined to bed or chair more than 50% of waking hours
Severely disabled. Hospitalisation indicated though death not imminent	30	4	Completely disabled. Cannot carry on any self-care. Totally confined to bed or chair
Very sick. Hospitalisation necessary. Active supportive treatment necessary	20	4	Completely disabled. Cannot carry on any self-care. Totally confined to bed or chair
Moribund	10	4	Completely disabled. Cannot carry on any

Karnofsky Status	Karnofsky Grade	ECOG/ WHO Grade	ECOG/ WHO Status
			self-care. Totally confined to bed or chair
Dead	0	5	Dead

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