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Position Statement

The British Intestinal Failure Alliance (BIFA) Position Statement

Palliative parenteral nutrition (HPN) for patients with malignancy

Authors: Mani Naghibi, Jeremy Woodward, Penny Neild and the BIFA Committee**

***Competing Interests: None declared*

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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). Historically, only a few patients in the United Kingdom (UK) were fed by parenteral nutrition (PN) in the last months of their life, largely due to concerns regarding the logistics of establishing PN in the community and its perceived risks. However, with a more streamlined patient pathway and the increased availability of appropriated trained nurses from the PN providers it is evident that there are patients with malignancy and IF, who have insufficient oral/enteral nutrition intake and can benefit from PN. Although PN may not necessarily improve nutritional status in advanced disease/refractory cachexia, the benefit can be both in terms of 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 PN 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. There is also debate about whether nutritional support (especially glucose) may increase tumour growth.

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Increasingly patients are being referred for consideration of home parenteral nutrition (HPN) as medical staff, patients, relatives and carers are becoming aware of it as a treatment option. The British Artificial Nutrition Survey (BANS) 2014/15 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. While the curative status of malignancy is not reported to BANS, the vast majority of these patients have advanced malignancy (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 measureable 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.
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 update has been finalised in 2020. 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 in patients with advanced abdominal malignancy

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

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

2. Those patients with higher performance status, i.e. a Karnofsky performance scale index (2) above 50 (ideally 70) or an Eastern Cooperative Oncology Group (ECOG)/World Health Organisation (WHO) performance status (3) ≤2 (table 1).

3. 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 (4-6), but the sensitivity and specificity of objective inflammatory markers are low and cannot be relied upon.

4. Existing guidelines (e.g. ESPEN (7,8)) 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%.

5. It remains extremely difficult 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 PN in patients with advanced malignancy

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

7. 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.

8. 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 patients 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.

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Other considerations at time of starting PN

9. When IF is due to bowel obstruction, there should be a surgical assessment to consider an operative resolution. 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.

10. 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.

11. 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.

12. 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.

13. When the capacity for compounding HPN is reduced in the UK, the likely additional delay in discharge should be communicated to the patient and family at time of commencing.

Discharge process

14. Early advance care planning, with patient and family, should include discussion regarding options for withdrawing HPN towards the end of life. In the last days of life continuing PN may cause more discomfort and intrusion than benefit. There should be a clear plan around monitoring, frequency of blood tests and the need for physical observations. As with all HPN discharges there should be details of whom to contact in a medical emergency or if equipment fails.

15. 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.

16. 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).

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17. 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).

18. There should be a discharge plan with, when appropriate, a record of a discussion around advanced 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.

19. 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.

20. 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.

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

22. Patients needing palliative care should have their individual needs/circumstances considered quickly by commissioned HPN centre and be fast tracked home or to a hospice (that accepts patients having HPN) within 14 days of the decision for HPN, providing they are reasonably medically and psychologically stable. (As in BIFA HPS position statement 2019)(8).

What type of PN is given?

23. 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) relatively user friendly. In addition the number of blood tests and time away from home for review should be kept to a minimum.

24. 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.

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25. Lipid is well tolerated in malignancy (9-13) 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

26. 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.

27. 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

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

29. 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.

30. 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

31. 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 and a will are recommended.

32. 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 advance 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.

33. 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.

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

35. 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.	30	4	Completely disabled. Cannot carry on any

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Karnofsky Status	Karnofsky Grade	ECOG/ WHO Grade	ECOG/ WHO Status
Hospitalisation indicated though death not imminent			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 self-care. Totally confined to bed or chair
Dead	0	5	Dead

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