



B A P E N
Advancing Clinical Nutrition

HOME PARENTERAL NUTRITION IN THE UNITED KINGDOM

A POSITION PAPER

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INDEX

<i>Introduction</i>	1 - 2
Home Parenteral Nutrition (HPN)	
Intestinal Failure	
Relationship between HPN and Intestinal Failure	
<i>Epidemiology of HP</i>	2
<i>Access to HPN Centres</i>	2 - 3
<i>Evidence of Variation in Standards</i>	4 - 6
Indications for HPN by Diagnosis	
Indications by Reason for Nutritional Support	
Age	
Dependency	
Residence	
Activity levels	
Outcome	
Venous access	
Homecare Company Involvement	
<i>Distribution of HPN by Centre</i>	6 - 7
<i>Travel To and From HPN Centre</i>	7 - 8
<i>Prerequisites of HPN Service</i>	9
<i>Funding Issues</i>	9 - 10
<i>Active Unrecognised Centres</i>	11
<i>The Scottish Dimension</i>	12
<i>Organisations Supporting BAPEN Proposals</i>	12
<i>National Specialised Service Definition</i>	12
<i>Department Of Health View</i>	13
<i>Proposals For a “Sub-National” HPN Service</i>	14
<i>Networks or Hubs and Spokes?</i>	14
<i>Conclusions</i>	15
<i>References</i>	16
<i>Appendices</i>	16

Home Parenteral Nutrition in the UK – A Position Paper

Introduction

Patients with intestinal failure (IF) cannot absorb all the nutrients (fat, protein and carbohydrate, minerals, vitamins and water) needed to sustain life. Absorption occurs primarily in the small bowel (SB) although the large bowel or colon has a vital role in mineral and water absorption.

Various diseases may cause the SB to malfunction and some lead to surgical removal of the small bowel. Nutrient absorption becomes seriously impaired and losses in the form of diarrhoea or stomal effluent may become life threatening. When IF is this severe, nutrition must be provided through a vein, initially in hospital and later at home as patients become well enough to return to their community. This approach is called Home Parenteral Nutrition (HPN).

As the technology of Home Parenteral Nutrition (HPN) improves patients survive longer, and many now survive over ten years with good quality of life. Approximately 500 persons in England are treated at any one time. This paper discusses how services can best be delivered in the modern NHS by PCTs and Specialised Service Commissioners.

Home Parenteral Nutrition (HPN) is a “low volume – high cost” life preserving treatment for patients with Intestinal Failure. For most, if not all, of these patients, nutrients and fluids required to sustain life must be administered through an intravenous catheter placed in a major vein. Venous access is literally a patient’s “lifeline”. Without venous access, nutritional support can no longer be given leading to severe consequences including death. Small bowel transplantation is available to only a few such patients in the UK. This paper will deal principally with adult HPN but paediatric HPN has many parallels and problems in common.

Intestinal Failure (IF) can be defined as a situation in which the bowel can no longer provide adequate absorption of the major nutrients (fat, protein and carbohydrate), electrolytes and water to maintain the integrity of body composition and normal function. Micronutrients (vitamin and trace elements) are also affected. Absorption of nutrients occurs primarily in the small bowel (duodenum, jejunum and ileum). In some patients, the length of small bowel (SB) available for absorption is too little. In others, an otherwise adequate length of SB fails to function properly. HPN is required for patients with irreversible intestinal failure (Type 3) and for those awaiting reconstructive surgery leading to restoration of gut continuity and function (Type 2). HPN allows IF patients to survive with an improved quality of life. HPN is a demanding, complex, expensive and potentially dangerous treatment. *It follows that this treatment must be applied to the highest standards. HPN should be made available to all IF patients who need it to ensure equity of access.*

Relationship between HPN and IF:

- All patients needing HPN have intestinal failure, but not all patients with IF need HPN.
- Only 55% patients treated for IF at Hope and St Marks require long term HPN since surgery often obviates the need for HPN by restoring adequate gut function.
- Not all patients with IF need further surgery but may require HPN alone. These patients require HPN training only.

Epidemiology of HPN

Data on numbers of HPN patients in the UK has been collected since the first patients were fed in the late 1970s. Since 1995, this function has been performed by the British Artificial Nutrition Survey (BANS), a constituent committee of the British Association for Parenteral and Enteral Nutrition (BAPEN). Each annual report has identified an increasing number of HPN patients (Figure 1). Despite BANS' best efforts, underreporting still occurs. Allowing for this, it is estimated that approximately 500 HPN patients are being treated at any one time in the UK (POINT PREVALENCE). The total number fed in 1 year (PERIOD PREVALENCE) is 507 according to BANS but may be as high as 600 allowing for underreporting.

There are however, major differences of prevalence and incidence in different regions (Table 1). The variation between Health Authorities of 0 - 36 per million exceeds that predicted from known variations in the underlying diseases which lead to Intestinal Failure and HPN treatment. There is a less than 1 in 1000 possibility of this variation occurring by chance alone. It follows that many patients who should receive HPN are not and this is the basis for the contention by BAPEN that there is ***inequity of access*** to HPN in the UK at present. Furthermore, there is a preponderance of patients around the major centres which suggests that patients are more likely to gain access to HPN if they live closer to a centre than otherwise. If it can be assumed that the prevalence around the major centres is meeting the demand for HPN, it follows that there is under met demand in regions more remote from major centres.

Access to HPN Centres

If patients requiring HPN are to access this treatment, it must be available either at a national IF centre or more locally. If there is no local centre, or the IF centre is saturated, access is denied. The distances which patients and their families must travel over the training period and subsequent follow up visits or emergencies are an important aspect of HPN care. The trend towards older, more dependent HPN patients makes long journeys to and from the IF centres difficult or impossible. The longer the journey, the higher the threshold required for patients to decide to inform their centre of problems and the more difficult for the centre to quickly assess the situation, e.g. line sepsis.

Anecdotal evidence from around the UK suggests that non-availability of local expertise or a centre affects decision making adversely. Older patients who have just infarcted their small bowel may be denied the opportunity to recover with TPN if HPN is not regarded as logistically possible.

The marked predominance of HPN prevalence around the major centres supports these observations. (Figure 2) It must be concluded that availability of an HPN centre satisfies local demand but only partially satisfies more distant demand.

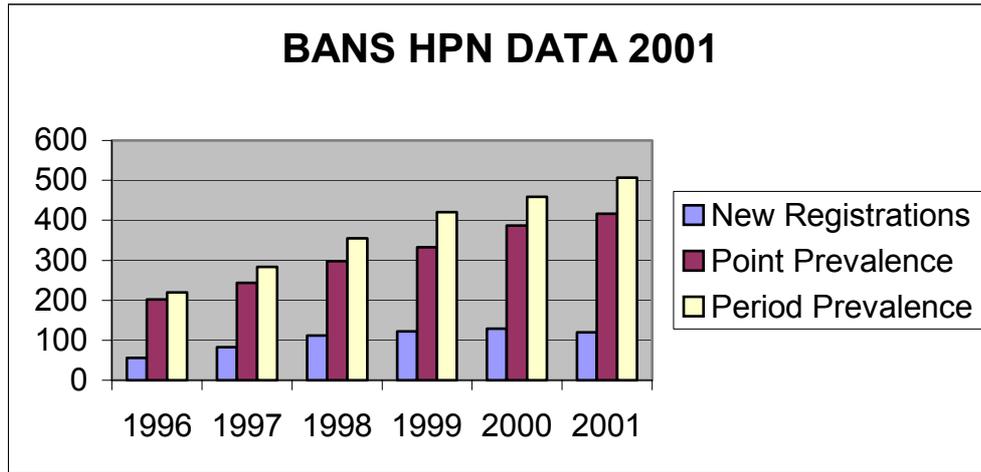


Figure 1

	Patients / million	Year of data
UK	9	2001
Scotland	14	2001
North West England	14	2001
West Midlands	4	2002
Wales	6	2003
Health Authorities –UK	0-36	1999
Denmark	12.7	1999
USA	40	1992

Table 1
Prevalence of HPN patients per million population

Evidence for Variation in Standards of HPN

HPN is a specialised form of nutritional care with possible life threatening complications. If care is to be effective, it should be provided from centres with adequate expertise. It is generally accepted that optimal nutritional care is provided through a multi-disciplinary team (Lennard-Jones 1992, BAPEN 1994). BANS data from 209 centres in 144 hospitals reveals that only 41% of respondents have a nutrition support team (NST) and that this figure has not risen for several years (Elia et al 2002). These figures over estimate the true proportion of hospitals with an NST since not all hospitals participate in BANS data collection. There has been a slight increase to 79% in the number of teams with a nutrition nurse. At the latest count in May 2002, there were 72 Nutrition nurse specialists from 50 centres registered as members of the National Nutrition Nurse Group of BAPEN. It is known that PN catheter related sepsis rates are unacceptably high when there is no NST. Surprisingly, 10/38 HPN centres report that they do not have a NST although some deal with 8 – 29 HPN patients.

In the most recent BANS survey, many hospitals do not even record and audit their catheter sepsis rates. Those that can report in-patient sepsis rates returned figures of 0 – 87%! If a hospital has poor inpatient PN sepsis rate it is unlikely to achieve a high standard with HPN. Some hospitals have very limited exposure to HPN with 12/38 having only 1 patient and 5 centres having only 2. Patient surveys have revealed perceived inadequacies of care with regard to knowledge of line care, management of catheter sepsis, variable training and post discharge support and information (Wheatley 2002). Centres which do not use commercial homecare companies to provide community support may offer a less than optimal service.

There is little published regarding standards in non major centres. but recent data on line sepsis rates from Dudley (Ransford et al, 2000, Freshwater et al, 2003) indicate that smaller centres can produce similar results to larger centres, (Bozetti et al,2002).

Indications for HPN by Diagnosis (Elia et al 2001,2002)

Crohns disease remains the most common indication for HPN but the proportion with Crohns has fallen from 37.5% to 21.8% of new referrals and from 44.6% to 31.5% of point prevalence. No new patients had HIV reflecting improvements in treatment of this condition. Vascular disease leading to small bowel infarction is rising. Cancer of the GI tract and elsewhere accounts for 14.1% of new referrals but only 6.9% of point prevalence reflecting the short survival in this group. There is some evidence that the proportion of HPN patients with cancer as the main indication is rising. In 2001, cancer accounted for 1 in 7 of new HPN patients. There continue to be major differences between the UK and mainland Europe and USA with regard to HPN provision for cancer.

Indications by Reason for Nutritional Support (Elia et al 2001,2002)

Short bowel syndrome remains the main indication for HPN in new patients in 2001; (46.7%) with malabsorption (11.7%), fistula (10%), GI obstruction (10%), and swallowing disorders (5.8%) making up the remainder. There is a higher representation of short bowel (61.3%) in point prevalence figures.

Age

The commonest age range for new patients on HPN is 41 – 60 accounting for 50% of new HPN. There has been an upward age shift overall and within the 41 – 60 range between 1996 to 2001. Patients between 71 and 90 now represent 14.1% of new registrations. Point prevalence in this age group is only 6.9% suggesting that survival in this group is not good. As established HPN patients become older, or older patients are referred for HPN, the support required will increase. This has implications for carers and commissioners of care. Ethical dilemmas will be inevitable.

Dependency

Although most patients are live relatively independently on HPN, there are signs that the ability of HPN patients to manage their HPN independently has changed dramatically reflecting a change in practice across the UK. The rate of independent living amongst new registrations has fallen from 75% in 1996 to 55.8% in 2001 and this is reflected in the fall in point prevalence (83.2 to 74%). Those requiring total help including their HPN administration have risen from 8.9% to 21.7% over the 6 years although this has not yet filtered through to the point prevalence figures, perhaps because some eventually achieve independence. These findings suggest that the threshold for selection of patients for HPN has changed to include those previously rejected on the grounds that quality of life and availability of support were not sufficient to justify HPN. The observation that mean age of HPN patients has shifted upwards accords with these findings.

Residence

In the four years that this statistic has been audited, there is already a trend away from patients living in their own home to nursing homes in which 5.8% of new registrations now reside. This has major resource and training implications.

Activity levels

New patients are more likely to be bed bound or housebound than six years ago and limited or full activity is less evident now than in 1996 but the majority of HPN patients are still able to demonstrate limited or full activity.

Outcome

Overall survival at one year is 92%. Many patients survive ten years or more with good quality of life. HPN patients have delivered normal babies after receiving HPN throughout pregnancy. Quality of life is often less than expected for age but better than for other long term illnesses and increases after introduction of HPN. Less than 1% of time is spent in hospital once on HPN although underlying disease states often demand complex care. Many patients cease to require HPN as they become able to return to enteral or oral nutrition due to intestinal adaptation or reconstructive surgery.

Venous Access

Venous access routes have shown a slight trend away from subcutaneous ports to tunnelled catheters with an external section. There is little difference between the new registrants and the point prevalence figures suggesting that there is no net trend towards switching from a port to an external section line as sepsis complicates port placement.

Homecare Company Involvement

It is generally considered good practice to involve a commercial homecare company in the provision of HPN solutions and equipment. There has been a clear trend towards use of such companies over the last 4 years (74.1% to 89.2%). However, even in Scotland, the largest centre has found it difficult to obtain funding for commercial homecare support of its 25 HPN patients.

The co-operation and partnership demonstrated by the involvement of Commercial Homecare companies reflects the government's policy on Public – Private partnership.

Distribution of HPN by Centre

The two nationally Intestinal Failure units at St Marks Hospital London, and Hope Hospital, Salford are responsible for 120 and 100 HPN patients respectively. Neither unit is funded or resourced to provide HPN beyond the requirements of an individual patient during specialist surgical treatment of Intestinal failure. Data from Hope Hospital indicates that 2/3 of readmissions are for complications of HPN, not the underlying condition or surgery. This has led to considerable delays in admission for patients on the waiting list for in patient treatment of Intestinal Failure. This in turn has led to a mortality of 14% for waiting list patients at Hope. These two centres have reached saturation point for HPN but their 220 patients represent only a minority of the total number in the UK. BANS has identified up to 50 centres providing HPN treatment. Many of these provide only a sporadic service often with no patient on treatment.

About twenty provide a regular service and act as referral centres (Table 2). None of these centres is specifically funded for HPN or recognised as an official centre. They have grown in an ad hoc fashion dictated by local needs. Some centres do not have sufficient or appropriate personnel to provide a high quality service but have been forced to continue despite these constraints since no other unit is available to provide an alternative service. Many centres have also reached their own saturation point and can take on no more patients or have been restrained from doing so by their managers or purchasers.

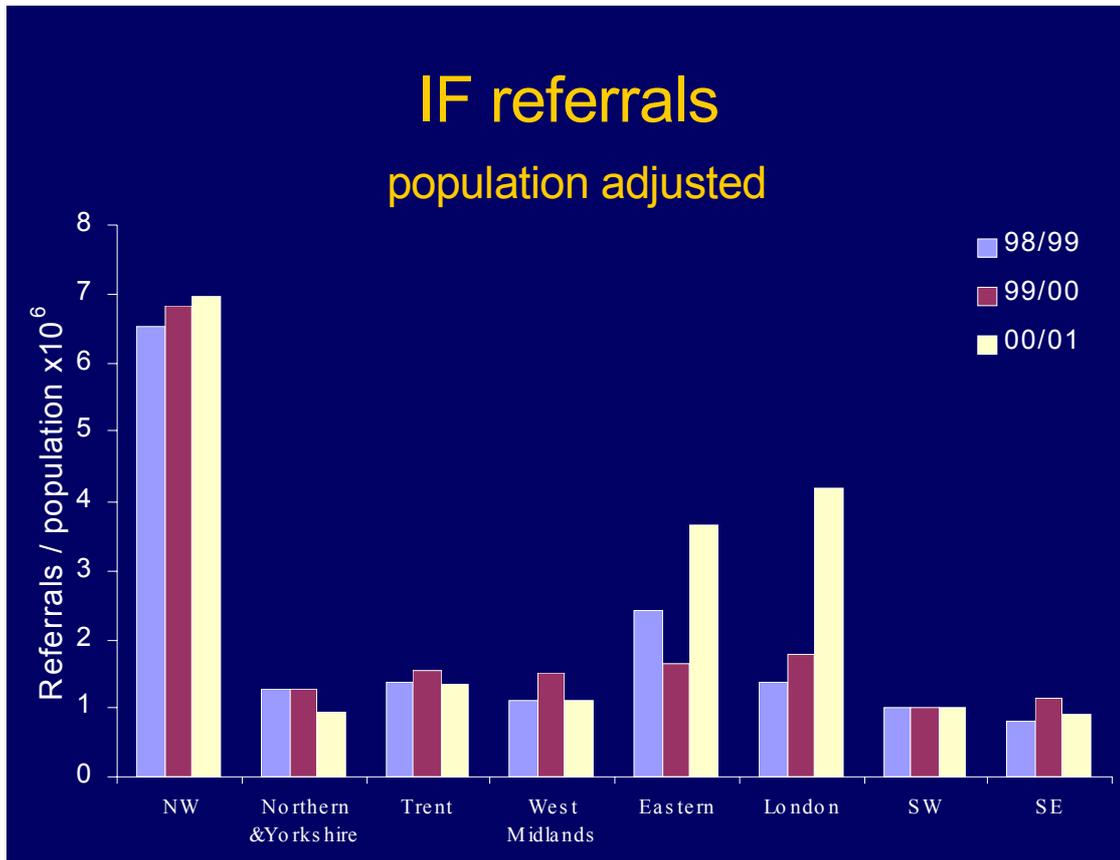


Figure 3

Data derived from combined Intestinal Failure Units (St Marks & Hope), 2001

Travel To & From HPN Centres

HPN patients may have to travel long distances for routine follow up or in emergencies, often at night. A recent survey of HPN patients conducted by the patients' group PINNT, has highlighted these problems. This survey relates to the 98 respondents from 200 circulated in 2001.

Number of Hospitals Attended

72% attended just one hospital, with 20% attending two. However, one person attended six hospitals.

Frequency of Visits

Four to six visits per year was the most common response, but three people attended 12 times a year for HPN related issues, whilst six people made more than 12 visits.

National Referral Centre Attendance

47.9% attended a national referral centre and 52.1% attended other hospitals. (Under present arrangements, care is in 1 centre only in most cases).

Distance of Travel

For both routine and emergency cases, people travelled a wide range of distances. Some people travelled in excess of 300 miles for routine or emergency visits, with one travelling over 480 miles for a routine visit and two travelling in excess of 400 miles in an emergency.

Mode of Transport

77% travelled by car, 10.5% by hospital transport. Travel by public transport is inadvisable when you are feeling ill. One person travelled by plane.

Cost

The average cost was £16.48, which is a lot for someone on restricted income. One person incurred £230 per hospital visit. Some people reported the need to be accompanied to hospital, whether for routine or emergency trips, which can incur greater costs.

Emergencies

All but nineteen respondents said they had not had an emergency. However, two people reported eight emergency trips to hospital.

Service Preference

78% said they would prefer closer more local services but 30% expressed dissatisfaction with present local services. Until local services are better supported and able to respond to urgent calls with a consistent high standard of care, patients will continue to lack confidence in them. This means greater dependency on the major centres. The Scottish MCN has approached this problem by attempting to bring all units with HPN patients up to the same standards of care within a properly organised and supported network.

Hope Hospital Travel Data

The above patient survey findings are supported by independent data from Hope Hospital Intestinal Failure Unit. In 1998, 16% travelled >150 miles, and 45% travelled >50 miles. 21% were older than 60 years.

Pre-Requisites for HPN Service

The National Specialised Service Definition series No. 12 HPN, provides a brief overview of HPN and the resources required. BAPEN Standards and The Scottish Clinical Standards Board draft provide insight into the specific requirements of HPN services. It is essential to recognise that HPN can only be provided when there is already an effective in-patient service. This in turn can only be provided by a fully constituted Nutrition Support Team. All centres providing a service at present have evolved in response to local need and available expertise. It follows that any future recognition and support of HPN should build on those units already providing an effective in-patient PN and HPN service. Units providing suboptimal in-patient services and only sporadic HPN should not receive recognition. Their HPN patients should be cared for by centres satisfying the above criteria. Centres wishing to become HPN centres should be encouraged to do so only if they can demonstrate adequate performance as an in-patient PN team and in conjunction with larger supporting centres.

The most important components of an effective NST are nutrition nurse(s) and clinician(s) with an interest in nutritional support. Most units have insufficient numbers of staff to take on more HPN patients.

There are three potential sources of increased demand on established units which need to be satisfied if inequity of access and variable standards are to be addressed.

1. Overspill from the main IF centres
2. Patients from sporadic centres
3. Patients not presently receiving HPN because of the maldistribution of available services.

It will not be possible to provide equitable high standard HPN to all those who need it without addressing the manpower issue, particularly specialist nurses. This should not pose too great a financial burden on the NHS and would be cheaper than setting up new IF centres. The present 2 centres will be able to function more efficiently if HPN patients can be returned to more local centres for routine HPN care. This should be a dynamic relationship so that patients can still access the main centres when necessary. Hub and Spoke, or Network arrangements will need to be forged and are indeed already developing (eg Dudley and Hope, Torbay and Hope, Cardiff, Swansea and Wrexham, Scottish Managed Clinical Network, St Marks and The Royal London). These developments require central DoH support in principal and SHA/PCT support financially.

Funding Issues

Funding of HPN has always been a contentious issue. For some years until 1/4/02, centrally reimbursed costs and later, top-sliced funding of District Health Authorities with cross charging between authorities, reduced the difficulties of discharging patients from hospital. National and Regional centres providing HPN must have standard agreements in place with all potential purchasers since discharge of patients is dependent on availability of funding.

Since the introduction of the "Shifting the balance of Power" policy, there have been no centrally agreed arrangements. This has led to a chaotic situation in which each patient requires individual enquiry on their behalf by the discharging centre which has trained the patient. PCTs have not yet been able to take on this sporadic demand since no central guidance has been issued. On the contrary, the DoH has indicated that each centre must negotiate with each commissioning PCT. This is an untenable and highly inefficient system not only for HPN but other specialised services. The TIMES published a summary 20/2/02 of the state of planning for various Specialised services including HPN. In only 4 regions had PCTs even started to plan for HPN services.

It should be noted that efficient training prior to discharge often takes less time than arrangements for funding, thereby incurring greater in-patient costs due to delayed discharge.

In Scotland, these problems were recognised by the Scottish Clinical Standards Board in 1999. As a result the Scottish Managed Clinical Network evolved. This has not yet solved all of the funding problems but the structure and will to do so is there, backed by the Scottish Parliament. No such trends have emerged to date in the rest of the UK.

Active Unrecognised Centres

BANS data has identified up to 50 centres with some experience of HPN at one time or another. Only 20 –25 have regular experience and provide a satisfactory service. Numbers of patients at any one time (prevalence) is shown. Where known, identified problems in delivering an HPN service are also shown.

Table 2

HPN Centre	Prevalence	Identified Problems	Comment
St Marks	100	Saturated	
Hope Hospital, Salford	120	Saturated Beds closed/staffing	
Royal London	20	Capped unable to take new patients	
Oxford			
Southampton	10		
Cambridge			Small bowel transplant service
Nottingham			
Belfast			
Bristol	9	1 clinician, 2 nurses	
Cardiff/Wrexham/ Swansea	10	Welsh commissioners considering support	Networking with Wrexham & Swansea
Rest of Wales	10		
Dudley	10	Only 1 NNS	
Leeds	29	No Nutrition Nurses	
Torbay/Plymouth	4	2 nurses, 1 pharmacist	Links to Hope/St Marks. Serves SW
Basildon			
Newcastle			
Scottish MCN	70	16 centres	Funded Co- ordinator
Queen Elizabeth Hospital, Birmingham	2		
Sheffield			
Leicester			
Liverpool			

Many of these centres are already working closely with the two national Intestinal failure centres There are other centres which could develop HPN services based upon established in-patient Parenteral Nutrition services (eg Stoke, Coventry, Central Birmingham).

The Scottish Dimension

The Scottish HPN managed Clinical Network was launched in November 2000. Its stated aims are to ensure equity of access and uniform high standards of care. All 72 HPN patients are now enrolled from 16 different centres. Extensive audit agreed with the Clinical Standards Board allows close monitoring of standards. (Annual Report, 2002, Dr R McKee and JP Baxter, obtainable from JPB, Ninewells Hospital, Dundee).

Organisations Supporting BAPEN Position on HPN

National NSCAG funded Intestinal Failure Centres (ST Marks & Hope Hospital, Salford)

BSG – British Society of Gastroenterology, Small bowel and nutrition sub committee

PINNT – Patients on intravenous and nasogastric nutritional Therapy

RCP – Royal College of Physicians of London

NNNG – National Nutrition Nurses Group

NSCAG – see attached letters

National Specialised Service Definition No. 12 - HPN

The formal position regarding this document was set out by Dr. E. Jessup in a letter to BAPEN, 23/7/02 (see below). This document is a reference document only. It formally recognises HPN as a specialised service in its own right and separate from Intestinal Failure. Providers and Clinicians may quote the definition as evidence that the NHS should secure funding to support that particular model and level of care.

The Department of Health's View

Initial contacts with the Department of Health (DoH) met with little positive response. We then wrote to Mr. Milburn, Secretary of State for Health in October 2001. In that letter, we offered BAPEN's assistance in helping the government to achieve its stated objectives of improving standards of care and equity of access. We pointed out that HPN provides an excellent example of "Public – Private partnership" also reflecting government policy. BAPEN's concerns regarding commissioning of specialist services such as HPN was highlighted. The fledgling Scottish Managed Clinical Network for HPN was used as an example of how we might move forward.

A response to this letter was received from Dr. G. Carroll, Specialised services adviser to NSCAG. In that letter appeared the following statement:

"The BAPEN proposal concerning devolution of stable HPN patients to other competent centres to allow the current two intestinal failure units to concentrate on selected patients that are in greatest need of tertiary services is important and I am sure correct."

A further letter was received in July, 2002 from Dr Edmund Jessup, also Medical Adviser to NSCAG. This letter provided further support for the BAPEN proposals. The main points made are as follows:

1. NSCAG commissioned Intestinal Failure services capacity is constrained by patients whose needs could be met at a lower level.
2. A "sub-national service " is required to solve the above problem.
3. This should be within structures and resources available.
4. The DOH/NSCAG can not instruct PCTS to give priority to HPN.
5. BAPEN to develop standards of care for national use by commissioners to assess level of care provided.
6. Existing strengths should be utilised rather than setting up new centres.
7. Investment would be required to support centres taking on more HPN.

Unfortunately, the Shifting of the Balance of Power to PCTs has made it difficult to proceed but NSCAG would appear to be offering support to BAPEN in its efforts to raise the level of awareness of PCTs and to enable efficient processing of funding for HPN patients.

The recent DoH paper "Reconfiguring Hospitals" (February, 2003) provides further support for local care convenient to our HPN patients.

HPN Centre Standards

BAPEN has generated standards for HPN care, which are now being updated. The Scottish Clinical Standards Board in conjunction with the Scottish Managed Clinical HPN Network has produced draft Standards.

Proposals for a “Sub-National HPN Service

As suggested by NSCAG advisers, it is now recognised that the position of the National IF centres needs to be strengthened by developing a non IF centres capable of providing HPN. This has been termed a Sub-National Service. No guidance as to how this should be constituted has been proffered. Instead, BAPEN has been advised to negotiate with PCTs. This is not an appropriate approach since individual units would have to negotiate with numerous PCTs. If there is to be uniformity of practice allowing interchange of patients between units, it is essential that agreement is reached on a uniform system for discharge of HPN patients and their subsequent funding. Such agreements should apply throughout the UK since referrals transgress StHA and even national boundaries. BAPEN therefore suggests that discussions be held with the Department of Health in order to agree a plan of action. This would include advice to StHAs and PCT Specialised Services commissioners.

Networks or Hubs and Spokes?

Ad hoc arrangements already exist between HPN provider centres in England. In Wales, the Welsh Assembly, through its new Specialised Services commissioners, has shown interest in the Scottish MCN model. A network comprising Cardiff, Swansea and Wrexham is being set up with close links to the IF centre at Hope which has already started the process of devolving patients to providers nearer patients' homes. Thus Dudley has taken patients from Rugby, Warwick, Coventry and Central Birmingham previously under Hope alone. Nottingham proposes a local network as does Leicester.

However, there has been no formal recognition of these innovations. If a sub national service comprising established centres is to succeed, there must be some investment, particularly in specialist nutrition nurses. As more Gastroenterology trainees become experienced in Clinical Nutrition as proposed by the RCP, London and BAPEN, the medical component of these services will also need to be enhanced by new consultants.

Such consultants will also subserve the increasing demands of the more numerous inpatient parenteral and enteral nutrition patients. BAPEN does not believe that networks can be set up by negotiation with individual PCTs. The document entitled “Commissioning Arrangements in the New NHS –Review into Commissioning Specialised Services” 2/7/02 available on the DoH website presumably provides the framework for BAPEN’s proposals.

It seems likely from projected BANS data that centres outside the two IF units will need to provide for 15 – 30 patients each with smaller units managing no more than 15 – 20.

Conclusions

1. HPN is a “low volume – high cost” life saving therapy.
2. Demand for HPN is rising year on year.
3. The age and dependency of patients is rising.
4. Equity of access to present services is unacceptably variable.
5. Standards of care vary according to workload and experience.
6. Present Intestinal Failure services are saturated by HPN patients.
7. HPN patients must be devolved to centres nearer patient.
8. HPN centres need investment.
9. The Scottish model may be appropriate in some parts of England and Wales.
10. Funding of individual patients must not be subject to delay caused by lack of uniform policy.
11. Urgent discussions with DoH and new Specialised Commissioners needed.
12. Central guidance from the English DoH is essential for the new Specialised Services Commissioners.

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Bozetti F et al, Central venous catheter complications in 447 patients on home parenteral nutrition: an analysis of over 100,000 catheter days. *Clinical Nutrition* 2002;21:475-85

Appendices

Copies of following letters are attached :-

Mr Milburn, Secretary of State for Health

Dr Geoffrey Carroll, Medical Adviser to NSCAG

Dr Edmund Jessup, Medical Adviser to NSCAG