Managing parenteral nutrition at home

Home parenteral nutrition is increasing in prevalence and doctors in other specialities may be called upon to treat such patients. This review outlines the practical management of these patients as well as potential pitfalls.

Home parenteral nutrition (HPN) is used for patients with ongoing intestinal failure who are going to require nutritional support for months or years and cannot be managed via the enteral route. These patients constitute a small but clinically significant problem as they are unable to survive without parenteral nutrition; the prevalence of HPN in the UK is 9.5 patients per 10^6 inhabitants (Jones et al, 2005). The most common underlying diagnoses are Crohn's disease, mesenteric infarction, radiation enteritis and cancer. The use of HPN in malignancy is controversial, but in those countries that advocate it, such as the USA and Germany, it makes up the majority of the patient caseload. In terms of anatomy 75% of patients have short bowel (Messing and Joly, 2006); and other causes include obstruction, fistulae and pseudo-obstruction. To deliver safe HPN patients require secure venous access that they or a nominated carer can look after at home, regular deliveries of total parenteral nutrition (TPN) and associated supplies with 24-hour back up available and long-term follow up to anticipate and deal with complications.

Feeding

Patients on HPN need to infuse volumes between 1.5 and 5 litres per day, from 3 to 7 nights a week, as they may be fluid and/or calorie dependent. Through the week they may have a combination of fat, glucose and electrolyte bags depending on their individual requirements. TPN is provided as single chamber bags that must be maintained at 2–8°C and brought up to room temperature before infusion. Infusion periods range from 10–16 hours, but most patients infuse over 12 hours overnight to minimize interference with day-to-day living. The minimum number of infusion cycles should be used per week to decrease the risk of infection and effect on lifestyle. Additives such as vitamins and heparin may need to be injected into the TPN bag directly before infusion as over long periods they destabilize the mixture and cause precipitation.

In addition to TPN the majority of patients are also able to take some oral diet, which as well as performing important social and psychological functions encourages bowel adaptation and decreases biliary stasis.

Training for line care

The majority of patients who are discharged on HPN are responsible for their own line care which, as they generally have no prior medical training, is a daunting task. It is vitally important that patients practice scrupulous line care and this has to be achieved within their home environment. Patients need to allocate a room or area of a room for their supplies and to set up a sterile field to access their line and change line dressings. The process of training takes an average of 4–6 weeks and ranges from correct hand washing and gloving techniques, to putting additives in the bag and dealing with common problems (*Figure 1*). Patients need to be confident dealing with their own line and 95% are totally autonomous with line care (Messing, 1994).

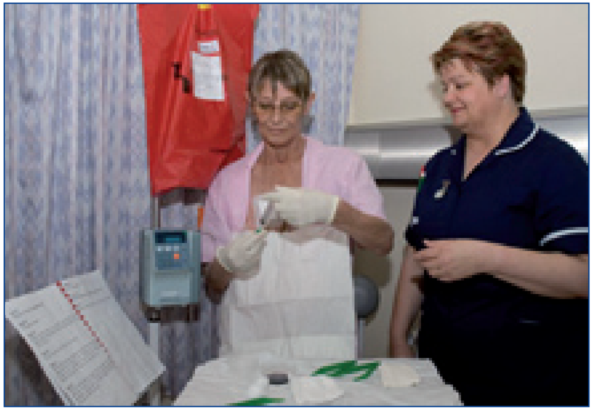
Home support

There are a number of home care companies in the UK who provide delivery of TPN supplies which include the prescribed bags with additional safety bags, additional crystalloids to manage dehydration, a refrigerator for storage, and all ancillaries such as the pump, drip stand and dressing packs. They are available for patient support, and may have to play a role in line care or training in some patients. Patients also need access to the unit that prescribes their TPN and that will be available for support, advice and to coordinate line care and the treatment of complications including further hospital admissions.

Vascular access

The majority of patients have a cuffed tunnelled line in situ, composed of either silicon or polyurethane. The most popular insertion sites are external and internal jugulars and subclavian veins. However, in patients with difficult venous access because they have had multiple

Figure 1. Patient training for line care.



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previous lines, thrombosis or stenosis, alternative sites such as femoral and lumbar veins and exceptionally direct cardiac puncture have been used. As with any central venous catheter the line tip should lie at the junction of the superior vena cava and right atrium.

Complications at the time of insertion include malposition, inability to insert, embolism and damage to surrounding structures, i.e. arteries, nerves and the thoracic duct. A few patients have a catheter with an implantable port; they have a better cosmetic appearance, and are easier to bathe and swim with, but have a limited life span and have to be surgically removed if infected. Cuffed lines have a lifespan of more than 10 years if properly cared for (Teubner et al, 2005).

Regular outpatient review

After initial discharge from the supported ward environment patients may need early follow up in the outpatient clinic; after this review can vary from 6-weekly to 6-monthly depending on the patient's stability. At each attendance patients should have a dietetic review with weight and anthropometrical measurement and metabolic blood tests. The consultation should address specific patient concerns as well as issues of fluid balance and weight change and is also an opportunity to monitor any metabolic bone disease.

Patients may need the quantity of their HPN increased or decreased depending on any deterioration in bowel function or bowel adaptation. Adaptation is a particular feature of short bowel secondary to ischaemia and over a number of years may completely obviate the need for TPN.

A patient perspective

'Leaving hospital and the intestinal failure unit to go home I must admit to feelings of trepidation and anxiety. After spending 2 years in a variety of hospitals I was scared of the responsibility of looking after my own line.

However, the reality was different and it certainly wasn't as bad as I had envisaged. The strict protocol and intensive training in the ward meant I was ready for every eventuality. Every morning and night it means half an hour connecting and disconnecting the feed.

I feed at night leaving the day for myself and my family and friends. The only drawback of this is the constant trips to the toilet as 3.5 litres of fluid drips into me. I find the bag very heavy so there is no social life at night.

Since being on TPN I've put on a welcome 2 stone. My hair and nails are stronger and I'm certainly better prepared for my next operation than before.'

Complications of TPN

Catheter-related complications

Catheter-related sepsis

Catheter-related sepsis is the most common complication and accounts for 0.48 episodes per catheter use year (Ugur et al, 2006) although rates vary considerably between studies.

Decreased infection rates are associated with single lumen catheters used exclusively for TPN and accessed only by the patient and experienced staff (Magnay and Nightingale, 2001). Increased rates are associated with opiate and sedative dependence as shown by Richards et al (1997) and those patients with stomata.

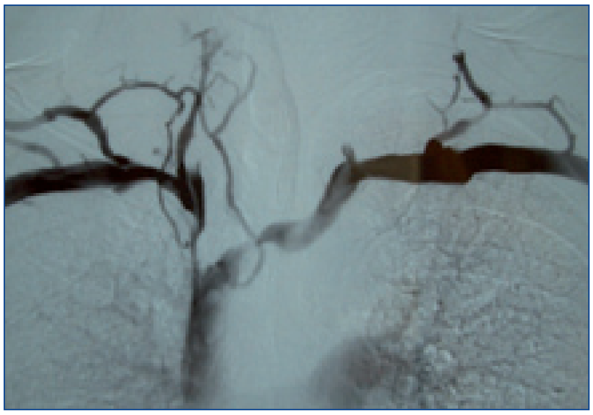
The hub connection is the most common site of contamination from which infections occur and the causative agent is usually a coagulase-negative staphylococcus. Over 50% of line infections can be cleared (Clare et al, 2007) with a line salvage protocol that includes peripheral antibiotics, and central line locks with antibiotics and urokinase. The classical history is of pyrexia and rigors shortly after starting to feed, however, the diagnosis can be difficult and should be suspected in any patient with a line in situ and pyrexia with no obvious focus. If suspected the line should not be used for further infusions. If the patient is septic and shocked the line needs to be removed immediately and the tip sent for culture, but if more stable central and peripheral cultures should be taken and the line locked off until the diagnosis is confirmed and line salvage instigated.

Tunnel infections around the line are rarely cleared, particularly if the cuff is involved and virtually always necessitate catheter removal. They present with fever, a tender, erythematous track along the line and pus at the exit site. Again the causative agent is usually a skin commensal.

Central venous thrombosis

Central venous thrombosis may be suspected if there is new onset pain or swelling in the area drained by the superior vena cava during infusion, or a blocked line that cannot be cleared and is identified on a venogram (*Figure 2*). Thrombosis is associated with those lines with a distal tip (in the brachiocephalic or subclavian rather than superior vena cava or right atrial junction), catheter sepsis, dehydration and high osmolality feed (Pennington, 2001). The risk can be minimized by adding heparin to the bags and using narrow, flexible biocompatible catheters. As well as the obvious concerns of embolism and oedema, thrombosis decreases the number of sites available for vascular access.

Figure 2. Venogram showing brachiocephalic thrombosis.



Catheter occlusion

Sluggishness in the line is a common problem with lines that have been in situ for many years. The most common cause is a fibrin sheath that forms at the point the catheter enters the vein and extends down to encase the tip, this classically causes a sluggish line that it is difficult or impossible to aspirate from as the fibrin functions as a one way valve. A sluggish line needs radiological confirmation of position and can be cleared with line locks of urokinase, or ethanol if occlusion occurs after a fat bag. Line brushing can also be attempted to remove physical debris from a line that cannot be flushed.

Metabolic complications

Micronutrients and vitamin

Micronutrients and vitamin depletion and excess were problems with early TPN, but there are fewer incidents with modern formulations. Some patients with high output stomata experience cyclical dehydration with symptoms of cramps when they start to infuse. The most common deficiencies long term are vitamin D and iron, as high levels in the TPN bags make them unstable.

Hepatobiliary dysfunction

The most common abnormality is cholestasis and biliary sludge, which is thought to be a result of bowel rest (Quigley et al, 1993); 25% of patients progress to develop gallstones and require cholecystectomy (Howard and Ashley, 2003). More seriously, 15% of patients go on to develop end stage liver disease after 3 years (Chan et al, 1999), which is characterized by micronodular cirrhosis on biopsy. Causative factors include excess calories, high lipid loads, underlying disease and the use of hepatotoxic drugs. It is estimated that 22% of deaths in long-term HPN patients are caused by liver failure (Howard and Ashley, 2003) and the only treatment is a liver or combined liver small bowel transplant.

Osteoporosis

Bone disease, seen on bone scan, is present in most patients on HPN and a third are symptomatic (Pironi et al, 2002). However, this does not appear to be related to the TPN itself as longitudinal studies only show an annual decline in densitometry similar to age and sex matched subjects (Hadderslev et al, 2004) and it may be caused by underlying disease or medication such as steroids. Regular bone densitometry is indicated in all long-term patients with infusions of bisphosphonates as needed.

Outcome

The chance of stopping HPN is dependent on underlying diagnosis, but approximately 50% of patients commenced on HPN are off at 1 year (Howard et al, 1995). For patients on long-term HPN 3-year survival is 75–85% (Messing et al, 1995), but over 90% for young patients with inflammatory bowel disease, and 80–90% of deaths are the result of progression of the underlying disease rather than HPN complications. So it is very important to consider long-term problems such as bone disease and scrupulous care of vascular access to ensure sites are not lost. Decreased risk of death is associated with younger age, more recent start of TPN and absence of chronic intestinal obstruction (Messing et al, 1995). Re-hospitalization rate is 0.7 per year of HPN (Pironi et al, 2003), and a third of these admissions are for HPN-related problems.

From the few studies that have been done, patients on HPN have a lower quality of life than those with short bowel not receiving HPN (Jeppesen et al, 1999), but does improve over the first 6 months of starting therapy (Chambers et al, 2001). Patient satisfaction is better in those patients who have previously had borderline nutritional status or have had chronic disease such as Crohn's disease or radiation enteritis before commencing HPN compared to those who were well and had a sudden intestinal catastrophe.

Conclusions

Starting HPN is a life-changing process for a patient requires psychological adjustment as well as thorough training; it medicalizes a patient's daily life and part of their home. Patients need regular review to assess ongoing needs and possible complications. Aseptic technique for catheter care is imperative and safe vascular access is literally the patient's lifeline. Complications most commonly involve the line, but also include hepatic, biliary and bone disease. Prognosis is good with half of patients off HPN after a year and a 3-year survival of over 75%. **BJHM**

Conflict of interest: none.

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KEY POINTS

- Patients on home parenteral nutrition need to be equipped to deal with their own total parenteral nutrition and line care.
- Scrupulous line care is vital to preserve lines that can last for many years.
- Vascular access can be difficult and a variety of access sites can be considered.
- Catheter-related sepsis is the most common complication, but lines should only be removed if the patient is septic or line salvage has failed.
- Complications include those associated with the line as well as micronutrient and electrolyte imbalance, bone, liver and biliary disease.
- Outcomes are good, especially for younger patients with minimal comorbidities.

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