

# A Practical Guide to Managing the Paediatric Parenteral Nutrition Patient at Home



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## Introduction

The provision of home parenteral nutrition (HPN) for paediatric patients in the UK has become an expanding area within the field of paediatric gastroenterology. The advancement within the field of intravenous nutrition over the past 30 years is highlighted in the ESPGHAN guidelines.<sup>1</sup> It is now well recognised that children with intestinal failure requiring medium to long-term parenteral nutrition (PN) can be given optimum nutrition intravenously. This allows them the opportunity to grow and develop normally and have a good quality of life, whilst good management can minimise the most recognised potential life-limiting complication associated with intravenous nutrition of intestinal failure associated liver disease (IFALD).<sup>1</sup> The optimum management of these patients requiring medium to long-term parenteral nutrition is in the home environment.<sup>2</sup> Holden (2001) has shown that children receiving parenteral nutrition at home generally suffer from fewer catheter related bloodstream infections (CRBSI) compared with being in hospital.<sup>3</sup>

PN is used to treat children that cannot be fully fed by the oral or enteral route.<sup>1</sup> Type 3 intestinal failure is a chronic condition requiring long-term parenteral feeding.<sup>4</sup> The children classified in this group would generally be those requiring parenteral nutrition to be administered at home. Examples of conditions where children may be described as having Type 3 intestinal failure are short bowel syndrome secondary to atresia, gastroschisis or necrotizing enterocolitis (NEC), enteropathies or neuromuscular disorders, such as chronic intestinal pseudo-obstruction (CIPO) and Hirschprung's disease.<sup>5</sup>

The precise epidemiology and prevalence of the paediatric HPN population in the UK is unknown. However, due to the advancements in the care of the surgical neonate patient, including improved surgical techniques and the intensive care of the neonatal patient, as well as improvements made with regards to lipid emulsions and amino acid solutions used in intravenous nutrition, numbers of patients surviving with a long-term PN requirement are increasing.<sup>1</sup> Three point prevalence surveys undertaken by the British Society of Paediatric Gastroenterology Hepatology and Nutrition (BSPGHAN) in 1993, 2010 and 2012, demonstrate a steady increase in the number of patients discharged on HPN over the past 20 years.<sup>6</sup> In February 2010, it was estimated in the UK that 139 children were receiving PN at home.<sup>6</sup> Further data, not yet published, has repeated this point prevalence survey in November 2012 and estimates 173 children were receiving HPN. This data illustrates that in the past, children requiring medium to long-term PN would have received this in the hospital setting. Instituting and maintaining intravenous nutrition at home is a major undertaking for a family and healthcare

professionals. Gupte *et al.*<sup>7</sup> describe the need for a multidisciplinary nutritional care team (NCT) (also often referred to as a nutrition support team [NST]) to prevent complications associated with HPN and improve the long-term outcome of these children. Key members of the paediatric nutrition support team in hospital include: a consultant gastroenterologist, nutrition nurse specialist, pharmacist, dietitian and a surgeon. Each team member's involvement may vary depending on the clinical needs of the child and family and the intensity of this may change depending on whether the child is at home or in hospital. However, each has a pivotal role with regards to ensuring that the patient and family are ready for discharge on HPN and that their progress is maintained at home.

## HPN provision

The way in which HPN provision is structured will vary from Trust to Trust. There may be additional members of the wider multidisciplinary team involved with the child and family, both in hospital and at home after discharge, such as psychologists, social workers, other specialist nurses, i.e. stoma care specialists, physiotherapists, occupational therapists and the staff numbers can vary widely depending on the individual hospital Trust. However, the overall aim of any team discharging a child on PN will be the identification of the patients with a long-term intravenous nutrition need early, in order to minimise potential complications. A prompt discharge is preferable to avoid protracted admission. The ultimate goal of any child requiring intravenous nutrition will be to wean to full enteral feeding if their underlying diagnosis allows.

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## Assessment for discharge

The initial challenge faced by any NCT is to assess the capability of each family in order to evaluate if they will be able to meet all of their child's complex medical needs after discharge. The home in which they live in may not be suitable for the administration of parenteral nutrition and this needs to be assessed by the nutrition nurse specialist before training can commence. It is then the responsibility of the NCT to ensure that the family is competent and confident with all aspects of their child's care before discharge and that they have the necessary support needed after discharge in order to allow them to continue to care for their child at home. The patients and families need to feel empowered and have a degree of autonomy instilled in them by the NCT in order to feel confident to be discharged home.

## Discharge and beyond

Discharging these complex patients is extremely daunting for any family. They are faced with the reality of providing all of their child's medical care in their home environment independently, without the watchful eye of nursing and medical staff. This may be the first time that they have taken their child home after birth. In addition to the administration of the intravenous nutrition, parents/carers may have a number of other medical interventions to undertake, such as stoma care, enteral tube feeding, frequent nappy changes, tracheostomy care and administration of medications. The family may also have other children; some may be single parent families or have a partner who works full time and very little support from the extended family. Whilst the discharging NCT will need be confident that the parents/carers can deliver the medical care required to the child before they allow them home, it is extremely important that the family are supported after discharge, know who to contact after discharge and are given the appropriate advice and treatment if needed. Without this, parenteral nutrition will be unlikely to be maintained at home in the long-term.

Due to the geographical distance patients and families may live away from the discharging hospital, a lot of the support given by the NCT after discharge may be by telephone or email. It is extremely important that the family can contact their managing hospital and NCT. At least monthly face-to-face clinic visits are recommended, more frequently if necessary.<sup>1</sup> However, it will not be unusual for daily phone contact to be provided initially by the nutrition nurse specialist after discharge to try to alleviate any anxieties after discharge. Telephone contact may become less frequent as the patient and family become more confident in managing their child in the home environment, but having the knowledge that an expert is readily available at the end of the telephone will be valuable for families to allow them to adapt.

They will need the local support of their health visitor, paediatric community nursing teams, GP, local paediatrician, school and school nurse where applicable. Effective communication between the discharging hospital and local teams is vital in order to ensure that the family are confident and well supported after discharge. Ongoing two-way communication between all healthcare professionals after discharge is imperative to ensure continuing collaboration between tertiary and local services.

Robust safety plans need to be put in place before discharge so that the families can receive prompt, appropriate treatment in an emergency/out of hours if needed. This initial emergency care may often take place in the child's local district general hospital. Strict protocols for local teams to follow are needed, particularly in relation to the management of a child with suspected central line sepsis. This will ensure that the local team is confident in the emergency care of HPN patients, whilst encouraging the family to seek timely local medical care in an emergency, which is important to minimise potential harm that could be caused to the patient if immediate emergency care is inappropriate.

## Quality of life

Intravenous feeding regimes need to be optimised to deliver age appropriate fluid and calorie requirements. However, the NCT needs to strive to discharge a child on a regime that promotes a good quality of life for the child and family.

It is important to consider the child that needs to attend school during the day.

Family life also needs to continue and attendance at social gatherings/activities and holidays should be encouraged. This may influence the intravenous feeding regime the child is discharged on, including the choice of pump to deliver the intravenous nutrition. Discharging a patient on a portable feeding pump is preferable to allow the family to have an optimum quality of life.

Overnight intravenous feeding regimes using a one bag delivery system as opposed to a two bag system should be promoted whenever possible. However, this can be challenging in a child with a high electrolyte or fluid requirement. The minimum amount of time on parenteral nutrition as well as considering nights off parenteral nutrition are also preferable for a family at home to promote quality of life, as well as being liver protective. Again this can be difficult for a child who can only tolerate small amounts of oral or enteral feeding or requires additional intravenous fluid for fluid management.

Oral feeding should be promoted whenever possible. However, if additional enteral tube feeding is required, regimes should try to be tailored to promote quality of life. Again, this may be limited by the child's underlying condition and ability to tolerate enteral feeds but it is vitally important that the patient's enteral feeding tolerance is pushed, whilst balancing the family's quality of life.

## Monitoring

There is clear guidance within the ESPGHAN guidelines<sup>1</sup> with regards to the monitoring of the paediatric patient on HPN. The assessment of the child's nutritional status is made by a combination of measuring the child's weight, height/length, head circumference, mid upper arm circumference (MUAC), tricep skin fold thickness (TSFT) and body mass index (BMI). Bloods should be checked at each monthly clinic visit, if not more frequently in the early stages of discharge, with trace element monitoring on a three monthly basis. This will allow the NCT to alter the PN and EN feeding regime if needed to ensure optimum nutritional and fluid management to promote growth and development.

## Possible complications

The two most well recognised complications associated with long-term parenteral nutrition are CRBSI and IFALD. In addition, there may be issues with venous thrombosis and pulmonary emboli;<sup>1</sup> not forgetting the more practical complications associated with the administration of PN, such as the more active/mobile child overnight, poor compliance in the teenage years and problems

with the medical equipment. Early recognition of any complication is vital in order to prevent any long-term complications. The families should be counselled with regards to the signs of CRBSI to allow for early detection and treatment. Results of liver function tests should be regularly reviewed by the NCT, as well as abdominal examination being performed at the face-to-face clinic visit to assess for any signs of organomegaly, suggestive of portal hypertension and liver disease. There should be a low threshold for further liver investigation, including abdominal ultrasound scan if liver disease is suspected. The ESPGHAN guidelines with regards to the formulation of the PN should be followed to promote liver protection.<sup>1</sup>

Complications associated with long-term parenteral nutrition can now be prevented and, if detected, managed. The introduction of a multidisciplinary NCT within Trusts providing a HPN service; advances in lipid emulsion to protect the liver; the good maintenance of the central venous catheter to minimise CRBSI; ensuring that children and families requiring HPN are trained, monitored and supported by professionals that are expert on their fields, have all impacted on the improved outcome of children requiring HPN.

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