



DRIPLINE



PNDU

Parenteral Nutrition Down Under

With this issue, we sadly farewell two precious members of PNDU, Lara and Aiden, who both lost their battle with their health issues. Aiden's mum has written a tribute to him. In this issue we look at HPNers moving to a different part of the country; we read the update on AuSPEN's HPN Model of Care Project; in Teen Talk we learn from James about his life on HPN; Professor Gil Hardy has updated and added to a series of articles that he wrote several years ago for Dripline, beginning with Parts 1 and 2 in this issue; and A Day in the Life of an HPNer deals with the need for a structured life. I hope you enjoy the read.

Gillian
Dripline Editor

CONTENT

- [Teen Talk – Life on HPN, by James](#)
- [A Tribute to Aiden: his Eulogy](#)
- [An Update on the AuSPEN HPN Model of Care Project, by Emma Osland AdvAPD](#)
- [What's in Your Bag? Part 1, Overview and Part 2 Glucose by Prof Gil Hardy](#)
- [HPNers Moving to a Different Area](#)
- [Birthday Corner](#)
- [A Day in the Life of an HPNer – A Structured Life](#)
- [Making a Cannula More Comfortable](#)
- [In Memoriam](#)
- [Upcoming Events](#)
- [Thank you](#)
- [Planning an Overseas Holiday](#)
- [PNDU Information: Membership, donations and contact information](#)





Teen Talk - Life on HPN

Words by James

Hi, I'm James and I've just turned 14. I'm in year 8.

I have been on HPN for nearly 3 years due to a volvulus that left me with short bowel syndrome.

Although I'm on PN, I feel I'm one of the lucky ones as I still get to eat and drink normally, I just don't absorb much of what I'm eating.

I like playing the Xbox, playing soccer and hanging out with friends. Soccer is by far my favourite thing to do. The best position to play is goal keeper, which makes mum really nervous every time I have a game on the weekend.

I train 3 nights a week with a soccer academy and try and train 3 more times a week with my dad, brother and, sometimes, friends. In winter we have a game on Saturdays.

I hate letting my health affect my life, but some days I'm so exhausted that I really struggle to get out of bed. I try and push through these days, but there are times when I just need to rest, as my whole body is so sore and aching. I also get a lot of gut pain, which has nothing to do with the PN, but it is a constant issue to deal with. On the days that I'm really sick or exhausted, I'm still able to connect with my friends through my X Box, which is a nice distraction from feeling horrible all the time.

I have PN 5 nights a week for 11 hours over night, and I have gastrostomy feeds 7 nights a week for the same time as PN.

I know that PN is really important and I'm lucky to have it, as it helps me with my growth, keeping weight on and my energy levels, but it would be better if I didn't need it, as there are a lot of negatives to PN.

I'm hooked up to a machine and have to drag an IV pole around with me for 11 hours; it can also be uncomfortable sleeping on the cords; and it stops me being able to have sleep overs at a friend's house or going away to school camps. I also miss a lot of school and spend way too much time at doctors' appointments. Another negative to PN and gastrostomy feeds is I have so much fluid going through me during the night and I sleep quite heavily once I'm a sleep, so I wake up wet in the morning.

Having PN so many nights a week means I need a central line, which has its own issues, as I can't swim freely with my family and friends - my mum and dad have bought me a dry suit which allows me to swim, but it is really hard to get on and off, so I need to make sure one of them comes with me to help me whenever I want to swim. It's also really uncomfortable and I can't stay in it for a long time.

Having the central line also means I have to go to hospital if I get a temperature - I already spend way too much time at hospital and hate being stuck in there and not being able to do fun things, like play soccer!



James last year, after winning the Grand Final



Words by mum, Belinda

When I started to think about Aiden it wasn't about the short number of years that he lived it was the life he packed into those years. When talking today about Aiden, I could start with his birth and how I jumped on a trampoline just hours before going into labour and I could even talk about his illness and how it affected him but he was more than that. He wasn't a simple child with simple things, he had many sides to him, and you certainly couldn't package Aiden neatly in a box and understand him as he was many layers deep. He was in his own special way trying to pack as much life as possible in what time he had.

Aiden had a side to him that made people fall in love with him, it was a natural side that wasn't just developed it was as natural as breathing to him, he had his moments where you would want to kill him but they were short-lived. His quiet strength or possibly less than quiet strength was what helped him through some exceedingly difficult days.

His less than quiet part was mostly when he didn't like something, he wasn't afraid to tell people what he thought of their ideas. A few times he told doctors that they could apply said treatment to themselves as he wasn't having a bar of it.

It always amazed me how many layers Aiden had, and he lived his life on his own terms. If you wanted Aiden to do something you had to make him think it was his idea. His negotiation skills were on par to hostage negotiation. I would use bribery as a tool for most things just to get the required response. I remember once in Sydney Aiden wanted to have bread but as it was on the excluded list, we went shopping to find something else that would work well instead. I found Bagels of which I was fairly sure was a bread product but Aiden was insistent that we try them, yes that made him sick upon which he told his gastro team they aren't bread they are savoury donuts which are not on the excluded list, none of us are sure how that works but it sure bought a smile to us all.

Aiden hated to be asked what video he was watching when he told people he was watching YouTube videos, it was a way to start a conversation with him or so people thought but for Aiden he would start asking would you rather questions – Would you rather fruit or vegetables? The answer was always fruit as tomatoes, peas, cucumbers, and pumpkins are all fruits! He had a whole book of these questions which were rather interesting and provoked a lot of conversation.

When Aiden was younger I was always anti-guns in the house until Nurse Karlie told me to go buy him a couple of Nerf Guns, this collection grew over time with my anti-gun turning into a collection that was a huge. Often buying more in Sydney or being gifted to us by the play therapists and starlight captains if we had forgotten to take them down with us. Nerf wars were a common sight in Aiden room and within the Starlight room, no one was safe. A ban on Nerf Guns in the hospital didn't stop Aiden and he would still proceed out to the walkways between Sydney Kids and Prince of Wales Hospital to test the accuracy and range of them.

Aiden loved art and craft – except paper pom poms – he could draw and create like it was as natural as breathing and his imagination knew no bounds. He made a whole battleship out of cardboard boxes and other items he found around the hospital, he could tie-dye in the most amazing colours with a story behind the colours chosen, he spent months drawing designs for a game he would one day create. He was never afraid to make a mess, one art project was to design a special brick as a project for the ward, so a large sheet of cardboard was bought in with water balloons, paint and a pin. You can see where this was heading! Balloons were filled with paint and air, then popped over the cardboard and of course the paint sprayed... everywhere! It was an amazing but very messy artwork the memory of which is still imbedded in the bed and walls! When he was not in hospital, he was collecting rocks or polishing rocks at the Craft Shed with the Lapidary family or doing another project at home he had found on You Tube.

Aidan also loved Lego, his collection of which was on par or maybe it just slightly rivalled the Nerf collection. He also collected Pokémon Cards based off a cartoon show, which he wasn't so fussed with, but he loved the games and movies. Aidan also loved electronic games as well; the complexity and depth fascinated him, and he would watch videos around these as well as play them. Hot Wheels cars were another favourite but over time he stopped taking them out of the boxes as they were worth more! Aidan collected items that often seemed random or weird, from marbles and dice through to bottle tops. It always surprised me what would become the next collected item and we could never throw away any of the collections!

Aidan other biggest love though was food; he complained if the hospital TV didn't have SBS Food, but his absolute favourite was *The Cook and the Chef*, which had Maggie Beer in it. Often, we would watch this together as we discussed whether or not we would eat what they were making. One of his many teachers contacted Maggie Beer on his behalf, upon which she sent Aidan a lovely signed photo and a DVD. A photo which went on the gallery he had on display already at the hospital and was pointed out to the many people who came to Aidan's room. Aidan also loved to design food; he was determined to make a pasta free lasagne by using bacon and cheese instead of pasta sheets. He had combinations of food that he wanted to try and was often spouting off about his "Grandma Juice", a combination of lemon, orange, grapefruit and maybe limes. The sourer it was, the more he loved it! Sour lollies were a favourite as well, but these were also a punishment for the staff when they did treatments that he wasn't quite so keen on - the face pulling always guaranteed a bunch of laughter!

Aidan loved to play board or card games and a recent trip away with Grandpa started a Monopoly bug for him, though he couldn't win against Grandpa and he hated the way I played! He started to collect the Monopoly versions he could find. A trip to Paddy's Market with Jessica and Bailey was a dangerous place to visit, with a lot of stuff for little boys like Aidan to buy. We managed to find a Pokémon monopoly version and after finding the strength against his pain and his struggle to walk, he proceeded to hobble the 15 steps to look at the game – how could Mum say no after that effort!

Another part of Aidan was his love of animals; he was often asking me for a pet baby goat; more cats (he had a list of the ones he wanted); chickens; and lizards; amongst many others. In hospital he had fake rubber spiders, of which he proceeded to scare the staff with the spiders. Charlotte, Scarlett and Steve were the start of a lot of arachnophobia nurse troubles - these were often placed on the back of their neck or on the pump for them to have to deal with as the legs dangled over the pump buttons and would have to be lifted so that they could access it. Aidan recently went on a trip to the Sydney Aquarium and was delighted by all the creatures on display and wanted to go through several times. If you asked him his favourite, he couldn't say, he just loved them all. Aidan also collected rubber ducks, a strange item, but he was impressed with the different styles and look but he couldn't have just one of each type, he would gather several of each type with the livewire hospital family adding to it regularly!

Aidan wasn't afraid to take the mickey out of people either – in the hospital and Bear Cottage the staff were always kept on their toes as he pulled pranks on them. A few of these were not telling a staff member that he had had red drink prior to her emptying his stomach, so a rapid response was called as she was worried he had an internal bleed; a syringe of water was hidden at one point in his bed and nurse Philly who was wearing a white t-shirt at the time copped a full blast in the middle of her shirt; another member lost his credit card after taking Aidan for lunch, and as the card was red Aidan proceeded to point out every red item on the way home from red buttons on the wall to red traffic lights. Aidan was also found to often reference his output to food items, turning many people off favourite foods much to his delight!

Despite all the gags Aidan pulled, he was also a big softy underneath it all; he loved his hugs but no kisses! Aidan's love for softness extended to his bed as well, with a mountain of pillows (4 standard, 2 long body pillows, 1 wedge, 3 cushions), plus several blankets including his sister's Wheezy blanket that he borrowed with the intention to never return, and mountains of teddies. It would take the nursing staff ages to clear the bed so they could remake it with fresh sheets for him, often resulting in some interesting designs being created. Once he was snuggled in nice and comfortable, I would curl up in the chair beside him and read to him from books as a special wind-down time for us.

No, Aidan was definitely not able to be categorised, but that was what made Aidan so unique and loveable, so as we leave here today, I pray that not only do we go on remembering all the love and fun we shared with him, but also remembering the love and zest he had for life. May we also put the same love and zest into our lives, because in the end, it isn't about the years we lived, it is about the life we put in the years!



By Emma Osland AdvAPD

On behalf of the AuSPEN HPN Quality and Education working group

Background

Nearly a decade ago, discussion began around the development of a national model of care for Intestinal Failure in Australia. A report was commissioned by the Federal Government, with a focus on HPN service provision and how intestinal transplant services may work in Australia. This process involved input from patients and their carers, clinicians and health services around Australia, including AuSPEN and PNDU members.

Unfortunately, the resulting report published in 2010 has done little to change how HPN services are currently provided in Australia.

Seeing the need to progress this important work, AuSPEN requested a working group be formed to undertake the task. This working group was formed in late 2017 by AuSPEN members of all professions involved in HPN care from within Australia and New Zealand, and throughout 2018 and 2019 some significant developments have been made.

Development and Publication of the AuSPEN HPN Quality Framework

One of the main gaps in being able to develop a model of care for HPN in Australia was the lack of agreed standards of care for HPN delivery. Therefore, the first job the working group undertook was to develop an evidence-based set of clinical standards and quality indicators based on the scientific literature and the resources used by other HPN services around the world. We were delighted to be able to incorporate the outcomes of PNDU's own consumer-led research work into the framework, and to have 23 PNDU members provide feedback on the framework documents during their development.

A further step was taken to identify the current gaps in Australian HPN services, and these were used as the basis of the position statements: These aim to provide practical actions to fill these gaps and thereby working towards a better quality of care to patients requiring HPN and their families.

The Framework can now be used as the practical basis for the new model of care and provides clinical guidance on what resources and processes are required to provide quality care in HPN. It also provides a structure for how these should be measured and reported.

The framework was published in the Journal of Gastroenterology and Hepatology last year, and can be found <https://www.ncbi.nlm.nih.gov/pubmed/31441085>.

HPN Model of Care Development

The AuSPEN Quality Framework provides the basis for WHAT quality care in HPN in Australia looks like. However, it doesn't describe HOW it should be provided. And this is where the model of care development gets a bit complicated – there are potentially a number of ways the Quality Framework could be implemented and achieved in practice, but would be the best of the available options? Consideration of issues such as

- Is it possible to implement the framework within existing (and differing) resourcing within centres currently providing HPN?
- What further resources are required to be able to implement the framework, and how can that be achieved equitably across the country?
- How should a national model of care be provided when health services are State-based? and
- What do HPNers value in terms of care, and how would they like their care provided?

These are some of the broader aspects that need to be considered and addressed, and obtaining this information is the next step in the model of care development.

Working towards this, the AuSPEN working group developed an outline of what needs to be done at each phase of the development of the model of care. It quickly became evident that despite the working group's commitment and enthusiasm for getting the model of care moving forward, this was a job far bigger than even the most committed working group would be able to facilitate alone!

But not to be deterred, we started working on another plan....

Project Officer

We identified that a project officer would be required to facilitate and lead the processes required to progress the model of care development. This concept (with a business plan and budget) was pitched to the AuSPEN Council in November 2019, in the hope that AuSPEN would support this important step in advancing the HPN model of care in Australia.

The good news is AuSPEN are supportive of this plan, and we are thrilled to be able to share that they have secured funding to employ a project officer to progress this project. We are hoping recruitment will be being in the near future.

In the first instance the project officer will obtain information on how HPN services are currently provided in Australia, and with what resources – in essence, they will undertake a baseline assessment of the resource and process quality indicators outlined in the framework, and this will provide a basis to start advocating and actioning the implementation phases of model.

Like so many things worth doing, this is not a quick or easy process, but we are getting there!

I would like to thank the members of the working group for their sustained commitment and enthusiasm for this work – they have been amazingly generous in the time they've committed to progressing things to this point. I would also like to extend a massive thank you to the PNDU members who provided feedback and highly valued input on the framework documents as they evolved; to Karen Winterbourn and Chris Walker for their feedback on the framework manuscript and business case; and for the support this work has attracted from PNDU members during the opportunities we've had to share updates.

What is a model of care?

A "Model of Care" broadly defines the way health services are delivered. It outlines best practice care and services for a person, population group or patient cohort as they progress through the stages of a condition, injury or event. It aims to ensure people get the right care, at the right time, by the right team and in the right place .

What is Standard of Care?

A standard of care is a clinical treatment guideline that specifies appropriate treatment based on scientific evidence and collaboration between healthcare professionals involved in the treatment of a given condition.

In the context of the AuPSEN Framework, standards of care are considered to be the minimum set of requirements that should be in place to provide a HPN service. It also means that the approach to providing HPN should be similar (standardized) between HPN centres.

What is a Quality Indicator?

Quality Indicators (QIs) are standardized, evidence-based measures of health care quality that can be used to measure and track clinical performance and outcomes. They highlight potential quality improvement areas and provide a means to track changes over time .

In the AuSPEN Framework, Quality Indicators are intended to translate the standards of care into a "check list" that can be used by HPN services of resources, processes and clinical outcomes that can be assess their compliance with the Framework and quality care.

What is a Position Statement?

In general terms a position statement outlines goal or an arguable viewpoint and provides a background and rationale to support the view taken.

In the case of the AuPSEN Framework, position statements have been approached as long term, aspirational goals or targets for HPN management. The AuSPEN Position Statements aim to highlight gaps in the current Australian health care environment that impact those requiring HPN and their families, with a view to provide areas of future focus to improve the health and community infrastructure to support optimal HPN care.

1) https://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0009/181935/HS13-034_Framework-DevelopMoC_D7.pdf, pg 3

2) https://en.wikipedia.org/wiki/Standard_of_care

3) <https://qualityindicators.ahrq.gov/>



Words by Prof Gil Hardy

***Editor's note:** These articles are written by Prof Gil Hardy for Dripline. Prof Hardy is a retired Professor of Clinical Nutrition, who helped found PNDU and is a Life Member. Together with colleagues at St Mark's hospital in London, he invented the first 3 litre bag for PN in the 1970's and has collaborated with Nutrition Support Teams in UK and New Zealand ever since. He has published over 250 papers on parenteral nutrition and has written several articles, and adapted others, for Dripline. He is a past chairman of the international clinical nutrition section (ICNS) of the American Society of Parenteral and Enteral Nutrition (ASPEN) and has just been appointed, as the first director from outside North America, to the ASPEN Board of Directors.*

WHAT'S IN YOUR BAG?

Parenteral Nutrition (PN) via a central vein first became a clinical entity, over 50 years ago, with the pioneering publication by the late Dr Stanley Dudrick and colleagues in 1968. Since then our understanding of nutrient requirements has expanded considerably, with exciting research leading to novel developments of industrially sterilised intravenous amino acid solutions and lipid emulsions, better designed catheters, solution containers and administration equipment, which have all improved nutrient delivery. Furthermore, the establishment of Nutrition Support Teams (NST) providing multidisciplinary team-centred patient management has significantly reduced complications, so that PN can now be regarded as safe and routine therapy.

Longer term or home PN (HPN) is likely to be required by patients with Intestinal Failure (IF). This occurs when there is reduced intestinal absorption of normal food, so that nutrition supplements, extra water and electrolytes are needed to maintain health and/or growth. Conditions leading to IF include; short bowel syndrome (SBS), non short bowel diarrhoea/malabsorption, inflammatory disease such as Crohn's Disease, radiation enteritis or motility disorders such as scleroderma and chronic idiopathic intestinal obstruction syndromes.

Most patients with insufficient gastrointestinal (GI) function are unable to maintain adequate nutrition or hydration without oral and/or parenteral supplementation and invariably will also be depleted in micronutrients. Many will have high demands caused by inadequate GI absorption, excessive losses, or abnormalities in storage or metabolism.

RANGE OF NUTRIENTS

A comprehensive range of nutrients should be provided for everyone on HPN. The nutrients must include amino acids (as substrates for protein), glucose and lipids (as sources of energy and essential fatty acids), electrolytes, vitamins, trace elements, and water. Individual nutritional requirements during illness are now better understood and a knowledge of how energy transformations are regulated to aid recovery are important recent developments in clinical nutrition.

Most basic energy and protein needs can be met by a range of standard HPN regimens. However, nutrient deficiencies may still occur because of increased requirements or increased bodily losses. Loss of bile results in fat malabsorption and eventually loss of fat-soluble vitamins. Limited absorption of fat-soluble vitamins may also be associated with low protein intakes. Chylous leaks and fistulas, conditions for which HPN is often required, result in additional losses, due to the large volumes of protein-rich fluid lost each day. These deficiencies can deleteriously affect enzyme functions and other biochemical processes, leading to organ dysfunction, muscle weakness, poor wound healing, and altered immune status. Micronutrient depletion can lead to clinical compromise, therefore it is important that the NST and other health care providers appreciate their importance and ensure there is adequate provision of micronutrients in HPN regimens.

The remarkable achievements of paediatric NST in sustaining infants for longer periods on PN have created a clinical setting in which micronutrient deficiencies have often only been manifested and unmasked during prolonged HPN, demonstrating the importance of prophylactic addition of adequate vitamins and trace elements. Premature and full-term infants on prolonged HPN, after GI surgery, with large intestinal fluid losses are at special risk of deficiencies without supplementation. Paediatric nutrient requirements therefore need to be separately considered. Routine monitoring of HPN regimens is recommended and, according to the AuSPEN Australasian HPN guidelines, this can range from weekly to 6 monthly, depending on the individual.

TRACE ELEMENTS

The requirements for trace elements have been estimated from the proportion of the element absorbed from a normal oral diet, but this can be quite variable in IF and the information available is limited. Additional amounts of some elements such as iron, copper, selenium or zinc, may be needed in the severely depleted patient because most commercial trace element solutions only provide sufficient nutrients to meet estimated daily needs, with no excess provision for the restoration of body stores. Deficiency syndromes due to the inadequate provision of trace elements have been described, especially during long term HPN. When used at recommended doses, toxicity due to trace elements is unlikely but competitive interactions between micronutrients can affect absorption via the GI tract and hence bioavailability.

VITAMINS

The requirement for vitamins in IF may be higher than for healthy individuals. Deficiencies can occur from losses through high output GI fistulas or with diarrhoea. Most water-soluble vitamins are absorbed easily from the proximal GI tract and in relatively short lengths of jejunum or residual ileum. However, provision of water soluble vitamins, above the normal estimated daily requirements to facilitate new tissue synthesis, and cover increased requirements associated with any disease, may be necessary in HPN regimens. Fat-soluble vitamins are absorbed in the mid- and distal ileum, as digestion of fat by bile and pancreatic enzymes is required. If the terminal ileum is missing then these vitamins become depleted. In conditions where fat malabsorption can occur, deficiency of fat-soluble vitamins is common.

Complex interactions between vitamins, trace elements and other nutrients during compounding, storage and administration of PN admixtures can all substantially reduce the amount of individual micronutrients delivered. Sunlight will also degrade many vitamins in solution. Minimising air content during compounding and covering the bag against sunlight during infusion can minimize chemical losses from light-catalysed oxidation reactions, but it may still be necessary to compensate for vitamin losses by occasionally increasing dosage.

Updated recommendations for trace elements and vitamins in adult PN were published by AuSPEN in 2014 and 2016.

The focus of this Dripline column "What's in your Bag" will be to review requirements for individual nutrients in a PN Bag. The causes of individual nutrient deficiencies will be described, and the needs for routine supplementation in long-term HPN addressed.



Words by Prof Gil Hardy

Glucose is the carbohydrate, or sugar, used in Parenteral Nutrition (PN) formulas. Glucose is the body's main source of immediate energy and a vital fuel for many essential functions. It is stored in the body as the carbohydrate polymer, glycogen, then released when required to feed the cells, heart, nervous system and particularly the brain, which alone requires about 100gram per day.

Because glucose utilisation may be inhibited in diabetes or liver disease, other energy sources have been investigated. The carbohydrate we know as table sugar is called sucrose and consists of a mixture of glucose and fructose, another simple carbohydrate. But fructose has a lower renal threshold than glucose and when processed in the liver it can cause acidosis and other adverse effects. These limitations deter us from infusing fructose or sucrose intravenously.

In nature Glucose exists in two forms, the D- form, often called Dextrose and the L-form, which is not used very efficiently by the body. Dextrose solutions of varying strengths are therefore the only sugar solutions used in PN. Ideally, we should try to avoid confusion by not referring to glucose or dextrose simply as 'sugar'. However, some health professionals still incorrectly use the term 'Blood Sugar Level' (or BSL) when it is the glucose level (BGL) that is actually measured.

In the sedentary adult the daily energy expenditure is approximately 2000 kcals (or 8372 kjoules if you have been trained to use this unit for energy). Energy expenditure increases when we exercise and decreases in the hospitalised patient at bed rest. Under normal circumstances glucose is the body's main source of immediate available energy, but if necessary it can also obtain energy from other carbohydrates and fats (lipids) or proteins.

Body fat is by far the largest and most efficient source of energy as we each carry about 150,000 kcals of fat compared to the relatively small amount of 500 kcals of glucose, stored as glycogen. We also carry approximately 15,000 kcals of energy in a fixed pool of protein, but unlike fats/lipids and carbohydrate, the body is not able to totally utilise protein for energy, without first breaking down muscles with potentially catastrophic results. Protein is therefore in reserve as a 'last resort' for energy.

In starvation, malnutrition or illness the limited glucose energy store of glycogen is exhausted after about 15 hours, but a glucose deficit adversely affects the balance and distribution of electrolytes in the various fluid spaces of the body. Hence the need for rapid replenishment, initially if necessary by a simple Dextrose 'drip', but for longer term energy and nutrition support, PN is required.

A Dextrose drip is normally a 5% solution of glucose (sometimes abbreviated to D5W) and provides approximately 200 kilocalories in one litre (or 837 kjoules) and is "isotonic", meaning that it has approximately the same consistency as blood and can therefore be infused into the small "peripheral" veins in our arms or the back of our hands. However, adult PN patients usually need about 1000 glucose kcals a day, in addition to the other nutrients, which would require infusion of over 5 litres of D5W!

Dextrose solutions up to 70% strength are therefore manufactured to combine with amino acids (the intravenous source of protein), lipids and electrolytes, into the PN bag to minimise the infusion volume.

Unfortunately, these very strong "hypertonic" solutions are much more concentrated than blood and would destroy small peripheral veins. Consequently, when incorporated into a PN bag with the other nutrients, they need to be infused into a large "central" vein near the heart where blood flow is rapid enough to dilute the hypertonic solution before it damages the inner surface of the veins. Your PN bag label probably has the Warning: THIS SOLUTION IS HYPERTONIC.

Uncontrolled hyperglycaemia (very high BGL) associated with too much dextrose administration can lead to increased infection risk. This is likely to be caused by depressed immune function as hyperglycaemia affects production of immunoglobulins and other cells of the immune system and enhances microbial virulence. For this reason some clinicians include insulin in the PN regimen to ensure that BGL are controlled within acceptable limits.

A typical 1.5 litre PN bag for adult HPNers will usually contain:

Glucose	100 -150 g (400-600kcal)
Lipid	20-60 g (200-600kcal)
Amino Acid	25-85 g (100-340kcal)

Plus electrolytes, vitamins and trace elements.

However, as you will know there is no 'typical HPNer' so your PN regimen and bag label might look different as it will be formulated specifically for your individual requirements. Nevertheless, it will contain sufficient glucose and the other nutrients to meet your needs.

HPNers Moving to a Different Area



***Editor's Note:** For anyone, moving can be a difficult, stressful experience; but for HPNers, they need to consider health related matters as well. I put these questions to 3 PNDU members who have made the move, and to 1 who is planning to move later this year, so that anyone who is considering a move themselves may be encouraged that it can be done.*

Renee - moved

Why did you decide to move? We were about to retire and were thinking about what we wanted for the next phase of our lives. We decided we wanted to move out of the city to the beach in a quieter area.

Who was involved in the move? Aside from the things that affect anyone who moves (working out where to go, finding a home, working out what lifestyle you will have, making friends, finding activities and meeting interests, developing a routine) there were the obvious health issues to address.

Also, Mervyn was still working three days a week at the time, which meant he had to commute, which was pretty exhausting in the beginning but it enabled a good transition to retirement.

Where did you move from and to? (In general terms) From Sydney to Jervis Bay on the South Coast of NSW. What preparations did you need to consider related to your HPN needs and hospital team? The most important decision was whether this was medically possible. My HPN team was incredibly supportive. I needed to find a gastro specialist and a good GP. I also needed to know how the local hospital would cope in an emergency. This is particularly difficult in a regional area.

Was it easy or difficult to move to a different hospital team? For me the critical thing is that I did not move teams. There is no HPN team in my location so I remained with my existing team. I still have all my regular blood tests there (travel to Sydney at least every three months, more as needed) and all care is co-ordinated from Sydney. I am fortunate to be in an excellent GP practice that liaises with the team as needed and are quite happy to take direction from the HPN nurse or Sydney gastro specialist. (Although I made contact with the gastro here, I have actually never been back). The GP is quite happy to allow me to access my own line when doing iron infusions.

I have had to attend the Emergency department of the local hospital twice with port problems and each time was dealt with skill and efficiency.

I changed from a Hickmans to the port while living here and the local hospital has a Venous Access Specialist (who used to be a PN nurse at a large public hospital in Sydney) who trained me in how to access the port. She was excellent.

When I needed to have a new port inserted and also had hernia surgery, I had that done in Sydney and it was organised by my team there. Therefore, the fact that I can commute to Sydney (three hours away) made a big difference. It would be harder, I believe, if we were more remote.

The PN is no longer paid for by my Sydney hospital but by Wollongong Hospital (even though I never go there) as they are the largest local regional hospital.

I have found other specialists locally e.g. endocrinologist, ophthalmologist, osteopath, physiotherapist and orthopaedic surgeon when I broke my legs! (Actually, while I was in Sydney).

How long has it been since you made the move, and are you happy that you made the decision to move? We moved over six years ago and have never regretted it. The fact that I can still see family and friends is very important.

What do you consider as benefits of your move? The quality of life is incomparable. We live a couple of hundred metres from the beach and are surrounded by endless walking paths, both along the water and the bush. There is plenty to keep us busy and we have found wonderful new friends, while being able to maintain our relationships with friends, many of whom love to come and stay. The peace, beauty, clean air etc are simply magical and we are grateful every morning as we watch the sun rise and go for a walk.

Have any unforeseen problems arisen? Being further from a main centre can bring issues. For example, when my pump broke it was hard to get another in time (Baxter did courier one but only with the help of my nurse). I now have two, so that helps.

There were some issues when roads closed because of the fires in January, but Baxter and the hospital were fantastic and I had no problems with obtaining my PN – though I was told to evacuate.

What advice would you give to any HPNer thinking of relocating? If you are moving for good reasons – that you will have a better quality of life in some way or for work...something that is important to you – I wouldn't hesitate. It is important to have the support of your team, to work well with your PN provider company and to find local medical people who you can relate to.



Hyams Beach at Easter during the Coronavirus Pandemic. (Renee and Mervyn on the right)

Carmel - moved

Why did you decide to move? There came a time when I could no longer look after a family home. My home was on a large corner block and while I loved my garden, it was too much for me to look after the way I wanted to. In addition, realistically, I needed to release equity in my house to pay for ongoing medical costs. And biggest reason of all, if I moved somewhere smaller, I could be more independent. I wanted to move closer to medical facilities, family, friends, transport links and the city.

Where did you move from and to? (general areas) I moved from the far south-west suburbs of Brisbane into the near city. I can walk to both my hospitals and the public transport (pre-covid-19) was amazing. I never looked at a timetable. Just wandered down to the bus station and, once used to the system, would get quite indignant if a bus didn't arrive in 3 minutes! Plus, I am also close to the train and will be close to the coming Brisbane metro system of transport.

Who was involved in the move? My daughter came and helped me the day before my move, the day of the move and spent a few days helping me unpack.

When house-hunting, there were a number of times, too, when I really liked a particular place that I asked a friend to come with me for a second viewing to get another person's perspective on a place.

What HPN related preparations did you need to make with your hospital team? While off HPN for a little while, my whole medical scenario played a huge part in my decision to move. Getting to a hospital could take 1-2 hours in traffic. The public transport system was not a good one and could be a very long, bumpy trip and just awful if I was in a lot of pain. It could be very socially isolating too. This was especially so as I had long periods when I was not able to drive and not well enough to cope with the bus journey. None of my doctors or hospitals changed because of my decision to move.

How long have you lived in your new place? 15 months, and now I wish I had done it earlier!

What benefits have resulted from the move? I have so much more independence. It is much easier to look after my own home without relying on anyone to come in to "help". At the moment, (we all know how things change) we have an incredibly good Building Manager.

The building I am in is Certified by the Dept of Health for Hospital in the Home. For example, this is a building where transplant patients from the country can stay after their discharge but while they recover and do rehab etc.

It is quiet and private but there is help available if needed.
It is close to amenities including shops and hospitals but also parks and walking tracks.
It is a very secure and safe unit.
I am much closer to family and friends.
It is easier to access hobbies and outings and public transport.
There is so much less maintenance and most of it I can manage myself.
My health has improved, I think, because I am under less stress.

While I do miss having a garden and a yard, I do have a generous deck with pot plants and I do know that I could no longer maintain a yard and garden. Plus, I have plenty of friends who need help in the garden if I have the desire to lend a hand.

Have there been any unforeseen problems with the move? The hardest part of moving, surprisingly was not selling. I sold my house in one week. The worst part was buying! It was the worst experience I have had and I have bought and sold since I was about 21 years old... back in the dark ages practically!
Touch wood, I have found unit living to be great and I am enjoying the convenience of being close to amenities.

What advice would you give someone who is planning a move? Research, research, research. Above all, take your time before you sell and buy.

In total, I probably looked for other suitable accommodation for about 3 years. I began very slowly in the radius from the city I was preparing to live in.

I used the internet to narrow my search and I began with the most basic place that I thought I may be able to afford.

I tried to keep an open mind and looked at a range of accommodation from 1 - 3 bedroom apartments and also every possible retirement village. I went to Financial Planners, both Centrelink and private. I kept a folder of every place with notes about them – for and against until I knew more about the market, what represented good value and that I understood the realities of my personal situation in every way including medically and financially into the future. I had never owned a unit and so I needed to learn all I could about Body Corporate and what constituted a reasonable amount per year to pay in levies per annum and also what those levies covered.

This did stand me in good stead as the apartment I did end up buying was advertised at a surprisingly good price. I knew that the Body Corporate Fees were reasonable and had a decent Sinking Fund for future repairs going forward.

Fay – lives between 2 homes in 2 states

Why did you decide to live between 2 different homes in different states? The climate in Qld, family in NSW. Where did you move from and to? (In general terms) Newcastle, NSW to Sunshine Coast, QLD.

What preparations did you need to consider related to your HPN needs and hospital team? I spoke with my PN team for approval, approval from Baxter (my PN provider), and I had to locate a Gastroenterologist in new area.

Was it easy or difficult to move to a different hospital team I haven't done that yet, but have met some of the new team in Brisbane and they tell me it will be easy.

How long has it been since you made the move, and are you happy that you made the decision to move? We bought the Queensland house 2 years ago and spend roughly 2mths at a time between houses. The only

thing that would make me happier would be to make the move permanent.

What do you consider benefits of your move? A better climate, closer to my sister, great neighbours.

Have any unforeseen problems arisen? No

What advice would you give to any HPNer thinking of relocating? Investigate the area thoroughly, including the availability of the specialists you need and location of hospital. Holiday in the new area more than once to get a real feel for the place. (We have been coming up here for 30 yrs.) Ask your team what is involved in moving. Try to meet the new team if possible and speak to them about your proposed move. I found everyone most helpful.

Karen - planning to move

Why did you decide to move? Financial and family reasons, along with the opportunity to live closer to a tertiary HPN hospital.

Where will you move from and to? (general areas) From an Australian state capital city to the state's second largest city.

What HPN related preparations have you made with your hospital team? I started discussions early with my former HPN team, GP and various specialists. My former HPN team made contact with the HPN team taking over my care, and sent a comprehensive report. The new team organised HPN clinic and gastroenterologist clinic appointments for me to attend before my move. I organised and attended final appointments with all former specialists.

Is it easy or difficult moving to a different team? At this point it's relatively easy... for me, at least! (Not sure if that's the case for the hospital teams!) As with everything HPN, early planning seems to have been helpful, especially as a comprehensive report takes a while to put together. I'm sure some things will be done differently by the new HPN team, so I'll have to get used to that. But for now, the new team has advised it doesn't intend to change my HPN set-up, which is reassuring. I feel very blessed by the support of clinicians at both hospitals.

What benefits do you hope will result from the move? Less travel time to family and HPN hospital, and a better financial situation.

Have there been any unforeseen problems with the move thus far? COVID19 has meant I've delayed the move till later in the year.

What advice would you give someone who is planning a move? Start discussions with your hospital team (and other clinicians involved in your care) well in advance, and get their input.



James celebrated his 14th birthday with a pizza birthday dinner with his family.

Once their fire pit is finished out the back, he is going to have a few friends around to celebrate his birthday with him.



A Day in the Life of an HPNer – A Structured Life



Words by Gillian

People often fall into one of two camps: those who thrive on routine, and those who hate it. For those of us who live with HPN, either as an HPNer or a carer, life is much easier for those who like structure and routine, because setting up HPN and infusing for long periods of time means that there is little chance for much variation. Those who like to respond to the moment, to make impulsive decisions about activities, who don't like to plan where and when and how long ahead of time, but go with the flow, will find that this approach generally won't work with life on HPN.

When I decided to write about this topic, I asked fellow HPNers on our 2 forums – email chat and Facebook- how long they infused for, and received replies from 8 adults and 1 carer of a toddler.

The range of times for infusing PN for adults was from 10 hours to 14 hours, with 12 hours the most common. Our toddler carer has recently changed from infusing 20 hours per day, 4 hours off, to 16 hours, with 8 ours off.

As you can see, once set up and infusing, the HPNer is more restricted in movement, and, therefore, with outings and activities, especially children. This isn't a complaint, simply a statement of fact. Nowadays, HPNers are supplied with portable pumps and backpacks, and even a trolley, to make getting about much easier than it used to be years ago, when hooking up meant using a large, heavy pump on a hospital pole.

However, even with the portable pumps, getting around can be onerous, because when you first set up, the 2-3+ litre PN bags are full, meaning you're carrying around 2-3+ kilograms in weight, plus the pump and backpack. For fit, healthy people this might not be an issue, but many HPNers are not fit and healthy, or are a child, and getting about can be a struggle. If you're at home, this isn't much of an issue; it's when you want to get out and about, enjoying Quality of Life – surely one of the purposes of HPN – that the HPNer might need to rethink things.

Most HPNers set up overnight, therefore infusing from 6pm-6am, or 8pm-8am, or thereabouts. It will immediately become obvious that this will have a major impact on evening events. The HPNer will need to decide whether it is practical to go out at all, or if changes to setting up time can be made. These changes should be discussed with your hospital team, so that if you're presented with a decision to make when they are not available, you already have their permission and ideas for adjusting your routine.

*Setting up might need to be done earlier than usual, and infusion either go for a longer period of time until the usual stopping time, or for the same period of time, stopping earlier. eg from 5pm - usual; or 5pm to 5am. In this situation, the HPNer would need to carry their PN around with them during the evening event.

*Setting up might need to be done after your evening event, setting up later than usual and stopping later. eg 10pm - 10am. This means being free of your PN backpack for the event, but the next morning will be affected by infusion continuing beyond the usual stopping time.

*If the event is friends getting together, then maybe the HPNer could host the event at their house to make things easier for infusing – but more tiring with social preparation.

Being an HPNer doesn't stop a social life, but it can make it more awkward, and demands more thought and planning than usual. Think of it as a challenge and give it a go!



Making a Cannula More Comfortable

Words by Gillian

HPNers often end up back in hospital for various reasons, either with problems related to our CVAD, or the cause of our Intestinal Failure. One of the first things that is usually done, is the insertion of a cannula for intravenous fluids or drugs. At some point, a nurse will attach a line to the cannula and commence infusion. Although I'm told I have good access to veins, I invariably end up with cannulas in a variety of places, some more comfortable and easy to get on with activities than others. But they all seem to end up with a large curve, which catches on things such as blankets and hospital gowns, which in turns gives a little pull to the canula, which can hurt a little. The curve of the line also tends to collapse in a bend, which occludes the line and sets off the pump alarm. This can happen several times during the night when we are asleep and unaware of our arm position.



It wasn't until I had been on HPN for several years (now 14), with several hospital admissions with the above experiences, that I had a nurse who, after connecting the line to the canula, produced the 'magic' little cover shown below. It's called 'Tubigrip'© and covers the line and canula and helps to hold everything in place. The photo below is of my arm last week; since the canula was put higher up my arm, the tube could just be slid on over the hand.

When I have a canula placed on my wrist, the Tubigrip© requires a small cut to be made in order for my thumb to anchor it in place – see the photos below.

No other nurse has ever offered this, but all have got one for me when I ask. In the long run, it's less work for them as it results in fewer pump alarms. Win-win!



A small cut made



Thumb anchoring the tube



PNDU remembers past HPNers

Over the years, PNDU has been reminded of the fragility of life, especially for those with Intestinal Failure. Sadly, PNDU has shared with family and friends in saying good-bye to these precious loved ones who have passed away, but who have also left wonderful memories of love, strength and courage.

Aidan – 21 May 2020, aged 14 1/2 years

Lara – 24th April 2020, aged 37 years

James – 9th November 2019, aged 28 years

Elise – 19th August 2019, aged 43 years

Ross – 23 January 2019, aged 67 years

Celena – 27 November 2017, aged 43 years

Emma – 9 April 2017, aged 35 years

Lara – 16 February 2017, aged 7 years

Teresa – 15 February 2017 aged 58 years

Natalie – 18 September 2016, aged 27 years

Sam – 13 September 2016, aged 14 years

Carol – 2 September 2016, aged 67 years

Jessica – 24 January 2014, aged 20 years

Tynesha Rose – 29 October 2012, aged 5 years

Aria – 20 June 2011, aged 5 years

Pauline – 29 April 2011, aged 38 years

Hebe – 3 January 2008, aged 2½ years



*May the cherished memories of these dear ones
never fade.*



Editor's Note: Despite the limitations and restrictions imposed by Covid 19, PNDU is still involved in, and preparing for, regular events. The Management Committee continues to meet via Skype, as per usual, about every 6 weeks.

1. PNDU AGM Monday 17th August

2. Winners of the PNDU Professional Awards 2010 announced at the AGM.

PNDU Awards are a way of showing our appreciation of the great work carried out within the HPN community by health professionals, industry employees and members of PNDU, as they go above and beyond in their dedication to duty, ensuring a high quality of care is provided for those living with Home Parenteral Nutrition in Australia and New Zealand. The PNDU Awards are open to nominations by all PNDU members, with winners

announced at PNDU's Annual General Meeting in mid-August.

Previous PNDU Award winners are listed on the PNDU website Roll of Honour <https://pndu.org/resources/pndu-awards/>

3. HPN Awareness Week 11th-17th October

PNDU's Management Committee has started preparations for our 10th Awareness Week, as the name suggests, Awareness week is a wonderful opportunity to raise awareness and understanding of what life is like, living with HPN for Intestinal Failure.

PNDU extends an invitation to all HPN'ers, Family, Carers, Hospitals, Clinicians and our Industry Friends, to join in the celebration of HPN Awareness Week 2020.

The slogan for 2010 is 'HPN - Pumped for Life'.

Due to the COVID-19 Pandemic, Awareness Week activities may take on a different appearance this year, but save the dates 11th - 17th October and keep an eye out for PNDU announcements on how to be involved and 'celebrate life' for approximately 280 adults and children across Australia and New Zealand, living with the complex life support therapy, Home Parenteral Nutrition (HPN) for Intestinal Failure.

Resources

PNDU will again provide a great range of resources to help you become involved in Awareness Week celebrations, help spread the word and raise awareness and understanding of life with HPN.

Resources for our member HPNers, family and carers will include a video to share, stickers, social media profile and twibbon, and an example newspaper article, so you can write and share your own story with your local newspaper.

For hospitals and industry friends, PNDU will again provide an HPN AW 'Resource Pack' with a list of available PNDU resources. (stickers, flyers, posters, crossword and video) along with wonderful ideas on how to help celebrate AW2020.

Unfortunately, HPN Awareness Week Pharmacy Tours have been cancelled for 2020, but

PNDU looks forward to working with our industry friends to make the 2021 Pharmacy Tours exciting and interactive for everyone.

4. World HAN Day 15th October

Thank You



PNDU is very grateful for the generous support given by the donors listed below. Their donations total \$9 654

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Planning Overseas Travel



As a founding member of [PACIFHAN](#) (International Alliance of Patient Organisations for Chronic Intestinal Failure & Home Artificial Nutrition), PNDU can put you in contact with sister organisations in various countries overseas (UK, USA, Czech Republic, Denmark, Italy, France, Poland and Sweden) which may be able to assist with any HPN travel questions in those countries. Just ask us at contactpndu@gmail.com.



Membership for Aussie and Kiwi HPNers and carers:



We welcome all Aussie and Kiwi HPNers (ie those living at home on Home Parenteral Nutrition) and carers to become PNDU members. To become a member, we invite you to go to our [website Membership page](#).

Benefits:

- Access to all areas of our website, including Members Only pages (Travel, Kiddies Korner, Pharmacy Scripts, Hints & Tips, Clinical Info and more ...).
- Access to one or both of our private on-line groups (email and Facebook), connecting you with a wonderful network of support from other HPNers and carers.
- Receive news/information on HPN-related issues.
- Opportunity to contribute to PNDU Inc.'s work in raising awareness of HPN and supporting HPN research.





We also welcome others to join PNDU as members, giving you access to all pages of our website, receipt of our newsletter Dripline and other HPN-related news, as well as opportunity to contribute to PNDU Inc.'s work in raising awareness of HPN and supporting HPN research. To join, please go to our [website Membership page](#).

Donations



If you would like to support the work of PNDU, we would welcome your donation, no matter how big or small. Please go to the [Donate page](#) on our website for [PayPal](#) and [Direct Deposit](#) details.

All donations over \$2 made to PNDU in Australia are tax deductible!

For our New Zealand supporters, PNDU has partnered with IPANEMA, to make supporting PNDU from NZ easy! Tax deductible donations to PNDU can be made by NZ based companies to IPANEMA, while individuals in NZ making a donation to PNDU through IPANEMA may claim a tax credit for their donations*. IPANEMA will pass on to PNDU 100% of such funds. (*This is general information only, please see your accountant for specific advice about your financial rights and obligations.)

Donating via direct deposit

Please provide your name as a reference. If you require an acknowledgment/receipt of your donation, please email us at contactpndu@gmail.com.



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Designer: MBE Hurstville