



Welcome to the latest issue of Dripline. This issue has quite a variety of articles, most written by our members. We read about Sal and Matt's great Tasmania holiday adventure; Ryan's thoughts and concerns as a carer; read about life after HPN for one of our early members' daughter; hosting two international HPNers whilst visiting Australia; preparing supplies for long holidays on HPN; about our medical play puppets and their tangle with customs; and more.

*Gillian* - Editor

## In this issue:

- [Medical play Puppets](#)
- [Puppets find their Home](#)
- [Life Without HPN](#)
- [Uses for Boxes](#)
- [Sal's Scenicruise of Tasmania](#)
- [A Carer's Thoughts on Relationships](#)
- [Cruising the Waterways with International Friends](#)
- [Birthday corner](#)
- [Travelling to Australia – an HPNer's view from the other side of the planet](#)
- [Conception, Pregnancy, and Lactation Despite Chronic Intestinal Failure Requiring Home Parenteral Nutrition](#)
- [You'd be More Healthy if You... comments from friends](#)
- [Long Holidays on HPN](#)
- [Recommended Reading](#)
- [The burden of treatment for patients with chronic conditions](#)
- [Night of the Alien...an HPNer's strange medical experience](#)
- [Recycling at its Best](#)
- [Reminding Health Professionals about Real Patient Power](#)
- [A Day in the Life of an HPNer](#)
- [Upcoming PNDU activities](#)
- [Thank You](#)
- [Membership, donations & contact information](#)

ISSUE #14  
Nov 2015  
-Jan 2016



---

# Medical Play Puppets and PNDU's experience with Border Security!

WORDS BY CHRIS

## Why?

Young children with special medical needs have many challenges to deal with. Two of the more complex and difficult to overcome are treatment trauma and body image. Distracting the child's attention during treatments with a variety of toys and modern electronic devices such as iPhones and iPads is a very successful technique. Innovative parents and carers have modified various toys to help their little ones cope with the numerous medical procedures and questions as to why am I different?



Jodee had this clever doll for Matisse.



Em's big bear, certainly was a hit at the PNDU gathering.

## How did it come about?

When I began looking into medical play toys a couple of years ago for my grandsons, there were a multitude of medical toys and dolls on the market, but there just didn't seem to be anything available to help explain central lines, NG tubes, MIC-KEY® buttons or stoma bags, all of which my grandsons have. (A medical play doll for central lines was located by another HPN parent, however was prohibitively expensive.) That was until we received 2 little stoma puppets with our order of ostomy products from our local association.

These puppets had been fitted with a stoma bag neatly tucked under a waist band, which was a great idea to help children with stomas relate to their own body image. I made further investigations and found the great thing about these puppets was they could be modified to mimic most prosthetic attachments eg central lines, NG tubes and MIC-KEY® buttons etc. - exactly what we were looking for. An unfortunate run of bad luck with hospital admissions for our family saw the idea shelved and almost forgotten. But when the idea of modified medical puppets with central lines for our young HPN members was raised at a PNDU Management Committee meeting in early 2014, I already had some details on hand and promptly pursued my contacts.



As the puppets are made overseas (with a wonderful group of volunteers adding the medical 'attachments'), involving exchange rates, international shipping and postage, and attempts to secure sponsorship weren't successful, the PNDU Management Committee agreed to fund the puppets for PNDU HPN children under 10 years of age. So in mid-2015, working closely with both the overseas manufacturer and the Australian distributor, orders for puppets mimicking their child's medical 'attachments' were received from PNDU families and the project was underway.

Quite excited, we all waited anxiously for news of the arrival of the puppets 'down under'.

## Best laid plans...

Unbelievably, our shipment of medical play puppets got "caught in quarantine"!! It would seem that some confusion existed in the Department of Australian Customs, and our shipment of puppets was held in quarantine, awaiting an emergency action plan from the overseas manufacturer (more information was required in relation to the medical condition) in order for them to clear quarantine. This was the first time this had happened to any puppet orders placed by our Australian distributor. Private forum members began to ponder:

- 'I wonder if they got their PN whilst they were held in custody?'
- 'Hope the staff used sterile procedure when they administered the PN and examined them!!'
- 'Maybe they think we're a cruel sadistic bunch??'
- 'We don't want to get in the same dogged trouble as Johnny Depp!'
- 'Do they think we have infected the puppets with our 'diseases' or something??'
- 'Maybe they could feature on The Dog Squad or Undercover Airport ... - they could frisk them on live TV and ask if they are carrying any food - No food on us -just PN!'
- 'I think we would have to answer some very serious questions about what we are doing to these dolls!!'

'We could be reported to the Puppet Protection Agency!'

After a further delay, information came that after being detained, unfortunately the little guys mysteriously disappeared, believed to have been destroyed!

Thankfully our contacts at the Australian distributor and overseas manufacturer were not easily deterred by this frustrating set of circumstances, determined to fill the PNDU order. The manufacture of a new batch of puppets was dispatched by a different courier, with identification numbers that could be tracked online and finally the puppets were on their way to PNDU members.

#### The result...

The overwhelming response from the PNDU children upon arrival of their puppets, (*see the following article*) and the way in which medical play is helping these children deal with issues of body image and treatment trauma, has made this one of the most rewarding projects I have been involved with.

PNDU is incredibly grateful for all the work, commitment and assistance from our friends at the Australian distributor and the overseas manufacturer (including the wonderful volunteers) who kept persevering and made this project a resounding success for PNDU's young HPNers. We look forward to assisting more PNDU HPN children in this way.

## Puppets find their home

*Editor's note: some of our parents share what these puppets have meant to their children.*

### Daniel and Johnny

WORDS BY ANN-MARIE

Daniel was born at 27 weeks gestation and weighed 595grams. Needless to say he was one of the premature babies that ended up with the dreaded NEC (Necrotising Entercolitis) and lost 80% of his small intestines.

Being on HPN (Home Parenteral Nutrition) since birth, he has always had several lines protruding out of him, including an NG (nasogastric tube), as we are very lucky to be able to formula feed him overnight as well as PN.

As Daniel is now three years old, he is becoming a lot more sociable and aware of what differences he has to other children. Thanks to PNDU, we have since welcomed our fourth member of the family, "Johnny"- the puppet.

Johnny was met with a great big smile and lots of laughs. Sometimes you have to wonder what a three year old would be thinking, especially seeing a puppet with the same CVL (central venous line) and NG lines as you.

Johnny sits next to Daniel during HPN connection and disconnection. He also is snug as bug next to Daniel in bed at night times. Amazingly, Johnny has started to educate a lot of our family and friends as well about central lines, NG's and Gastrostomies.

Daniel's next step will be to change from an NG to a Gastrostomy when the time is right. When Johnny was ordered he came with an NG, a CVL and a Gastrostomy. Daniel has had his line replaced surgically on the opposite side and so Johnny then was adapted very easily. When the right time comes for Daniel's Gastrostomy, Johnny will already have his, be able to show Daniel how to be brave and then they can be matching HPN buddies together.



*Daniel and Johnny*



One very excited little girl this afternoon to find her Emily puppet waiting on the front door step! She has already planned the next few medical procedures!



*Ariel and her puppet*



*Emily with her 'Emily' puppet*

*Carter and his puppet Ric - which he loves and thinks is very cool!*



**Right** - Sebastian and his puppet

**Below** - Molly (nearly 2 years old) and puppet 'Sally'. Molly kept wanting to kiss Sally.







It's Jordan's playtime and I think the smile says it all! AAARRRR, it's Pete the Pirate and it's time for a patch change, flush the central line, aspirate the intestinal tube (mickey button) and drain the stoma bag. You have to wear gloves because poo on central lines can make you very sick, says Jordan. Jordan loves Pete the Pirate!

## Sam and Sammy James Jr

WORDS BY SHIRLEY



*The parcel arrives!  
Sam and Sammy James Junior*

Sammy James Junior was born yesterday when Sam ripped open his parcel [his puppet]. He landed on Saturday at 3:58 pm, weighing in at about 1 kg. He has thick dark hair, olive skin and stomas just like Sam. His accent varies according to whose hand is up his jumper, but it's been amazing to see Sam come to life and communicate with this little guy with the same tubes as he has - adorable! Sam named him and spent hours playing with him. He is very excited that he is taking him to [hospital] on Tuesday for his appointment.

At the hospital...

Today Sam had a GA (general anaesthetic) for a CT scan and broncoscopy. Normally Sam is terrified when he goes into the CT room - the massive machines and the bed send him screaming and fighting. Today his 'brother' (puppet) was 'talking' to him as we went in and it totally reassured him. Sam was hesitant but when 'brother' sat on the bed with me he was happy to.

This puppet is such a great tool to help Sam communicate and be reassured. With pride he introduced him to everyone in hospital.

I know it's just bits of fabric and wool, but the concept is genius and so much more than just a doll. Sam's interaction with it is quite simply magical and it has opened Sam up as he will talk to the doll as he knows he gets his world.



We are so grateful to the volunteers at PNDU in Australia who made this happen for the under 10 year old kids on HPN in Australia and New Zealand. Truly, Sammy Jnr is going to be a fabulous tool to work with Sam. Just tonight Candace (sister) was working Sammy Jnr and asked Sam if he had eaten food today. Sam said 'no', then Sammy Jnr said, 'I think I might try and lick some food tomorrow, would you like to try with me?'. Sam is open to anything when his 'brother' suggests it - and yes this power has already been abused by his siblings who were quick to figure out how to make it work for them!



*'Brothers' in hospital together*

---

## Life without HPN

WORDS BY RACHEL

**Editor's Note: Rachel was one of PNDU's earliest members and was very active and involved as a member of the Management Committee.**

Our daughter, Sacha, is a bright and energetic 7 year old. She was dependent on PN (Parenteral Nutrition) until the age of five. For the past two years, she has been fed via a gastro-jejeunal tube, which means some food goes into her tummy and some goes into her jejeunum (small bowel). Being off HPN (Home Parenteral Nutrition) has been miraculous for Sacha and a joy for us as a family.

PN is like any drug or therapy - some people have few side effects, while others have a terrible time. Sacha fell into the second category. During the years she was on PN, Sacha developed agonising gallstones and had to have her gallbladder removed. She had three life-threatening bloodstream infections. She had a troublesome port-a-cath which caused hospitalisations and complications no doctor or nurse had ever seen before (that's not the way you want your child to be unique!). Damage from extensive blood clots and neonatal central lines left Sacha with very limited venous access.

No one really knows why Sacha needed HPN in the first place. She was tube fed as a baby but developed severe failure to thrive and couldn't tolerate any type of feed. Her gastroenterologist thinks there were a few reasons why she ended up so sick, including severe food allergies (even to breastmilk and low allergen formulas), and gastroparesis (a condition where the stomach stops being able to empty food).

By about age 3, Sacha's gastroparesis was hugely improved and we had two glorious weeks free of HPN. But then Sacha developed a severe gut infection from a hospital super-bug, the dreaded '*c. diff*' (clostridium difficile). This set Sacha back severely and it was another two years before her gut improved to the point that we finally weaned her off PN. These days Sacha is fed a low allergen 'modular feed' made of pureed solids with supplements and vitamins added to make the food nutritionally complete.

Life without HPN has been wonderful for our whole family. For Sacha, it has been miraculous in ways we could never have imagined. Sacha was non-verbal at age 5, but started talking within weeks of coming off PN. Her speech therapist commented that Sacha is a case study in what can happen to a child's development when their health improves and the amount of trauma in their life is reduced (Sacha lived in constant dread of port-a-cath needling and the complications that kept landing her in hospital).

Within weeks of coming off PN, everyone who knew Sacha - doctors, nurses, friends and family alike - all commented on how much more



*The old days of Sacha connected to her PN*



confident she seemed within herself. Her learning and development improved. She went from being frightened of water to enjoying daily long, deep baths.

Our life is still filled with loads of doctor and allied health appointments, and a daily regimen of tube feeds and medications. But it's far less stressful now that we don't have to worry about maintaining aseptic technique or rushing to hospital at the first sign of a fever. Only PNDU-ers would understand how lucky we felt when Sacha spiked a temperature recently and we gave her panadol rather than rushing to hospital to start IV antibiotics!

We are very grateful that when she needed it, Sacha was provided years of HPN by the public hospital system - something we could never have afforded privately. We are even more grateful that Sacha hasn't needed HPN now for some time. We don't take anything for granted and we feel very blessed.



*The new Sacha!*

---

## Uses for Boxes

PHOTOS COURTESY OF RYAN AND JODIE

***Editor's note: Ryan and Jodie (HPNer) have found an interesting, fun way of recycling our delivery boxes and at the same time, providing cheap, fun toys for their son, Daniel***



---

# Sal's Scenicruise of Tasmania

## WORDS BY SAL

One of the most important things I have learned from my illness is that life is a gift, and I need to take it as it comes and squeeze every moment of goodness that I can fit into each day. So on that thought, we decided to get game and trust the bus (the 1967 Ansair Scenicruiser Coach) would behave, and leave the safety of mainland and head to Tassie with our family. Our eldest was just about to finish school and family holidays with the 6 of us were going to get harder to happen. I was well and stable, and despite the chance of gaining approval for a new treatment option in the meantime, which could change things for me dramatically, we decided to book it back in September, and just prayed that all would fall into place. Well the approval never came through for the treatment, so that didn't change things; and despite pulling half the kitchen out, installing replacement windows and redoing the rear suspension in the bus in the months before we left, Matt managed to get the bus ready to go in time as well.

So we left home, being serenaded by our 2 dogs singing a sad song, (they don't like it when we leave them, even to collect the mail!) Despite the heat and the bus engine getting a little too warm going up the hills of the Hume, we made it to just out of Albury and camped by the Murray River for the night. To sit in the cool, connected up to my PN and having dinner with the family, doesn't get much better than that. It was so tranquil, despite the distant sounds of a cow mooing! I love lying in bed in the bus and being able to look up through the hatch and seeing the stars twinkling and then opening the curtains at the end of my bed in the morning and seeing the Murray water passing by, as galahs and cockatoos chorused that it was time to get up.

We continued to cruise down the Hume until suddenly the smell of burning rubber was overwhelming and we had a serious lean to the left. Matt safely pulled over and the kids, well drilled in our bus repair stops, helped Matt set up the safety triangles and investigate. Fortunately it wasn't a ruptured suspension airbag, as first thought, but just a bolt had left the levelling bar for the air suspension and a replacement was found and the problem was fixed. We headed to the Yarra Valley next and stopped to enjoy a very chocolatey lunch at the Chocolaterie and caught up with some friends from our bus club for the night. The next day we caught up with an Auntie of mine, and then explored Melbourne with the trams until it was time to board the Spirit of Tasmania.

Some people had asked how we were going to get the bus to Tasmania, and I said with a few floaties and a snorkel! Of course

the boat is big enough for our 11 tonne, 11 metre bus! It was a little rocky and I felt a bit green at times, but the kids had a blast exploring the boat, as it was our first time on a boat this size, and playing X-Box. It was great to awaken to see us heading into Devonport. We were worried the bus wouldn't start as we left, but it fired up despite the solar house batteries being flat. We headed out to meet some other bus club friends, who took us to Anvers Chocolates for taste testing- there is no such thing as too much chocolate is there?! We also visited a place called Reliquaire, an



*Tahune Airwalk*



*Our Bus next to the Clipper*

antique and nicknacky store, jam packed with amazing things for sale. There were porcelain dolls and clowns, antiques, Star Wars and Dr Who things, quirky gifts, medieval suits of armour and more. The building was like a maze, too. My youngest had to be dragged away from the medieval room. Sadly, we were to learn that this place burned down 10 days later on Christmas Eve, after an electrical fault almost took the life of the owner's daughter, when she turned the power on that day, and unbeknown to them at the time, a fire started as well. Our friends went in convoy with us in their recently restored 1952 Fxible Clipper to Campbell Town, where we stayed in the park for the night.

The next day we explored historic the towns of Ross and Oatlands, before discovering how the narrow Hobart streets were not designed for buses. We visited the Cascades Female Convict Factory and the Salamanca Markets area before going to stay the night at one of my old nursing classmate's property. I hadn't seen her for 20 years, since we had graduated. We had a lot of catching up to do!!

We did some touring around the South Arm and enjoyed the little beaches there before heading back into Hobart and having a tour of historic house "Runnymede". My PN didn't arrive as planned at the hospital, so we continued on south and camped by the Esperance River for the night. Next stop was getting mobile range to be able to



find out how my eldest son did in his HSC and for my daughter who had completed a couple of HSC subjects in an acceleration program. Both did very well and my daughter made it to the honour roll as well for her results, which was exciting. We then headed to Hastings Caves and thermal springs and enjoyed the caves before relaxing in the chlorinated thermal water pool. I even went in for a dip, just as far as my central line placement would allow me! That night we camped at the Arve River, but this time we didn't have the area to ourselves and Bradden, my youngest, built a rock wall with some of the other children staying there. Our next adventure was to do the air walks amongst the trees at Tahune and walk along the swing bridges and see Huon Pine. The view from the tree tops was pretty awesome. We also had a ride on the Eagle Glider, which was fun. We then had to head back to Hobart to collect my PN, and continued to Richmond, another historic town, for the night.



*Port Arthur church ruins*

Port Arthur and its history kept us busy the next day and we also found the "Remarkable Caves", which lived up to its name, on the way out, before we went to camp at Fortescue Bay. We entertained the other campers as Matt carefully manoeuvred the bus between tents, trees and wallabies! Port Arthur and its history did upset my daughter in her dreams that night and it was a long night for us all. We hadn't seen a Tassie Devil, so the next day we headed to the "Unzoo" and got to see them being fed there, as well as some quolls and other Australian birds and animals. We found some other geological wonders before heading north and camping by the water at Bagot Point, near Swansea for the night. We enjoyed another beautiful Tassie sunset and saw the sandy beach come to life with crabs at dusk.



*Aptly named Remarkable Caves*

The next day was hot and deemed a bushfire risk, so the Freycinet National park was closed and so we were left finding other things to do in the heat. We decided to camp at Friendly beach, and we were a stone's throw from the water. The water was turquoise, with a white sandy beach and it was as beautiful as those you see on telly for an ad or cruise for a tropical island in the Pacific! A well-kept secret of Tassie, the beaches are spectacular! The kids and Matt cooled off at the beach while I caught up on some shut eye. It was very hot in the afternoon, even on the beach, so we played Monopoly in the bus to bide the time until the cool change came at last. We even gave a wallaby some cool water to drink- it drank 2 bowls, it was so hot and thirsty.

Fortunately the national park opened again the next day, so we did the Wineglass Bay Lookout walk along with all the other tourists. The view was worth the trek for me. Our next night camp was at Swimcart Beach along the Bay of Fires and again another romantic beachside view. My boys found a dead penguin had washed up on the beach, and they gave it a ceremonial burial and grave. To go to sleep with the sound of the waves gently crashing was magical.

*Views from Bagot Point*



*Wineglass Bay lookout*





*Swimcart Beachside stop*



*Tassie's tropical waters*

Our next adventure brought the windy roads near Scottsdale, which the bus managed slowly but surely. The diesel fuel in Tassie is so much better quality than on the mainland, and the bus was running like a dream. Though if you were unlucky enough to get stuck behind us on one of the many steep, windy hills, you might not have thought that!! Matt was always courteous and would pull over at every chance to let those behind get past. Despite the bushfires at George Town, my PN made it to the local hospital and we stayed the night at Low Head and caught up on washing there. Launceston was next and we enjoyed the Cataract Gorge and the chairlift and walks there before trying to find a spot big enough for the bus, so we could explore the City Park and see the monkeys there. Launceston has very steep hills and one way roads too, as we discovered the slow way!! We then headed out to Carrick to catch up with another of my nursing class friends, who we also had 20 years' worth to catch up on!



*Our Bus at a riverside camp*



*Smiths at Smithton*

We stayed the night at another bus club friend's property at Longford and then went berry picking with them the next morning, which was Christmas Eve. We then had another drive to the other side of Tassie, to go to Dismal Swamp and see the Tarkine Sinkhole and have fun on the slide and explore the swamp. The wind had picked up and it was too windy to stay at Marawah, so we found a sheltered spot near Arthur's River to spend Christmas Eve and morning. After a quiet Christmas morning we headed around the Tarkine drive to explore "the edge of the world" and other features before making sure we checked out "Smithton". Stanley was next and the boys climbed "the nut", while Matt, Juliet and I explored the old houses. We then camped at Black River and Sawyer

Bay area and I cooked up a Christmas turkey, roast vegies and smoked ham for a Christmas feast and fun, followed by a Italian Panettone. It was a beautiful place to spend Christmas. Boxing Day took us to find "Dip Falls" and a stringy bark tree that was 16m in circumference, before hitting the windy roads through Rosebery and arriving at Strahan in time to watch the pantomime show "The Ship that never was", which is about a boat stolen from the penal colony on Sarah Island. It was a lot of fun and the audience all gets involved too. We had the opportunity to go on a cruise on the Gordon River to the World Heritage area and Sarah Island the next day, which was very picturesque with the mirror like waters of the river. That night we found a spot to camp near the Mackintosh Dam, and enjoyed playing with the echoes you could make there. Cradle Mountain was next on our agenda, and it did not disappoint. There was not a cloud in the sky to obscure the view, but it was heavily packed with tourists. We did the Crater Lake walk and somehow I managed to do over 10km of walking, even if it was slowly on the uphill bits. I was glad I had an extra bag of PN, which I used to boost me that night. We stayed back at where we had started, with our bus club friends. They took us to "Tasmazia", where we got thoroughly lost and confused in some awesome and fun mazes. We had fun being driven in their 1952 Clipper, which turns everyone's heads as you drive past. They took us to Lake Barrington and the surrounding areas before it was time to get sorted and ready to go back on the boat and head home. It was very sad to leave Tasmania, as we had so much fun, but number two son had the Australian Scout



Jamboree to get to. It was smooth sailing home on the boat and with the bus too. This time we were parked with all the trucks in the boat, which meant we were first off. We delayed getting home by one more night after catching up with yet more friends from our bus club near Bundanoon and the next day we arrived home, much to the delight of our dogs, with a happy song for us. Matt drove over 5,500kms and we walked over 60kms. We had such a wonderful time as a family. I felt so blessed to be well enough to push myself to do as much as we did. I know we have created a lifelong memory for us all. We coped really well managing my PN on the bus and the new half of the kitchen improved it even more. I hope my story can encourage others to just go for it and not let the PN stop you from enjoying our beautiful Australia, or creating your own family memories in whatever you enjoy doing.

*Gordon River Mirror*



*I made it to the top at Crater Lake*



---

## A Carer's Thoughts on Relationships

WORDS BY RYAN

I've had this sitting on my mind for a long time, but haven't been able to gather my thoughts on it easily. Any illness, or anything apart from the normal, is something family has to learn how to manage. It has an impact on them, and makes life more difficult. There are 2 parts though that have been going round and round in my mind, but I haven't been able to pin them down.

The first one is that I know, thinking of my wife, she would feel personally responsible for causing difficulty for our son and me. Like if she was better, then life would be easier and better for us, and that somehow it is her fault.

I'm sure it would be easier in some respect, but it is quite odd how we take health for granted isn't it, then something else becomes a difficulty in life. Like when your baby sleeps through the night for the first time, then you instantly get used to it, then suddenly it is MUCH harder when they stop sleeping through the night again... My point being, although I wish with all my heart my wife was better in health, for her as well as us, I think much more important is our personal attitude and how we come to terms with it underneath. That is something we can change, and it makes a world of difference. And personally I've found we are still on that journey, trying to figure out this strange thing called life, and what sickness does is create a catalyst for that journey. You have to come to terms with some things, or it becomes increasingly difficult to function in society and relationships.

I'm a people pleaser. To the max. Could never say no to anything. It wasn't a problem (I didn't think so at the time anyway) when I was single. In hind sight it was a problem, I just wasn't aware of it - but that is another story I won't ramble on about. The problems started happening when I didn't have enough 'spoons' [equated to energy level in a forum chat] to keep everyone happy. And what makes it more difficult, it seems, comes with sickness; the amount of spoons taken to have a healthy relationship with my wife kept increasing. I'm a pretty stubborn person (I can picture my wife in my mind as I write that nodding like that is an understatement), so it took several times to breaking point for me to have to change.

What I discovered was that although physical (and mental) health demands time, it is the health of the relationship that is the most important part, and that part tended to suffer in light of the other things. I'm almost certain the causes of stress and difficulty come mainly from the relationship rather than anything else (which in turn stem from our own personal fears and hang-ups). So often it can get overshadowed by more "pressing" issues. But really, in the end, for me I've decided it is the relationship that matters. And furthermore, it seems to me it is the relationship that has the biggest impact on most of our other endeavours.

Although I can't say what life would have been like without sickness, I'm fairly certain that I'd still be dancing around

many issues I've had to face head on. Like I said earlier, it seems to be as though sickness is a catalyst. The other thing I've learnt is a massive appreciation for time, more so since our son's coming along.

So back to my wife feeling like it is her fault, and that her sickness shouldn't affect us. Whatever effect it has on us, I think is a reflection on our character. It takes two sides to any relationship. Sickness provides a catalyst for growth. I don't think sickness creates problems in relationships by itself... and it is relationships that really matter and make the difference in our lives.

The second part for me is how sickness will impact our son, and what to do as a parent about it. In a practical sense, it probably means less opportunities for him. And I'm sure at some point (he's 3) he is going to figure out that his family isn't "normal".

I often think as a Dad, if there is one thing I can teach him in life, it would be courage. Not to dance around issues, but to get to the heart of it, face it and conquer it. Again and again and again. I had thought that before he could walk and talk, and you know what, he is scared of EVERYTHING, he is really going to need courage. I don't know how to teach courage, I think I have to show and live courage. I'm only going to be able to do that if there are things I have to face and overcome myself.

We can't always control our circumstances. We could be living in a different country, in a different age. I'm really thankful we've been given a shot at life and we have a health system so my wife and son are alive, and that my wife has some quality of life.

So it brings me back to before. As a dad, raising my son, I want to teach him courage, but most of all have the relationship with him as number 1. At the end of the day I can't control the opportunities he has. Don't get me wrong, I desperately want him to have all the opportunities in life I can give him, and I can influence that, and it drives me, but never at expense of the relationship. And I know there are going to be many practical issues to face, money always being one, but I find the biggest issue money causes is to aggravates relationship issues.

Daniels only 3. I don't have any other kids, and I'm sure, like most Dads, feel like I have no idea what I'm doing. If even one good thing has come out of sickness, it is that I am much more aware and trying to be much more deliberate about my relationship with my son than I ever would have otherwise.

Sickness isn't your fault. Really, it isn't. You didn't do anything specifically bad and get sick as a punishment. You didn't deserve it. And you don't have to make up for it. And I know you want to minimise it, and the affect it has, and the struggles that you have. But please don't do that at expense of relationships. Relationships seem to work best on being honest, with each other, and with yourself.

And, you are worth just as much as everyone else, no less, never any less. Never. Not even a tiny bit. Never. It's hard to look at ourselves like that. But in a relationship, remember that we (as in carers, husbands, partners), don't think of you as less. So people don't undervalue yourself to us either, or judge your value in terms of practical help. You are so much more than sickness, and so much more than any physical limitations. For those men on HPN, it applies to you too.

And for carers and partners, remember you are important too, and the relationship to you is probably the most important thing to your partner.

---

## Cruising the waterways with international friends

### WORDS BY KAREN

In late 2015 at our spring Sydney gathering, some members of PNDU had the pleasure of meeting a young intrepid HPN traveller from the USA who was in Sydney for a couple of months of tertiary study. Organising and surviving a 3 month stay in a country that does HPN quite differently to her own and as a result, not being able to get her own exact formulation, was an amazing feat and wasn't without some problems, which hopefully we will hear about in a later issue. I want to tell of the lovely day Gillian, Ray and I had sailing the waters north of Sydney, showing Emmy a beautiful part of greater Sydney not always seen by international tourists – the Hawkesbury River.

Emmy and I were cutting it fine on that early November morning, but with Gillian and Ray (who had missed meeting Emily at the Sydney gathering) messaging us ahead about the parking situation at Brooklyn, we were able to streamline our arrival and board the 'Riverboat Postman cruiser'... last and just in time! The boat was big!! Much bigger than I expected. And it was full!!... full of pensioners!! Don't get me wrong, I have no problem with that – I just wasn't expecting it. If I felt rather young in comparison, Emmy was sure to feel it. But having already met Emmy at our Sydney gathering the previous month, I knew that she is one of those special young people who is happy to mix with people of all ages.

It was an absolutely perfect spring day in Sydney. After morning tea, we went upstairs into the fresh air to take in the stunning scenery as we travelled around the Hawkesbury stopping off at various jetties to drop off the mail – it's not called the 'Riverboat Postman' for nothing! Our ports of call included Dangar and Milson Islands, Kangaroo Point, Bar Point, Marlow Creek, Fisherman's Point and Milson's Passage (also known as the 'Republic of Milson's Passage')



where its self-nominated 'Mayor' on his throne, received the mail delivery!).

We chatted and shared stories and compared notes about our own HPN experiences. Emmy's life-long experience with HPN and her ability to articulate what it was like at the different stages of childhood, adolescence, and now young adulthood is fascinating and so helpful for understanding what young HPNers face. Emmy shared how she coped, when and why she kept her HPN private, how friends and peers coped with her HPN, and the occasional uninformed but funny comment many HPNers will hear, such as 'if you just ate better and got some more exercise, you'd feel so much better. Hasn't your doctor told you that?'. We had some good laughs and great conversation – how good it is to be able to talk with other HPNers/carers who share the same or similar experiences, no matter where in the world we live! But also how amazing it is that we live in an era when people with Intestinal Failure are able to live! And live well!!! To be able to get out and enjoy the good things in life, and to travel! We are so fortunate!

We went back inside after a while for some shade and then a beautiful 'ploughman's lunch' from which all of us were able to get something we could eat, and enjoyed the rest of the cruise in the comfort of shade and air-conditioning before returning to Brooklyn just after 1pm and returning home.

Emmy – you're an inspiration, not only to other young HPNers and their carers, but to HPNers of all ages. Your desire to make the most of life and not let Intestinal Failure hold you back, but roll with the punches, is wonderful to witness and a great encouragement to others. Keep enjoying life and we look forward to keeping in touch and hearing where life takes you.

And soon after one international HPNer leaves, we are looking forward to the next visit 'down under' by yet another international HPNer – PNDU's long-term friend and encourager-extraordinaire – Laurie and his wife, Shirley, from Canada. If any other HPNers and carers in or near Sydney would like to join us when we meet with Laurie and Shirley on Saturday afternoon 13<sup>th</sup> February in Randwick, Sydney please contact us at [contactpndu@gmail.com](mailto:contactpndu@gmail.com).



*HPNers 3 – Karen, Emmy and Gillian*



*A hearty 'ploughman's Lunch – Emmy, Ray and Gillian*



*The beautiful views from the Riverboat Postman cruiser*





*Ray, Gillian, Emmy and Karen with the Riverboat Postman cruiser in the background after dropping us back at Brooklyn*

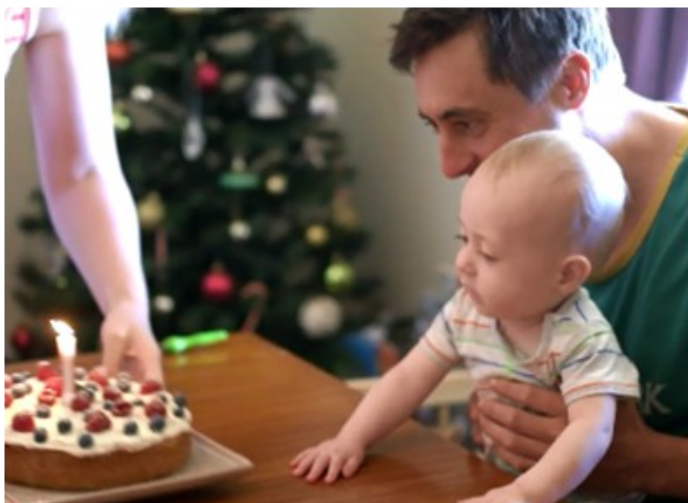
## Birthday Corner

Carter and [twin sister] Gabby had a great day on their birthday, turning 8. We went to a farmyard zoo and then an aquarium. Carter got lots of lego for his birthday so was very happy! He has had an ongoing infection around the skin and on the point of his hickman line for a couple of months and is starting a 5th lot of antibiotics, so it was great to be out and about and enjoying the sunshine.

Unfortunately, there are no clear photos of the day – somebody is always obscured at the last minute!

We celebrated Ariel's 5th birthday with a little party and a big bunch of balloons. She had a ball!

Here are a couple of photos of Sebastian (HPNer) from his birthday celebrations. We had a quiet day for Seb's birthday, spending it with his family and then we all went to the Christmas Eve service at our church that night.





---

# Travelling to Australia – an HPNer’s view from the other side of the planet

WORDS BY CAROLYN WHEATLEY

**Editor’s Note: Carolyn Wheatley is the Chair of PINNT, UK’s support group for those on both HPN and HEN (Home Enteral Nutrition)**

My personal mantra nowadays is “have backpack will travel”. When I first started HPN (Home Parenteral Nutrition) 32 years ago, I made a conscious decision to try and live life to the full. Yes, there would be obstacles I may not be able to overcome, but I quickly learned that there is usually a way round them if you can’t get over them. Being a pioneer of HPN in the UK, not by choice but by fortune, I found I had few peers to turn to for advice, given I was the youngest HPNer under my hospital. I believe there was a twenty-year difference between me and the next HPNer.

Prior to severe illness, travel was my passion. Okay, it was limited to partying on the sunshine island of Ibiza in the Balearic Islands; culture really didn’t float my boat. I worked hard, saved hard and holidayed at least twice a year. It all came to a halt when HPN became the norm. I was desperate to go on holiday once I’d settled into my new life on HPN and a dare from a dear friend rekindled my passion for travel. Five years after starting HPN I plucked up the courage and went off on my first trip abroad with PN, yes – I was going back to Ibiza, but I had curbed my partying lifestyle by then.

Ibiza was just the start of travelling with PN; a few more test trips back to Ibiza and then to visit family in France gave me the confidence to consider going further afield. Initially self-catering [apartment] was the best option to ensure a fridge, then I tackled the difficulty of trying to get a fridge at a hotel. If I am honest, I have had a few disasters from no fridge, to a freezer to mini bar fridges – I can’t put in writing where I have chanced storing my PN over the years! I live to tell the tale though ...

My dream was to visit Australia. A few years ago my husband and I travelled to a friend’s wedding in Adelaide. We enjoyed a whistle stop tour of Sydney and Melbourne. I felt truly supported and upon returning home always had that nagging desire to return.

They say you should be careful what you wish for, but sometimes wishes come true and they are just amazing! I had the opportunity to visit Brisbane and Sydney in September 2015 – I couldn’t believe my luck. The difference was I would be travelling alone on this trip. Alone in terms of a companion, but not in terms of support. Prior to travelling, my nutrition team were amazing and arranged support from Baxter in Australia, along with medical support in the event that I needed help. Baxter were truly awesome both here in the UK and in Australia – fine tuning all relevant details and information; having HPN friends in Australia was a bonus that many people don’t have. Having prior knowledge of how it works in Australia, which is different to the UK, made it easier to plan and prepare for.

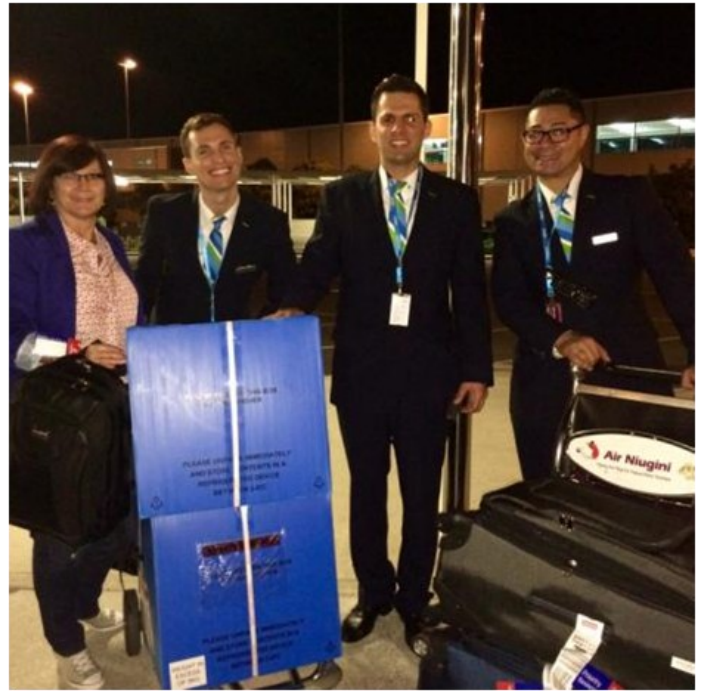
Boarding the plane bound for Brisbane was surreal, all the planning was finally falling into place. The airline support was tremendous, all the flights connected perfectly and when I finally arrived in Brisbane all my luggage was there along with the PN I had brought with me – yay! It was a bit of a bind having to infuse on both legs of the long-haul flights but better to stay hydrated!

Despite being there and attending a conference, what was more precious to me was meeting fellow HPNers and their families. Sometimes at a conference you can be in a room full of people yet feel so alone. Through the tremendous support of PNDU I attended patient gatherings and enjoyed chatting with others and truly felt like part of a family. We had a common treatment but such varied lifestyles and choices. Sharing and listening to everyone was truly heart-warming. To travel so many miles and meet like-minded people really struck a chord with me. I think many of us could have talked for hours. Despite it being part holiday I don’t think we ever stop observing. I noticed the difference in homecare, products and fluids. Despite these, I think I voiced it on more than one occasion – “we should all be grateful for Home Parenteral Nutrition”.

As I look at photos and recall the experience, I think it highlights two things for me. First, we can all offer each other support no matter where we live. Secondly, I can’t wait for my next trip to Australia.



*'Duty first' - Brisbane Conference, with Karen*



*'A little help' – Ground-staff at Brisbane airport*



*Selfie on a Sydney ferry*



*Lazing at Berowra – 'Bliss'*

---

## Conception, Pregnancy, and Lactation Despite Chronic Intestinal Failure Requiring Home Parenteral Nutrition

BETTINA M. BUCHHOLZ, MD ET AL.

Department of Surgery, University Bonn Medical School, Germany.

Nutrition in Clinical Practice 2015;30; 807-814

**Background:** Short-term parenteral nutrition is commonly accepted to be safe in pregnancy, but knowledge about the management of pregnancy during long-term home parenteral nutrition (HPN) is sparse.



**Methods and Results:** A systematic literature review revealed that the published experience is limited to 15 pregnancies with parenteral nutrition from preconception to delivery and beyond. Maternal morbidity was surprisingly low, and fetal outcome was good; however, micronutrient deficiencies may have contributed to fetal anomalies.

Herein, we additionally report the case of a 26-year-old Caucasian woman with long-term HPN dependence secondary to short bowel syndrome caused by recurrent thromboembolic mesenteric infarctions who delivered a healthy fetus at 37 weeks of gestation. Individual macronutrient support and adequate micronutrient supplementation ensured normal maternal weight gain and fetal development. Based on the individual maternal risk of recurrent thrombosis, anticoagulant treatment was carefully titrated throughout pregnancy. Furthermore, loss of abdominal domain with a rigid maternal abdominal wall secondary to short bowel syndrome and multiple laparotomies resulted in food intolerance during the third trimester. Still, with multidisciplinary efforts, both mother and the breast-fed infant were in good health at 12 months after delivery.

**Conclusions:** Taking the reported literature into consideration, we conclude that under the premise of optimal medical care, the risk:benefit ratio for pregnancy of HPN-dependent women seems to be justifiable. To minimize the risks, we recommend preconception counselling and early referral to a tertiary center offering both a high-risk pregnancy unit and a nutrition service. In particular, maternal micronutrient levels should be monitored.

**Additional Notes from Gil (Prof Gil Hardy, lifetime member of PNDU and Professor of Clinical Nutrition at Massey University, NZ for 8 years, a member of PNDU's Management Committee and currently Chairman International Clinical Nutrition Section (ICNS) American Society of Parenteral & Enteral Nutrition (A.S.P.E.N)):**

The 15 pregnancies were in 14 women between 1983 in Manchester UK (that I remember being involved with) up to 2014 in Germany. Two thirds were SBS with a remaining intestinal length of between 0 and 150 cm. Oral intake varied widely and HPN had been given for an average of 4.9 years (ranging from 1 month to 24 years). Maternal weight increased from an average of 48.5 kg at conception to 59.8 kg at delivery. The majority of foetuses were delivered vaginally at term or near term with an average birth weight of 2650g (range 1380-3900g). Foetal outcome was generally good, but a few abnormalities were reported, such as temporary anaemia, vitamin K deficiency and bilateral congenital cataracts.

---

## You'd be More Healthy if You...

**Some comments from our members who have received some pearls of wisdom regards their diet and lifestyle. If only it were so simple!**

We had a chuckle today with Emmy – Emmy has had someone tell her that if she just ate better (ie drop the salt, the carbs, fat, etc), ate more fruit and vegies, and got some exercise, she wouldn't be having these health problems! Surely her doctor has told her that?!

I know my diet, although pretty basic, is not what you would call healthy. Stodge is so much better. A friend recently cooked a beautiful lunch, forgetting that 'healthy' is not good for me, and I ended up with partial blockage the whole of the next day. Difficult to say at the time I couldn't eat it when she'd gone to so much trouble. It was mighty yummy too. **Karen**

It's funny, isn't it, when well-meaning people give advice on what and how to eat. Before Bryley started to eat, especially during Kindy and Primary School, if I told anyone about the fact she doesn't eat, the first thing they would say is "have you tried chocolate"? I only wished chocolate was the cure for Bryley's bowel problems and all our other problems as well!!!! **Gail**

The comments from well meaning people are often very funny, like this next one I had from my father. After years of IV hydration he suggested I sit in a bath and let my skin absorb the water. **Jacqueline**

On Tuesday, I was told that I shouldn't have had problems at the high tea I was at as they had provided plenty to drink...I shouldn't have needed IV fluid.... Some people just don't get it, do they? **Jane**

---

## Long Holidays on HPN

WORDS BY **GILLIAN**

Holidays are times of both joy and fear for the HPNer and their carer. Joy, obviously, because it means you can still continue with one of life's normal pleasures, exploring new places or simply relaxing and destressing in one spot, recharging your batteries and getting away from the everyday demands of life. Fears, because the unknown, which can present acceptable challenges whilst healthy, are exacerbated with challenging health conditions and knowing that line infections and other problems can happen to the HPNer at any time.

It would be a shame for someone on HPN to allow those fears to overcome a desire to get away for a while. Several of our PNDU members have ventured overseas whilst on HPN and PNDU's Travel Booklet (available on our website [Travel page](#)) has been of great help in planning those trips. Ray and I have been to New Zealand, but we mainly confine our travels to caravanning around Australia. We recently had 7 weeks' fun in the sun, travelling as far north as Cooktown during the months of September and October. I thought I would share some hopefully helpful tips on preparing for a long trip on HPN.

A long trip must be approached with flexibility – after all, you need to be in a place accessible for PN deliveries, so as well as your personal planning, before anything is booked, you must liaise, through your hospital team, with Baxter/ Biomed, to check that they can actually deliver to that place on that date. You may have to rearrange your itinerary or your dates.

Also, you need to let your hospital team know your plans in case they have any doubts about any aspect of the planned holiday, or your health.

In our case, we began our plans a few months before the trip dates, mainly because we only stay at en-suite sites at caravan parks and these need to be booked well ahead at popular places in order to secure one (even so, we've twice turned up at a caravan park which didn't have it for us- one was only overnight, and the other gave us the key to one of their family bathrooms for our stay). We choose en-suite sites, despite the extra cost, partly for personal reasons – close to the van for convenience during the night, always clean, never closed for cleaning, etc - but also because it's where we store our travelling car esky/fridge for my PN. I can keep 3 or 4 bags in this, which means only needing caravan fridge space on delivery day for up to 3 bags (I keep one out for that night when delivered).

So, for us, the down-side is having to lock in the entire trip ahead of time, which allows no flexibility- deciding to stay longer here, less time there- but it means that we know for sure where we'll be. If you didn't want an en-suite site, or were motelling, you could simply book your 'delivery day' nights, plus the next night in case of delivery failure, and travel at your whim in between.

Ray and I worked out our preferred itinerary, written out in 7 rows of 7 places (like a calendar), representing 7 weeks of travel, without actual days attached to the places. We then looked down each row, trying each row as a Tuesday (my regular PN 'delivery day'). It's no good having your delivery on the day you arrive for just one night, for example, because if it is held up, which has happened twice, then you have a problem. When we first checked, every row had this problem, some a few times. We then chose the best row to be Tuesday, made a slight change in the number of days we stayed, then wrote the rest of the days of the week at the top of the rows and found out our departure day that way.

I then emailed my desired Tuesday stops and dates to my hospital team to forward on to Baxter, who responded almost immediately. There was a problem which I hadn't foreseen – the October Labour Day holiday, which meant that I couldn't get my delivery until Wednesday. Baxter would send one extra bag the week before to tide me over. That meant an adjustment to our schedule, as we needed to stay an extra day at the Wednesday place. Once I had Baxter's approval in principle, I then went on to immediately book the caravan park sites. Luckily, all but one were available on the dates I wanted, and there was another park close by at the place which was fully booked.

I have always found Baxter to be very amenable in planning trips. For example, last year we had a 5 week caravan holiday around Victoria. One of our main destinations was The Grampians, staying there at Hall's Gap. However, Baxter couldn't deliver there within the necessary 24 hours of compounding needed for my formulation, but we really wanted to be there at that time and couldn't rearrange our itinerary. So I looked at a map and chose a town within easy reach of Hall's Gap, and asked if Baxter could deliver to a depot at that town. They liaised with the delivery company and this was agreed. Ray and I would simply use that day for an excursion to that part of Victoria. However, it became even easier when the company in question rang me regarding the delivery and offered to deliver it to a shop in a town much closer to us.

It had been about 4 years since I'd asked my hospital team for a letter describing my health situation and what needs to be done if I present to hospital with a line infection, so I decided an updated letter would be a good idea just in case, even though I haven't had a line sepsis for over 2 years. Again, I requested this well in advance so that my doctor had time to fit it into his busy schedule.

When I plan a long trip, I look to see which towns have a hospital, again, just in case. This probably gives me a false sense of security as many of the towns have very small hospitals and might never have seen a patient on HPN or with a central line, but it gives me some reassurance.

About a month before the trip, I do the maths and work out the number of peripheral supplies I'll need so that I can order enough before I depart. Supplies for a long holiday are bulky and I keep 2 or 3 Baxter boxes to put them in. Travelling in a caravan, I keep a week's supply of peripherals and ileostomy items easily accessible, and the boxes for the rest of the trip in the storage area under the bed. If travelling by car and motelling, you would need to have enough space in the boot or back seat or floor of your car. As they grow older, many people downsize their car, but we have come to realise that if we want to travel, we need storage space for my medical supplies.

When I work out how many of each item I need, I always take extra as well, in case of damage or dropping. So, for example, I use 2 x 10mL syringes per day, so for my trip that worked out to be 98 syringes, which I then rounded up to 110. In the case of dressing packs, which are the bulkiest item to pack, I use 8 per week – 1 each day plus one for



doing my dressing change on my central line. However, because I swim, I sometimes do an extra dressing change straight after, if it's in a pool that has had lots of children swimming in it. So instead of just 56 packs, I took about 70, just in case, as well as the corresponding number of gloves and IV3000 for a dressing change. My advice is to make a careful list of all the items you use in the course of a week – including drugs and ostomy supplies; write how many you need per day or per week and then multiply this for the duration of your trip, then add in the extra for spares. I have never run out of supplies, but with Baxter just a phone call away, you can probably arrange an emergency delivery if needed – you would need to check this with Baxter during your planning. [PNDU also have available a spreadsheet which can be adapted using the items and number you use. You then insert the number of days you're away and it does the calculations for you. Contact us at [contactpndu@gmail.com](mailto:contactpndu@gmail.com) if you'd like a copy.]

If all this sounds a bit daunting, then start off with a short trip away, and build on the experience you gain doing this. If you feel well enough, there is no reason why your home country (Australia or New Zealand) can't be your oyster!

*Beautiful coast near Airlie Beach, and swimming at Josephine Falls near Babinda (near Cairns)*



*Shell-seeking*

*Typical Far North Queensland beach*

---

## Recommended reading

***A couple of our members have already read this book and we will be including a member review in a future edition. Remember, when you are purchasing books, PNDU receives a small percentage of the purchase price if you buy through The Book Depository link on our website or simply click [here](#).***

***Meanwhile, below is the publisher's overview of the book.***

***["It Takes Guts : A Story of Love, Hope and a Missing Bowel"](#) By [Evelyne Brink](#)***

It Takes Guts is the true story of little Tuffel, who upon birth was sentenced to death. This is a remarkable tale of the human spirit rising above the seemingly impossible, told by his mother, Evelyne. Growing into her new role as a mother and carer, she takes you on a journey of personal growth and trying not to lose 'it', herself or him throughout sleepless nights, hospital life and medical jargon - all while keeping her sense of humour along the way. Tuffel has become the first survivor of 'ultra short gut' syndrome: living with no small intestine. This uplifting and deeply emotional journey will fill your heart with new hope for what is possible for each and every one of us.

---

# The burden of treatment for patients with chronic conditions

*Editor's Note: In June, 2013, PNDU members (adult HPNers only) were given the opportunity by French researchers to be involved in a global survey to 'Share your experiences and help physicians understand how you adapt your life in regards to your treatment'. The survey involved 1053 participants from 34 countries (including 6 PNDU members who participated).*

The full paper is 15 pages and [a pdf is available for reading on our website](#)

Below is an email from **Dr Viet-Thi Tran** informing PNDU of the publication of his international survey in which PNDU participated.

*You have helped us perform a study about the burden of treatment. Results have been recently published in BMC Medicine: <http://www.biomedcentral.com/1741-7015/13/115>. I also copy you a pdf version of the paper.*

*All participating associations have been mentioned in the paper (Appendix 2). Our article has also been highlighted through social media on [@BMCMedicine](#) twitter account. Feel free to share it using you own social media.*

*Again, I thank you for your help and participation in this study*

*Best regards*

**Dr Viet-Thi TRAN (MD, PhD)**

*Chef de clinique en Médecine Générale, Université Paris Diderot*

*Centre de Recherche Épidémiologie et Statistique Sorbonne Paris Cité (CRESS-UMR1153)*

*Hôpital Hôtel-Dieu, Paris, France*

## Taxonomy of the burden of treatment: a multi-country web-based qualitative study of patients with chronic conditions

**Background:** Management strategies for patients with chronic conditions are becoming increasingly complex, which may result in a burden of treatment for patients. To develop a Minimally Disruptive Medicine designed to reduce the burden of treatment, clinicians need to understand which healthcare tasks and aggravating factors may be responsible for this burden.

The objective of the present study was to describe and classify the components of the burden of treatment for patients with chronic conditions from the patient's perspective.

**Methods:** We performed a multi-country qualitative study using an online survey and a purposive sampling strategy to select English-, French-, and Spanish-speaking participants with different chronic conditions. Participants were recruited by physicians, patients' associations, advertisement on social media, and 'snowballing'. The answers were analyzed by:

i) manual content analysis with a grounded theory approach, coded by two researchers, and ii) automatic textual analysis by Reinert's method.

**Results:** Between 2013 and 2014, 1,053 participants from 34 different countries completed the online survey using 408,625 words. Results from both analyses were synthesized in a taxonomy of the burden of treatment, which described

the tasks imposed on patients by their diseases and by their healthcare system (e.g., medication management, lifestyle changes, follow-up, etc.)

the structural (e.g., access to healthcare resources, coordination between care providers), personal, situational, and financial factors that aggravated the burden of treatment; and

patient-reported consequences of the burden (e.g., poor adherence to treatments, financial burden, impact on professional, family, and social life, etc.).

Our findings may not be applicable to patients with chronic conditions who differ from those who responded to our survey.

**Conclusions:** Our taxonomy of the burden of treatment, provided by patients with chronic conditions from different countries and settings, supports the development of tools to ascertain the burden of treatment and highlights potential targets for interventions to minimize it.

**Viet-Thi Tran et al. BMC Medicine 2015: 13:115**



## Appendix 2

<b>Patient associations that agreed invite their members to participate in the study</b>	ACS - Action contre les Spondylarthropathies AFLAR - Association Française de Lutte Anti-Rhumatisme AFS - Association France Spondylarthrite Alliance du cœur AMVF - Association des Malades des Vaisseaux du Foie ANDAR - Association Nationale de Défense contre l'Arthrite Rhumatoïde Associació Catalana de Fibrosi Quística Association des sclérodermiques de France Association Francophone pour Vaincre les Douleurs Association Patients du Canada Atrial fibrillation Association Australian Patient Association DEBRA International EMSP - European Multiple Sclerosis Platform Epilepsie France FNETH - Federación nacional de enfermos y trasplantados hepáticos Heart Sisters HTAP France Ligue Contre le Cancer Lupus Europe Lupus France Pain Alliance Europe <b>Parenteral Nutrition-Down Under</b> PHA Europe Renaloo SOS hépatite Wired4Life
--	---

---

# THE NIGHT OF THE ALIEN

WORDS BY JODIE

**Editor's note: be warned that some description is quite graphic.**

Once upon a time, in a hospital far away, there existed a 13-year-old girl whose life was surrounded by a sphere of mystery and desperation. The girl's name was Jodie. The girl was me.

I can't remember all the details of my history, which is annoying. I'm guessing my memory is patchy because I had intense experiences, permeated by high levels of emotion.

I'll try to recollect one especially peculiar scene for you...

This scene unfolded during a time when I was debilitated in hospital. My abnormal body had produced an abscess where a jejunostomy tube had been removed from my gut wall. Why did an abscess form? The answer is unknown.

I was lying, supine (as I often did) on my plastic mattress bed, watching TV. It was an average night on the teenager ward at Princess Margaret Hospital. I was reasonably happy because the dressing around my gut 'hole' had been fashioned by a skilled nurse. The dressing was secure, so stomach acid wasn't burning my skin, as it so often did during this particular admission. It was a pretty ordinary hospital stay.

Then average changed and the ordinary got real weird. (Not that I wasn't already familiar with all sorts of weird...)

Stomach acid began to seep under the expert dressing and sizzle away at my epidermis. The ostomy pouch secured over the hole (for drainage) puffed up with gas. I sensed impending doom.

When weird things happened to my body, as they did on semi-regular occasions, I felt astonished. But this time, I said, 'Woaaaaah, check this out!' to my mum who was sitting nearby.

We knew something was quite wrong when the pain started. Mum rushed off for a nurse.

The nurse, who tailed my mum back, loved grotesque human secretions. (Nurses are generally curious, fascinated creatures.) She took the ostomy pouch off. A foreign, disgusting smell filled the air.

What happened next was almost like the alien chest-bursting scene in the movie, *Alien* (or the rip-off version in *Spaceballs*). Funny thing was, I didn't order the daily special.

What erupted out of my gut wasn't an archetypal alien... But it was green, it was slimy and it was *definitely* disgusting. My adrenaline level soared. I stared at my tummy, grimacing, as if it were someone else's bodily dysfunction that I was observing. It bubbled as it exited, like a creature moving of its own accord. The mass

discharge happened in a matter of seconds.

Straight after the alien had slimed out of my gut hole, all covered in mucous like a baby - it burst.

The first thing the nurse said was, 'Cooooo!' All I could say was, 'FAR OUT!' *My body* had produced this. It was surreal to see the abscess on the outside of me, after it had been causing so much trouble inside me.

What followed was a decent clean-up effort and animated talk between medical staff. The best thing, after this episode, was that I was free, for now, of physical pain. Finally, I had my jejunum back. Now, hydrochloric acid wouldn't leak out, over my skin and torture me.

I may not have slept so well since The Night of the Alien.

---

## Recycling at its Best

RYAN



Every few months I do this. They last about an hour and all gone

---

## Reminding health professionals about real patient power

[International Alliance of Patients' Organizations](#) (IAPO) CEO Kawaldip Sehmi recently wrote a guest editorial entitled 'Patient Power' for the [HealthManagement.org](#) "Journal" VOLUME 15 • ISSUE 3 • 2015

### Patient Power

We hear often about patient-centred care and patient involvement, but how aware are you really of the experiences and needs of the patients you serve? Do you know their views of health services and systems they navigate, beyond your experiences of individual interactions or information reported in patient 'satisfaction' surveys? To what extent do patients in your hospitals and communities understand and take part in discussions about improving healthcare for everyone, against a backdrop of rising costs, restricted budgets, innovative (yet expensive) medicines and diagnostics, and rising demand? At the International Alliance of Patients' Organizations (IAPO) we seek to answer these questions and to identify effective examples and models for improvement, and support improvement locally, nationally and globally. Our vision is a world where patients are at the very heart of health, from global policy-making to decisions made locally and within healthcare teams. Our member patient groups are all patient led, and can be small grassroots





organisations led by volunteers, national level disease-specific bodies, or associations crossing regions and continents. Presently we have 250 members covering around 65 different disease areas and countries. We fundamentally believe that communication and collaboration are at the core of the challenges to meaningful patient involvement, and that this is also where solutions will be found. We aim to be a voice for patients at the global level, advocating and collaborating on World Health Organization (WHO) projects and on pan-European projects. For example, this year we are working with academics, physicians and medical student representatives as part of a WHO project to deliver an online training resource for health professionals about the social determinants of health. At the European level we are working with health professionals, researchers, regulators, pharmaceutical companies and payers to test different ways to bring new and better medicines to professionals and patients faster. At the individual level, informed and empowered patients are able to make choices about their treatment options, and many patients can and do take responsibility for their health and management of conditions. With all countries facing ever-increasing demand for services and rising costs for chronic condition management, new technologies offer patients more options to selfmanage and to truly have a partnership with their healthcare team. However, this can only work effectively within systems that support patients' right to be involved. Trust and open dialogue is needed, alongside access to advice and support about medicines, treatment and how to recognise and respond to any problems. Online 'apps' already empower many patients to manage their own conditions and are a good example of how new technology can assist the healthcare team and patients by offering the potential for sharing data, improving communication and shared decision-making, as well as the opportunity to tell industry what patients and professionals really need to help improve condition management. Patients and patient groups are increasingly involved in hospital boards and committees, staff training and open days, or patient advocacy groups. In some hospitals and jurisdictions patients are involved in the review of and decisions about new medicines. Members have been involved with reviewing research proposals and patient information leaflets, and in specific disease areas patients have completed surveys on weighing up the benefits and risks of different treatment options. However, meaningful patient involvement remains inconsistent, and often no feedback is provided about what difference their input has made. There are clues about where further gains can be made. For example, a patient representative told us that if she was involved in the earliest stages of forming research questions, she would highlight a group of women who are not having their needs met by research or clinical practice. And we have heard examples where clinicians are wary about benefit/risk preference elicitation surveys, because the survey presents treatment options to patients that may not been discussed. Patient representatives can also add value to improvement initiatives in healthcare services, because they are often closest to a patient and their whole experience. When mapping the patient journey and showing it to clinicians, patient representatives can shock health professionals with the complex, time-consuming and overlapping interventions and pathways. Health professionals often only see the part of the patient experience that overlaps with their own focus. Health is a human right and patients are the ones who bear the impact of many decisions made without them. Better services can be designed and outcomes delivered by communicating more openly and effectively, listening to and involving patients at all levels, and feeding back to patients on changes, improvements and ongoing challenges. We appreciate the journal's willingness to promote discussion and encourage you to seek further information on IAPO and our partners, guidance, toolkits and activities at [www.iapo.org.uk](http://www.iapo.org.uk).

---

## A Day in the Life of an HPNer

### WORDS BY GILLIAN

One of the frustrations of living on HPN (Home Parenteral Nutrition) is that life can be going swimmingly, then suddenly a current takes you unexpectedly. I guess that's true of life in general, but when it is related to HPN, that's what we blame.

One of the most common problems of HPN is line sepsis (infection), when you might be feeling fine, but suddenly your body shakes uncontrollably with rigor and your temperature soars... so off to ClubMed (hospital) for a few days at least, never mind what your diary says you should be doing!

Since I received a new line two and a half years ago after a fungal infection, I hadn't been in hospital, but a few months ago, my monthly blood tests showed that the markers for the liver were all higher than usual. My PN (Parenteral Nutrition) was adjusted and again monitored, but during that time, Ray and I were on our 7 week caravan trip to Cooktown (last issue of Dripline was written and put together largely during that trip; this Dripline issue is being written and fine-tuned in hospital!) Seeing me every day, Ray and our friends didn't really notice physical changes in me, except I became a bit tanned from the sun. However, when I returned, my daughter Sally took one look at me and said 'Your eyes are yellow'. As I knew this was one of the results of liver problems, I quickly got my next blood test done and my concerned GP arranged to quickly see the specialist who monitors my liver.

I saw him on a Wednesday (my work day) and he put me straight into hospital for tests. So home to pack and to check the diary for upcoming events that would either have to be cancelled, postponed, or have Ray take care of. Not only does this impact on me, it impacts on Ray, my carer. In fact, it is worse for the carer, because they have to keep the home running – bills paid, washing and shopping done, etc- as well as visit the hospital, including finding a park, with each day adding to the load. As the stay lengthens, it's a matter of bringing more ileostomy supplies, more clean underwear, more books to read, my pump lines and PN etc.

When admitted, I asked my specialist how long the stay would likely be. He just looked at me... 'Oh', I replied, 'how long is a piece of string?' So the days drift by with a battery of tests and visits from doctors from haematology and rheumatology, giving their opinion. And of course from my liver specialist and my HPN team, trying to decide what is causing this problem. A decision was made to take me off PN for a few days (6, in fact) and replace with just saline, which means that my jeans are getting looser. Now I've just recommenced PN, but not the full amount yet, and a decision has to be made as to whether to change the formula, and in what way – a highly complex decision.

Meanwhile, I have to keep my mind on what day it is, so that I can make my own decisions:

- Ring school where I work to inform them that I won't make it to the Year 6 farewell dinner.
- Ring a company which was sending a representative to interview me for my medical supply company's survey of patients, postponing the interview until the following week.
- Ring my hairdresser, cancelling my appointment for a haircut, which means I won't get another appointment until at least after New Year's Day.
- Ring church friends, cancelling our last Bible study evening for the year.
- Ring school, letting them know that I won't make it for my last day before retirement, which is also the last day of school- still in hospital.
- Ring school, informing them that I have a pass to go out at night to the staff night out, but unsure if I'll feel up to it.
- Ring interview company again, informing them that I'm still in hospital and that we'll either need to hold the interview in hospital or cancel it.
- Ring Ray reminding him to pick up my ileostomy supplies for the month.

Luckily, in my case, I feel well enough to do all this. As a result of changes to my PN formula over the next several weeks, or simply because of damage to the liver, I feel very tired all the time and achieve very little during the day. Again, Ray has to step in to take up the slack. I've been very lucky for the past nine or so years, because I've always had lots of energy to get things done, so now I have adjust my own expectations of me.

Hopefully, things will settle back to 'normal' soon, until the next unexpected current takes me elsewhere.



*Gillian in hospital, flying the PNDU colours!*

---

## Upcoming PNDU Activities

- February – Management Committee members to visit Francis Maurice Charity Cards preview to choose this year's PNDU Christmas card designs
- February – 13<sup>th</sup>. Another Sydney PNDU gathering to meet with HPNer Laurie and his wife, Shirley, visiting from Canada. Laurie is a regular Dripline reader. Any HPNers and carers interested in joining us, email us at [contactpndu@gmail.com](mailto:contactpndu@gmail.com) for details.
- April – 29<sup>th</sup>-30<sup>th</sup>. AVAS (Australian Vascular Access Society) inaugural Annual Scientific Meeting in Brisbane. Karen to attend and speak on behalf of PNDU.

---

## Thank You

We wish to thank the following for their generous donations which totalled \$2570:

L Peek, NSW

K Winterbourn, NSW

G Hardy, NZ

Fresenius Kabi Australia Pty Ltd



---

## PNDU Membership for Aussie and Kiwi HPNers and carers:

We welcome all Aussie and Kiwi HPNers and carers to become PNDU members. If you are interested in joining PNDU, please email us at [contactpndu@gmail.com](mailto:contactpndu@gmail.com), telling us about yourself.

**Benefits:** Through membership you are invited to join one or both of our private forums: our Google Groups email forum is where conversation relevant to living 'down under' with HPN happens; and our closed Facebook group is more of a noticeboard where members can easily keep up-to-date with PNDU activities. You also have access to all pages of our website, and are on our mailing list to receive Dripline and notifications of other important occasions.

**No computer?** For those who prefer communication the 'good old-fashioned way' – by letter or card – PNDU offers correspondence with one of our members. If you are an Aussie or Kiwi HPNer or carer and are interested (or as a clinician, you have an HPN patient whom you think would benefit from letter/card correspondence), please contact us at [contactpndu@gmail.com](mailto:contactpndu@gmail.com) or PNDU, 128 Rainbow Street, Randwick NSW 2031, Australia to find out more.



---

## For HPN clinicians, overseas HPNers, carers and those just interested:

We also welcome others to join PNDU as Associate Members, giving you access to all pages of our website as well as receiving Dripline and notifications of other important occasions. To join, please sign up on our website [www.pndu.org](http://www.pndu.org)

---

## Donations

If you would like to support the work of PNDU, we would welcome your donation, no matter how big or small. Now that incorporation has been achieved(!), PNDU has its own account!

When making direct deposits, please provide your name as a reference. If you require an acknowledgement/receipt of your donation, please email us at [contactpndu@gmail.com](mailto:contactpndu@gmail.com).

### AUSTRALIA:

**Direct deposit** (Australian dollars only) to PNDU Inc.'s bank account:

Bank: Westpac  
Account name: PNDU Inc.  
BSB: 032056  
A/c No: 482738

### NEW ZEALAND:

For our Kiwi members, our sister charity IPANEMA (Charities Commission Registration CC21178) kindly continues to receive donations on our behalf:

**Online donations:** PayPal via our website

[www.pndu.org](http://www.pndu.org)

Or **direct deposit** (New Zealand dollars only):

Bank: ANZ  
Account name: IPANEMA  
A/c No: 0602730308799-00  
Payment Ref: IPANEMA "PNDU"

---

## Management Committee members

**President** – Karen  
**Vice-President/Editor** – Gillian  
**Secretary/Public Officer** – Miranda  
**Treasurer** – Chris  
**Assistant Treasurer** – Gil

## Contact us

Parenteral Nutrition Down Under Inc. ABN 49742201085

If you have an experience with Parenteral Nutrition that you would like to share, or if you have questions please email these to [contactpndu@gmail.com](mailto:contactpndu@gmail.com)

PNDU Inc.'s privacy policy is available on our website [www.pndu.org](http://www.pndu.org)

**DISCLAIMER:** PNDU has made every reasonable effort to ensure that the content of this newsletter is accurate, but accepts no responsibility for any errors or omissions. The views expressed are not necessarily those of PNDU and no reference to any product or service is intended as a recommendation or endorsement. You should always seek advice from your own team of healthcare professionals in relation to your specific needs/treatment.

Designer: Sal