DRIPLINE

PNDU

Parenteral Nutrition Down Under

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2020

The November to January issue normally celebrates a happy time of year – Christmas, New Year's and summer. However, along with the happy events, this issue also remembers two of PNDU's members who sadly lost their battle for life and we read tributes from a loving sister and a close friend. One of our members, living close to some of the relentless fires that are raging around our country, decided to evacuate and she writes, giving us a glimpse into the tense situation being experienced by so many of our population. On a happier note, two of our members have won prestigious awards; and there is also a member's story; we read about a Starlight Foundation wish enjoyed by an HPNer family; Kelly shares her romantic wedding vows renewal organised by her husband; we learn the story behind PNDU's first Published Paper, with a link to it in a medical journal; we read of the joy our HPNer's pets give them; and Alexander, a young teen member, shares his school assignment based on PN bag covers, with us, as well as catching up on PNDU events and more. I hope you enjoy all aspects of HPN shared with you.

Gillian
Dripline Editor

CONTENT

Stop Press!

One of PNDU's members, Julia Rollings, has been become ACT's Local Hero in the Australia Day Awards. She received this for her work over two decades as a foster carer, including caring for infants who have medical problems, such as withdrawing from drugs, or suffering affects of trauma. She is currently caring for an HPN dependent infant, which is how she came to be a valued member of PNDU. She has written her story in a book 'Love Our Way'; or follow the link to see Julia on The Project. **https://10daily.com.au/shows/theproject/exclusive/v200123iecqz/the-local-hero-whos-been-a-parent-to-over-50-kids-20200123**

An incredible competition win; an incredible NYE!

Words by Karen

As a result of an exciting competition win, courtesy of my electricity company – Red Energy, Mum and I saw the arrival of 2020 watching the magnificent Sydney fireworks in style from Taronga Zoo. The prize entitled us to 2 Gold Reserve tickets (bench seats in the bird show amphitheatre) plus a food hamper. Total value $700! I had been so hoping to see Sydney NYE fireworks one last time before a planned move to Newcastle this year, but living with SBS-IF, HPN and a tight budget, the logistics seriously did my head in. So, when I saw the competition, I asked God 'pretty please' ! The win was a dream-come-true (I was nearly in tears when I received the phone call in Coles!).

While there was understandable controversy and safety concerns over the Sydney Harbour fireworks proceeding this year (in light of the weather conditions and the ongoing bushfire disaster), we simply felt incredibly blessed and overawed by the experience. The smoke haze lifted by the time the fireworks began and we had an awesome view of what was a spectacular fireworks display. Words can't adequately describe just how spectacular.

An amazing way to welcome 2020. And so encouraging and appropriate that the event was combined with a bushfire appeal.

Smoky Sydney from Taronga Zoo   With our hamper. PN pump, backpack and trolley behind me.

HPN and Bushfires 2019/2020

Words by Renee

Hazy smoke, grey skies and sticky dust was the new 'normal'. I live in Jervis Bay on the South Coast of NSW. The Currowan fire started in remote bushland to the South West of the Shoalhaven Local Government Area on 23rd November. Nobody realized how serious this fire would become as it made its way, out of control, up the South Coast before merging with the Tianjara fire to our west, before crossing the Shoalhaven River at Nowra and moving towards Kangaroo Valley and the Southern Highlands. The Comberton fire started to the north of Jervis Bay around 18th December. We were effectively surrounded.

We began to fully understand the seriousness of these fires on 21st December, when the pall of the Currowan fire turned day into night. This photo was taken from our front verandah at 4.15pm that day:

Photo taken 4:15pm

Thick ash and burnt leaves, whipped up by angry winds, landed on our beaches and gardens. Ember attacks were always a possibility, but we did not feel directly threatened (yet!)

On New Year's Eve, the same scenario played out. The sky grew dark, the wind roared, branches crashed to the ground and an eerie silence descended. There was absolutely no birdsong. The streets, beaches and restaurants were deserted at a normally buzzing and happy time. I met with a group of friends nearby as we meditated and prayed for the safety of all. The cost to communities further south soon became apparent. On New Year's Day the deathly hush remained but the streets were lined with the caravans and cars, loaded with animals, of people who were forced from our south by the fires. Roads were closed but opened again later on New Year's Day.

On Thursday 2nd January, the heroic Rural Fire Service issued a Catastrophic Fire Warning for Saturday. We were told to enact our bushfire plan (we knew where to go, what to take with us, where the evacuation centres were). Everyone was discussing whether to evacuate or stay and defend. We still considered staying as we do not live directly in bush, our home is clear of debris and we felt we would be okay. I examined options for emergency electricity supply.

On Thursday afternoon the local area Emergency Controller gave a community briefing. After listening to him, it became clear that we had to evacuate. Tourists were given a compulsory evacuation order. We were told that unless we could actively fight the fire we should leave. Given the particular needs I have on Home Parenteral Nutrition for electricity, and the potential for lengthy road closures, we knew it was time to go. More than that, I felt it would be irresponsible to stay: How could I call on emergency services at such a dire time when I can in fact anticipate my needs and plan for them? Calls from my HPN nurse only confirmed this decision. I rang Baxter and they could not have been more helpful – asking me to keep in touch, they said they would deliver supplies to me wherever I was.

We packed carefully – all the HPN bags we had at that time, two boxes of long life PN, a box of plasmalyte, taurolock syringes, two weeks' supply of ancillaries, two pumps and backpack as well as essential documents and everything anyone who was evacuating would need – plus our dog Alex and all his necessities. We wet the garden, moved all outdoor furniture and anything flammable inside. Our garden was already free of dead leaves. We sealed the home, closed the blinds and left.

We were fortunate – a friend in Kiama offered us her home (with a spare fridge). And I have numerous options in Sydney. Others had nowhere to go. From early Saturday morning the access road to Jervis Bay was closed. Electricity went off – but only for about four hours. However, our electricity company had also warned us to evacuate. There were many evacuees in Kiama and an air of tension was around. But we were very fortunate to be in a safe and comfortable place. Too many lost their homes, businesses and were out of options. Jervis Bay was spared: A little peninsula surrounded by burnt out land.

We stayed in Kiama until Monday 6th – when we were confident of a stable electricity supply and that the relevant roads would remain open. Baxter and the hospital both rang to check on me and work out where to deliver my supplies. On arriving home, we were greeted by layers of sticky, dark ash that had to be cleaned before we entered our home so we did not track the dirt inside.

Piles of ash, burnt bark and leaves are everywhere, leaving dark gashes on our normally pristine beaches. It is a ghost town. National parks are burnt or closed. All holiday makers have left, businesses are quiet and many are losing their jobs as there is no work.

We are so blessed. I have a friend who was evacuated on 31st December in Bermagui – with a host of animals including two horses - who is still not home (today is 10th January). You don't need me to tell you about the scale of the loss. I never knew I would have to learn so much about the location and spread of fires. The destruction is devastating, so much rebuilding and healing will be needed. I am grateful to be safe and only wish to support those in my community who have lost so much and are deeply traumatized.

Editor's Note: ***Elise passed away on 19th August, 2019, aged 43. This is a tribute written by her friend, Monica.***

A Tribute to Elise

By her friend, Monica

Elise was a very gifted person. Her drawings were amazing, her photography exceptional. She had an eye for detail. She loved people and would always engage in a conversation with people she had just met.
In Elise's younger years she trained as an elite gymnast at the Australian institute of sport. And loved being at a peak fitness level.
But her childhood was quite abusive, and through a traumatic event at the age of 13, she developed an eating disorder.
This led to eventually, later in life, after she had got married and had a family, that she was constantly fighting the eating disorder and went into depression.
Her marriage broke down, and she couldn't care for her family.
She reached out for help, but found herself in another abusive relationship with the therapist.
During this time, she was experiencing numerous issues with her bowel, which was affected by medications and the past experiences as a child.
She had her large bowel removed. She was also diagnosed with Gastroparesis, Fibromyalgia, amongst many other associated issues.
She constantly suffered bowel obstruction and twisting of the bowel. And was unable to hold any food down.

It was around this time that Elise entered my life 11 years ago. I saw a person in great distress with no support. But I also saw a person with courage and tenacity who just kept getting back up again every time she was knocked down. I knew she needed a friend who would walk with her. I was a counsellor at the time, but realised that in that capacity I would be limited to the help I could give her. So, I told her I wouldn't be her counsellor, but I would be her friend.

We began a journey together which was one of the hardest, but the most fruitful experience I have ever lived.
It was such a privilege to walk this journey, I have never met anyone with such courage. Or anyone who experienced such pain without complaining.
She would say "If I wait until I feel well, I will never do anything." She was in hospital so many times that she knew most medical procedures and terms by heart.
Many of the skills she could do better than the nurses. Elise would encourage nurses who were nervous.
She was also a very quick learner. When it came to learning how to hook up to the PN,
she went over it and over it and mastered it in about 10 days. Two reasons; one, she didn't want to be in hospital any longer than necessary; two, she trusted herself to be absolutely sterile.
She was meticulous in her sterile procedures. And never got an infection. She trained nurses on the importance of being completely sterile when dealing with the PN.
Elise had a very good heart; she would help anyone, even if she was not well. She was very generous and gave where she could see a genuine need.
She was very protective of those she cared about. Her faith in God was strong and she trusted him with her life.
Many times she could have died, But God raised her up again.
Elise was passionate in the way she lived, the way she loved, and in what she believed. She loved truth and hated lies.
Elise impacted all who met her, be it child or adult. That was evident at her funeral. There were doctors, nurses and other professionals, amongst the 80 people who attended.
Over and over people expressed to me how much her life had impacted them. For me I felt like someone special had just left the earth.

I'm Including a couple of my favourite pictures of Elise.

Editor's Note: *James passed away on 9 November 2019, aged 28 years. He had a multi-organ small-bowel transplant in May 2016. This tribute is by Clara, James' sister.*

A Tribute to James

By his sister, Clara

James Gray was the most amazing son and brother anyone could ask for and I was lucky enough to call him my brother. He was on HPN for 20+ years. Even though his kidneys failed after transplant and his body struggled with dialysis, he never complained and was happy to be alive. Even though he had a life far from what is described as normal, he tried to live his life to the fullest.

After the transplant he could eat, which I never got used to, but I was so happy he could. When he first tried hospital porridge, he said it was pretty good. But as time went on, he was very picky in things he liked. We were all at his and mum's house for her birthday and we were getting KFC for lunch, but he exclaimed "I don't eat KFC, I eat healthy". (But we were still getting it because it was what mum wanted.) I have never laughed so hard in my life when we gave him a piece of chicken while he was on dialysis and we went to get the plate, and it had been eaten to the bone – there wasn't a single piece of chicken on it. It became a joke with us and was constantly brought up.

Then there were the times when he was well enough and we would meet up in the city, which he loved to do. But he couldn't have Hungry Jacks or McDonald's like the rest of us because he didn't like it as once again, he only ate healthy.

I remember he had this coupon for an Asian restaurant, and he was determined to find it. I think we walked for 45 minutes to find it. When we found it, he sat in the restaurant by himself and enjoyed his lunch, even though he was pretty unwell when he got back home from all the walking.

He had the funniest sense of humour and he was competitive, but most of all he was so caring. No matter what James was going through, he was always there to check on you. Whether it was an assessment or just an appointment, he always checked in to see how it went for you and to offer words of wisdom, which you couldn't help but laugh at, even if some of it was pretty good advice.

Even though he never had much in his bank account, if he had ten dollars and you needed to borrow it, he would always be there to help you. But he had to add a funny side to it because that was James. He created the bank of James, and it always had a 0.02% interest rate. On the day the loan was due, I would wake up to a text saying "This is the bank of James. Your loan of 10 dollars with a 0.02 interest is due today". And you would get the text every few hours till you paid the loan. Then you would get a text saying "thanks for banking with the bank of James".

Yes, he was my brother but he was also my 'night friend'. He was on a lot of steroids, so he would get very chatty at night, and when mum was in bed, he would call me and sometimes talk for hours at a time. I would get a message saying 'night friend?'. Then he would call. If I didn't reply, he would say 'night friend sad?'.

Then there were the Xbox challenges we had every month. In the 12 months we were competing, I beat him once. Even with all his hospital stays! I still think he had to have cheated to win all those times. When I was beating him, he would get pretty cranky, which made me much more competitive.

There are so many more funny things I could share about our relationship, but we can't forget how he was with our little brother. When Noah arrived, James took on the role of the 'man of the house' and took it seriously. They were the 'troublesome two' and were the best of friends most of the time. While they fought like brothers fought, it never lasted long. They had their first sleepover together in the lounge room, and they had to have a late night snack together. They always wanted to play Xbox and they fought over who got it, so James found a cheap Xbox for Noah to use. In the weeks before everything went wrong, James completed a parenting course so he could be a better brother to Noah, which I will always look up to.

Even though everything went wrong in those final weeks of his life, James wasn't ready to go and was determined to keep fighting, but it became too much for him.

James will always keep a huge place in my heart and our family's lives, but we will keep going and keep making him proud because that's what he would want everyone to do – keep fighting no matter what challenges come our way, live life to the fullest and enjoy the little things, like he did.

James as a toddler

James (with the giggles) with sister Clara and her partner Matt,and little brother Noah

James with twin brother and little brother Noah

A Romantic Gesture

Words by Kelly

So! My husband surprised me on Sunday with the renewal of our wedding vows. He has apparently been planning it all year long! All I knew was that he had arranged a family photo shoot for our 15th Wedding Anniversary for the kids and us, at the same place we got married.

I spent ages trying to decide if I pull out my line, or leave it in for the family photos. Both my kids said to leave it in, as it's part of who I am (and they both wear insulin pumps and CGM's, along with hubby too -

something I've always taught them is nothing to be ashamed of or hidden). Hubby and I talked about it and he agreed with the kids. Also, the dressing has caused a white patch under it where no sun reaches, and the dressing would make my skin bright red at the very least once taken off, and my port is so close to the surface and it's looked very dark and bruised lately anyway. I figured I'd just let my hair hang over it.

It all went out the window when I was in shock with the surprise of my life... with all our friends and family there, including our celebrant from our wedding! I tried to remember to cover it up, but a couple of the sneak peek pics from the photographer have the port in view. Surprisingly, I now find I don't really care... it is who I see in the mirror everyday anyway and I need to learn to accept it is part of me now. It was amazing to see how much has changed in the past 15 years... some loved ones who are no longer with us, new loved ones, new friends, a whole new generation of children, our family and friends all growing older along with us... how lucky we are to be alive and enjoying this beautiful life thanks to medical advancements and of course HPN. Anyway, best day ever and so very much in love with my husband Daryl.

I've attached a pic of my little family, and a pic of hubby and I when I was surprised by all our family and friends (port in view).

Editor's Note:

Unfortunately, as is quite typical for people on HPN, life changed quickly for Kelly shortly after she shared her story on PNDU's chat forum. HPN provides HPNers with nutrition, but is not treatment for the underlying condition causing Intestinal Failure. Kelly has kindly agreed to sharing the whole updated story with Dripline readers, and I'm sure we all hope that life is again upbeat for her and her family soon.
Kelly writes,

"I lost that port only a week or so later from infection... I'm still in hospital... My immune system is genetically suppressed, so it's simply not keeping up at all. I also have...lots of new scars to add to my body that now resembles a patched up old quilt. I'm definitely not feeling upbeat and positive at the moment. The feeling of acceptance of my conditions was very brief and was even more swiftly stolen away again. To finally come so far and now be back to square one is heartbreaking and discouraging. I'm also sure I'll move out of this funk soon enough; it's just been a very challenging stay this time around.

But what is still relevant is the love I have for my husband, children and family... they really are my entire world and I am incredibly blessed that they also love me back despite the medical issues I put them through."

Teen Talk - Alexander's Assignment ... On PN Bags!

Words by Alexander

Editor's Note: ***What a clever idea of Alexander's to think of ways to make looking at our PN bags more interesting! He got an 'A' for his assignment. I have chosen 1 written section, as well as all of his designs. What about it, Baxter, Biomed and Fresenius Kabi??***

My name is Alexander and I am 13 years old. I had a school assignment to do about 'Brilliant Bodies', and decided to relate it to my health and my HPN. I decided to do my assignment on trying to make the HPN bags look better for different age groups.

When I first went on HPN, when I was in hospital and was eight years old, it was very scary to see this grey bag come in every day and get hooked up to me. I think it would have been made a little easier if the bag was more brightly coloured. I think the plain old grey bags are boring. Also, I just think it would be a lot easier and nicer for anyone on HPN to not have to look at those horrible grey bags that look so much like you should be in a hospital and that you're very sick.

This is what [part of] my assignment looked like when I was finished.

PN Bag 2 (Teenagers)
What techniques will you use to make the packaging more appealing to your target audience?

I used repetition because I used a similar theme of popular video games. I thought it would make the teenagers in this age group feel better about having to be in hospital and have PN.

What is the name and slogan you want to use?

Heroes Medicine

What colours, images and logo will you use?

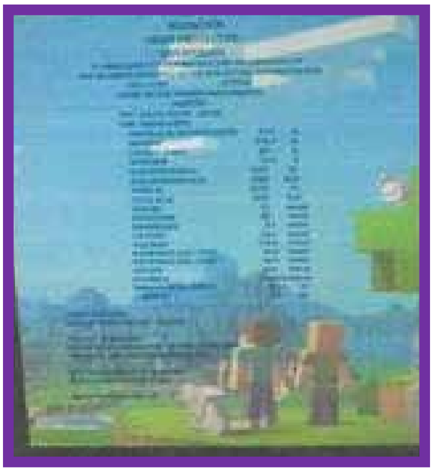
I used video games because I knew they would appeal to teenagers needing HPN. I think, as I have said before, it is a very frightening experience to need to have PN and this would be cool to see on the bag a nurse brought in every night to hook you up. I chose the game Fortnite, Mario and Minecraft because they are the most popular, and when a child is sitting around hospital and starts to feel better, this is what they do - play video games.

What nutritional claim/s will your PN bag make?

The nutritional information for PN is on the front of the bag and this is not made up by me. There are many different doctors who use PN for different reasons and they decide what nutritional things are put into it. I just know it gives you everything nutritionally you would get if you were eating. This is why I'm gaining weight.

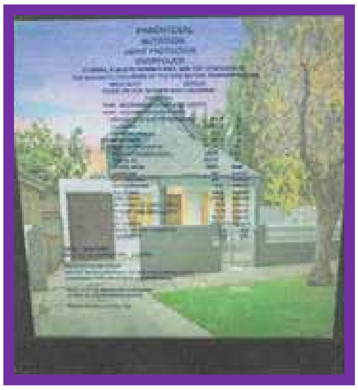
Justify the above choices and giving at least one reason why each of the above design elements (underlined above) will help sell your product to your chosen target audience.

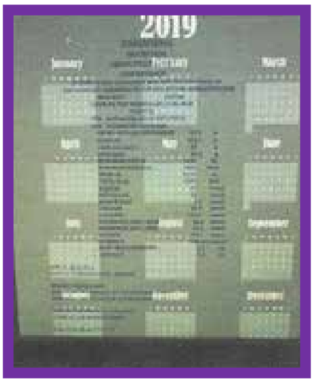
I think because they are video game bags and teenagers can relate to that. I called it heroes medicine because a lot of teenagers look up to these characters in these games as some sort of hero. I also believe that anyone that has to go through something as bad as needing HPN is a hero to me.

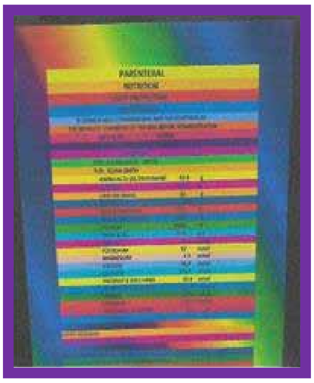


PUTNEY WUTEY WUT Bag

This Putney Wutey Wut PN bag would be made for me because my cat is my world. I love her very much and think it would be extremely amazing to be able to see my cat on my PN bag while I was in hospital, especially when I'm feeling sad. It would be pretty cool to have it at home as well. I think what I'm going to do is maybe ask the hospital if there is any way we can either get the bags made better or get covers that go over the bags so they don't look so bad.







My Story

Words by Alida

I have a condition that is undiagnosed; the closest we can get to a name is Intestinal Failure (IF). Basically, this means that my whole digestive system does not work. I do not absorb anything, even when I eat, and I cannot keep the food down, as I either vomit or end up with a bowel blockage. It started about 10 years ago with various symptoms of incontinence, vomiting, constant nausea and stomach bloating that left me looking pregnant, for which I was given some very unagreeable looks of disgust when out in the public. As, at the time, I was already in my late forties, this left me feeling very uncomfortable and self-conscious.

After several years of different tests, I had my first bowel operation in 2015. I was fashioned with an ileostomy and bag but unfortunately my bowel decided to use the stoma as an anchor to twist itself around and only caused more blockages. After a few more operations trying to correct this complication, the doctors decided to try a colostomy bag instead. We were starting to run out of options by this time and I was still vomiting a lot, losing weight and getting sicker by the day.

My doctors consulted other doctors all over the country via video links to try and find answers, but no one seemed to be able to explain any of it. They looked into doing a bowel transplant, but unfortunately my nerves would not cope with this surgery and would reject the transplant so that was also not an option for me. After ruling out options we went ahead and did the reversal of the ileostomy and fashioned a colostomy instead. Unfortunately, to start with, I still got a few more blockages and by this time I had lost a huge 30 kilos of weight and was still losing more by the day.

In the meantime, the doctors had brought in the dieticians and we tried several different diets such as high protein high energy, soft food, clear fluids, etc. When this didn't work, they decided to try feeds through my nasogastric tube into my stomach, but I was still sick. Next, they tried to bypass the stomach and go direct into the intestine but alas that did not work either. By this time, I now weighed only 34kg and had no energy and was very weak. It was at this time the doctors and dieticians decided to feed me via central line in desperation to get some nutrition into me.

I had my first PICC line inserted and the feed called TPN (Total Parental Nutrition) was started. I had 1 more emergency surgery for another blockage and was told that whilst I would survive the surgery, it was unlikely I would survive recovery due to its size and how weak I was, however I had other ideas! After a short stay in ICU, I did pull through and continued with my TPN feeds. I spent 9 months of that year as an inpatient in the hospital, and many more months in the following 2 years. The hospital had become like my home and my doctors, nurses and dieticians became extended family. They were there for me when my immediate family had to work or fulfil other commitments. I feel they all went above and beyond to ensure I had everything I needed 24/7; even on the days when I just needed to cry, they were there to just listen and comfort.

Eventually I did get to go home to my normal life, but I had a lot of work ahead of me. My husband, daughter and I had to learn about my PICC lines and HPN (Home Parenteral Nutrition) feeds. We had to learn how to administer medication and how to connect me to my PN bags and how to change my dressings using aseptic techniques. Over the years, I have had a lot of infections in and around my lines which gave me high fevers and can become extremely painful as they grow which causes me sometimes to be quite sick, but also means I take a lot of antibiotics. I am now used to recognising the signs of these infections in the very early stages, which makes a big difference as to how severe they become and the discomfort they end up causing. There were so many things we had to adjust to when we first got home. Another adjustment was learning to deal with the likes of colostomy bags bursting or leaking sometimes all through the bed or sometimes just while sitting on the couch in my clothes. I felt like I smelt disgusting all the time and was very concerned other people could smell me when I had to go out. I was embarrassed that my family were subjected to this and had to clean this mess up all the time, as I was still too weak to do much.

Another new routine was ensuring husband or daughter were available to put my PN on at the right time of night and there again to take it off in the mornings. My husband and I both had to get used to the bright light from the pump and being woken constantly through the night with my pump beeping to tell me there was air in the line. I sleep with lines across my body and I was unable to fit through the door of my en-suite with my IV pole, making toileting during the night difficult. I awoke one night to find myself and my bedding covered in blood. It was ok, it looked worse than it was, but my bung had become detached during the night and so my blood was draining back; pretty scary when this happens for the first time. These are just some of things you learn about once you go home through trial and error, but in the end it's not as scary as it seemed at first.

This disease has had a huge effect on both myself and my family, although I think it has been harder on my family more than myself because I live with this disease and all that comes with it every day, I have gotten used to living this way. For my family though, they always have it in the back of their minds that they thought they were going to lose me and that this could still happen at any time. I see the worry and anguish in their precious faces every day as they wait to see how I am feeling each morning when I get out of bed. All that said though, we deal with it together and we all carry on as normal as possible with a positive and happy attitude appreciating the time we have together and understanding this problem might not again happen for many years to come.

Now today, thanks to HPN, I have regained all my weight and I'm reasonably healthy again. My doctor has found me a medication that dramatically increased my energy levels and I now live a fairly normal life doing almost anything I want to attempt to do. I have travelled overseas for up to a month at a time on holiday, been on a cruise and we go camping regularly. Although it all takes a bit more planning and a lot more luggage, I am living mostly the life I am used to living and enjoying every minute of it. I love watching my family grow and communicate and support each other, something most of us either take for granted or forget to do.

The services and support I have received from all the staff at the hospital has been second to none and I could not have asked for more. Sure, I am at home looking after myself most of the time now, but I still have their ongoing support and could not feel this happy and secure in this, my now normal life, without any of them. I would also like to point out that they are there for my family members as much as for myself. If you are going through something like me, please be assured whilst it was very difficult at the time, if you stay positive, I can assure you your life will come back to some normality soon. It took a few years, and it does take time and hard work, but I am living proof it can happen for you too, so please just try to persevere - it's worth it.

My daily regime now includes 3 injections of medication, which I administer through a sub cut butterfly port, my HPN that goes on at 6pm till 6am, at which time I feel free again, and some other basic tablets I take in the hope they do something. When I get up in the morning, I am usually feeling sick and nauseous, so I just have to just sit for an hour to see if it subsides before I start my day. I do small amounts of housework such as dishes, wiping benches and washing which someone else will hang out for me and then I'll fold once it is dry, and ironing in small amounts. Sometimes I'll do a little gardening or watering which I find very relaxing. Every week I do my groceries with help and I cook dinner most nights for my family. I usually start to run out of energy by around lunchtime every day at which time I sit down, put my feet up and watch a movie or a book until dinner time. So, as you can see, I have a fairly normal life again.

A very sick, and thin, Alida

Alida today, with the benefits of HPN

Logan's Starlight Foundation Wish

Words by Chris

The Starlight Children's Foundation has a mission: 'to brighten the lives of seriously ill children and their families'. One way in which Starlight does this is through the wish granting program.

A Starlight Wish is a once-in-a-lifetime experience for a seriously ill child and their family.

An incredible gift of hope during the toughest of times, Starlight Wishes help sick kids and their families dream big and leave the pain of treatment behind.

From the moment a child is told their Starlight Wish is to be granted, the excitement begins. Dreaming, planning and talking about the wish is a great distraction from treatment and surgery. It's the light at the end of the tunnel that lifts spirits and brings families together.'

When Logan was asked by the Starlight Foundation, if you could wish for something very special, what would you wish for, Logan, aged 6 years replied, "I want to sleep with the animals! I had a dream about sleeping with lions, tigers, monkeys and giraffes," Logan told everyone with great excitement and detail, "I wish I could really sleep with the animals."

Making a little boy's dream come true

The Starlight Foundation set about contacting several Australian Zoos who offer different packages and experiences for people to stay overnight. The Taronga Western Plains Zoo in Dubbo NSW, seemed just as excited as Logan was, to make a little boy's dream come true and offered a 3-day, 2-night stay at the zoo. With the best available travel dates confirmed for the first weekend of the October school holidays, the travel arrangements began. This proved to be an exercise in "Logistics" (Noun: - the detailed organisation and implementation of a complex operation). How to get 4 adults and 3 children, 2 of whom, Jordan and Logan are HPNers and require a truck load of medical supplies and equipment, from Newcastle to Dubbo. Direct flights, with the amount of luggage required, were not possible and the alternative flight options via Brisbane or Melbourne were simply out of the question. A 5-day road trip seemed to be the only solution. Working closely with the wonderful team at the Starlight Foundation and Dubbo Zoo, we soon had everything organised and eagerly awaited this great adventure.

All of our luggage, medical supplies and equipment were carefully packed into 2 cars, along with 3 very excited children. The drive out west to Dubbo was enjoyable and the weather for the trip was very favourable. Arriving at Quest apartments in Dubbo, we were met by very friendly and helpful staff, check-in was a breeze, and the boys' Parenteral Nutrition was unpacked and refrigerated as we settled in for a very comfortable overnight stay.

The next morning as we arrived at the Zoo, the excitement level of all 3 boys, Dylan, Jordan and Logan, went off the scale. Trying to contain their excitement was near impossible.

Zoo staff had us booked in a flash and the early planning by the Starlight Foundation ensured the boys' Parenteral Nutrition, packed safely with ice packs in a large esky, went straight into the catering cool room and we were free to explore the zoo for day one.

2pm on Day 1 saw us all check-in to the Zoofari lodge. Again, we were met by the most amazing and helpful staff. We were soon settled in to our tent style accommodation, 5 star all the way, Glamping not camping. Kicking back on our balcony, enjoying a complimentary cheese platter, with the zoo animals right on our doorstep. Giraffes, zebras, elands, blackbuck, rhinos and an ostrich were all fed by zoo keepers in front of us.

The boys, and especially Logan, were excited beyond belief. We had binoculars supplied, but they weren't needed, with all the animals less than 10 metres from us.

4pm on Day 1, a behind-the-scenes tour had been arranged for us as part of the Zoofari experience, plus a guided tour around the zoo for close encounters, talks and photo opportunities with Black Rhino, elephants, hippos and lions, before returning to the Zoofari lodge for wine tasting and canapés, prior to an African inspired banquet, enjoyed by everyone - Top Shelf!

Jordan and Logan were connected to their Parenteral Nutrition, before sitting out on the balcony to say goodnight to the animals, then, exhausted, it was time for bed. Yes, a truly memorable time sleeping with the animals.

Logan enjoying the animals

Day 2 at the zoo began early with everyone up before 6am and ready for another guided tour behind the scenes, with a chance to hand feed a giraffe, guided tours of the Ring-Tailed Lima, Spider monkeys, cheetahs and White Rhino, before a very special encounter with an elephant. Jordan and Logan were entertained the entire time by our zoo keeper guide and made to feel very special.

We returned to the Zoofari lodge for a buffet breakfast, before venturing out to explore the zoo again. The staff at Zoofari were wonderful, taking care of the Parenteral Nutrition in their cool room and going out of their way to make sure our second night's accommodation at the Savannah Cabins was arranged and ready for us to move into at any time, also ensuring we had contact numbers for zoo staff, should the boys encounter any problems during the day.

Electric carts were organised for us to explore the zoo with ease and we ventured off to join the Savannah guided tour. Again, our zoo guide was amazing, explaining the different animals to the boys, helping them on and off the tour vehicle and posing for photos. We continued exploring the zoo via electric carts and soon received a phone call from Ben at Zoofari lodge, checking on our wellbeing and with a very big surprise - a special guided tour of the lion enclosure, compliments of the zoo. Talk about going that extra yard for Logan's wish! We can't thank Taronga Western Plains Zoo staff enough for their help and support. Late in the afternoon, exhausted, we all returned to the Savannah cabins for a little R&R, before venturing into South Dubbo Tavern for dinner. The tavern has one of the biggest children's playgrounds I have ever seen; the adults may have been tired, but the kids seemed like they had fresh batteries as they played the entire time we were at the tavern.

Savannah cabins were very comfortable and spacious, and provided a view of the animals across the open savannah exhibit. Very tired, we all enjoyed a good night's sleep.

Day 3 at the zoo saw us return for one last lap. Logan had to make sure we hadn't missed anything, and wanted to stop at the gift shop for souvenirs.

The time soon came to say good bye and a very big thank you to our friendly zoo hosts for helping to make a little boy's dream come true.

Returning to Quest apartments in Dubbo, we were again greeted by friendly staff and soon settled in for some well-earned R&R. While the boys played games in the air-conditioned apartment, a complimentary bottle of red was enjoyed on the balcony, topping things off for some rather worn out adults.

The trip home was an enjoyable drive, stopping at the town of Merriwa for lunch. Although tired, the trip seemed to pass quickly.

Logan was beaming with joy when he arrived home and passed on the most heartfelt thank you to everyone who made his wish come true.

A very big thank you to everyone at the Starlight Foundation for granting Logan's wish "To sleep with the animals". It was a once in a lifetime experience that will be remembered for many years, not only by Logan, but by our entire family, who had the most amazing time. A dream come true!

AuSPEN Annual Scientific Meeting – 2019 Adelaide

Words by Chris

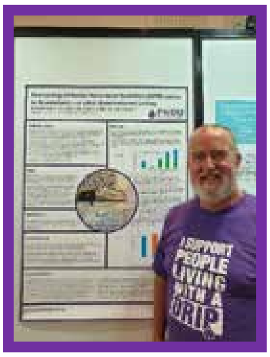
PNDU would like to thank AuSPEN for the opportunity to once again exhibit free of charge, at the AuSPEN ASM held at the National Wine Centre in Adelaide on November 25th – 26th 2019. This annual clinical conference provides PNDU with the wonderful opportunity to engage with HPN clinicians and industry friends from across Australia and New Zealand. A big shout out to the AuSPEN Conference organisers and Corporate Communique staff members Ben and Nick, who were simply amazing, ensuring everything went smoothly for PNDU. We were provided with an exhibition booth, complete with PNDU signage, in an excellent location. Fay and I ran the PNDU exhibition and were able to engage and speak with a great number of clinicians. Fay and I handed out a lot of PNDU resources and encouraged clinicians to let their HPNers know all about PNDU and the work we do as a patient support group. We met with old friends of PNDU and made new ones too, as well as catching up with our wonderful industry friends.

The PNDU Poster, a summary of the PNDU retraining survey, was accepted for display at the conference. I had the opportunity to discuss the poster and survey with lots of clinicians during the lunchtime breakout session on Sunday the 24th. The PNDU Poster generated a lot of interest from clinicians with follow up visits to the PNDU exhibition booth for a printed copy of the Retraining Paper.

PNDU is very happy to announce the retraining survey is now a peer reviewed and Published Paper appearing in the AVAS Vascular Access Journal Vol 5 issue 2 (2019), also featuring in the global publication IVTEAM update on New Year's Day (2020). The PNDU MC is thrilled and very grateful; AuSPEN has already included the matter of retraining in its recent HPN Quality of Care position paper. NB links to access the full paper are in the article 'PNDU's First Published Paper' later in this issue of Dripline.

Overall a very successful conference; we are extremely grateful and thank everyone involved in providing PNDU with the wonderful opportunity to be part of this annual conference.

Fay and Chris at the PNDU Booth



Chris presenting the retraining poster

Chris and Fay working the PNDU exhibition booth

Chris and Fay with Baxter Industry friends

Chris with Fresenius Kabi industry friends

AuSPEN HPN Consumer Workshop Adelaide 2019

Words by Chris

PNDU is very grateful for the opportunity to learn from professionals working in the field of Parenteral Nutrition and would like to thank AuSPEN, and workshop organisers Suzie Daniels and Margie O'Callaghan, for organising and hosting the 5th annual AuSPEN HPN Consumer Workshop, alongside the 2019 AuSPEN ASM, believed to be the only consumer workshop of its kind, hosted by a professional society, anywhere in the world.

The AuSPEN HPN Consumer Workshop allows HPNers and their family/carers to hear presentations on a range of HPN related topics, directly from clinicians and provides the opportunity to ask questions with regard to these topics.

The HPN Consumer Workshop was held on Saturday 23rd November at the Adelaide Health and Sciences Building. The event was attended by the 9 PNDU members who travelled from interstate and 9 local HPNers and carers, a very successful turnout for this event.

The workshop was opened and we were warmly welcomed by AuSPEN President Ibolya, who spoke of the wonderful ongoing association between AuSPEN and PNDU. I was able to present an update on PNDU activities and the work we do as a patient support group, before handing over to the guest speakers, who presented a range of very informative presentations. Kirsty McDowall – Oral and Enteral Supplements and Fluids to complement HPN; Dr Steve Gallucio – CVAD's Choice of Catheter, Placement and Complications; Dr Andrew Holt – Sepsis in HPN; Margie O'Callaghan – HPN Ongoing Monitoring and Management; Emma Osland – AuSPEN Update – HPN Model of Care and Health Outcomes.

The feedback from everyone who attended the workshop has been very positive and we thank the HPN clinicians for sharing their expert knowledge with us. Thank You, and we look forward to the 2020 HPN Consumer workshop.

AuSPEN HPN
CONSUMER WORKSHOP

Program

12.30pm - 4.30pm Saturday 23rd November 2019

Room 3068, Level 3,
Adelaide Health and Medical Sciences Building
Cnr North Terrace and George Street, Adelaide, SA

The AuSPEN HPN Consumer Workshop is a unique opportunity to learn more about your HPN from expert clinicians working in the field.

Chris, Ibolya, Emma

PNDU Annual Social Gathering.

Words by Chris

PNDU hosted the annual social gathering at the Minor Works Building (MWB) in Adelaide on Friday 22 November, 2019. The event was attended by 9 interstate visitors, PNDU President Chris and wife Tanya, PNDU Management Committee member Fay (HPNer) and husband Lindsay, three PNDU members who received a PNDU travel sponsorship, Justine (HPNer), Naomi (HPNer) and Kylie, Steve and their young HPNer Deklyn. We were joined by 4 locals, South Australian PNDU member Annie (HPNer), who was accompanied by her Mum, dad and sister.

The PNDU annual social gathering is a wonderful opportunity to meet other HPNers, carers and their families, the chance to exchange stories and make lasting friendships with people who share and understand our journey, living with the rare and complex condition of Intestinal Failure requiring Parenteral Nutrition.
PNDU hired the MWB in the centre of Adelaide, to ensure we could provide a venue close to transport and suitable for all weather conditions. The annual gathering proved to be an amazing event for all our attendees, conversations continued for many hours in a relaxed atmosphere. One little HPNer, Deklyn stood out in the crowd and kept everyone entertained, even adopting a Nana Tanya for the day; I had to check my bags before I left, to make sure I didn't have an additional grandchild.

I would like to personally thank everyone who was able to attend the annual gathering and make this a very special day on the PNDU calendar. I look forward to another wonderful PNDU annual gathering in 2020, details of which will be published in Dripline later this year.

Minor Works Building Adelaide

Tanya and Deklyn

PNDU annual social gathering (Annie's dad took the photo)

HPNers, L-R, Naomi, Fay, with Deklyn, Annie and Justine

Editor's Note: *Some of our members have written about how important the love of their pet is to them. Unfortunately, some hospital teams dislike their HPNer having a pet, as they are concerned that the animal might cause infection – have a discussion with your team if you are unsure.*

Annie




I recently had a perma-cath placed for plasmapheresis. My doctor is amazing and allowed one of my new puppies to come in. Best medicine!!

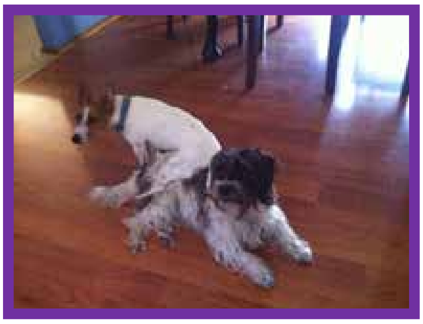
But I lost my older dog whilst I was in hospital. I'd had her since I was 5 years old. My doctor allowed me 30 minutes off treatment to go say goodbye.

I held her hand as they put her to sleep.

Sal


This Is Pip, above right and below. She is 6 and a pure Jack Russell. She would play ball all day if she could! She has what we call 'the royal bottom' as she will not sit on cold or hard floors. Instead she sits on our other dog Jazz (above, left). If Jazz isn't available, she will make her bottom hover and never touch the ground! Jazz is very tolerant.

Jazz is 13 now and a Shih Tzu and Jack Russell cross. She is obsessed with food and our fridge. She tells us when it's time to cook dinner or when it's time to give her tablets as we put it in food. Jazz comes and tells me when it's time for a rest and they both come and lie with me.

The 'Royal Bottom'

This is Jazz. She is telling me it's time for her morning tablet as I was near the fridge!

Pip somehow ends up in our bed under the bedclothes every night, even in Summer. We never know when or how, but she is always there in the morning. Jazz sleeps on the end of our bed but often snuggles up on a cold night. Yes, they are very spoiled dogs, but they bring us so much joy and love. They are great companions for me and sit in my home office and keep me company during the day when I'm working. They make excellent door bells and cat alarms.

Callum was studying for his HSC here and Pip has stolen his socks and wanted to play, but his legs made a nice warm spot to rest!

Jacqueline

We have 3 dogs: Nellie, Hugo and Questie. They love their walkies, especially if it incorporates a car ride. They are all rescue dogs but they have actually rescued us too. Without them our lives would be so much poorer. Our three all came to us with sad stories. We adopted Nellie and Hugo when they were two and then Questie when she was three.

They all get on well together, but Hugo looks after his girls with gusto. He's had three surgeries for mast cell cancers, but that's never stopped him.

Nellie lives for her ball but won't drop one unless you have a second one to throw.

Questie...well she's really a queen...everything on her terms. Loves her neck massaged and a cosy bed.

They love their walkies, their food and our attention. Our lives are fulfilled with their unconditional love.

Nellie, Hugo and Questie

Susan

This is Nylah. She's 2 years old and has a beautiful personality. She has kept me happy when I'm feeling down and stayed with me when I'm sick. Spoilt rotten though, but I don't care. I have had no issues with infections from her.

Renee

I have attached two pictures of our kelpie/border collie cross, Alex, having a wonderful time on the beach. Alex was rescued from the pound where he was on death row and we found him at a working dog rescue site. He had a rather traumatic start and was a frightened dog when we first got him ten years ago. However, we fell in love with his beautiful eyes. Now, he is accustomed to a life of love and luxury. He has three beds, one of which is on the verandah so he can survey his estate. He takes his responsibility for ensuring the security of the building and his family very seriously. He lives by the beach and enjoys two beach walks each day where he can meet his pack and sniff around to see who is new to the neighbourhood. He's beginning to age, like the rest of his family, but is doing well.

He has been a loving and loyal companion and if I need to rest or am not well, he just comes and lies next to the bed. As he has to walk it gets me up and going so it's a great start to the day to have some exercise, see the beauty of nature and say hi to a few human friends too. I think dogs do wonders for the health of humans.

Alex

Hannah

This is my French bulldog, Zoey. She is my little buddy and shadow, who never fails to make me smile, especially on the rough days. It's nice to have a wee companion that you can focus on when feeling unwell and who can keep you company during long nights whilst I'm awake, to doing silly things that make me laugh. My life has changed since having her. She's the light and joy in my life. Definitely what keeps me fighting each and every day. So thankful for this precious fur baby!

PNDU’s first published paper!

Words by Karen


VASCULAR ACCESS

Retraining of home parenteral nutrition (HPN) users in Australia and New Zealand: a consumer audit

You’ve possibly already heard the exciting news that the paper, “Retraining of Home Parenteral Users in Australia and New Zealand: a consumer audit” by Winterbourn et al, was published in the October 2019 issue of Vascular Access (DOI https://doi.org/10.33235/va.5.2.29-37). I’ve been asked to give a bit of the background story for Dripline.

PNDU believes regular retraining and updating in HPN procedures for central line care is an important but largely overlooked clinical matter for HPNers and carers, particularly for many on long term, even lifelong, HPN. As the paper mentions, no articles or studies investigating the matter could be found worldwide; only recommendation of HPN user retraining in the event of repeated line infections – not regularly as part of routine HPN care, nor any updating in protocols.

The paper was based on PNDU’s member survey of this matter conducted in late 2018, the results and analysis of which were presented as a poster at the Australian Vascular Access Society (AVAS) conference in May 2019 and at AuSPEN conference in November 2019 (see PNDU’s Surveys and Studies page for the abstract and poster). Many thanks to the various clinicians and PNDU members for their assistance and encouragement in the completion of this survey and analysis, including Sharyn Ingarfield (PNDU member), Gillian Ray-Barruel, Emily Larson, Tricia Kleidon and Nicole Gavin, as well as all the PNDU HPN members who took part in the survey. Grateful thanks also go to PNDU’s lifetime member, Prof Gil Hardy, for his legacy of member surveys as a credible and non-threatening way for PNDU to raise HPN consumer issues, including at clinical conferences.

It was while presenting the survey poster at AVAS conference last May that encouragement was received to submit the analysis for publication in a medical journal (thank you Catherine Miller!). AVAS’ very supportive journal editor at the time, Gillian Ray-Barruel, welcomed our submission. The survey analysis was then peer-reviewed by two experts, after which news was received that, with ‘minor’ requested changes, the paper would be accepted for publication in the medical journal, Vascular Access! While the term ‘minor changes’ was used, for a complete novice the requested changes were huge and took many, many hours and weeks of work to achieve. Thank you to Suzie Daniells for the invaluable feedback during this process, and thank you AVAS, Gillian and Vascular Access for your consumer-centred culture and this amazing opportunity for PNDU.

This published paper is a significant achievement for PNDU, and has already received lots of very encouraging feedback, such as “I believe it’s vital that we hear more from consumers about the challenges they are facing”; “This is great information for us as clinicians”; and “we are thrilled to see that the excellent consumer driven research PNDU is leading is getting out there. Thank you for the great contributions you’re making to our understanding as clinicians about HPN patient/carer perspectives”. In addition, on 1 January 2020 the paper appeared in the international newsletter IVTEAM (based in the USA), which features published papers concerning vascular access; it has been circulated through HPN networks ‘down under’; and significantly, AuSPEN has included regular HPN user retraining in its position paper for the development of an HPN Model of Care. These are very exciting outcomes already for which we are so pleased and grateful, and hopefully the paper’s impact will continue and expand for the benefit of all HPN users and PNDU.

Personally, I’m incredibly grateful and feel very privileged to have had this opportunity before I finished in PNDU’s Management Committee last August. I’m also so very thankful to all those who assisted, supported and encouraged along the way. The full published paper can be found on the PNDU website’s Surveys & Studies page, and I encourage everyone to read the full paper, if you haven’t already, to find out more about this matter and why it is important.

Trick or Treat – Halloween 2019

Editor's Note: *Halloween is slowly creeping into Australian suburbs, and 2 of our HPNers joined in the fun of trick or treating.*

'Pumpkin' (HPNer)

Cateleya (HPNer) with brother Desmond and her best friend Tyler

PNDU'S President Named 2019 NSW Grandparent of the Year

Words by Karen

NSW Grandparents Day celebrates the contributions grandparents make to their families and communities. The campaign recognises the diversity of grandparent relationships across age groups, cultural backgrounds, and geographical locations. Grandparents, grand-friends, kin, and those who take on the role of a grandparent in their family or community are celebrated for their contributions. It aims to foster intergenerational learning and offers older people ongoing opportunities to participate in their local communities.
NSW Grandparents Day is held every year on the last Sunday in October.

The Grandparent of the Year awards aim to recognise and celebrate the wonderful grandparents, grand friends and kin carers for the work they do in our community and to thank them for all the support they give.

Chris Walker has three grandsons, two of whom Jordan and Logan, were born with a rare disease. Chris has become a tireless advocate for the boys, achieving fantastic outcomes not just for his grandsons but for many children living with rare diseases in Australia. Chris was formally recognised for his tireless work during an award ceremony at NSW Parliament House Sydney, hosted by the NSW Government Department for Community and Justice. One of three finalists, The Acting Minister for Seniors announced Chris Walker as the NSW Grandparent of the Year for 2019.

Winner of the 2019 NSW Grandparent of the Year Award
PNDU President Chris Walker with wife Tanya.

Medication Compliance, Adherence, Concordance in the USA

Words by Emily

Editor's Note: ***Emily is young American adult HPNer, who spent a semester studying at a Sydney university, and whilst there, met several Sydney HPNers at social gathering. She is a regular contributor to Dripline.***

As an individual living who a chronic illness, the patient perspective is nothing new to me. All I see is from my lenses. Why do hospital clinics only operate from a 9am to 5pm timeframe when the majority of the working population is busy at that time? Therefore, to see my doctor I have to miss work, i.e. the people who provide me health insurance in the first place to pay said doctor. For a long time, the patient perspective was the only perspective I had. I always figured there was more behind the curtain, but was never given the information to understand the healthcare system, nor why it operates in the way that it does.

However, my perspective as a patient has shifted ever since I gained employment within the mental healthcare system. My world has flipped and now I'm the provider. This world is different, we sit around a table talking about Stages of Change or different types of behavioral therapy. We think about how everything impacts everything. How does my client being homeless impact the job opportunities available to him and how does that impact his income and how does that impact his housing choices? It's not all different, we talk about medication side effects and being patient centred too (we call it stages of change). Our clients commonly talk about their medications, access to them, and the cost of healthcare.

Now that I'm the one writing notes in the electronic health record, there's one word that never fails to bother me.

Medication Compliance

Ugh, I hate it so much I find myself avoiding talking about it in real life. My notes are meant to be a snap shot, just a paragraph to give the reader a review of my meeting with a client. As the note writer, I can list five reasons why my clients might not be taking their medications and I don't put it past them. I know them and I see them every week, I can emphasize with the powerful side effects being too much to handle, or that some of my clients are so sick they can't remember to take them, even though deep, deep down I know they want to. And compliance just sucks all the empathy right out. It's such a cruel word. Like "you will comply to my demands." Can someone who uses the phrase medication compliance be a patient-centred provider? But is there a better way to say "this person isn't taking their meds" with far less words?

Well ladies and gentlemen, I present to you...

The Lexicon of the pharmaceutical industry, medicine and the healthcare system – selecting words without judgement

Medication Compliance – according to the Merriam-Webster Dictionary, is "the act or process of doing what you have been asked or ordered to do." The term "compliance" suggests a restricted medical-centred model of behaviour and that a patient takes orders from a health provider.

Are sometimes used interchangeably,
but have different meanings.
Both words imply a dichotomy:
either you are adherent or you
are non-adherent. *

Medication Adherence – according to the Farlex Partner Medical Dictionary, is "the extent to which a patient continues an agreed-on mode of treatment without close supervision." "Adherence" implies that patients have more autonomy in defining and following their medical treatments. "Adherence" is the World Health Organization's recommended term.

*A patient can be unfairly marked as "noncompliant" in their health medical record due to factors outside of their control that impacted their ability to take medications, such as cost or availability of medication. Furthermore, compliance and adherence can stigmatize patients who may not have taken every pill at the desired time and, in turn, can interfere with relationships between the patient and future health providers.

Medication Concordance – according to the Miller-Keane Encyclopedia and Dictionary of Medicine, Nursing, and Allied Health, Seventh Edition, is "a negotiated, shared agreement between clinician and patient concerning treatment regimen(s), outcomes, and behaviours; a more cooperative relationship than those

Birthday Corner

Thanks everyone for the birthday wishes (on PNDU's chat forum) and thank you for the lovely birthday card which Ariel was excited to open!

We had an early birthday party for the kids (all 3) on the weekend with family and friends. We were lucky to be blessed with a relatively clear day smoke-wise, which meant that they could enjoy their birthday present- a giant trampoline. Luckily for them we didn't realise how massive it was going to be until it was set up (taking up half our yard) and not returnable!!!

Florence, Ariel, (HPNer) and Eadie

A Day in the Life of an HPNer...Every Day Decisions

Words by Gillian

Everyday decisions that people make without much thought or conscious decision-making can take much consideration for an HPNer or carer, and can affect the activities in the relationships we have with our friends and family. Even those who know us well forget how simple issues can create dilemmas for us on HPN. HPN is keeping us alive, and we want to make the most of every day if we feel well, enjoying quality of life, as well as wanting to maintain friendships, both for our sake, as well as our partner's and children's sakes. I've written some common scenarios, all of which I've gone through over the last 13 years that I've been an HPNer, so nowadays, I don't have to think things through for as long as I once did – I usually know what to do that is best for me; and I don't usually get caught out making the wrong decision, which can create problems and embarrassment.

Some common scenarios: ***(NB some of these scenarios involve eating, which some HPNers cannot do at all.)***

- You've just finished a day's shopping with your friend, who suggests a coffee before heading home. For the HPNer about to travel home, eating/drinking close to travelling means that you will almost certainly need to access a toilet before getting home – will this be possible?

- You're shopping for clothes and you spot the perfect dress/top/shirt – lovely style, colour AND it's on sale! But when you try it on, you discover the neckline is a bit lower than you realise and your central line and dressing shows – do you buy it anyway, thinking that it can provide a talking point, or do you leave it, not wanting to make yourself the centre of attention?

- You need new pants or skirt, but you are restricted by considering how it will fit as your ostomy bag fills up – will the clothes cling too much?

- You go for a picnic with friends to a National Park and after lunch, they suggest a 1 hour bushwalk. You know that, having just eaten, you'll need a toilet while you are walking, but of course, there won't be one – you'll have to 'go bush', hoping there is a big enough tree or enough cover beside the track so that you won't be seen when the time comes.

- Friends ask you to their wedding. You need to decide whether to set up your PN before heading out, and carry the backpack around with you and hope the reception venue has enough floor space around your chair to prop it, OR leave setting up until you get home and have the PN continue into the morning, meaning you will have to carry the backpack around while you do your daily chores. Also, carrying the backpack to the wedding will probably rule out dancing.

- Friends ask you to join them for a day's outing in summer – train to the city, ferry to the zoo, walk around most of the day, then home again. You need to decide whether or not you will have enough energy to do all that, and whether or not dehydration will become a problem as the day progresses.

- You're heading to a family get-together for Christmas. Part of you enjoys these gatherings and catching up with relatives that you haven't seen for a while (maybe since last Christmas). But you know that there will be the usual comments telling you that you look great (even if you feel sick and are in pain); or people telling you that your health would improve if you only tried a particular diet/miracle food they've read about; or hurtful comments minimising the affects that Intestinal Failure and HPN have on your life because they don't understand. Or little, or no, accommodation of eating restrictions, either due to lack of understanding or because 'it's Christmas and that is what we always eat at Christmas.' (PS I haven't experienced this scenario myself, but some of PNDU's members have.)

- Your child has been asked to a sleepover and desperately wants to go. But (s)he needs to set up, not get the central line tangled in a game, fix the pump if it signals an occlusion, etc. Should you work at enabling this event to happen, or just say no?

- Your child wants to play a contact sport, but you're worried that they might get their central line yanked, broken or somehow exposed and infected. Should you agree, or say no?

These are just some of the common everyday decisions that people on HPN, and their carers, need to make, based on their knowledge of the way their body reacts, as well as making risk assessments. It's a learning experience for us all, and, as with most things in life, we get better and quicker and wiser as we go along.

__Editor's Note:__ These photos arrived too late for our last edition, which had the write up of PNDU and HPN Awareness Week activities, so I have added them to this edition, because PNDU really values hospital participation during the week.

Awareness Week Hospital Photos

(Above) Gold Coast University Hospital GCUH – morning tea provided by Fresenius Kabi.

(Below) Centre sitting - PNDU member Alida sharing her story with GCUH Staff.

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.

James – 9th November 2019, aged 28 years
Elise – 19th August 2019, aged 43 years
Ross – 23 January 2019, aged 67 years
Celena – 27th November, 2017, aged 43
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.

Original images by FreePik, bear and flowers

Upcoming Events

28 Feb 2020	Rare Disorders New Zealand - Launch of the "Fair for Rare" Campaign, Parliament House Wellington NZ
29 Feb 2020	World Rare Disease Day
27 - 28 Mar 2020	Intravenous Nursing New Zealand (IVNNZ) Conference Christchurch NZ
29 March 2020	PNDU Gathering Christchurch (TBA) for more information and to RSVP contactpndu@gmail.com
3 Apr 2020	New Zealand National Intestinal Failure Service (NZ NIFS) Education and Network Day, Wellington NZ

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.

Thank You

PNDU wishes to thank the following for their generous gifts, totalling $2,200:

- G. Hardy Fundraiser
- F. Munro for K Winterbourn
- M. Einstein Donation of Baxter Honorarium
- G Anderson Donation of Baxter Honorarium
- S Smith Donation of Baxter Honorarium
- M Koonin
- R Stallard
- Pay Pal Giving Fund

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.

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

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.

Australia ($AUD) Bank: Westpac Account Name: **PNDU Inc.** BSB: 032 056 A/C No.: 482 738	**NEW ZEALAND: ($NZD):** Bank: ANZ Account name: IPANEMA A/c No: 06 0273 0308799 00 Please include reference "PNDU" IPANEMA (Charities Commission Registration CC21178) is a NZ charity

Management Committee Members

President - Chris
Vice-President - Gillian
Secretary/Public Officer - Miranda
Treasurer - Belinda
Editor - Gillian
Committee Member - Fay and Ryan

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