DRIPLINE

PNDU
Parenteral Nutrition Down Under

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As we commence another year, PNDU turns 12. Thank you to all of our HPNer members for providing support for each other via the email chat forum, Face Book, Instagram, or through contributing to Dripline. In this issue, we learn of some ways that our members celebrated Christmas; how we can make today the best that we can; some ideas for helping our HPNer children; we read of Tracie's journey to living life on HPN; and we learn of the importance of Vitamin B12 in What's in your bag? I hope that these articles will be helpful in learning about life on HPN (Home Parenteral Nutrition).

Gillian
Editor

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Images soured from: http://happybirthdayworld.net/birthday-banner-vector-png-6/
http://getdrawings.com/balloon-vector-png#balloon-vector-png-7.png

A Covid Christmas

Words by Gillian

Christmas 2020 was a challenging one for those who had the day disrupted in many possible ways by Covid 19 restrictions. However, our members were still able to find joy in the day, which some members shared with us.

Lisa

With the help of Taurolock™ I managed to have my first Christmas at home in 3 years NOT having sepsis! My thanks to my team, because with extra education in hooking on and off, that must have helped too! It was great to be at home!

Tracie

This year I was in hospital for Christmas, so my Christmas was celebrated very differently to other years. The goal was to be home for Christmas, but my kidney function was going off rapidly. Unfortunately, nothing worked and I was here for Christmas Day and Boxing Day. I had organised presents for the little children - a bicycle each - but my husband did the shopping for the older people's gift cards.

Christmas Day was like most days, except I was on FaceTime, with my husband at my step daughter's. Seeing them open presents, especially the little ones, was lovely, and I also helped to prepare lunch, by giving cooking instructions. I then hung up and had a beautiful plum pudding, with ice cream and Brandy custard for lunch. In the afternoon, I spoke with all my family, wishing them Merry Christmas.

On Boxing Day, Pat (husband) and I were both FaceTiming, talking to all the people at my parents' place, watching my niece get her bike as well. Great afternoon watching my niece learn to ride her bike on poppy's driveway. We were in the family Xmas photo. (see below) Overall, it was great to be involved and able to watch present unwrapping.

Tracie's family

Karen

My Christmas celebrations with family in rural NSW weren't affected by COVID restrictions and were very enjoyable. My travel there was delayed a couple of days however while I waited for COVID test results. I was so grateful for the way Baxter accommodated the resulting necessary, but very last minute, change to my PN delivery. The delivery plan was then in limbo until negative test results eventually came through and we could go ahead with Delivery Plan C (or was it D?!).

Gillian
My son, daughter-in-law and 3year old grand-daughter are living in America for 2-3 years; their plan of returning for Christmas obviously didn't happen. But thanks to the wonders of technology, we were still able to open presents 'together' via FaceTime. They FaceTimed us Christmas morning (their evening Christmas Eve) so we could chat as they watched us open our presents; then they Face-Timed again on Boxing Day, their Christmas Day, so we could watch them open the presents we sent to them. It was great seeing our granddaughter as she excitedly discovered what was in the parcels.

Our son, daughter-in-law and granddaughter in New Mexico, USA

Sal
We went to church, all masked up, and then had some family time in the afternoon with our kids before my parents and my brother and sister-in-law and nieces arrived. We shared in some traditional Christmas fare and gift sharing. It was extra special with our newlyweds and the about-to-be-married couple there. Church was different to usual - no singing from congregation, just the music team, numbers up to the 4sqm rule so reduced attendance to normal, social distance seating and no morning tea. It was live-streamed as well.

Renee
We don't celebrate Christmas, but our holidays certainly changed when visitors from Melbourne, and Sydney friends who had been to the Northern Beaches (which went into lockdown), were unable to visit. On the positive side, our son, who lives in Sydney, decided to leave the restrictions of the city and spend two and a half delightful weeks with us on the NSW South Coast.

Philip
My little sister (ha! she's 2 years younger than me, and I'm about to turn 60) rang the week before Christmas and said "I think they're about to close the border; I'm doing a road trip south" (from the Hunter Valley, way out of Sin City). So, I got to spend the week with my sister, who said later it was the best week of not doing very much that she had had in a long while. Being not very traditional at all, I made Bouillabaisse, and she did the trifle. When I get to eat again, (waiting for surgery, not enjoying the live octopus in my abdomen - that's what it feels like) it's back to doing that most enjoyable of things, cooking, which kept me sane.

Kelly
We went away Boxing Day on our first real family holiday in years. The weeks and months of planning TPN and alike, all came together in the end. I even swam for the first time in years. Monkey Mia and Kalbarri.... only 6 nights total, but amazing! Beats every other previous year of late, spending Christmas either in hospital (last year I'd just got out from sepsis and all... so don't remember much) or just out with us all being a bit medically weird. Family time and building positive memories is our biggest goals in life.

Jane
We couldn't have my brother and his friend as it would have been too many but apart from that it was a very good time.

HPN Awareness Week 2020 - Update

HPN Awareness Week 2020 was a wonderful success with 21 hospitals, 4 pharmaceutical companies and over 200 PNDU members involved. Unfortunately, these pictures arrived too late to make the write up in October's issue of Dripline.

Maya (HPNer) and her grandma wearing their AW stickers

Staff from the Royal Brisbane and Women's Hospital with a display for AW week

The HPN Challenge undertaken by Baxter executives proved to be a big hit. Read about it in October's issue. PNDU would like to thank the UK support group PINNT for providing the executive challenge idea.

Making Today the Best Day it Can Be

Words by Gillian

I came across a Winnie-the-Pooh cartoon that got me thinking.
Pooh asked Piglet 'What day is it?'
Piglet replied, 'Today'
'Oh great! That's my very best day!' cried Pooh.

A great philosophy, but what about those who aren't well? I thought I'd ask members how they cope when they're feeling nauseous, or are in pain, or weak or depressed. Hopefully these comments will inspire or at least give some ideas of how you might be able to improve 'today'.

Karen

I'm very blessed that I haven't had pain/nausea for years now, but there were many years prior when I did. I found singing in my head (and filling my mind with) a good song helped. One of my go-to songs was "One Day at a Time" ("One day at a time sweet Jesus, that's all I'm asking from you - to give me the strength to do everything one day at a time").

Tracie

I do art in hospital to take my focus off long days. Paint by numbers is awesome as they come in a pack and all you need is a cup of water to wash the brush. They make great conversation pieces and brighten the room up. I was bringing my art supplies, but it was a good size bag alone as I had sketch books, pens(different types), pencils(different types) and the list goes on and on, so this is easier.

I have 2 mantras that help me. "I am Tracie, I am alive, I can live one day at a time" and "If you get lemons, make lemonade."

Stanley
I haven't got a particular idea to share, but following your Winnie-the-Pooh theme, I read a book "The Tao-of-Pooh" which was filled with wonderful thoughts using the Tao culture/tradition collaborated with stories from Winnie-the-Pooh which may provide some encouragement.

Jodie
Some thoughts: To ride the wave until it gets to shore. No emotion is ever permanent. Dreaming about all the things I'd one day like to do used to help me fight. And then making some goals to realise the dream. Even if they're tiny flags to reach on the journey. Like if you dream of getting to Spain but can't even get out of bed, you can at least learn the language. Or read some stuff about the place. That kind of thing.

Lisa
I immerse myself in a good book and practice a lot of self-care, knowing, as Jodie says, to just ride the wave until it passes.

Julia
There is so much to be grateful for. I think about "What if she 'Pumpkin', (HPNer toddler) had been born 40 or 50 years ago and hadn't even had a chance at life?" "What if we lived in a country without ready and reliable access to health care?" "What if I didn't have this wonderful support around me … family, PNDU, our medical team?"

Sal
I tell myself that I want to know how the story ends that I've started, to see where my children go in life and I want to be as much a part of it as possible. I want to make each day count and be an example to my children of how we can all be the difference and make a difference in the world. Like the little train engine that you used to say 'I think I can' until it made it to the top, little steps can help us get through the tough moments and days.

This helps to recentre the negative thoughts that if you start, then they tend to make you spiral downwards.

My Journey to Life on HPN

Words by Tracie

My story is very different to others with intestinal failure (IF) as mine is the result of life saving surgeries. As a child my life was normal and I was healthy. I had the normal things, such as tonsils out and appendix, but I never got really sick until I was 16 and had Glandular Fever during my HSC.

Antiphospholopid Syndrome (APL), an autoimmune disease, was diagnosed when I was 18. It was bought about by the pill; my body developed clots in my leg and they travelled to my lungs. Over the years, I had several bouts of clots in my leg and lungs.

Everything changed in 2010 when I fell pregnant and lost our baby in my second trimester. It was heart breaking, but we wanted answers. Little did we know how life changing it would be for us. Doctors wanted me to see specialists as my liver wasn't working correctly, and I was diagnosed with primary biliary cirrhosis of the Liver (PBC). The liver specialist noticed I was always slightly out of breath, so more tests. (I had put it down to being overweight). I had to go for a heart-lung stress test, but they stopped the test as it was dangerous to continue. The formal diagnosis was Pulmonary Hypertension (high blood pressure in the lungs). This was the result of all the blood clots in my lungs that never resolved and blocked the arteries.

After 2 years of drugs, home oxygen and not being able to breathe, the talk of a possible surgery came up. I begged for the surgery to be done, as the other option was 18 months of fighting to breathe and heart failure from the damage to heart from the lungs, leading to death.

When surgery day came, I was prepped for surgery at 6am and said my final goodbyes, as I was told that I had high risk of dying on the table. I was scared shitless! For the first time I had another emotion apart from being numb from not digesting all the news and what had happened to me. I just was a "yeah", lock it off and I'll be fine, never really dealing with anything.

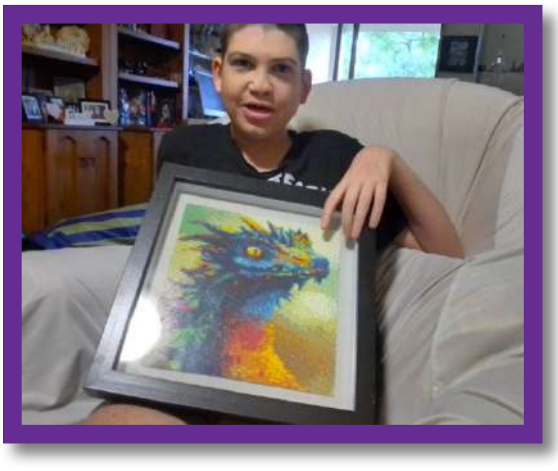
Surgery went for 12hrs and the surgeon came out to see my husband afterwards. They had removed 8 clots out of my lungs and I was on my way to ICU. Big news! I had survived! Great start! However, while in ICU, I had complications. The major one was the start of my IF journey. I developed a bowel infection C.Diff colitis with a toxic mega colon. I had temperatures of over 40C. They rushed me to emergency surgery and I was lucky that one of the ICU doctors coming on had seen one case before in the USA where he had trained. He was able to diagnose the issue, get me into surgery and have me pull through. They all seriously had thought I would die and had started preparing my family for this outcome. I am the specialist's "miracle" he says, as I was in the room where most people die. The cause of the infection was too many antibiotics as I was always getting sick with infections - the weaker I became, more antibiotics. I survived and got better, but now I had an Ileostomy.

Life went on. I was finally diagnosed in total with 4 Autoimmune disorders, but a year after surgery, I developed 4 hernias and was having issues with my ileostomy stopping due to the hernias, so back for more bowel surgery.

Many hospital admissions and surgeries followed, and in the interim years took their toll, and I basically loss track of life as I was going between hospital (Sydney and Dubbo) and home. I had many continuing issues.

In December 2017 I went for surgery to have permanent Ileostomy as I was having issue with remaining large intestine. I developed diverticulitis which causes all sorts of issues including bleeding from bowel. This surgery went for 12 hours due to adhesion issues - my bowel had grown through the mesh used in the hernia surgery and there had been an infection. After this surgery I had major complications and bowel perforation bleeding and ended up with a drain to remove the stool spilling in to my abdomen from bowel. I was in hospital for 3months before they did another massive surgery bowel surgery to fix the leak and clean my bowel. It was very damaged and they had to remove a lot of small intestine, leaving mostly the top of it. They told me they measured my remaining bowel and it was 2m, so I shouldn't have issues with short gut syndrome. Someone forgot to tell my body!

My stoma became an express food processer with food going in and out in 1-1.5 hrs and a daily stoma output over 2 litres - closer to 4 litres a day. I was on all sorts of drugs to slow my bowel and stoma down. Some of the drugs, like codeine, wiped me out and I just slept all day and night. This continued for a year until I stopped the codeine, as wanted my life back and it wasn't doing what it was meant to do. Mid way through 2019 with my hydration fluctuating (my body was always lethargic and my kidney function taking a nose dive) I was hospitalised and PN (parenteral nutrition) was started. This is delivered



Tracie and her granddaughter and her son through a Hickman's catheter in my chest). PN is a fluctuating thing for me as my body reacts differently to others and my liver issues are becoming a problem, so talk of changing me to another variant of PN. I was referred to PNDU (Parenteral Nutrition Down Under) by my stoma group, as I was struggling at home alone. I had no friends that understood, but I did have the most supportive husband and family. PNDU is where I learned about rare diseases and IF. They have helped me realise I'm not the only one and that although we have travelled different paths, we have had similar end results. I'm very lucky that I can eat food and drink fluids, but I just need that top up my body cannot get from food. I have dealt with a lot of the emotions I locked up, but I still have side effects. I get claustrophobia and need to have the door always open, even when in the bathroom in hospital. I have anxiety about procedures and live with depression. I have a daily mantra "I am Tracie, I am alive, I can live one day at a time"

Tracie and her husband

Helping your HPNer Child to Cope

Editor's Note: This article evolved from the responses on our forums that formed the article 'Making Today the Best Day it Can Be'. A few people began commenting on their concerns for their child, having to watch them suffer and feeling helpless. A couple of our members, sick since childhood themselves, responded.

Anna

I think it's always really hard for children to understand why they have to go through [pain, suffering, procedures]. There's always that big 'but WHY?' I think it's something you can only begin to understand as you get older and look back.

We are having a tough week with pain and probable major surgery soon, and as much as I try to prepare for longer hospital stays with toys, books, art, new games, photos, decorations and appropriate post-surgery clothes, drawings from cousins for the wall and FaceTime, covid stays are even harder. All this with a definite 2.5 year old's 'NO' for everything!

As parents we need to advocate when we know we can, or fight to be heard if necessary.

My advice to nurses is don't just do all the obs because that's just what you do for all your kids. Can you use your clinical judgment- is an inaccurate blood pressure going to change your care-giving overnight, because you will try and try, and he will scream and be unsettled for an hour, and the reading will be high and you say 'oh, not accurate because he was screaming'. Yes, because you woke a 2-year old in the middle of the night. So, I'll say before we sleep, unless his other obs are abnormal, or directed by a doctor overnight, let's not do a BP- 'oh sure'- or if they push back and insist - I quote the hospital policy; simple, but just a small advocacy on the list of many I've learnt.

My advice for doctors - do 6 of you need to enter the room? Doctors, nurses, students - half the time they introduce themselves to the parent, but they also need to acknowledge the child. I have now started requesting procedures to be scheduled on availability of having his Child life therapist present - I always ask, but it doesn't always work.

Ebony

When I'm very unwell, or after surgery, holding my mum's hand makes everything feel better.

Julia
I find it very hard to watch 'Pumpkin' in pain that I can't fix. So far, we've got pretty good pain relief when it's been serious stuff (fentanyl for sepsis a couple of weeks ago) but I'm thinking more of the gut pain, fever (I don't give her Panadol as readily as I would another child as I worry about masking a fever that should be taking us to hospital), the constant blood tests and bloody cannulas they can never get in. There's so much everyday discomfort and pain that our little Short Gut warriors go through, and not much parents can do to relieve it except with hugs. During her most recent hospital stays in November and again in December, she's taken to pushing her arm out through the cot rails to hold my hand for even painless procedures, such as temperature checks. At first, this surprised me as she knows these procedures don't hurt. Then I realised she lives in a world where painful procedures happen without warning. Doctors never come in and say to a two-year-old "I'm going to have to put in a cannula now" or "Sorry, but we need to repeat bloods". They say it to me, not her. If holding my hand helps her feel protected, then my broken sleep is worth it.

When I feel overwhelmed at the mountain I imagine ahead for our sweet toddler, with all its unknowns, I then choose to imagine the what if's. Not "What if she didn't have these challenges?" but "What if she had been born 40 or 50 years ago and hadn't even had a chance at life?" "What if we lived in a country without ready and reliable access to health care?" "What if I didn't have this wonderful support around me … family, PNDU, our medical team?" So much to be grateful for. This pandemic has really brought home to me how extraordinarily fortunate we are to be in Australia.

Renee
I have been sick since I was eleven and from then until the age of 18 I did not have a single day of remission from Crohn's Disease – which ultimately led to Intestinal Failure and HPN. I was in pain, vomiting, had diarrhea and fevers every day. There was not much emotional support around and I just muddled through each day as best I could, sometimes too ill to go to school, sometimes in the school sick bay, sometimes just soldiering on. Doctors tried to help but there was nothing that really made a difference. *I think I learned a resilience from that and have learned to make the best with what I have.*

Even though there are so many challenges still, I am glad I never succumbed to just 'being sick', and so I finished school, completed university degrees, had a very rewarding career, married, had a wonderful son, made many friends and have a rewarding life. This does not mean it was, or is, easy. It means that there is so much good that I cling to this as much as I can: 'looking at the bright side of things'. So, gratitude, and also understanding there are so many people worse off helps. As I matured, I learned not to push myself so much and also to accept the support of others, which makes a huge difference. It means not being obsessed by my body and its limitations when my mind, heart and spirit are whole and free.

For those with young ones…I know it's a worry having ill children, but there are gains too, and I would not be who I am had I not been ill. As a mother, I was also often ill and that is hard on kids. But I always made sure my son knew it was not his problem and he was not responsible for me. He did learn to have great compassion.

Jodie
I was 8 years old when I became severely unwell and started getting hospitalised. Books were a solace for me in hospital, as well as games. I loved receiving gifts when people came to visit. It made me feel really special. The hugs and physical touches make such a difference. As a child suffering with intestinal failure, my mother's head strokes and tummy rubs always made such a difference. From them, I felt like I wasn't alone. I felt safer and more secure. My mother hardly ever left my side and I know I wouldn't have gotten through all the pain and suffering without her physical touch and just her presence. So please don't underestimate how much of a huge impact [parents] have, even though you can't magic wand the troubles away. She definitely lowered my anxiety and increased my comfort, even though, like you, it was so painful for her that she couldn't fix it all.

Something else which was a huge benefit for me, was my mum advocating for me. It probably goes without saying, but, as a child, you don't really have a voice, so having someone there to speak on my behalf was a huge safety net.

On a similar note, something that would have helped me cope a lot better in the long run, is if I had been given more agency. It's a tricky one because kids don't know what's best, but I wish I'd been given some choices over the body that was mine. I would never have agreed to medical photograph documentation. That scarred me big time, among some other events where I wasn't given a choice or any measure of control.

What's in your bag? [Part 4] Vitamin B12

Words by Prof Gil Hardy

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

Vitamin B12, also known as Cobalamin, is one of the eight B group water soluble vitamins essential throughout life for growth and human health. It is involved in the breakdown of dietary fats and carbohydrates, helps to keep our red blood cells oxygenated and can prevent a type of anaemia, called megaloblastic anaemia that makes people feel tired and weak.

Natural vitamin B12 is found almost exclusively in animal products such as fish, meat, dairy and eggs, from which we can usually get our daily requirement of 2.4 microgram for adults (2.6mcg/d in pregnancy) and 1mcg/d for children. B12 is normally absorbed in the terminal ileum (the last part of the small intestine and first part of the colon) where it has to combine with a protein, called intrinsic factor (if), that is produced in the stomach. Absorption is a two-step process: first, hydrochloric acid in the gut extracts the vitamin from proteins in food. B12 then combines with if enabling the vitamin to be absorbed by the large intestine.
Normally only 50% of dietary B12 is absorbed and as we age, our ability to absorb B12 decreases. Consequently, vegetarians, the elderly, malnourished and those who have had their colon and/or part of their terminal ileum removed, will not absorb sufficient B12 and need to supplement their diet with between 5mcg and 20mcg per day, as advised by their health professional.

Common consequences of poor or no absorption leading to B12 deficiency are, megaloblastic anaemia, neuropathy and increased blood levels of the amino acid, homocysteine, which are associated with vascular disease, atherosclerosis and Alzheimer's. Signs of vitamin B12 deficiency to look out for, include:

1. Extreme tiredness/fatigue from not having enough oxygen in red blood cells leading to anaemia
2. Pins & Needles in the arms, legs, hands, feet
3. Forgetfulness, confusion or decreased cognitive function, especially in the elderly
4. Altered taste due to loss of taste buds (small red bumps on the tongue)
5. Depression, moodiness and irritability may be due to brain's inability to produce enough of the mood regulating neurotransmitter serotonin
6. Blurred vision, light sensitivity from blocked blood vessels in the retina and optic nerve
7. Appetite loss, and lack of hunger because food is tasteless
8. Ringing in the ears or tinnitus
9. Mouth ulcers
10. Increased urinary losses of the vitamin by smokers

Foods in Australia that are fortified with vitamin B12 include some soy milks, marmite/vegemite, and vegetarian meat substitutes such as soy-based burgers and sausages. Most breakfast cereals are not fortified, so that around a quarter of our populations may not be receiving enough of the vitamin.

Multi vitamin products available in Australia and New Zealand for HPN contain 5 or 6 ug of cyanocobalamin, the stable synthetic form of B12. This is the PN dose for adults recommended by ASPEN, AuSPEN and ESPEN. Although this is about double the recommended daily oral dose (RDI) there is no evidence of any PN toxicity. Additionally, during PN there may be significant losses in the urine, as up to 25% of unbound B12 'first passes' the kidneys and B12 secreted into the bile may not be recaptured by ileal receptors if the ileum has been resected. Extra B12 supplementation may be required after gastric resection (including bariatric surgery), ileal resection, atrophic gastritis, pancreatitis, pernicious anaemia and in older age.

B12 status is assessed by measuring plasma or serum levels, red blood cells and folate levels, but if a multi vitamin product is included routinely in the PN prescription then deficiency is unlikely in short or long term PN. Nevertheless, deficiency signs, may unfortunately take several years to appear making diagnosis difficult, so periodic blood testing is advisable for long term HPNers.

At the present time there is a lot of interest in the potential for high dose vitamin B12 to alleviate the symptoms of Covid 19. The corona-virus has become a global pandemic, providing huge medical challenges, especially in critical care. Mortality has been higher in those patients older than 70 years, particularly those with pre-illness comorbidities such as obesity, diabetes, cardiovascular disease, cancer and chronic respiratory disease.

Covid19 largely kills through Acute Respiratory Distress Syndrome (ARDS), a sepsis related process to which those who may be immunocompromised are more susceptible. Vitamin B12 (cobalamin), is a central regulator of our immune system, and has been used for many years in some countries as an antidote to cyanide poisoning. There is now increasing evidence that the antioxidant properties of cobalamin boost the body's natural killer cell levels and is critical for regulating the pro-inflammatory and anti-inflammatory sequences of the immune response.

Initial research data suggest that high dose parenteral vitamin B12 may prove a promising approach to critically ill patients, especially those with severe sepsis/septic shock. In this setting, vitamin B12 looks able to modulate the systemic inflammation contributing to the anti-inflammatory cascade that leads to ARDS and thus, hopefully, reduce mortality from the deadly virus.

Birthday Corner

I just wanted to share with you some pictures of Ariel's (HPNer) birthday and to thank you for the lovely birthday card! Ariel has had an epic birthday, with about 3 different celebrations all in one day. We even went out to a restaurant in town for dinner - like a big girl. Can't believe she turned 10 years old today! (And no one thought she would make it past 3 years when she was born!) Thanks to HPN and other small miracles.

Evidence Based Central Venous Catheter Care

Editor's note: This excerpt is from IV Team newsletter. The full text is found **HERE**

"Unfortunately, the presence of indwelling CVCs increases the risk of the formation of thrombi, emboli, and infection than patients with peripheral catheters by 200%" Ball and Singh (2020).

Excerpt:
Central venous catheters (CVC) are frequently used in critical care units, hemodialysis units, and oncology units for the administration of intravenous fluids, medications, blood products, parenteral nutrition, vasoactive medications, hemodialysis, and hemodynamic monitoring. Unfortunately, the presence of indwelling CVCs increases the risk of the formation of thrombi, emboli, and infection than patients with peripheral catheters by 200%. Central line infections are more common than any other healthcare-related infection and account for 33,000 deaths per year. Additionally, CVC infections are associated with increased morbidity, increased mortality, increased length of stay, increased healthcare costs, increased diagnostic tests, and increased antimicrobial use. The development of central line-associated bloodstream infection (CLABSI) may increase the patients' length of stay up to three weeks for an average additional healthcare cost of $33,000. Recommendations have been established and published by the Healthcare Infection Control Practices Advisory Committee (HICPAC) and the Centres for Disease Control and Prevention (CDC) to guide health care professionals in the use of evidence-based practices for central line care.

Reference: Ball M, Singh A. Care of a Central Line. 2020 Nov 1. In: StatPearls . Treasure Island (FL): StatPearls Publishing; 2020 Jan–. PMID: 33232068.

A Day in the Life of an HPNer - Exercise

Words by Gillian

When you are dependent on daily HPN to keep you alive, you have a daily regimen that needs to be followed; and as many living with HPN suffer from medical conditions which also require additional, specific daily care, the last thing you want is to add to that daily list, especially if you are feeling very sick, or have no energy. However, I've come to realise that as I age, my body needs regular exercise and stretches to keep my mobility as good as possible, so that I can remain as independent in my care as possible.

Obviously, people have to adapt what they are able to do to their current health and strength, but you can always start very small and hope to improve over time. Some exercise is better than none, I believe, even if you'd rather sit and read a book! (My default activity) My choices of exercise are daily walking, weekly Pilates and daily stretching.

Walking came about before my Intestinal Failure, when my mum commented, when I was in my 40's (I'm now in my 60's) that I was putting on weight and should get some exercise. (Gee, thanks mum!) However, I had also been looking to find time for regular prayer, and I decided these 2 could go together and achieve two desired outcomes. It worked well, and as time passed, I actually felt fitter and less tired. So, 10 years later, after my life changed to living on HPN in 2006, after 3 months of inactivity in hospital, the first thing I decided to do was to recommence walking to build up my strength. For quite a while, Ray would drive the car up our hilly street to the flat roads on top, and walk with me around the block, with me stopping for a rest on the front fences every house or two. Eventually, the distance I could walk increased, until finally, I got back to my normal level of fitness. I continue to walk for 25-30 minutes most days.

Pilates started when I commented to my GP, a while after leaving the hospital on HPN, after I had regained much of my strength, that I still felt weak and my joints ached a bit. She recommended doing Pilates, so I went to a studio once a week, which helped greatly in my improving my strength, flexibility, balance and endurance. My early lessons were done at a much more basic level than I was eventually able to build up to. After several years, when I knew lots of the exercises and routines and the importance of holding my core muscles while completing them, I began doing this for about 45 minutes a week at home by myself, which is what I'm still doing many years later.

Stretches began when I decided that I was fed up with my lower back 'going' on me a couple of times a year, resulting in physio and exercises for a few weeks until it improved. I decided to do one of the physio's exercises, combined with three of the Pilates stretches, every morning to see if I could strengthen my lower back muscles. I do 3-4 repeats of each stretch, gently. I haven't had lower back pain now for a few years, so it has worked. I then had a bit of knee pain, so my GP told me to strengthen the muscles supporting the knee, so I added my Pilates squats to the morning stretch regimen. I do 10, plus 20 'bounces'. And sometimes my neck hurts, which makes it hard for me to look down to change my stoma bag, including cleaning around the area, so I have lately added some neck stretches and shoulder rolls to the (growing) morning list, because I'd hate to lose the ability to self-care if exercising now will help later. I do 3 of each stretch, gently – tilting to each side; looking down diagonally to each side; turning my head to each side; looking up and down; then rolling my head in each direction; then rolling my shoulders forward then backwards. These stretches only add up to about 5 minutes.

You might only be able to walk around your home or yard at first; hold on to the dining table and lower yourself gently and up again a couple of time, but try to make the effort to start if exercise isn't part of your life at the moment. Knowing that you are doing something for your own health improvement is a great feeling.

My Daily Stretches

1. Face and knees to opposite directions (x4)

2. Lie relaxed, small of back slightly arched, then gently push down onto the floor (x4)

3. ‘Peel’ the back off the floor, in a rolling action (not just lifting up) (x3)

4. Gently pull each leg towards the chest (x3)

5. Bend forward slightly and go down and up again (x10)

6. Shoulder roll forward (x3) and backwards (x3)

7. Gently tilt the head to the right, then left (x3)

8. Look down to the right, then left (x3)

9. Gently look to the right then left (x3)

10. Gently look up, then down (x3)

11. Gently roll your head clockwise, then anti-clockwise (x3)

Upcoming Events

3 February 2021	Rare Voices Australia (RVA) Parliamentary event - Virtual Rare Disease Day via video link.
4 March 2021	RVA Education Webinar: NDIS Parliamentary Inquiry and consultation processes. RVA will be a lodging a submission into The National Disability and Insurance Agency's (NDIA) consultation into access and eligibility policy with independent assessments.

Thank You

PNDU would like to thank the following people for their generous donations, which totaled $229.75.

- **Ipanema**
- **G Hardy**
- **J Lee-Daniel**

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.

In addition, on its website, PACIFHAN provides an electronic Dictionary of Home Artificial Nutrition (HPN and HEN) words, in 8 different member languages, that you may need when in another country.

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.)

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