

PENG is supporting HAN Week 2020.

We are delighted to share
#ThisIsMe stories to highlight people
dependent HAN as well as members of
the nutrition team at the Freeman
Hospital, Newcastle-upon-Tyne.



This is me... *Kate Hall, Chair PENG*



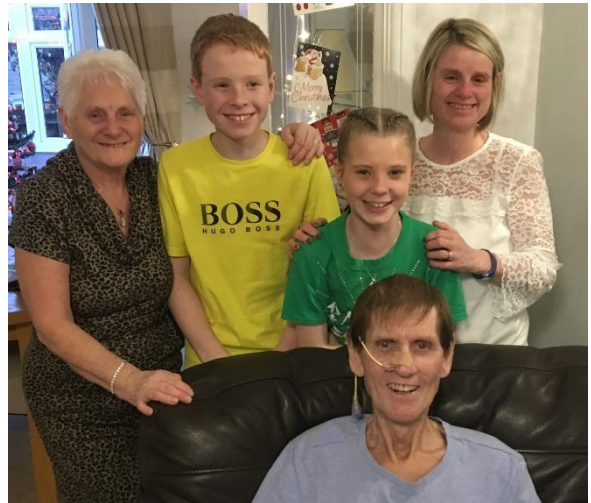
PENG is proud to support PINNT's HAN Week 2020. It is humbling to read the stories people have shared, their own personal experiences, both patients and the multi-disciplinary healthcare team members, and those of the home care support services and networks too. Everyone has a different story and each with different needs and aspirations. It is so important that the support that is provided recognises this. Whether you receive your nutrition artificially or not, nutrition is a lifeline and key to quality of life. The **#ThisIsMe** campaign is simple and a great way to start that conversation and raise awareness.



This is me... *Ernest Matthews*

The story probably started some four years previously, where I was experiencing frequent stomach upsets and generally feeling unwell, running to the loo sometimes as many as six times in a morning; due to this my weight was decreasing by a serious amount. We saw various specialists to try and identify the root cause of the problem, so over a period of the next 18 months to 24 months I had a number of tests without any real conclusive evidence as to what was causing the symptoms.

Eventually my surgeon said there was a test called a capsule endoscopy where the camera went through the whole intestine to identify what could be causing the discomfort. The test was very successful in identifying the problem. As a result, my surgeon decided that an operation was required to remove the infected area, which would mean cutting out approximately 200mm of bowel and then disconnecting my bowel and redirecting it through a stoma.



My weight at this time was down to an alarming 47kg so they had to give me supplements to help me gain weight; a tube was inserted up my nose to feed me directly into the stomach and help me recover from the operation. I was also taking Fortisip with various flavours; the doctor also had me on steroids again to help my appetite. My weight had increased slowly to 59 kg at the beginning of March 2019. My weight remained inconsistent for no apparent reason dropping down to 54kg on the 20th March. My surgeon decided that we needed a different way of supplementing my food intake, so he introduced me to the nutrition team who explained the benefits of total parenteral nutrition (TPN).

Initially the nurses in the hospital would connect me to 3000ml of the TPN every evening at about 7pm. It would run all night until 7am the following morning. The feed was working as my weight started to increase steadily and by mid-April it was back up to 60kg. I had a visit from the nutrition team at the Freeman - Hayley and Lisa. They advised that they were

transferring me to the Freeman as they specialised in this type of care and they would train me to self-administer at home. On Tuesday 16th April Hayley started training me to self-administer and advised that this would take about two weeks giving me a discharge date of 1st May. The training was quite intensive requiring me to carry out all the different procedures myself before moving on to the next stage. I quickly picked up on how clinically clean and sterile everything must be. The backpack was introduced at the latter stages and I was shown how to place the PN bag into the carrying case, which made everything portable and ideal because it meant I no longer had to drag the tripod around with me. On 1st May 2019 I was discharged from the Freeman as planned weighing 62.6kg.

The first night Hayley helped my wife and I at home by supporting my first connection which was useful as we were a little apprehensive; she also called the following morning to help me to disconnect.



We now do everything ourselves - Joan my wife plays a major part in helping to connect and disconnect every day. Joan prepares the sterile surface by cleaning with wet wipes, drying off the surface and then cleaning with alcohol wipes as directed in the training.

Next, we both wash our hands thoroughly and start the procedure as directed by Hayley. We still follow the written guide that was prepared in the hospital to ensure we stick rigidly to the sequence of operations.

We find that since using the TPN it has given me my independence back and a life which I didn't have four years ago. It's now nearly a year of administering the TPN and my weight is steadily increasing now.

Life is much better now as we are so familiar with what needs to be done daily. My appetite is not great, but I still eat for pleasure having snacks whenever I feel hungry, but the TPN feeds me the bulk of the nutrition needed to keep me ok. I continue to be reviewed by the nutrition team at Freeman Hospital who are building me up for my next surgery.



This is me... *Martin Fluke*

After suffering from Crohn's Disease for 30 years, in September 2018 I had a nasty flare up and started losing weight. I noticed the pain I was having in my lower abdomen was like nothing I have ever had previously. By November, I had no choice but to go off work sick as I was not able to function on a day-to-day basis. My consultant at the time tried doing a Trough Level test to check the levels of antibodies I had in my system. This came back within normal parameters, so he was able to almost double my dose of Infliximab. This did nothing and I continued to be in horrendous pain and the weight just dropped off me. I lost 43 per cent of my body weight within four months and now weighed just 8st 5lbs.

By March 2019, I was referred to the Intestinal Failure team at the Freeman Hospital in Newcastle who confirmed that I had indeed developed intestinal failure. My digestive system

had packed up. I had a meeting with the lead consultant who did not pull any punches as to the severity of my situation. At that point, he said if I needed emergency surgery I would probably not survive. He went on to show me the results of the scans I had of my abdomen and pointed out the fistulation, infection and inflammatory mass in my pelvic area (which was causing the pain I was in).



I was admitted to hospital to have a Hickman line™ put into a central artery and started on home parenteral nutrition (HPN). I was told that I had short gut syndrome and any food I ate would be purely for pleasure and I would get my nutrition from PN. I spent a few weeks in hospital being trained on how to manage PN at home and obviously to get the levels of nutrients right before being discharged.

I went home and although I did start to gain weight, I was still in the same amount of pain especially after eating. By the end of July, I had developed a DVT (deep vein thrombosis) and my blood tests showed that the amount of infection in my pelvic cavity was putting pressure on my urinary tracts and this was

impairing kidney function. I was admitted that day back to the Freeman hospital where I was immediately put on blood thinners and we discussed having a drain put in to remove the infection. The surgical options we had, were also discussed. The first option was to have a large operation that would involve the removal of all the digestive system that was beyond repair and have a stoma. The other option was to split the surgery into two and have an ileostomy and return in six months to have the damaged and infected gut removed. It was agreed to go for the second option and on the 3rd August, I had an ileostomy. This was successful; however, my surgeon had a



tough time bringing my small bowel out to form the stoma due to severe adhesions and the poor state of my skin.

I went home a week after my surgery and, apart from becoming extremely anaemic, needing a trio unit blood transfusion and becoming dehydrated due to drinking too much making my stoma output go through the roof, having the ileostomy has been successful in stopping the pain. The current plan now is to let the infection subside prior to the second round of surgery that will probably take place in 2020. In October 2019 I also had a stroke in



my eye that left me partially blind in that eye. Tests are currently underway to determine if the clot that caused the stroke was from the DVT in my leg or if it was a new clot. Since having my ileostomy, I have been doing some resistance training and am starting to gain some good muscle mass. I am aiming to get as fit as possible leading up to my planned removal and resection of diseased/damaged small bowel in the coming weeks.



This is me... *Lisa Gemmell*



My role is to support patients at home on parenteral nutrition with intestinal failure. I also look after inpatients that have long hospital stays with intestinal failure. I support them to make changes to their fluid and dietary intake to help control stoma/fistula output/bowel frequency. In combination with the nutrition team I formulate parenteral nutrition and fluid prescriptions. This is done carefully to minimise any unnecessary burden on patients and their families. Initially when a patient is referred to our intestinal failure team, we often visit the patient in the referring hospital to talk about what to expect when they arrive with us. We also

liaise closely within our Northern Nutrition Network to share practice and to facilitate remote care of intestinal failure patients. Above all improving the quality of life of patients with intestinal failure is my focus. In my spare time I love spending weekends at the Northumberland coast with my family.

Lead IF dietitian at Newcastle Hospitals and Parenteral and Enteral Nutrition Group (PENG) lead for parenteral nutrition (PN)



This is me... *Dr Chris Mountford*



I am delighted to support Home Artificial Nutrition Awareness Week and the important work that PINNT do to support patients and their families.

I am a Consultant Gastroenterologist at the Freeman Hospital, Newcastle-upon-Tyne. I am part of the hospital nutrition support team and also the regional home parenteral nutrition team for the North East of England. I am very lucky to work in such a beautiful part of the country, in one of the best hospitals, with a fantastic team of colleagues to support our patients who require nutritional support (though clearly that is a personal opinion and I am biased in that view!). My interest in nutrition

developed when I was a trainee and I was struck by the importance nutrition has in recovery from illness, but also sadly how it can be forgotten amongst all the other treatments patients may need.

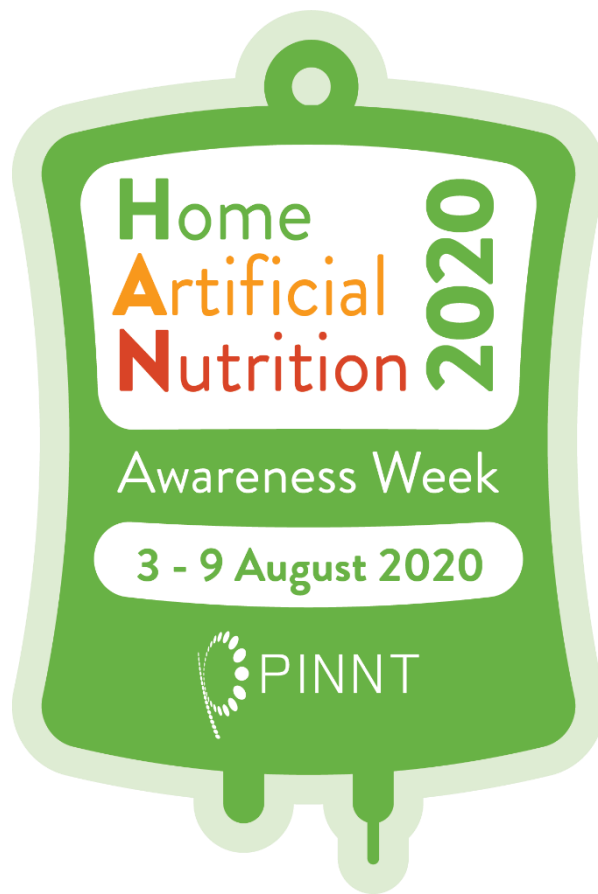
We support patients coming into our care from Newcastle and more widely around the north-east region. I will often see our patients at some of their lowest moments, in many cases at a time not long after serious illness and associated malnutrition has significantly impacted on their lives, but seeing the progress and recovery that can be achieved with time is very rewarding. There are sometimes setbacks along the way, but one of the great things about my job is that both myself and the rest of our team have the opportunity to get to know our patients over a period of time, which I think really helps in building trust and reassurance that support is available along the way. As a team we share some of the highs and lows alongside our patients living with long-term conditions. I am frequently reminded of how determined and successful our patients are at getting on with their lives, even with the, sometimes daily, imposition of nutrition support.

I really enjoy working in a team and nutritional care is very much a team effort. I work with nurses, dietitians, pharmacists, other medical doctors, surgeons, radiology doctors, administrators, managers and many others. My weekly timetable consists of a wide variety of activities. Although nutritional care forms the main part of my job, in an average week I also do inpatient ward rounds, general gastroenterology as well as specialist outpatient clinics, multi-disciplinary meetings, endoscopy lists, bowel cancer screening colonoscopy and I work on the medical admissions unit and gastrointestinal bleeding emergency on-call rotas. I also enjoy teaching medical students, supervising doctors in training and I am currently very involved with charity work for BAPEN (British Association of Parenteral and Enteral Nutrition), a charity that raises awareness of malnutrition and works to advance the nutritional care of patients and those at risk from malnutrition in the wider community.



Outside of work I live with my wife and three children who are great fun to be around and keep me busy and on my toes. I find cycling around Northumberland and the North Pennines a fantastic way to switch off after a busy week.





#HANWeek2020

#ThisIsMe

www.peng.org.uk

www.pinnt.com

