

Home Artificial Nutrition Awareness Week

PINNT (Patients on Intravenous and Naso-gastric Nutrition Therapy) is hosting its 5th Home Artificial Nutrition Awareness Week. This is a week where hundreds of people receiving enteral and parenteral nutrition @home come together to raise awareness on home artificial nutrition therapies.

Fresenius Kabi Homecare Service is focused on providing a first class service to patients' requiring Enteral/Parenteral Nutrition, and/or fluid and electrolytes in their home.

An experienced team of Homecare Nurses and Patient Care Co-ordinators are dedicated to providing a safe and reliable service.

Fresenius Kabi Patient Story

My name is Sorcha Mc Elchar and I am 20 years old. I have a rare genetic medical condition called APECED Syndrome, which means my immune system attacks various glands in my body. As a result of this, I have several different auto-immune diseases such as Type 1 Diabetes, Addison's Disease, Hypothyroidism, Hypoparathyroidism, Growth hormone deficiency, Pernicious Anemia, Keratoconjunctivitis and Malabsorption of fats and vitamins.

The one that has been the hardest to deal with is most definitely the malabsorption. I've had it the longest, since I was two, and it has basically taken over my life.

Weight has always been an issue for me. As I'm unable to absorb my fats and vitamins, it's almost impossible for me to eat enough to put on and maintain weight. I could have a good week where I'd be eating well (for me) and I'd manage to put on a bit of weight, then my stomach would decide to pack it in and I'd lose it all again. It was a constant battle. I'd miss so much school from being ill and 90% of the time it was because of an issue with my stomach. I was constantly in and out of the hospital for dehydration and I have been always tired and cold. I was 17 years old and I could fit into my 9 year old sister clothes. Looking back at pictures now it's scary how thin I was.

Home Parenteral Nutrition (HPN) was my last resort. It had been mentioned to me before, but I wasn't keen on having a Hickman line inserted and being hooked up for hours at a time. The process was daunting, but finally I realised I needed nutrition before I faded away to nothing. Getting the central line was scary, but having to look after it and learn how to flush the lines and change the dressing was even scarier. And I didn't like the thought of being hooked up to a drip at home. I

mean, home is home, not a hospital.

But we got stuck in and my mum and I were trained in Our Lady's Hospital for Sick Children, Crumlin. It's like driving a car. At first you're nervous and slow but before long you just do it.

In the beginning, I was on HPN 7 nights a week, now I'm down to 4 nights a week. Before HPN I was only a paltry 26 kilos when I should have been 45 Kilos. The proper nutrition has allowed me to reach the normal weight for my height for the first time in my life and I feel I have so much more energy. It's unbelievable how much better you feel when your body is getting the right nutrition.

I still eat normal food, but I don't feel the pressure to eat just to be healthy. I just eat when I'm hungry! If my tummy isn't feeling the best I know I don't really have to eat because I've gotten my nutrients from my HPN. HPN has literally saved my life

"HPN has literally saved my life because the way I was going I wasn't going to be around for much longer."

because the way I was going I wasn't going to be around for much longer.

It was great putting on weight, I'd go to put on a pair of jeans and when I couldn't get the zipper up I'd be so excited cause it meant a new pair of jeans was on the cards! I had some lovely clothes just lying in my wardrobe that previously looked hideous on my skinny frame that I could now take the tags off and wear. I had colour in my cheeks and my days were filled with laughter instead of tiredness, mischievousness instead of sleepiness. I hadn't realised until I was feeling so good how really bad I had felt for all those years.



I'd highly recommend HPN to anyone with gut problems. Although it can get annoying at times and you do have to plan your life around it, it's definitely worth it. I feel so much healthier inside and out. Being on HPN has not stopped me doing the things I want to do. There's a way around everything, for example, my family and I recently went on our first holiday with the HPN and it was a great success. Fresenius Kabi were extremely helpful and put our minds at ease.

We were worried about so many things, like what happens if we ran out of HPN while we were abroad? They assured us that if that did happen or if anything happened to the bags so that we were unable to use them, they would be able to get us more bags, no problem. We are very grateful to Fresenius Kabi for being such a great support. Looking back myself and my parents realise we should have agreed to HPN sooner. It was daunting at first, but I'm so glad I did it.