PINNT
A SUPPORT GROUP FOR PEOPLE RECEIVING ARTIFICIAL NUTRITION

HAN
HOME ARTIFICIAL NUTRITION AWARENESS WEEK
WWW.PINNT.COM
8th – 14th August 2016

"TPN is a gift not a curse"

My name's Elise, I'm sixteen and live in Brighton on the South Coast of England. I have a genetic disorder called Ehlers Danlos Syndrome (type 3). It affects me in many ways; it includes a multi-systematic failure of my urological, autonomic, neurological, allergy/immunological systems and has left me with very lax and loose joints from hypermobility. But undoubtedly one of the greatest challenges for me is the debilitating gastrointestinal condition it has left me with. My condition has rapidly deteriorated following a virus I contracted at the age of ten.

I had my first NG tube in 2011 when I was admitted to the hospital malnourished. I became acidotic and hypoglycaemic and fainted twice from dehydration. The first tube didn't last long because two weeks after I was discharged I ended up collapsing on the bathroom floor, vomiting large volumes of blood and bile, and I was then placed into HDU for observation. The next week I had my first NJ placed, but unfortunately jejunal tubes could never be placed correctly due to lack of peristaltic movement within the gut due to intestinal dysmotility. It soon became clear that naso jejunal feeding was just as poorly tolerated. I was in constant agony from it, and would regularly end up in hospital, continuously vomiting and severely dehydrated. Doctors were scratching their heads!

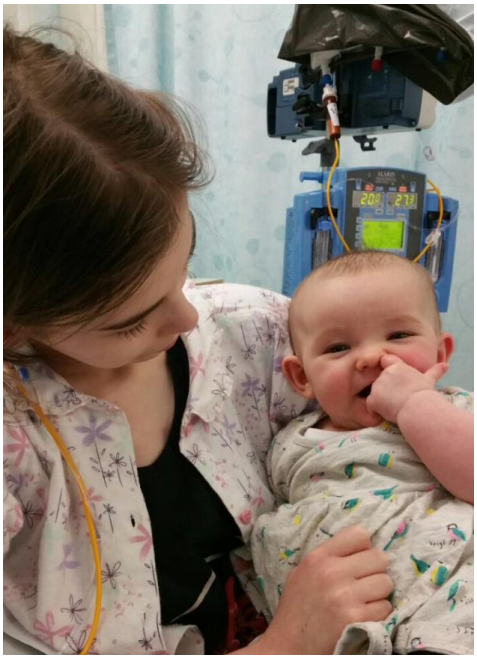
My struggle with weight loss and malnourishment continued; I was living on whatever I could tolerate. During the four years I spent on enteral feeding I tried different formulas, brands and concentrates, medication, timings methods of feeding and tube positioning. I was repeatedly hospitalised and passed around specialists without signs of improvement. It was found I had very high inflammation in my bowel, now thought to be due to allergies within the gut, and it set in motion years of tests and studies. All the while I was deteriorating and without nourishment. I was losing the physical and mental strength to cope with my health.

In January 2015, four years after first getting that first tummy ache and after losing more and more weight so that I was 4.5 stone and barely clinging onto each day, I sat in my wheelchair and was told I was to be put on total parenteral nutrition (TPN) as an emergency. I remember my parent's relief - the glimmer of hope was back once again. However, when I first heard those words I went home feeling miserable. I'd heard about sepsis, I'd heard about liver failure, blood clots, embolisms, lack of central access - it terrified me. But standing strong and aware of those risks, I would have nourishment, and hydration and more importantly I would have a life.

Reversing some of the damage took time; we spent four weeks out of the initial ten-week admission reintroducing my body to nutrition. Refeeding syndrome was such a worry, but with gradual introduction to TPN and supplemental infusions I was finally beginning to catch up. Unfortunately in my first year of TPN I also suffered from four line infections, but after having a Hickman ® line placed and only allowing my me and my mother to access the line through aseptic non-touch technique we have managed to avoid further infections since November last year. Despite our best efforts my GI system continued to deteriorate and I am now TPN, IV and drainage dependent. However we still have hope that in the future I can start trickling small amounts of feed into my jejunum to reduce the risk of early liver damage.

Just a few weeks ago I turned sixteen - which could never have happened without parenteral nutrition! I'm now fully TPN trained myself and due to have a sink placed in my room for that purpose. I think there is a general anxiety that comes with living on TPN; you have to be very astute and aware of any risks or threats and put your efforts into reducing them as much as possible. I live in a busy six-person household, and each one of them takes on a vital and much cherished role in my support. We have recently moved house, and the new place is so much more accommodating; I'm finally getting to go outside and feel the warmth again during the summer.

One of the constants of being tube fed is people ask me if I miss food - it's usually one of the first things they say after having the awkward, "I can't eat" talk - and I guess the answer has changed over time. At the beginning of my illness I was constantly craving foods and missed eating, and for a few years I couldn't stand even the smell of it - I spent my life with such debilitating nausea and sickness that I couldn't bear tasting any flavours. Since I've been placed on drainage and IV anti sickness the nausea has immensely improved, I can now (carefully and slowly) drink and drain fluids out through my gastrostomy, as well as have boiled sweets and gum. It gives me the opportunity to taste the flavours I once loved, and although in my lifetime I know I may not be able to eat again, it does help socially and mentally to be able to join in with conversation about food which is such a huge part of our social life.



Never take your dinner plate for granted; the ability to eat is truly a blessing. My 5.5 year long struggle with gastrointestinal failure has taught me how incredibly complex our bodies are and how much work nature does for us, supplying us with vitamins, minerals, carbs and fats - a lot more pleasant than getting it mixed in a lab. Now I'm growing older into my teenage years I'm hoping my life on TPN is much more enriched with the nutrients I once lacked; for once in my adolescence my cheeks protrude when I smile, my mother can hug me without feeling bone, I can be warm enough to enjoy the summer heat and my baby sister will know me as a thriving person. TPN is a gift and a curse - but certainly, in my case, more of a gift.