



# "I'm a big music fan"

Hi, I'm Hanna. I've suffered with digestive issues my whole life, from struggling to keep milk down as a baby to increasing pain and nausea as I grew up. I was diagnosed with atypical inflammatory bowel disease and coeliac at Great Ormond Street when I was sixteen and underwent two years of steroid and immunosuppression therapy. At the end of this treatment I no longer had raised inflammatory markers or had inflammation in my bowel but I still struggled with constant nausea, pain, bloating and vomiting. When I was nineteen I was admitted to hospital and started my first NG feed. Unfortunately I didn't tolerate it very well so this was switched to an NJ feed which I came home on. Six months later I was fitted with a PEG which was eventually swapped for a PEG-J. Aged twenty I received a diagnosis of Ehlers-Danlos Syndrome and severe small bowel dysmotility also known as enteric neuropathy.



I have a love-hate relationship with my enteral nutrition. It's my primary source of nutrition with whatever oral intake I can manage. I began on only ten hours of enteral feed a day which I received overnight and meant I was free of my pump during the day. However as my bowel has worsened, the hourly rate of feed that my body can tolerate has decreased and I am now attached to it for twenty-four hours a day. I still struggle with constant pain and sickness and would reduce it further if I could but I can't make the days any longer. I was admitted to Salford Intestinal Failure Unit last year for an HPN assessment but they decided that it was not appropriate at the moment as my gut still had enough function to cope with enteral formula for now. Alongside broken pumps and displacing my feeding tube, the pain and additional sickness caused by running a feed forms part of the hate

relationship that I have with my enteral nutrition. But that's not all there is to it.

When I was admitted to hospital to start my first NG feed I was severely malnourished. My hospital notes describe me as 'skeletal' with a 'poor quality of life'. I'm now nearly twenty-four and since starting enteral nutrition I have completed my A-Levels, done a sky dive, swum with sharks, travelled to France and Turkey, been scuba diving, held down full time jobs, survived camping at music festivals and graduated with a first class honours degree in English Language. There was even a time when I had the energy to take up jogging, get a gym membership and complete a 5K run in thirty minutes. I've lived away from home for the past three years and thanks to my enteral nutrition I am alive and able to live my life independently. Enteral nutrition has both saved and

changed my life. It has given me a life that I never would have had and subsequently so many wonderful opportunities.

I carry my feed around in a backpack and most of the time nobody even notices it. I've lost count of the number of times people have said 'Can I take your bag?' I'm a big music fan and unfortunately my feed hasn't always mixed well with bag searches or big crowds but it's a learning curve and it has led me to campaign for awareness of unconventional disabilities at live music events. Whilst at Glastonbury (working as an Access Steward) my feeding pump completely broke down on me. Since I rely on my pump twenty-four hours a day, I thought the festival was over. But thanks to an exceptional service provided by my nutrition supplier, I was able to get a pump delivered to the campsite immediately, meaning that I could carry on camping and enjoying the festival.

I'm so grateful for all the experiences and opportunities that enteral nutrition has allowed me. When my bowel is feeling unwell and grumpy that I'm feeding it, I must remember that we all need nutrition to stay alive and I am no exception. It would be rude not to grab every opportunity that is available to me and embrace the life that enteral nutrition allows me to live!