



# "I finally felt like me again"



I have gastroparesis (and dysmotility in my intestines and oesophagus, among many other things), caused by my Ehlers-Danlos syndrome. I've had problems eating and receiving sufficient calories since early childhood. Food sat in my stomach for far too long and rotted. My body coped relatively well on a liquid diet up until the beginning of 2014 when my gastroparesis suddenly deteriorated rather rapidly. I grew weaker, then my stomach stopped accepting even my liquid diet and I was lucky if I could tolerate 200ml of water a day. Frequent vomiting prevented me being able to keep anything down. My body was starving but somehow I kept going! I started tube feeding in December 2014. By the time I started naso jejunal feeds I was extremely ill and was a lovely shade of yellow as my liver was very unhappy (as were many of my other organs). I felt absolutely awful; I was so weak I couldn't lift my head off the pillow without assistance. I hope to never, ever feel that weak again; it was terrifying! But when I received those first few calories I perked up! I sat up, alert and chatty! My doctors and dietitian were amazed at how quickly I bounced back! The feed was introduced slowly; my electrolyte in-balance was corrected - I felt like a totally different person! I stopped passing out as often and felt wonderfully alive, fully alert and engaged with the world around me for the first time in months and I was well enough to leave the ward for short periods and "escape" to the shop and cafe downstairs!



I'm naturally a very active and sporty person. I've played and competed in para badminton for a few years now, playing in my special wheelchair; so getting up, moving and gently exercising felt absolutely heavenly. It was awesome! I finally felt like me again.



I struggled with the naso jejunal tubes as I had allergic reactions to the plastic and so had a lot of pain (especially as my tube was a triple lumen one with a stiff drain tube in it) and scarring, but it was definitely worth the pain and discomfort as it made me strong enough to have my PEG-J fitted about six weeks later. I was recommended to name my tube to make it easier to accept it and make it less scary, so I called her Peggy-Sue (I was a huge Buddy Holly fan when I was a child!) Having my PEG-J meant I could go home! Yay!

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I'd known for years that I'd likely need to be tube fed at some point in the future but had been very apprehensive and scared about it. I have been extremely anti-tube for many years, but I rapidly realised that my fear was totally unfounded. It's nothing like I expected it to be; I thought my life would stop along with all the activities I enjoyed but it's done the complete opposite. I'm able to do far more now I am tube fed - instead of limiting me it's given me my life back. I will be eternally grateful for Peggy-Sue my faithful tummy friend.

I often make people laugh; all too often I forget about my feeding rucksack and end up dragging it behind me. I once shut it in the boot of my car and tried to wheel away. My sister in law nearly wet herself with laughter when I was stopped dead by the tube. It took me a good few minutes to figure out what I'd done.

I generally don't have any problems dealing with the tube and feeds now; I just mentally added it to the list of things I need to stay alive and healthy. I have to fix hundreds of joint dislocations a day and that gave me an advantage as I was used to doing medical "stuff" so it wasn't such a big change to my life. Having a hidden treatment and condition is sometimes very hard. People don't always react positively about what I have and my treatment when I am out in public. I started to think positively about the stares and questions and I offered to explain what it was. It allowed me to explain about tube feeds and help tackle the stigma attached to tubes.



I expect to be tube fed for the foreseeable future, but that doesn't bother me at all. Thanks to my enteral feeding I'm alive and able to do the things I love - so I love my tube. It allows me to be able to look after and play with my gorgeous kitty cat, Arioch and it allows me to be able to play and coach badminton and compete for my county in tournaments all over the UK. My main aim for the future is to get on the GB para badminton team for the 2020 Tokyo Paralympics and thanks to my tube I have a very good chance of succeeding!

