



"I thank my lucky stars"

My name is Paula and it was my 40th year of living a happy carefree life, happily married to Tony my soul mate, whom I adore and my two beautiful children (both doing well in education), a career I enjoyed, a nice house and a dog!

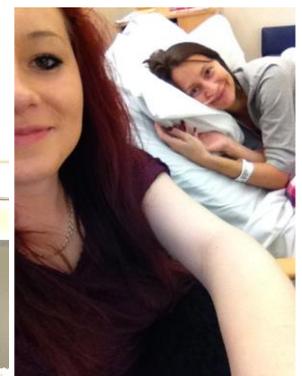


Things began to change during spring of 2014 when I started to be sick and have pain after eating a meal. It would come on a couple of hours later and would make me feel lousy. I left it for a while just thinking that it might be an upset tummy and would resolve itself. Unfortunately it did not and weight

started to fall off me; it didn't matter what I did I could not stop losing weight. By the following October I was admitted to hospital for the first of many admissions. Ultimately I ended up with my first feeding tube whilst tests were carried out and I was on a waiting list to have a full thickness bowel biopsy carried out. There was a rare condition that I might have but this was the only way they could diagnose it and although there was no cure it would be treatable.

Once the NJ tube was starting to make a small improvement I had my first PEG-J placed and began to feed from home - it was all very alien to me but over the months I started to try and accept that this could be life for a little while.

A couple of months after the bowel biopsy the results came back and they confirmed that I had myenteric plexitis, a rare condition that many doctors have not heard of. I was given my first course of steroids which seemed to have a positive effect and I was able to start eating small low fat meals. This continued for a couple of months before I began to deteriorate once more; unfortunately this time it did not help and by September I was admitted to hospital with malnutrition. I could not tolerate the infusion rate high enough for the nutrients to help me, so they inserted a PICC line to get the nutrients straight into my bloodstream bypassing my stomach and bowel. I was weaned off the steroids and told that this treatment was no longer an option.



Another couple of months passed with the PEG-J feeding but my body could just not tolerate the feed at a high enough rate to make a difference. By the end of November I was malnourished and had pancreatitis as a result. I was told that they could wait no longer and that I needed to be admitted to hospital to have a Hickman ® line inserted so that I could receive nutrients intravenously. I felt like I was in a whirlwind and unsure what to expect but I trusted my gastroenterologist one hundred percent. I was discharged from hospital the week leading up to Christmas and everything felt very alien. I had nurses coming to the house twice a day to connect and disconnect the TPN. Over the next couple of months I went to quite a dark place; I felt I had no life and was struggling to keep my part time job going. I had to decrease my hours from full time in order to manage. My employer was extremely understanding and supported me all the way; on the days I was not well enough to go to work I was able to work from home. This helped so much to be able to hold down my job.

It was suggested that I talk with someone to help me come to terms with all the changes to what was once a normal life. I agreed and it was a positive decision. One thing I will always remember being told is that it is grief that I am experiencing and it will take some time to come to terms with it. It is just as though one had lost a family member, you have lost your former self and I had to learn to be the new me. Over the next couple of months I struggled, feeling quite low. I was admitted to hospital with sepsis in my Hickman ® line - it was quite scary but at the same time I now know what to expect in future and should it happen again I would recognise the symptoms immediately.

In May of this year I attended an outpatient appointment with Dr Burch and at that appointment I was told that she expects that this is my life from now on. I have type III intestinal failure and as well as having the TPN I also take lots of medication to try and make my bowel work which, at the moment is futile. No matter how many laxatives and enemas I take daily there is very little movement! At that same appointment I was told that if I didn't have the TPN I would no longer be here. It was at this point I realised how lucky I am, my Hickman ® line is my lifeline. I have an amazing medical team looking after me and a husband who is there for me unconditionally. He is always there to pick me up on my bad days, hold my hand on the days that I am sad and there to enjoy our good days together. All this baggage arrived twenty years down the line and my gorgeous husband has never once questioned our relationship. He takes the rough with the smooth and always understands and for that I owe him more than I can ever repay.



I have very good friends, who always visit me when I am poorly, and my best friends travel one hundred and twenty miles each way to come and visit me when I am in hospital - nothing is too much trouble. My kids have also gone through these changes and their family life is very different from that of a couple of years ago; they do not complain and they are now used to helping and supporting me when necessary.



This year I was able to experience my son's graduation from University with a First Class Honours degree in Physics and my daughter passing her driving test. I am so very proud of the beautiful adults they are becoming – something I would not have experienced if I didn't have my lifeline.

So I thank my lucky stars that I am able to enjoy my life, albeit very differently, but it's my life now and I am learning to embrace it.