



Patient case study

Patient information

Name

Brendan

Age

31

Treatment duration

4/5 years

Background

Reason for home artificial nutrition: Unable to maintain weight and fistulating Crohn's disease

Length of time you were not well before treatment:

Roughly 1 year but I have had a 14 year history of refractory Crohn's Disease and quite a few operations during that time

Experience on home artificial nutrition

Overall I have had a very positive experience with TPN. Before there was a clinical need for me to be on TPN, I actually enquired about going on TPN due to the fact that I have had multiple surgeries due to Crohn's. After my last operation, I felt that I needed to eat 3000 or 4000 calories just to maintain my weight and having active Crohn's disease I always found it difficult.

It was only when I developed fistulas that my team saw a clinical need for me to be on TPN as I was losing weight so rapidly and could not eat. But as soon as I started TPN I immediately saw an improvement. My bloods also improved dramatically and overall I felt so much better in myself. For the first time in my 14/15 year history of Crohn's, I felt I was on a treatment that I was actually benefiting from.

The main benefit that I got was that I felt I could actually make plans which I'm sure most people take for granted. It also

allowed me to excel in college and in work. When some of my friends realized I was on TPN in college while studying financial maths, they wanted to report me as I had the highest grades in the entire college across all courses and they felt it was some performance enhancing drug. Even though I ran the TPN during the day when I was in college no one was actually aware I was on it. It was only when I was asked to give a talk that I informed the class that I was on it as it would have looked strange going up in front of a class with a backpack on when giving the talk.

The biggest change overall was 12/13 years prior to going on TPN I always looked sick from my Crohn's and I was always underweight. So people automatically knew I was sick. However since I have been on TPN even though I still have very active Crohn's, I actually don't look sick so people are shocked when I tell them what I have been through and they always comment but you don't look sick.

Describe your daily, weekly routine including hobbies and activities

I honestly don't know how to answer this as the last couple of months I have been in and out of hospital due to my Crohn's so I have found it very hard to have a structure. I had an appointment yesterday which I was worried about for quite some

time so I haven't been up to much. However I got better news than I was expecting so it gave me some encouragement to work on a couple of things and have a structure again.

What advice would you give to new patients?

I think everyone going on TPN should look at the benefits of it. There are plenty of forums online where people talk about the negatives. I feel that a lot of the issues people have are related to their underlying condition as opposed to TPN itself. You will probably hear plenty of stories on what you can't do when being on TPN. But I honestly think TPN can open a world of opportunities that you didn't have before. For example in my case I was able to travel to the US for 4 weeks last year when I was on TPN 7 nights a week. This definitely would not have been possible in my case if it wasn't for TPN.

Secondly, I would stress how important good line care is and under no

circumstances should you try and take short cuts. Even though the nurses drilled into me how important it was. I was actually a bad patient to begin with and tried taking short cuts which led me to getting sepsis. But since I took the proper steps I haven't had an infection in over a year and a half.

And finally, I would like to stress how discrete the actual set up is. The pump is tiny and there is a bag that is provided that almost looks like a laptop bag where you can put the TPN and pump. This allows you to have the freedom of leaving the house while being connected. I have climbed mountains, flew, shopped, worked, jet-skied etc all while being connected.

Testimonial about our homecare services

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I couldn't praise the service Fresenius Kabi offer enough. There was a time that I moved to a different hospital and they worked with a different provider but I was adamant that I wanted to stick with Fresenius Kabi. Edel and Sammy in the office are always so helpful and really go out of their way to help me in any way they can.

The nurses have also been fantastic and honestly were so flexible around my college and work when I first started and are always available to take calls when you have any concern or if you have general

questions related to TPN. But I have to make a special mention to Maggie, she really went out of her way the first time I flu when I was on TPN. I had concerns that I might be prevented flying so she actually went ahead and called the airline to notify them of my circumstances and she even checked in with me on the morning of my flight to make sure I got on ok. The flight if I recall was sometime before 6:30 am.

I almost forgot to mention the delivery drivers that work with Fresenius Kabi. They have also been fantastic and I have never had any issues with my deliveries.

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What is the best thing about the homecare service?

I couldn't pinpoint one thing in particular but I think the staff as a whole make the home care service the best that it can be. The reason I refused to move to a different provider is I felt it would be next to impossible to get the same level of service elsewhere.

Patient Associations

I joined a Facebook group and it was helpful when I had questions about travel especially to the states. However I am not sure if I would be advocating for new patients to join one as sometimes these forums are used when patients are down more so when things are going well. So for a new patient, it could cause a lot of needless worry.