



**FRESENIUS
KABI**

caring for life



Patient case study

Patient information

Name

Siobhan

Age

18

Treatment duration

16.5 years

Background

Reason for home artificial nutrition:

Background Cystic Fibrosis- Initial severe reflux, nasal gastric to nasal jejunal feeding, Nissans and peg fitted at 1yr, continuous feeding regime initially to a night time support eventually 1000mls/1500 kcals on top of daily intake

Length of time you were not well before treatment:

1yr on tube feeding regime

Experience on home artificial nutrition

When I was born with Cystic Fibrosis I was fitted with a microgastric tube in my stomach from 1-5yrs. I was totally dependent because I had such an aversion to food (None by mouth until 5). This was due to the fact I vomited an average 20 times in a 24 hour period. I then began to swallow liquids such as water and actimels at around the age of 5. Before this, I would have been given bolus' of feed throughout the day and then I was on continuous feed overnight. As the years passed, I was on a normal food diet during the day and then continued to be supported by the peg feed at night. After transplant, my appetite was completely normal and I stopped the peg

tube feeds all together. My mickey tube was removed in February 2020 when I was 17 and I am now completely independent from it. Even though I was quite dependent on my peg tube feds growing up I did not let this restrict my life and tried to have as normal as a childhood as possible. As the pump itself was so small I was able to transport it and bring it places with my easily which allowed me to continue with life as normal. It comes in a very compact bag that you can carry whilst on a feed. The bags that the feed come in are very secure and once primed they are hung for the day. The pump will only alarm if the feed is not sitting upright.

Describe your daily, weekly routine including hobbies and activities

My daily routine consisted of physiotherapy, nebulizers, medications and many inhalers. I also attended many hospital appointments and admissions when I was ill. As well as this, I really enjoyed swimming, walking my dog and going out with friends.

What is the best thing about the homecare service?

The ease of access to a homecare specialist to resolve any problems. They would call to get services done on pump and sort out any stock issues on tubes. The homecare staff were really helpful.

What advice would you give to new patients?

Don't let the fact that you are on home feed prevent you from living a full and normal life. They did not stop me from having sleepovers with all my friends as we planned in advance and I was able to manage my own care after a few years. It does become very much a normal thing for me with my feed.

Patient Associations

I had the support of the CFI. They were very helpful to make me aware of grants and supports available. They also provided access to support networks.