



I am twenty one years old and I live in Carlisle. I have a twin sister and she is totally fine and healthy. Due to Ehlers Danlos Syndrome (type 3) (EDS) I have full intestinal failure and gastroparesis. As a result of this I am fully dependent on **Total Parenteral Nutrition** (TPN). I am unable to eat, take any enteral supplements or feeds. Previously I did try naso-gastric and jejunostomy feeding but neither worked for me.

I've been on total parenteral nutrition (TPN) four years now, **15 hours, six days a week**. I also have an ileostomy stoma and a urostomy bag (for my bladder as it's also failed due to the EDS). I also have a percutaneous endoscopy gastrostomy (PEG) to drain my tummy to help reduce the sickness and

# Always Think Positive

Jodie



vomiting. **My mum does most of the procedures** related to my TPN. When I feel well and I'm not too sore and tired I sometimes manage to disconnect myself.

### Life on home artificial nutrition

**(HAN):** I have a dog call Louis, I love spending time with him. Snuggling up with Louis when I am having a bad day makes all the difference to me. Odins is our family dog, a big Newfoundland – not as cuddly!

Helping other people is really important to me. Two years ago I started raising funds for a local charity and I continue to **use my personal experiences to help others**. My life is full of ups and downs but I always bounce back. If I can help or inspire someone else to face their own personal negative experiences then I feel I can make a difference. I truly believe that despite having health issues and treatments we can all achieve our goals. **Helping other people** see this is important to me.



Knowing that despite not being able to eat I can still receive all my nutrition from TPN is a comfort. TPN has provided me with **a good quality of life**, despite all that is associated with it; I feel so much better since I started it.

It's important for me to be part of a group; we all have an understanding of the day to day issues and how it impacts of our lives and those of our family and friends. PINNT continues to network to help improve life on HAN for those who need it. This provides a **huge sense of hope** for the future. Just knowing that our views and experiences are contributing to improvements and a better understanding of HAN means so much. The PINNT community is amazingly positive, friendly and approachable. It's good to meet other people on home artificial nutrition; we inspire, support and encourage each other to live a relatively normal life.

My hope for the future is to keep as well as possible, **enjoy life** and carry on helping charities while always trying to do a little bit more.

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**HAN**

Home Artificial  
Nutrition  
Awareness Week

10-16 August 2015



**PINNT**  
www.pinnt.com  
info@pinnt.com  
Tel: 020 3004 6193  
or 01202 481625



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**PINNT: "Supporting people on home artificial nutrition"**

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