

In 2009 I was diagnosed with Severe Gastroparesis. Two years later in 2011 it was confirmed that I had intestinal failure related to a diagnosis of Mitochondrial Neurogastrointestinal Encephalopathy (MNGIE). For the past four years I have been on total parenteral nutrition (TPN).

My medical conditions and treatments are time consuming and I never know when I will have a 'good' day or a 'bad' day. I try to work on the basis that every day will be a good day so I can enjoy my family and my life.

Little Miss Sunshine





Life on home artificial nutrition

(HAN): My nickname, Little Miss Sunshine, was given to me by the nurses on the team when I started my TPN. Smiling helps me cope and I want people to see me as person and not someone with an illness.

We recently moved from London. I now live in a lovely little village near the sea in north Somerset with my husband Eric and our daughter Jordan. I still travel back to London for hospital appointments and to see family and friends.

TPN is my lifeline that has **given me back some quality of life** and has allowed me to still do some of the things I enjoy, such as travelling within the UK and abroad and socialising with family and friends.

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PINNT: "Supporting people on home artificial nutrition"



Relying on TPN is very challenging and it's easy to feel isolated. However the support from family, friends and PINNT, and the network it provides, has helped me to **face these challenges**.

Having access via PINNT to fellow patients, companies and healthcare professionals has helped me cope with a smile on my face. PINNT provides a reliable platform for information.

My hope for the future is to be play a greater role within PINNT. I am joining the executive committee this year and following on from some the other meetings I have been involved with, I can help PINNT with a very busy agenda. No doubt I will be learning new things along the way as well as using my personal experiences to help others.

