AMY'S STORY

When I was a baby my mum and dad took me to hospital, because I wasn't eating properly. They didn't know what was wrong with me.

So they kept referring me to several hospitals until we visited the Royal London Hospital.

They discovered I had short gut syndrome. So they gave me a Hickman line, and parenteral nutrition (PN), so that I was still getting fluid as I couldn't eat properly.

Age of patient
11 years old

Reason for home artificial nutrition
Short gut syndrome

Type of Therapy
Parenteral Nutrition

Length of time patient was not well before treatment
6 weeks

Country
United Kingdom

AMY'S STORY

BRIEF STORY ABOUT EXPERIENCE ON HOME ARTIFICIAL NUTRITION

When I was little I had PN, every night and half a day. And when I was at Primary School, I had a little blue backpack on my back, and I had the pump in it as well as the fluid bag and everything else.

I overcome my fear by saying to myself, I can go outside, as long as I'm careful and don't spoil my line. When I first saw a video of someone living with parenteral nutrition, on Facebook on my mum's phone, I realized that other people have a line and PN through it like me, and it made me understand that I'm not the only one, other people have it as well.

ADVICE TO NEW PATIENTS

AMY'S MOTHER: The advice I would give to a parent or carer, starting out on their PN journey, would be I think to have faith in themselves, and trust their own instincts, give themselves a break, it's a lot to take on.

And don't be afraid to talk to medical professionals, they're not scary. They're amazing and they very often are glad you are asking the questions that you are asking, and wanting to know what is happening to your baby.

Your baby doesn't have a voice, so you are their voice. And just trust in what you believe in.

AMY: The advice I would give to other children would be, to try your best, and never think that you're not like other people, because there's more people like you.

DESCRIBE YOUR DAILY, WEEKLY ROUTINE INCLUDING HOBBIES AND ACTIVITIES:

I go to a Safari Park every Christmas and I have lots of fun. Going on the santa train, going to the zoo, it's really good. It just means I take my line stuff with me. But I still enjoy it whilst I am there.

On Sunday we got our new dog, Lottie, and she's half Springer, and half Cocker Spaniel, so you call it a Sprocker, she's really bouncy, and she's really fun.