

### **Can you please tell me a bit about Charlie?**

My son Charlie is 5-years old. He is like a firecracker; he literally does not stop from the moment he opens his eyes to the moment he closes them at night. He loves to play with his games, loves his little action figures and anything that is active. He is a very sociable little boy and he loves to be around people.



### **What was Charlie's diagnosis?**

When Charlie was first born, he started vomiting straight away. He tried different medicines and had to have several endoscopies to check his oesophagus as he was sick all the time. They did routine blood tests just to rule things out and when the results came back, they diagnosed Charlie had two abnormal chromosomes. This is when it all started, and Charlie has now been tube feeding for about a year.

### **How did you feel as a mother when you were told Charlie needed tube feeding? What were your concerns?**

As a mother when you are told your child needs to tube feed it is soul destroying. I found it difficult to accept the situation and was very resistant. I kept thinking Charlie would eventually eat but with time I realised tube feeding has been a massive blessing for him and now I can give him all the right nutrients he needs.

When I take Charlie to parties or Christmas events, he will sit there at the table with you, he knows what food is and what to do with food, but he has no interest. You can see all the other kids at the table eating their food and all you can think is *Please just pick that up, please just have a taste*, but he won't. He doesn't mind though; he is the most laid-back person you will ever meet.



### **How has Charlie been ever since he has had the feeding tube?**

Charlie is very switched on and ever since he has had a feeding tube whenever we go to hospital he wants to know why, what are we going for and what are they going to do. Sometimes he knows they may need to put a needle in his hand or do a specific procedure and he gets upset but he manages to overcome it. As far as he is concerned, he has a second belly button, but he is just the same as everybody else. He is brilliant.

## How is your relationship with Charlie?

### And how is the support from the Nutricia Homeward Nurse?



The relationship I have with Charlie is fantastic which has really helped us on this journey. I am very honest with him and tell him everything. When Sally, our Nutricia Homeward Nurse came to see us for the first time she brought loads of information as Charlie likes to know everything and understand what's happening. It made a huge difference because Charlie was prepared for what was going to happen and it made it less scary for him.

Charlie loves Sally and she has really supported us getting him ready to go back to school, training the teachers and she is always just a text away. At school Charlie does connect his own extension, but he knows the teachers can help him or Sally and I are just a phone call away. This made everyone feel happier and safer knowing we had been trained.

The support from Sally has really enabled Charlie to have a normal life and not be any different from other children. He is still a little boy who likes to go out to play and live life and just because has a feeding tube that shouldn't stop him.

### What are your hopes for Charlie for the future?

I remember last Easter he pinched a piece of easter egg and ate it. I just looked at him and cried because I thought, *he's actually eating something!* Other people take eating for granted but for me it was *Oh my god, he's eating a chocolate button!* - No words can describe the feeling. My biggest hope for him is that one day he will be curious enough to want to try different foods and one day he will eat.

### What would you say to someone who had just been told they need tube feeding?

My biggest advice to someone who has just been told they need tube feeding is to not be afraid and to listen to what people tell you.

You hear of other people's stories and what has or hasn't worked for them, but I always think try it for yourself and don't worry about what other people think. At the end of the day it is what works best for you. When I don't understand something and confuse myself, I go to Sally because I know that she will tell me the truth and she will guide me in the right direction.

### What was your biggest learning associated with tube feeding?

I have been so pleasantly surprised at how easy it has been for him, how accommodating and how lovely everybody has been because it is scary when you go into something new. Even when he goes to school, I have had to learn how to put my trust in the teachers and that was a learning curve for me. But I have learnt to trust people more and to ask for help. Work with people, don't be frightened because the support and the help you get is amazing and you are not on your own.

- **Sheryl, Charlie's Mum**



Charlie and his Iron man friend share having a second belly button and change the water at the same time!