

CASE STUDY - Riley and Stanley

“The Hospice at Home nursing team has been a lifeline to our family”

Shailza is a mum of two adorable boys, Riley and Stanley, aged just one year apart. Both boys have been diagnosed with a very rare genetic condition involving a duplication of an X chromosome which has left them with very poor muscle tone and requiring constant care.

The condition is so rare that not even the hospital specialists are able to predict what the future looks like for Riley and Stanley - but it is likely they will never be able to sit, walk or speak like other 4 and 5 year olds their age. The family must take each day as it comes.

Shailza shares her story about life with her boys and how the Children’s Hospice at Home team the Pepper Foundation help to fund has become her lifeline. . .

She said:

“I was so happy when I found out I was pregnant with Riley. I’d had a few problems conceiving and had almost given up hope it would happen naturally so when it did, we were delighted.

“Riley grew normally and was a very good baby, and it was not until he was about 4 or 5 months old that I started to think things might not be right. Riley became seriously ill when he was 6 months old and my GP sent us to the children’s Accident and Emergency department where the consultant said something was wrong and was concerned that he was not holding his head.

“We were referred to specialists who started to ask about our family history. It was only at this point that I connected some events that had occurred in my family and realised that there might be a hereditary genetic problem. There followed a raft of genetic testing for members of my family and the disorder, which affects only males, was identified.

“By this time Riley was 8 months old and I was already 20 weeks pregnant with Stanley. We had found out that he was a boy and we knew that there was a chance he would have the disorder too, but it was only a chance and as it wasn’t possible to test Stanley at this time, I couldn’t consider a termination - there was a chance that he would be fine.

“The extent of the effect of the condition on Riley was becoming apparent at this stage. He could not sit or roll over and it was clear that he was not going to be able to walk. He also did not develop speech and could not do anything for himself. Life became a constant round of hospital appointments and managing Riley’s care around the clock which was exhausting.

“We were referred to the children’s Hospice at Home service and they began a weekly three hour respite visit when one of the nurses was able to take over all of Riley’s care needs to give my husband Daniel and I a break.

“Stanley arrived three weeks early by emergency caesarean as he was breach. The hospital checked him for muscle tone and they said he was fine. He was a strong baby and very different to Riley, so I convinced myself that everything was ok. I didn’t even ask for a genetic test.

“When he was three and a half months old I took him to India for my sister’s wedding and the minute my Auntie saw him, she said he was the same. She could see it. I was very emotional but we decided to ask for the genetic test which confirmed what we had feared, Stanley was affected in the same way as Riley.

“It was at this point that worries for the future really hit me. I felt very scared about what would happen and what our life would be like. Would the boys die and how would Daniel and I cope?

“But we are coping. The boys’ smiles really keep us going and the children’s nursing team play a large part in helping us cope too.

“It is immensely reassuring to know that the Children’s Hospice at Home nursing team is only a phone call away, 24 hours a day, every day of the year. The whole team is fantastic and feel like part of the family.

“Caring for both boys round the clock is exhausting. The boys’ needs are increasing all the time but with the help of the nursing team, we are accessing as much extra support as we can.

“The Children’s Hospice at Home service the Pepper Foundation help to fund has been a lifeline for us. It is very important to have someone you can rely on. It is so reassuring to know that if we ask for help and advice, it will be given without hesitation, whatever time of the day or night.

“We are just taking each day as it comes. We don’t really know what the future holds but with the nurses just a phone call away, we face that future with much more confidence than we would otherwise.”