



children's hospice

SOUTH WEST

Registered Charity No. 1003314

Case Study



Marie from Bridgwater has 2 children, Daryl 10 and Aysha 9, her son Lloyd sadly died when he was just 2yrs 5 months old. She has used Little Bridge House in Fremington for respite care, with Aysha who has a life-limiting condition, for the past 7 years. "I was concerned about using the hospice because the word 'hospice' seems so final, but it couldn't have been more different to what I imagined, it is like part of our family now"

Marie explains about Aysha's condition

"When Aysha was born at just 26 weeks she weighed less than a bag of sugar, just 1lb 14oz. The doctors at Musgrove Park Hospital in Taunton warned me that she could 'go at anytime'. Aysha is life-limited, she has cerebral palsy and Renal Tubular Acidosis (RTA) means that she needs round the clock care, is prone to fitting and can stop breathing at any time. Despite this, she continues to fight against the odds, even overcoming numerous chest infections, removal and then re-growth of her tonsils and adenoids and kidney rejection. In the face of all of this, I love her to bits and would not be without her, which is why the care and support we receive at Little Bridge House is so vital"

Aysha has a respite carer for 1 ½ hours a week at home, giving mum a precious moment to herself, but other than that, Marie is the full time carer for Aysha.

"Coming to Little Bridge House for our respite stays are brilliant, Daryl loves the attention and fun he has with the sibling team, he has been coming since he was 3 so he sees the sibling team as if they were his Aunties. Aysha loves it to, she is

so well cared for by the care team, Christine our care contact is just wonderful, and I trust her with my life.”

As is common in our families, it is often hard for parents to let go of the care and let themselves have a rest.

“I find it very hard to let anyone else care for Aysha, although I have been coming for the past 7 years, it was only on our last visit that I left Aysha’s full care in the hands of the care team and went out for the day. It was hard to do, but I will do it again. It was Daryl my son who made me do it she explains. Daryl said, “I told mum we had to make a deal that she would let the care team look after my sister while mum went out. She spends all her time looking after Aysha so I told her she needed some time on her own. I was very pleased when she went out and had a break”

Daryl is very protective of his sister and likes to be involved in her care. His time at the hospice allows him to do normal things a 10 year old would do, he says his favourite rooms are soft play and messy play where he creates his masterpieces!

Marie explains how the support of other families in the same situation has been helpful.

“Meeting other families is great as I am able to contact them when we are not at the hospice and we can give each other support. The families are also very understanding of each other, if there is an emergency for another family, we will move our planned respite to another time. I am happy to do this as I know that the other families would do the same for me if Aysha needed emergency care at short notice. The greatest thing about Little Bridge House is knowing that when we need their support they are always there, that means so much to us”