Clare and Ben have three children: Connor, Esther, and Zachary, who was a surprise baby for them. Ben works full time and the family have no relatives nearby. When Esther was six weeks old family picture suddenly became very far from normal. After being called for a routine blood test Esther was diagnosed with Diamond Blackfan Anaemia (DBA), a disease so rare that only 125 people in the country had it, each of them with their own unique set of symptoms. Progression of the disease is different for each sufferer so it’s virtually impossible to predict the future treatment path for them.

For Esther, her steroid medication has been working well, stimulating the bone marrow to produce more red blood cells, but how long this can be continued is unknown. For Esther, the DBA syndrome also resulted in profound deafness in one ear, which has affected her education and her daily life. As DBA is so rare, even medical specialists are not wholly informed about the disease, so Clare’s contact with other parents of DBA children and social media groups has been important for her. She needs to be on the alert for any changes in Esther’s condition which might reveal that the treatment is no longer as effective as before.

A further blow for the family came when Zachary was three months old and was also diagnosed with DBA. Both Ben and Clare were tested but were not found to be carriers. This was a shock for them, and Clare said that it really knocked the family off course. Unlike his sister, Zachary didn’t respond to the steroids, didn’t sleep, and didn’t gain weight either. Admitted to hospital again at five months old, his future was somewhat unknown.

It was at this point that Clare contacted Rainbow Trust Children’s Charity to ask for some help. She wasn’t sleeping properly, and her mental health was reaching her limits. They met Christina and Nicki, Family Support Workers, who provided practical help by coming to hospital appointments with them - with three children this was invaluable – but, equally important, they were able to give Clare the vital emotional support she really needed. Looking after two children with complex needs along with an 11 year old had left her feeling isolated. In her words “with Nicki’s help, we feel human again, having someone there just for us, somebody who is independent and professional who understands our situation. It really does fill that gap when you have a family in crisis.”

Rainbow Trust’s Family Support Workers can give more than just logistical help, they can also provide that emotional support that is so crucial for families struggling to stay afloat.