When Hope was just a year old, she was diagnosed with severe asthma, severe angioedema, inflammatory bowel disease, seizures, and coeliac disease. These are all conditions with unpleasant symptoms and have resulted in well over 200 hospital admissions, physiotherapy four times a day, and 22 daily medications.

As Hope admits, life has been a real struggle, as she is so restricted by all her conditions. Friendships have been tough to maintain when she has been unable to get out and about, and coping with a world that is not always accepting or understanding of illness has been quite a challenge for her too.

Help for Hope and her family came in the form of a Rainbow Trust Family Support Worker. Amanda has supported the whole family for several years, through some very difficult times. Visiting Hope either at the hospital or at home, she helps her with arts and crafts or simply chats with her. As Hope says, “Amanda makes it fun, she’s great company that isn’t my mum!” Now in the sixth form, Hope has made some great friends and would like to work with children and be a teacher if she can.

For Hope’s mum Sharon, having Rainbow Trust there for them has been a lifeline, supporting the family both emotionally and practically - especially the latter – particularly with hospital appointments. Having so much information to take in, the addition of someone else being there to listen and hear what the doctors are saying is invaluable. Just having Amanda to keep them company makes the sometimes very long waits at the hospital more bearable for Hope and Sharon.

For the rest of the family, Sharon’s husband Jim and Hope’s three siblings, Elise, and her two brothers - both of whom have autism and learning difficulties - the support from Rainbow Trust has been vital. Sometimes Amanda will sit with Hope in hospital so Sharon can be at home with the boys, which also means that Jim doesn’t have to take time off work. At other times Amanda takes Elise out for playdates or simply sits and talks to her, giving her some respite from her role as a young carer.

For families like Hope’s, Rainbow Trust has provided some desperately needed support. Thousands of other families with a very sick child also need that support. Funding for more Family Support Workers could bring help to them as well.