



About Contact

Contact is a UK charity which supports families with disabled children. They provide information and support, run workshops, host family events and also have services such as By Your Side which supports families when their child attends hospital.

By Your Side

Parents need support in how to navigate being a parent-carer and knowing where best to get support, when their child has complex health needs as well as additional support needs. Contact's Parent Adviser visits the Queen Elizabeth Hospital in Glasgow once a month to meet parents and supports them through their initial request for help, via phone, email and meetings. In this case study we hear about one family's experience of using the By Your Side Service.

This parent has a child with Tuberous Sclerosis complex - a rare condition affecting around one million people worldwide. The child is nasogastric tube fed which requires full assistance. They also need help with their personal care. This child has daily seizures requiring 24/7 supervision, has a complete loss of left visual field and a cerebral visual impairment which adds a danger to daily tasks. Their child also has a motor disability meaning she is a full-time wheelchair/supportive chair user. The child requires full supervision and assistance with each daily task.

The parent described how they were struggling with the number of services involved in the child's care and the services not communicating well with each other. On top of being a parent-carer they had to organise all the child's medical appointments, medication, and information daily. The parent described how it could be very difficult to access services because of the need to use certain 'key words/phrases' just to be deemed as needing help. This was very difficult to navigate and could be very upsetting. Contact's Parent Adviser supported the parent by first getting them to contact their local carers centre and social work to receive a carers assessment and made them aware that their child was entitled to a list of different assessments. The parent hadn't been aware that they were entitled to a Carers Assessment and their child was entitled to a Section 23 assessment and others.

Since talking with the Parent Adviser both assessments have now progressed. They were also talked through different housing options and associations to apply to so they could find help with the unsuitable housing situation and find solutions to accommodate their child's needs. The child also needed a suitable adapted

wheelchair, and the Parent Adviser provided a list of potential organisations who would be able to assist with the costs of a new wheelchair for their child.

This support helped the parent's mental health, which made a huge difference to how they were feeling. The parent said, "I feel I have someone who understands, is supportive and is on my side."

"Thank you for being there to listen to me and support me when I needed it. Without your information and excellent support, I would not be as far along in our assessment processes, and I won't have had all the information the Parent Adviser has provided, and I suspect my mental health would have suffered further."