

Baby Eva - Complex care from birth

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Eva was delivered via emergency caesarean section in November 2018. Her parents, Esther and Sam, were both fulltime teachers and were unsure what to expect as new parents.

Eva was born with a rare condition called KCNQ2 Mutation Class V, which causes seizures.

She was also diagnosed with global developmental delay, learning difficulties and gastroesophageal reflux.

This was a shock to Esther and Sam and the reality of a new baby with complex care needs felt daunting.

Navigating care at home

Before Eva was discharged from hospital, she had to have a nasogastric feeding tube inserted to support her hydration and nutrition.

This is a narrow feeding tube placed through your nose down into your stomach.

This carries risks such as displacement and incorrect insertion but without it, Eva would not be able to eat and drink enough to maintain a healthy weight.

The prospect of managing this as new parents was understandably scary.

The family were granted a care package by their Local Authority to help support them when they returned home.

The first days following hospital discharge saw the young parents become extremely exhausted.

To give Eva their full attention, they began caring for her in a shift pattern. One of them cared for Eva during the night, and the other during the day.

But this meant that they had to give up the jobs they both dearly loved.



While they were grateful for the help from healthcare professionals, the coming and going of many different people and the logistics of managing different third parties, as well as Eva, soon became overwhelming.

They craved structure and it became evident that a specialist provider was required to help them navigate the clinical challenges of Eva's care.

Consistent support

We were brought in to deliver a care package to support Eva and her family at home to give Esther and Sam some much needed consistency and respite.

We began providing support for four nights a week. We provided consistent and experienced healthcare assistants that gave Eva and her parents the care and support they needed.

This allowed them to develop a routine, so they could regain some control and balance in their lives again.



After just a few weeks of our support, Esther and Sam fed back how our support had allowed them to feel more organised and relaxed.

Sam even felt able to recommence his duties as a teacher.

Eva's bespoke care

While our input made an initial difference to the family, Eva had very challenging complex care needs, and the care we provided needed to be flexible.

Eva was at extreme risk of regurgitating her feed into her lungs, known as aspiration, due to her reflux disorder and her frequent seizures meant she was also at risk of choking.

These complications meant that Eva was in and out of the hospital with infections, prolonged seizures and breathing issues.

To reduce the number of hospitalisations, we provided personalised training for Eva's needs so our healthcare assistants could manage the nasogastric tube when feeding and medicating.

This means we can ensure baby Eva doesn't aspirate as often, reducing her breathing complications.

Eva had an operation called fundoplication to stop her regurgitation problems. Her nasogastric tube was also replaced with a gastrostomy tube that goes directly into her stomach.



This is a much safer and long-term solution to Eva's feeding needs.

Here we provided further bespoke training so our healthcare assistants could manage her PEG.

Building on improvements

In the last two years, we've worked closely with Eva and her family to develop care techniques that work for them.

Our support and continuity of care has helped to improve Eva's health by reducing the frequency and severity of her seizures.

We've built a great relationship with Esther and Sam and they are happy with the support we've provided so far.

They now have a consistent care team that help them to feel more supported while offering structure to their lives.

Esther said, "You've been a lifeline for us. We're able to have some much needed respite, knowing Eva is being cared for by highly trained healthcare assistants who know and understand her needs."



Visit our website to find out more about complex care for children and young adults.

About Us

We provide nurse-led care and support for people under the age of 25 who have a variety of complex care needs.

Our personalised care helps individuals remain at home with their families and within local communities – **where they belong.**



Get in touch

Contact our friendly enquiry team to discuss how we can support your child, young person or client.



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