

Caring for Cleo's complex care needs

Visit our website to read more stories!

Having a baby can be a magical experience. But for new parents Jess and Charlie, it has also been the hardest time of their lives.

When their daughter, Cleopatra (Cleo), was born a month early in December 2020, their world turned upside down as they embarked on an unexpected complex care journey ...

Unexplained health needs

Despite lots of tests and monitoring, when Cleo was born, she weighed just 3.6 pounds and it was clear she had some unexplained health needs.

After a month being cared for around the clock by experts, in the neonatal intensive care unit (NICU) at King's College Hospital in London, the family were finally discharged.

But the following weeks were far from the newborn bubble they'd expected.

Jess, Cleo's mum, said, *"We had a few stressful weeks at home with her not growing, not feeling well and her breathing was very laboured. Then in March 2021, we ended up at the Evelina Children's Hospital."*

This is a specialist hospital in London specifically for children and young people with health conditions. Here, they identified a grade four upper airway tracheomalacia and bronchomalacia.

These rare conditions cause collapses of cartilage, blockages and secretions in the airway, making it difficult for Cleo to breathe by herself.

After a number of touch-and-go moments while Cleo was in hospital, it was decided she needed a tracheostomy to stabilise her breathing.

It was Cleo's third surgery in five days, leaving her new parents exhausted with worry and tiredness.



Thankfully, the tracheostomy surgery was a success. Sadly though, because of her narrow upper airway and unsafe swallow, Cleo became completely food averse and needed a percutaneous endoscopic gastrostomy (PEG) fitted.

But things were improving and finally, after long days and even longer nights, Cleo was ready to go home.

Returning home

Cleo's tracheostomy and other complex care needs requires 24-hour care. This meant a care provider and specialist equipment needed to be in place before she could return to the family home.

Jess recalled, *"At the time, I just wanted to get home and didn't care if there were carers coming in. But I very quickly realised how essential that was for us."*

After an assessment, the Clinical Commissioning Group (CCG) agreed to fund five nights of care and support so Jess and Charlie could get some sleep.



*"We were getting impatient, and didn't know how it all worked, so I started looking for care companies. **Voyage Care** jumped out at me and I just fell in love with the company. Then when the discharge nurse informed me they would be our care provider, I was so happy!"* said Jess.

Shortly after, one of our Nurse Managers called Jess and Charlie to explain how the process worked, answer their questions and arrange a meet and greet with the two Healthcare Assistants (HCAs) who were selected to support Cleo.

Jess remembers the meet and greet and said, *"It was quite nerve-wracking, but we quickly clicked with the two HCAs, especially Monica. When she first met Cleo, she gave her the biggest cuddle and just said, 'me and you are going to be best friends.' It was so heart-warming."*

Making a difference

Since that first encounter in July 2021, we've provided Cleo's family with complex care overnight so Jess and Charlie can recharge their batteries.

This is provided seven nights a week, topped up by Jess and Charlie privately.

"If we didn't have them, I truly don't know how we'd survive. To not have our angel carers coming in is not worth thinking about," said Jess.

Importantly, Cleo has made good progress since **Children's Complex Care** have been supporting her.



She's only had one stay in hospital and has recently started sitting unaided.

This marks a big step in her development, providing much needed reassurance for Jess and Charlie, who are still navigating their new complex care world.

Looking to the future

The cause of Cleo's complex care needs is a mystery. Despite endless genetic tests, genome sequencing, surveys and scans, specialists are still no closer to a diagnosis.

For Jess, this has been one of the most difficult parts of their complex care journey.

She said, "During our extensive time in hospital, we met families that had something to explain their baby's situation, delays or development problems. For us, not knowing or having a benchmark, is a really difficult place to be."

For now though, Jess, Charlie and Cleo are taking it one day at a time; together. And we're delighted to play a part in making that possible.



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.



020 7407 7704



CCCreferrals@voyagecare.com



www.voyagecare.com