

Freddie the fighter

Freddie is one of the amazing children we support. A funny, creative, curious bundle of joy and energy, Freddie comes to ARCOS for speech and language therapy and stimulation.

Charlie, Freddie's mum, tells the story of her incredible little boy, the challenges he and the whole family face, and how ARCOS is making a difference.

At birth, Freddie was a 'ghost baby', having lost 70% of his blood whilst in the womb. Not breathing, and with no heartbeat, he was quickly resuscitated but, having been oxygen deprived for so long, his prognosis very poor. Suffering continuous seizures, we were told he only had a 1% chance of survival.



Not only did he survive, he thrived.

Freddie was born fighting and has never stopped. Diagnosed with Hypoxic Ischemic Encephalopathy 3 (HIE3), the most severe form of brain damage caused by oxygen deprivation, Freddie has extensive and widespread damage throughout his cortex. Upon leaving the Neonatal Intensive Care Unit we were told that Freddie's best chance to thrive was by stimulating him through varied experiences and plenty of therapy. Unfortunately, Freddie was born at a time of drastic cuts to the NHS therapy services, which were then exacerbated by the Covid pandemic.

By August 2021, Freddie was four and amongst other conditions was diagnosed with cerebral palsy. This left him with low oral tone, which had significantly impacted his speech. He could only make a few speech sounds and had a small range of monosyllabic words and short phrases. However, despite his clear need for therapy, Freddie had not seen his NHS speech therapist for over a year and a half and every private speech therapist I contacted didn't specialise in children with oral motor problems. We felt abandoned and failed by a broken system.

Becoming increasingly desperate, a fellow cerebral palsy mum told me of ARCOS, having heard of its reputation. And as soon as I looked through the ARCOS website - the aims, the case studies of children so similar to Freddie - I felt I had maybe found what I'd been searching for. After talking to Kay, ARCOS's brilliant director, I felt more positive regarding Freddie's speech and the path ahead than I had in years. Within a few short weeks Freddie had met Kay and her team, we had a thorough assessment, and a plan in place. Finally, Freddie's future was looking decidedly more positive.

In our NHS sessions, Freddie had never spoken, refusing to take part in activities or even acknowledge the existence of our therapist. Contrastingly, he cheers whenever we go to ARCOS to see who he lovingly calls 'my Kay'. He adores spending time with Kay and, with her cheery and ever positive persona, she knows exactly how to engage him. The

sessions are full of fun, guided by Freddie's interests. And because she knows Freddie so well, any activities and targets are perfectly designed to help him take the next step forwards in his speech.

Moreover, ARCOS has helped us far beyond the bounds of our speech therapy sessions. They provided advice when applying for our ECHP and training opportunities. They have provided equipment such as speech therapy tools and adapted cups to use. And most of all they have lent us an Augmentative and Alternative Communication device, a computer that Freddie can use to help him communicate, for an extended period of time, along with training in how to use it.

With Kay's support I was able to petition the NHS to provide him with his own AAC device, which he now enjoys and is steadily gaining in confidence in using. Without Kay's input this would not have happened.

Since finding ARCOS, Freddie's speech and ability to communicate his thoughts have improved dramatically. Previously, he was virtually silent beyond his closest family. Now he is becoming more confident in talking with a variety of adults in increasingly longer and more complex sentences.

He is even now able to communicate with his peers. For the first time he has friends.



At times I worry that people do not see beyond Freddie's long list of diagnoses. That assumptions about his ability are made and this holds him back from reaching his potential. At ARCOS this is far from the case. Freddie is loved and welcomed with open arms as part of the family.

They see what I can see. Not a damaged child but a little boy with a bubbly and brilliant personality who has so much potential and so much to offer the world.

