

## Home-Start Oxfordshire Consortium

**Facing the challenges of becoming a new mum while dealing with neurological conditions affecting her mobility left Lizzie feeling totally alone and frustrated. Support from Home-Start Oxford has helped her find light in the dark...**

When I found out I was pregnant I was elated, but at the same time I felt a deep sense of anxiety about how I was going to cope as a disabled mum. I suffer from two neurological conditions; Episodic Ataxia and Postural Orthostatic Tachycardia Syndrome. As well as having trouble walking, balancing and swallowing, I can suffer from bouts of vertigo and when I stand up my heart rate rockets and I can pass out.

I was so worried about how I was going to move around the house with a baby, and push a pram. I just wanted to feel happy and confident about becoming a mum but the worries about practical things really got me down.

When I found out that Home-Start support was available in Oxford it was such a boost. At first I was supported by Lisa, one of the Family Support Coordinators (who has been a fantastic 'cheerleader' throughout), and then in October last year I was matched with the amazing Silvia. As a parent Silvia really understands the day to day pressures and what I'm up against. I never have to explain why I want to do things – she just gets it.

Our Zoom chats have been invaluable and Silvia really helps me think outside the box. She's a life coach and so it just feels like the perfect match! Together we've thought about all of the challenges that face me - even what would seem like simple things like standing to prepare meals, or tidying toys away - and we've come up with workable solutions. She's also helped me think about 'safe spaces' to put Eli should I have an attack (which can be like a stroke or being really drunk) when home on my own.

Housework goes up so much when you have a child. My husband, James, is a fantastic carer to me but he already does so much, he can't keep on top of everything. And that's the thing, I don't want other people to do everything for me. I want to be Eli's mum. I want to cook meals and all of that stuff. Sylvia has helped me adapt the cooking, now I buy prepped veg and use the slow cooker so I don't have to stand up stirring a pan for ages. What I love about having Silvia's support is that she helps me work through things. She doesn't just come along and tell me what to do. I'd hate that! I want to overcome the challenges myself.



One of the biggest challenges I've faced is how to get out and about with Eli. I'm able to drive, and on my own I could get about, with my mobility aids, quite independently, but adding a little person into the mix changed everything! I knew I couldn't walk and push a pram so I did start investigating a charity that could help make me an adapted vehicle, but lockdown meant that option was shut down. To be honest at that point I felt pretty defeated, and from October when we were back in Oxford we pretty much stayed in the house for 6 months. Eli's Dad would take him for a walk sometimes to see the outside world but other than that we were stuck indoors. Back then I really had no idea what the light at the end of the tunnel might be and that was really worrying.

Silvia and I did some research into adapting a mobility scooter set up ourselves, but found I'd need a lightweight mobility scooter from Canada, that could fold up and go in the car, and they're really expensive! It was Silvia helping me to set up a GoFundMe page to raise the money for it that really changed everything. We were able to get the money together within a couple of months and in April Eli and I got our 'magic wheels'!

We're now getting out of the house most days, and have been exploring the area together – visiting shops, parks and even the fair! We still face challenges, for example it's quite long so won't fit into some shops, but Silvia and I have been doing loads of research and finding out what works and what doesn't!

The other week Silvia was away and I really wanted to take Eli swimming. People have said 'why don't you get his dad to take him' but that really upsets me. Why should I have to miss out on that experience just because it's a challenge? I thought about the approach she'd taught me to take with shops – going to speak to the manager and finding out how to best access the building - and so off Eli and I went to do a recce. I found out that I could pull up outside the building along the poolside and head straight into the pool. So far we've just sat on the steps and had a little paddle but for me it's been a huge win!

It really is all about confidence for me. Mine gets knocked all the time, and I feel that there are more and more things I find I can't do. But Silvia has given me this new confidence in myself. Now I find myself thinking 'do you know what, why can't I do that!' – I just need to find out how I can do it a little differently.

Now we're also able to go on the Home-Start buggy walks in Witney and meeting other mums in real life has been such a lovely experience. Just getting out every day has a huge positive impact on both of us. I felt like I'd totally lost my independence and freedom but thanks to Home-Start I now have it back!

As Eli grows up I know that we will continue to face new challenges in relation to my mobility, and the adaptations we need to make will evolve, but I now have the confidence to deal with whatever comes our way. For me, Home-Start support has been absolutely brilliant, it's really fills a gap in terms of the support that's needed for all sorts of cases for which there's so specific support available. Home-Start really understand the big deal of the small things!

### **Lizzie's Home-Start Oxford volunteer, Silvia, said:**

"The first time I met Lizzie I could see a really resilient person but someone that needed some self-assurance and some guidance on how to be able to take care of her baby and herself. I worked with her to organise herself in a way that would allow her to do a lot of things she had not been able to do in months, like cooking, organising cupboards, organising a space for her baby to start crawling. She started coming up with her own brilliant ideas, like fundraising for a scooter so she could be more mobile and be able to take her baby out by herself. Until then she had to be accompanied by someone.

Now Lizzie is so much more independent and keeps working on improving her house to make it more adapted to her needs and those of her baby. Really proud of all she has accomplished during these difficult months".