

## Florence's story

Written by Pip Heffer for the 'British Association for  
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As I battled through the doors of Queen Alexandra Hospital, I needed air, I couldn't breathe. I needed to run. Run as fast as I could, scream, and cry... WHY? Why us? Why her?

We had just been given the devastating news that our baby couldn't see a thing. Her precious little world was black. A black hole filled only with sound and touch.

Florence was a surprise conception, but a very welcome and wanted one. Through what seemed a fairly easy pregnancy, as like any expectant mother I had the normal worries. Was everything going to be ok? Were there going to be two arms and two legs? The thought of under developed eyes and no sight never entered my head.

On March 16th 2010 our beautiful bundle of joy entered the world, kicking and screaming. My world felt complete but nothing could have prepared me for what was to come in the months to follow.

I had lost my waters two weeks prior and was advised it was ok to carry her as long as possible to enable her lungs to develop and mature. I was booked in for a planned caesarean section on March 17th. Florence decided to bless us with her presence the evening prior. From that moment, I knew she was strong, a fighter.

Throughout the following days on the Maternity ward, all the regular new born checks were carried out, concluding everything was fine even though Florence was born with what looked like conjunctivitis. The one thing that stands out in my mind, which never did seem quite right, was her eye tests.

We had been assigned a trainee Paediatrician who struggled to examine her eyes as they were so stuck together. After her first attempt, she signed off one eye as being completely normal including the presence of a red reflex but unable to examine the other. She requested we stay overnight and see her again in the morning. Upon examination the following day, she again concluded everything was fine and signed Florence off as having very healthy, normal eyesight.

In the weeks to follow, Florence never opened her eyes. I sought advice from all of the professionals involved with her early care, including four visits to my GP, querying the fact her eyes were so encrusted and not opening. Each time I was assured everything was fine, that she was a new born, that being born five weeks early explained her lack of awareness! I knew something wasn't right already being a Mum of two and had an uneasy instinct, yet no one seemed to listen.

At approximately ten weeks old, I took her to my GP's surgery regarding reflux. We saw a Locum Doctor whom we hadn't seen before. Following his examination for reflux, he said "What's wrong with her eyes"? I was delighted. At last someone had noticed. Someone else on this planet saw they were not normal functioning eyes. He proceeded to have a good

look at them and wrote a referral there and then to be seen immediately by an Ophthalmologist.

At that time Florence was under private health care so we were fortunate enough to be able to be seen the following day at the Spire in Portsmouth. I will never forget the look on the Ophthalmologist's face, after examining Florence. He looked shocked and seemed unsure as to how to communicate with us. He left the room for some time and upon his return, explained that he had re-referred us to a Paediatric Ophthalmic Surgeon at Queen Alexandra and that we were to drive there immediately. He wasn't in clinic but came in specially to examine Florence.

At that very moment, I knew it was serious. I was petrified, an immense feeling of nausea and heartache. The only information he could provide was that he could not see any pupils in Florence's eyes. No red reflex, just dark little windows to a beautiful soul.

Upon our arrival at QA, we were met by the Ophthalmologist and he spent in the region of two hours examining Florence. My world was about to collapse. No eyesight, no pupils, eyes undeveloped and yet another referral but this time up to London, to Great Ormond Street and Moorfields Eye Hospital.

As time went on, I grew angry at the thought of our baby having spent so long, alone and in darkness. Having been assured time and time again that she was just sleeping lots, I didn't pick her up a great deal other than to feed. The only comfort I could encourage myself with, was that she would have heard and sensed her loving family around her. Her brother and sister who were so desperate to see her open her eyes and engage, as we all were.

It left me empty and full of guilt. I had let her down; I should have been holding, soothing and comforting her so much more. In those first 10 weeks of life, she needed to know life was full of love, not darkness. I felt extremely let down by the system including all those involved in her care up until the point of our visit for reflux!

We went on to attend our many appointments in London being given the diagnosis of:

Bilateral dense cataracts

Bilateral Microphthalmia

Bilateral anterior segment dysgenesis

Florence was also diagnosed with Glaucoma in her right eye last year.

We were initially advised not risk the surgical removal of the cataracts as they were so dense. They had been left too long and the risk of losing the eyes completely was extremely high. The optimistic chance of gaining very limited sight was extremely low.

However, without hesitation, we decided that the risk had to be taken. To gain even a little light for Florence, would change her world. All I could hear was a teenage girl asking me "*Why? Why didn't you even try, Mummy?*" 15 years down the line. It was imperative the surgeries on each eye took place immediately.

This had an enormous effect on our immediate and extended family. Our two other children, Jake who was 9 at the time and Phoebe, 4, were devastated. The birth of their baby sister

was such an amazing and exciting time; somebody had taken a pin and popped their bubble. Neither of them could understand how and why. They saw their parents broken, unable to answer their questions. The feeling of elation in our home had diminished.

Florence's father and I did our best at home, attempting to keep life as normal as possible. Giving time, energy, love and support to all three children. I'm not sure we did a good job. When I look back in hindsight I was absent, numb, lost and broken.

I realised that Jake felt embarrassed. Being of a vulnerable age made it hard for him to cope and to understand why his brand new little sister wasn't "normal". I became aware of this when I went to collect him from school one day and he asked me not to go to his class door with Florence. Something I had always done every school day. It seemed hard for him when his peers asked him questions and like us, he had no answers. Phoebe would constantly ask "When will Florence's eyes get better?", "Why can't she see?".

Their love for Florence was certainly unconditional but it didn't take away the pain and devastation they felt for numerous different reasons. I'm sure there are still a lot of underlying emotions unspoken!

Florence's father and I grew unexpectedly distant. We dealt with Florence's diagnosis in different ways; our inability to communicate our separate devastation was one factor leading to the later breakdown of our marriage.

I spent many months numb, angry and so very sad. He spent months disbelieving; he couldn't accept the diagnosis. On reflection, I think we were both quietly blaming ourselves. We seemed so alone in the world, feeling like we were the only ones this had happened to. Was it my fault? Had I done something throughout pregnancy? There was no one to talk to, turn to or explain the medical details in layman terms. I was bamboozled by all the information. Not having a great knowledge of the basic, normal human eye, let alone one with four defects.

I spent hour upon hour on the internet looking up facts, researching every avenue I could think of from basic facts to treatments around the world. I would arrive in London with a notebook, with lists of questions I needed answered. My questions seemed endless but I think it was my subconscious way of dealing with my grief. I couldn't accept it until I understood the facts, the reasons, the hope and possibilities or future outcome. I was mourning my child's eyesight, the biggest loss of my life. This indulgence into research helped me through.

From the moment of Florence's diagnosis, we were offered no emotional help and support in any way. It felt like we had been sent home with our blind baby and just expected to deal with it and get on with it. A great feeling of pessimism and guilt was present.

There was no follow up from any health professional locally for some time. No offer of emotional or factual support, counselling, advice or written information. I feel the lack of support in the early stages prolonged my transition period to a mother of a child with a visual impairment.

I recall finding it very hard to come to terms with not only the fact Florence was blind but that my life had changed forever as a mother. The needs and expectations had changed

dramatically. We choose to be mothers for the rest of our lives when we conceive but this seemed to take me into a different world. I felt suffocated and that made me feel guilty.

The positives that have come from Florence's arrival come in abundance. Other than being able to give her my own eyes, I wouldn't change her for the world. Florence is now nearly 3 years old, full of life and energy. She is strong, determined, confident and extremely happy.

The removal of the cataracts was successful in both eyes. Florence became light sensitive, more alert and responsive and although her vision is extremely limited, she now uses what she has to the best of her ability.

Many aspects of her development have been delayed, yet she has had the strength and determination to overcome most obstacles and deals with life in an amazingly optimistic manner and always strives to do her best. She copes with every day disabilities in her own way, in her own world. The most positive part for me as her mother, is to have the privilege of watching her blossom into whom she is today. She is an inspiration.

For Jake and Phoebe, I feel it has been tremendously significant in the awareness of disability, whether that be with Florence or anybody else. They are extremely protective of her and Florence has given them an early journey in life, "acceptance". Learning to realise that things happen in life that we have no control over, cannot change and just are! I feel as time has gone on, they have learnt to understand and accept, Florence is Florence.

I have become more optimistic with time, slowly learning how to gain the support that is needed not only for Florence but us as a family unit. It is particularly exhausting always having to seek and battle for help, even at this stage. Whether that is emotionally, for practicalities or financially, to supply and support Florence with the facilities that are required to cater for her visual impairment. Over time it has become very apparent that if Florence was physically disabled alongside her visual impairment, help would be more readily available.

The economic climate seems to have had an adverse effect on Florence's support in terms of continuity of services. Following a very lengthy wait for professional services such as Portage and STAVI, there have been many cut backs affecting not only the consistency of visits but also the staff changes. Both factors have influenced the routine and Florence's opportunity to build strong relationships with the people involved with her care and progression.

I found STAVI very helpful in the early stages. Providing information, explanations of medical terms and offering to research certain aspects of Florence's condition. They have provided me with useful advice in promoting delayed development and have offered certain toys and equipment for Florence to use. I am currently in the process of preparing Florence for Nursery. I have received a lot of support from Florence's Teacher Advisor in terms of communication with the Nursery, providing them with information and ideas to enhance Florence's transition into a social setting. She will be visiting Florence in her setting, ensuring Florence's needs are met and the safety standards are in place.

I have also received occasional support from the Mobility Officer, which has been reassuring and helpful. I have been advised this will be much more frequent as Florence becomes older. She too, has been fantastic in regards to the Nursery setting.

Accompanying me to a meeting and inspecting the areas Florence will use in her sessions, advising of any changes and adaptations that will be necessary to ensure her safety.

Portage, I found extremely beneficial in the earlier stages rather than more recently. They gave me ideas to enhance Florence's development and provided very basic equipment that improved her fine motor skills.

Ultimately these three services have assisted in teaching me how to teach Florence.

KIDS Early Support have been helpful throughout the last two years, offering management of TAC meetings, enabling the professionals involved with Florence to come together and review progress and share ideas. Jake also attended a KIDS Young Carers scheme in 2011 but he didn't find this particularly beneficial.

Within the first year I contacted many Visual Impairment Charities. I was offered support, information and advice from the RNIB, The Eyeless Trust and MACS. I found them all to be exceptionally informative, friendly and available. MACS (Microphthalmia, Anophthalmia & Coloboma Support) have helped us immensely and are whom we have the most contact with. They have been tremendous in offering social events for not only the children with related eye conditions but siblings and families who are made to feel equally welcome.

Florence's Consultant Paediatrician has been fantastic throughout. Initially our visits were relatively frequent but have become more occasional as Florence has progressed and developed. These are the only medical appointments that Florence and I attend in which I feel relaxed, heard and unhurried. The support and advice is informative, referrals always following up and advice is always given gladly if any concerns arise.

My entire experience as a mother of a visually impaired child has been a rollercoaster ride. As I boarded the ride, the operator disappeared and I don't think he's coming back... yet as time goes on, I get more used to the ride and it's becoming more bearable as each day passes. As I watch Florence blossom, I realise I love it and wouldn't change it for the world. She's perfect and so is my ride. (I just have to pinch myself sometimes to remind myself!)

Acceptance has been my biggest journey throughout this experience.