

# Meet Daisy

## Early Challenges...

In the beginning, my pregnancy with Daisy was straightforward. All the scans were normal, although she was measuring smaller than average.

As my pregnancy progressed, I started to become more worried, I hardly ever felt Daisy move or kick. During my whole pregnancy I only felt Daisy kick twice.

I was back and forth to the hospital with reduced movement, but each time I was told that Daisy was just small and that there was nothing to worry about.

When Daisy was born, she only weighed 5lbs. Her brother was 10lbs when he was born so something just didn't feel right.





I had so many questions I needed answers to. I wanted to know what life was going to be like for Daisy. I wanted to know what the future would look like for our family.



Shortly after she was born, a paediatrician told me that Daisy had dysmorphic features. I had never heard this term before, I didn't know what it meant. They said I should have learned that something was wrong during the scans I had when I was pregnant.

I was so panicked and distraught that another paediatrician was called to offer a second opinion. The other paediatrician tried to reassure me that Daisy was perfectly fine, but I couldn't shake off the feeling that something was wrong.

She wasn't feeding properly or gaining weight and despite several hospital admissions we didn't seem to be getting anywhere.

At ten months old Daisy had a seizure. I put her in her bouncy chair and when I came back, I thought she had died.

She wasn't moving or breathing. I called an ambulance and had to give Daisy CPR and try and resuscitate her.

When we got to the hospital a team of 20 doctors and nurses started working on Daisy and eventually after 75 minutes the seizure stopped.

I can't explain the fear of thinking your baby has died. That image will stay with me forever.

Whilst in hospital Daisy was diagnosed with a very rare genetic condition called Wolf Hirschhorn Syndrome. The consultant took me into a side room and handed me a printout from Wikipedia. He said that he had Googled it, and this is what Daisy had.

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Following Daisy's diagnosis, we weren't offered any support, follow up appointments or any further information.

I was sent home with a vulnerable baby who I had very nearly lost. A baby that had been diagnosed with a syndrome so rare, it seemed like no one had ever heard of it.

Our world fell apart as we did our own research about Wolf Hirschhorn Syndrome. We read that it was unlikely that Daisy would live past the age of two.

## Searching for Support...

I have had to fight tooth and nail every day ever since. For tests, for referrals, for appointments. It is a never-ending battle. The nurses at our local hospital call me the Lioness.

There should be more for Mum's like me, for families like us after such a devastating diagnosis. It has completely turned our lives upside down. I feel anxious all the time and I am always frightened.

The syndrome that Daisy has affects anyone who has it, differently. No two cases are the same. I can't look at another child or person with Wolf Hirschhorn Syndrome and think "that's what Daisy is going to be like". The future is so uncertain.

I called the health visitor when Daisy was a few months old because she wasn't meeting any of her milestones. She was like a rag doll. She couldn't sit up or hold her head.

Daisy started having regular physiotherapy sessions and we would go to a specialist early year's playgroup once a week for an hour. But it wasn't enough – I wanted more for Daisy. She needed and deserved more.

As a Mum, you know your own child. I knew that Daisy would need to go to a specialist nursery. At three, Daisy couldn't walk or talk, and she still only weighed 17lbs. I was doing everything I could, but I never knew if I was doing the right thing or if what I was doing was helping Daisy.

I was told by the local authorities that Daisy would get a place at a specialist school but that wouldn't be until she was five years old and even then, she would not be offered a full-time place.

It felt like Daisy was being denied the opportunity to go to nursery like other children. Access to schooling isn't something anyone should have to fight for.

## Finding Hope...

I started desperately looking for somewhere else for Daisy to go. I remembered a parent I had met; her son had the same syndrome as Daisy, and he came to Pace for therapies. She encouraged me to get in touch with Pace and said how brilliant they had been with her little boy.

It wasn't until I made the phone call that I realised Pace was a school and that they had a space for Daisy to join.

I arranged to go and look around the school and on my very first visit, I knew instantly that this was the school Daisy had to go to. After all my searching, I couldn't believe that somewhere like Pace existed.

Right from my very first meeting with them, the staff and teachers were amazing. They were optimistic and encouraging. They said Daisy had so much potential. They said that they would create a learning programme tailored to Daisy's needs and that they would get her walking and talking.

## Fighting for What's Right...

I felt so happy and relieved but at the same time I was frightened, I knew how much I was going to have to fight to secure a place at Pace for Daisy. I knew the fight would be at the expense of spending time with my son and husband and us spending time as a family.

The last year and a half, I haven't had a life. I have just been fighting. Fighting so that the local authorities would grant my little girl access to the education and support she needed and deserved.

I am exhausted. Some days it makes me feel ill. It feels like my whole focus is Daisy and I feel so guilty when I think about my son. I am spread so thinly; I try to my hardest to do it all, but I never feel like I am doing a good job.

I should be taking my children to new places, on holidays and having fun days out but instead I am fighting tribunals.

It took nearly a year to get Daisy a place at Pace. Getting to this point, has nearly killed me. Why should it take that? Why should a Mum be on her knees just trying to get her daughter the education, support and therapy she is entitled to? No parent should ever be told that their child cannot go to school or have the same opportunities to learn and make friends because they are disabled.

I had lots of independent reports carried out, to help support our case, all the specialists agreed that Pace would be a wonderful opportunity for Daisy.



When I found out that the local authorities had agreed for Daisy to go to Pace, I cried and cried. I couldn't believe it. Daisy was finally going to get one to one support, in a specialist special school environment so she could learn and develop.

But the truth is your fight never stops. I am terrified that they will move her – I live in constant fear. I touch wood every day that Daisy will get to remain at Pace.

## What Pace does for Daisy...

One of the first things that struck me about Pace, is that nothing is ever too much of a problem. It's just so lovely here. They go over and above to be able to help and offer support.

The children are at the centre of everything they do. The way they teach is different from other schools. Not only that, they are a lifeline for parents like me. They always ask how I am and if I am ever worried or upset, they take the time to talk it through with me. For the first time since Daisy was born – I feel supported.

Every child is different, Daisy is an individual and that is exactly how she is treated here. She is encouraged and supported to make progress at her own pace. As a family, we have all seen a huge change in Daisy.

Since joining Pace, Daisy is thriving. She is talking more and has learned to use communication aids. Now when she needs or wants something, she can ask for it and she is able to express herself and say how she is feeling.

She tells me all about her teachers and her friends and what books she has enjoyed reading. At the weekends, she'll ask if it is a school day. She absolutely loves school.

When Daisy started at Pace, she would shuffle on her bottom to get where she wanted to go, she couldn't pull herself up to stand for very long. Now she is up on her feet and taking a few steps.

I'll never forget the first time I saw her walk, I was waiting outside the classroom to pick her up and she took five steps towards me, I remember being so excited, I screamed and the teachers and assistants from the other classrooms came out to see what was going on.

Pace have really supported me in being able to help Daisy at home. Daisy has a PODD book which they have helped me learn how to use too. Daisy started using a Scoot at school to help her be more mobile and to encourage her to become more independent. We now have one at home too.

Daisy is flourishing and she is learning all the time. She is learning through playing and having so much fun. She is getting stronger and stronger.

Daisy is starting to do the things every parent is excited for when their child starts school. She gets to go to her friend's birthday parties and school discos. Her brother gets to go along too so we are starting to do more as a family. Daisy absolutely loves her brother. She loves playing with balls and cars. She loves wearing hats and playing with dolls. She has so many. Daisy loves playing with the toy kitchen at school, she loves to pretend to cook and make different things. We bought her a toy kitchen for her to play with at home, which she really enjoys.

Daisy is a strong, determined, funny and extremely loving little girl. Daisy has taught me so much. The biggest thing Daisy has taught me is that Daisy is Daisy, not a syndrome and I am beyond grateful to have found a school that realises this too.