



steps

We don't take walking for granted

Amelie

Diagnosed aged 6 months

Treatment to date:

Closed Reduction, 5 months
in Spica cast, due to go into
Splints

Amelie's story

Amelie was born on the 25th October 2007, she was full term and weighed a healthy 7lb,12oz. We were delighted to have a little sister for Neve our three year old daughter. Neve had been born with Bilateral DDH, diagnosed by ultrasound at six weeks of age. Although Neve's hips appeared normal on examination at her 'baby check', she had been breech and it was routine at the hospital where Neve was born to scan all breech babies. Neve spent four months in a Pavlik Harness, which was thankfully successful.

Throughout my Pregnancy with Amelie I had been assured by various Health care professionals that Amelie would be scanned for DDH due to the strong family history (there is also a female cousin in the family who has been treated for DDH). I was therefore very surprised during Amelie's 'baby check' (the day after she was born) with the hospital Paediatrician to be told her hips were fine (I did comment that Neve's had also appeared fine at her baby check) and that they didn't have it in the NHS budget to scan babies 'willy nilly'. Tired from labour and I suppose happy to hear Amelie's hips were ok I just let it go.

Once home though it began to play on my mind, so at Amelie's two week check with our GP I mentioned it, I was once again reassured that Amelie's hips felt fine. Unfortunately in the following weeks Amelie spent time in hospital with Bronchiolitis. I mentioned her hips to various Doctors on the children's ward (by now

starting to feel like a paranoid mother). I was once again told that on Physical examination they felt fine. Once Amelie was discharged, like a dog with a bone I went off to see a different GP, who also felt Amelie's hips were fine on examination. However I was given a request form to have an ultrasound on Amelie's hip to put my mind at ease. I called my local Hospital to arrange an ultrasound but was questioned by the Receptionist as to why Amelie was having this type of scan (I was quite frustrated by now; you would have thought a request form from a GP would be enough!) I was asked to send in the request form along with a letter from myself explaining why I wanted Amelie to have an ultrasound.

About ten days later, I received a call from my GP to tell me our local hospital had contacted her explaining they didn't have the expertise to scan for DDH and recommended a city hospital. My GP kindly wrote to the recommended Hospital and we received an appointment to have Amelie checked by a Orthopaedic consultant on the 4th April 2008.

Leading up to the Appointment I have to say myself and my husband were not particularly worried. We had been told so many times Amelie was fine, we had come to assume that Neve's DDH was down to her being a breech baby. I basically felt that Amelie's appointment was for my peace of mind and nothing else. The day of her appointment arrived and Amelie was examined by her consultant, it was clear from his face he suspected a problem. He sent Amelie straight down to X-ray. Amelie was diagnosed with bilateral DDH the same day.

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We were told at six months of age her abductor tendons were quite tight and she was now too old for the Pavlik harness, as this could do more damage than good. We were then told Amelie would have to come in to hospital in around six weeks time for a General Anaesthetic and closed reduction (with the possibility of her abductor tendons been cut to ease this procedure) she would then be placed in a Hip Spica cast. I cried the whole journey home, we couldn't take it all in; it was all such a shock.

Unfortunately due to waiting lists Amelie's appointment was changed from May to July. This extra wait only made things harder, by now Amelie was rolling around, sitting up unaided and desperate to crawl. We didn't encourage this as we knew it would only make it more difficult for her once she was in cast. I felt awful watching her rolling around, unaware of what was coming.



The day of her appointment finally arrived; we were very nervous and extremely worried by the idea of Amelie having a General anaesthetic. Our nerves were eased by the stream of caring, knowledgeable doctors and nurses who came to check Amelie before she went down to theatre. We were warned by her consultant that if they were unable to perform a closed reduction, Amelie would be woken up to be operated on at a later date. Only one of us was allowed down to theatre with Amelie whilst she was induced and there was no budging on this. I decided as much as I wanted to be with Amelie, she would probably gain a lot more reassurance from her Dad, who was not yet the quivering mess I had become. We waited around an hour and a half (the longest wait of our lives) before we were taken to see Amelie in recovery. She looked so pitiful and small lying there still fast asleep in her little hospital gown, It was however a relief to see she was now sporting a neon pink spica cast; so her closed reduction had obviously been a success.

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We received lots of advice on the ward from the nurses and occupational therapists. We were shown how to pick Amelie up, how to make her comfortable and how to change the dreaded double nappies! She unfortunately didn't fit in her old car seat anymore, so we were advised to purchase her a spica car seat. Luckily though she did still fit in her pushchair. The occupational therapist gave us some information about steps and the grant they may be able to offer towards Amelie's new car seat.

We went home the same night (out of choice, the ward was very noisy), Amelie seemed totally un-phased by her new 'pink trousers', she lay on her bean bag stroking her cast and tapping the bar with her toy hammer. Within a

week we received her new car seat, partly funded with a very much appreciated grant from steps. Amelie continued to be her happy chilled out self; she was quite comfortable lying on her beanbag as long as plenty of toys were handed to her and her big sister was in view for lots of entertainment. Nappy changes quickly had become second nature, although we switched from the recommended size 0 on the inside to size 4+ after realising the others just weren't absorbent enough for a baby her age. Bath times consist of a wash down with a flannel and a top and tail bowl. She does still have her rubber duck to keep some fun in her washing routine. At bed time she has a pillow under her legs to ease the pressure and stop the cast from digging in her back. After around two weeks she had learnt to drag herself around on her tummy, she was very pleased with herself! She also learnt to flip herself over, this was quite painful to watch at first; the cast would come crashing down onto the floor. She soon got quite graceful at it though after lots of practice!



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Amelie had another Cast change after six weeks, we were less nervous to begin with having been through it before. However this all changed when the one and half hours I expected Amelie to be under again came and went, she was actually away for two hours in total. I was beginning to get quite hysterical! When they finally told us she was fine and in recovery. This time when we were taken to her she looked more like the 'Queen of Sheba' than the little pitiful thing we had witnessed last time, she was a lot brighter and smiling at all the nurses who were cooing around her. It was quite obvious that the reason she was away longer this was down to the fact she had spent more time in recovery before they called us. So there really had been no need to panic! Her Consultant came to tell us that Amelie's hips were now stable, and that he is hopeful that come the end of September Amelie will be able to come out of her cast and into splints, fingers crossed!

We are not bitter that Amelie's diagnosis was delayed, just happy she is now getting the treatment she needs. We don't blame anyone, after all GP's can't be an expert at everything. I do feel though our story highlights the need for more babies to have their hips scanned for DDH as physical examination alone is not always enough. I also strongly believe that if you are concerned perceive until you get what you want, as parents some times we do know best! I hope our story brings comfort to those in similar situations. A diagnosis of DDH is extremely upsetting, but please don't feel its

the end of the world. Neve is now a happy active, boisterous little girl and Amelie has accepted her life as it is (in her cast). She still goes out everyday in her push chair; she even manages a go on the swing at the park if carefully balanced on my knee. There is lots of support and care available if you ask for it. We feel grateful that in this country we have a extremely high level of care and expertise available to us through the NHS.

Best wishes to all, Victoria, Andrew, Neve and Amelie (now in red trousers).

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