



steps

We don't take walking for granted

Sophie

Diagnosed aged 14 months
Treatment to date: Open reduction, Pelvic Osteotomy, Femoral osteotomy, 3 months in Spica, due in brace

Sophie

Sophie was born at home at 41 weeks. I had a normal pregnancy and delivery.

Sophie was my first born. I also had an extremely small bump although no concerns were raised about this. As she was born at home I attended the local hospital's children's unit the following day. She had all the newborn checks, including her hips and other than having an umbilical hernia she was given a clean bill of health.

Sophie had her 6 week check at the GP's and again she was given a clean bill of health regarding her hip. She was diagnosed with reflux.

To us Sophie's development appeared normal. In some areas it was very good. She was crawling by around 6 months.

When Sophie began to stand we noticed that she often stood on tiptoes on her right side. When beginning to walk she appeared to lack confidence and wouldn't do so on her own. She appeared to walk better when holding her right hand. We mentioned this to two health visitors when Sophie was around 14 months old. They said that there was 'something' about the way Sophie walked and recommended we got it checked by her GP. They assured us she would be fine and there was no mention of hip problems.

A couple of weeks later I got an appointment for her to see a GP. Her GP watched her walk and commented on her lack of confidence considering how long she had been walking. When she attempted to check her hips as soon as she tried to move her right hip Sophie began to scream. She explained that she felt it would be appropriate to refer her to a paediatrician.

A few weeks later on the 17th of June Sophie had an appointment to see a paediatrician. He watched Sophie and then examined her. He told us he thought she had DDH and he was concerned about the possible damage it was doing to Sophie's spine when she was trying to compensate for the uneven leg length. He wanted us to see a surgeon and have x rays done either the same day or the following day. He seemed very concerned and we realised at this point it was more serious than initially thought!

We had to return to the hospital the following day. Sophie had x rays prior to seeing the surgeon. As soon as we walked into his office and saw the x rays we knew there was something seriously wrong! *No normal hip looks like that!* He explained that Sophie did in fact have a DDH and the kind of surgical procedure required. However, there was no paediatric anaesthetist at this particular hospital so he would have to refer us to another hospital and he did so the same day.

We had to wait weeks for an appointment to be seen again. I even rang to see if they would bring it forward. Eventually I rang the original consultant and he got them to bring the appointment forward a week!!! Once we saw the surgeon who would be doing the operation we were given a date for the open reduction.

The doctors were great for giving us information about the surgical procedure etc. But, there was no one to support us or anyone to answer questions we had! I had to search the internet for hours and a lot of the information related to dogs!!

Sophie had her operation on the 7th August. The staff at the hospital were good but again we were sent home with no support!! After Sophie broke her cast (the first time) the hospital referred us to a community nurse. They have been extremely

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supportive and have said that they are there whenever we need them!!!



Looking back now Sophie had all of the signs of DDH. She had a deeper crease on one side (it was always red too), one leg was shorter than the other, looking at photo's one leg was always held differently and it moved differently when changing her and she walked on tip toe.

We knew nothing about DDH nor did her grand parents; we were given no information, no mention of it in any books (including the Birth to Five book) and would certainly have followed it up earlier if there was. If I knew what the signs were Sophie could have been treated much, much earlier! As a new parent you are told that every child is different so I thought these things were ok!!

It still astounds me that new parents are given no information about this serious condition, the public think it is some minor complaint and the lack of training to medical professionals. Why are health trusts still using such out dated methods to check for this instead of ultra sound??

After diagnosis, why is there no support?? Why did I have to do my own research and thankfully find steps??

I feel that as a family we have been repeatedly let down by the NHS!!!!!!

Without steps I would have no support, no one seems to realise the severity of this condition or understands what we are going through including employers and local government (it seems to be considered a minor ailment)!! I feel that everything is a constant battle and I have to fight for even little things that Sophie is entitled to make our families life as normal as possible!!!!!!

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