



steps

We don't take walking for granted

Kai

Diagnosed aged 6 Years 10 Months

Treatment to date:
Arthogram, awaiting Bi-Lateral Femoral and Pelvic Osteotomies

Kai's Story

I became pregnant when I was twenty-one, in my last year of university. Not the best timing, but once the morning sickness was over with I concentrated on my final exams, and looking forward to having a baby, becoming a parent. At my 18 week scan the radiographer looked a bit concerned, and told me that while everything else looked fine, it seemed the baby only had one kidney. There was a bit of hustle and bustle, and I was taken to see a doctor who explained that this wasn't really a significant problem, and was probably due to my family history, as my brother had been born with four kidneys.

Everything carried on as usual, but then at 38 weeks I was sent for a check-up by the midwife, who was concerned about the lack of fluid around the baby. They did a scan, and measured every little bone of the baby, and kept going back and double checking every one. Eventually they told me that the dates from the 18 week scan were wrong, in fact I was only 34 weeks pregnant, not 38. Don't ask me how! Because of the lack of fluid around the baby they carried out a trace every few days, to show the baby's heart was coping. Finally I went into labour naturally, two weeks before my 'new' due date and Kai was born on September 24th, 2001.

The first reaction from the midwife was that she wanted Kai to be examined by a doctor, but didn't really explain why - after the doctor saw him he was taken to intensive care, even though his apgar score was 9. We were told this was due to his kidney problems, but when we came up to SCBU later we were told by the doctors that he had a number of 'dysmorphic' features, and they had taken blood to check for a genetic problem, although they had ruled out Down's Syndrome. When blood results came back ten days later they showed that Kai had a unique chromosome abnormality - he was missing pieces of two separate chromosomes, and was expected, because of this, to have a number of problems including developmental delay, mental retardation, and epilepsy. The reason my dates had

been changed was because his head was so tiny, which was because of this condition. We left hospital with Kai when he was two weeks old, with very little idea of what to expect as time passed.

The first couple of months were a blur of appointments and tests - we saw paediatricians, physios, geneticists, heart specialists - you name it, we probably saw them at some point. Things started to calm down however, and we could get on with enjoying time with Kai, with input from the physiotherapist every few weeks.

Kai surprised everyone - although he was very late reaching the traditional milestones, he was very happy, and loved being around people. At the age of one he still couldn't sit unaided, and had started having seizures, but was clearly enjoying himself the rest of the time! At this point Kai started at 'School for Parents' - officially a physiotherapy group for children with Cerebral Palsy, Kai somehow managed to get in. For an afternoon each week, Kai and I were one of five families who received instruction from the physiotherapists and occupational therapists about exercises we could do, games we could play to try and encourage Kai's development.

By the time Kai was three his seizures were mostly controlled by medication, he could sit up properly, and while he relied on a few gestures such as waving and his facial expressions and sounds to communicate, he was very interested in his little brother and sister and watched everything they did. Kai was seen by a pediatrician every year, and when he started at nursery we had to leave School for Parents but was pleased to find that the physio who had worked with Kai since he was just a few weeks old also worked at the school, so there was continuity for Kai.

By the time he was four Kai had got the hang of shuffling along on his bottom, and by four and a half had mastered pulling himself to a standing position. He didn't know what to do when he was up, but at least he could do it! He would always lean slightly to

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one side, taking his weight through one leg, but we were so pleased he was up that that we didn't ask any questions. At five he was taking steps with a walking frame; at six he was taking a few steps independently. Since Kai was three he has always had splints of one kind or another inside his shoes, to hold his ankles in the right position, as we were told he had very tight hamstrings and Achilles tendons.

By this time we were seeing a paediatrician every year, a neurologist every few months as Kai's seizures had worsened, an orthotist for splints every six months, physiotherapist every week in school, occupational therapist every week in school, and a partridge in a pear tree!

At an appointment with the neurologist In June 2008 he asked if we were aware of any problems with Kai's spine, and when we said no, he suggested we ask the physio to look at it as it looked as though it was slightly curved. The physio agreed that there might be a very slight curve, known as a scoliosis, and referred Kai to the orthiconics at the hospital.

We had an appointment through for July, and when the orthopedic surgeon saw Kai walk two steps and asked me to help him onto the examination table so he could have a look. In my naivety I didn't realise what he was looking for as he bent Kai's knees outwards and up to his chest, and when he sent us to the x-ray department for hip and spinal x-rays I assumed the hip one was because that was where the spine started! We took the x-rays back up to outpatients, and were called back in to see the surgeon. He put Kai's spinal x-ray up on the screen and pointed out the very obvious curve, and explained that while it was mild now, it could become much more serious and so would have to be carefully monitored.

Then he hesitated, and said "But...I'm really much more concerned about his hips..." I was completely confused, as he explained that Kai's hips were very abnormal, and was going to need surgery and a spica cast as soon as possible. I left the room in

something of a daze, feeling as though somebody had dropped a house on us.

Kai has now had an arthrogram, where dye is injected into each hip while he was under a general anaesthetic, so they could move his legs around and see exactly where the cartilage is. The next step is a bilateral femoral osteotomy, which involves surgically breaking both legs, and a pelvic osteotomy, which will effectively break his pelvis, and then the pin everything back together with metal pins and plates. After working so hard with Kai all his life to get him on his feet, the idea of holding him in my arms while the anaesthetic takes hold, and leaving him with a man who will break both of his legs...it's just heartbreaking. Of course it is far more complex than that, and not at all the gory violence I'm portraying, but bearing in mind Kai was diagnosed with CDH at the age of six years and ten months, he's really going to be fighting the odds.

The confusing thing from our point of view in this is the number of people who didn't realise that there could have been a problem. We keep all the letters and reports from his therapists, and have lost count of the number of comments about Kai standing asymmetrically, appearing to favour one leg and so on. At a recent meeting with the paediatrician I was told that looking at the x-rays, the hip bones have formed incorrectly and so were *never* normal, and yet his eight week baby check states that his hips were 'normal'. For months we have commented that Kai walks like an elderly man after one too many beers - there's a real stagger to his steps, which is worsening as time passes - now we know why.

Because he had been diagnosed with global developmental delay his late walking was attributed to that, and no further checks made - something I am now struggling to understand. No wonder he couldn't walk for so long! Now that we're waiting for treatment time seems to pass so slowly, and every time Kai stumbles, every time he asks to get into his wheelchair rather than walk I ask myself why I didn't realise something was wrong. Thinking like that doesn't help Kai, of course, so I'm trying not to, but I

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don't think that feeling of guilt will ever go away. Now we're in limbo, waiting to find out what the options are now for Kai, and keeping our fingers crossed that he will be able to walk into adulthood.



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