

steps

Baby Hip Health Week 24 February to 1 March 2008



Baby hip checks and the importance of family history...

I was born in 1971 and was not diagnosed with bi-lateral CDH until I was 2 ½ . My Mum had thought something was wrong with my walking (or lack of) and took me several times to her GP. He dismissed her worries as an over anxious mother. Eventually Mum changed GP and he referred me to a specialist. After x-rays it was found that both by hips were dislocated, and my Mum was told that was why it was missed, as it is harder to diagnose if both hips are affected. My Mum on the other hand is adamant that I was not given the baby hip check in hospital after birth, and perhaps if I had been, bi-lateral CDH would have picked up much earlier. My parents waited for six weeks after being told I would need urgent treatment, or face life in a wheelchair from age 12. No appointment came through, so they took me to yet another GP for advice. Thankfully, he knew of an orthopaedic surgeon but he worked at a hospital, 40 miles away from my home. By this time, my parents didn't care, and I was immediately admitted and was put in traction before an open reduction on my left hip, and then in my first spica cast from chest to ankles for six weeks.

I vividly remember my sixth birthday which was spent in the RUH Bath in a spica cast after a pelvic osteotomy on my left hip. I was again in a full-body spica cast, but allowed home for a few days at a time. I remember having a low trolley which I used to scoot around on.

At 10 years old I underwent bi-lateral femoral osteotomies. This for me sticks in my mind the most. I was at an age where I understood (to a limited degree) what was happening, but of course the Dr's never actually spoke to me about what was happening, it all went above my head. My parents were brilliant at preparing me for the surgery, and that it was going to be a long time in hospital, but the hospital was 40 miles away from home during the summer holidays. I was in a ward which was really for teenagers, as they thought I was too old to be on the children's ward, but I was often on my own or the youngest. I was in a plaster cast from my waist to my ankles, with my legs out at an angle, and lying down for six weeks. You can image at 10 I did feel embarrassed with this sort of plaster cast. I had to use a bed-pan for the whole time, and inevitably the back of the cast became wet and smelly. I couldn't wait for it to come off.

When eventually the spica cast came off, there was hydrotherapy and physiotherapy. I had to learn to walk again with crutches. When the plates and pins were removed a year later, I had moved from primary to secondary school. Due to the surgery I 'd had, I was restricted in the sport I did at school. I didn't join in with team games, and I didn't go on field trips or outward bound courses. However, my mobility improved and I continued with a pretty

normal life. I always walked with a limp which was more pronounced when I had walked any distance and was tired, but I enjoyed aerobics, walking in the Lake District, swimming and cycling, and pretty much enjoyed life to the full.

That was until eight years ago, aged about 28, when I started to get pain in my groin, which went down to my knee and then to my foot. I went to my GP and was prescribed painkillers and physiotherapy. After further visits back to the GP with no improvement, I was referred to a new Consultant. By the time I got the appointment for the consultant I had become pregnant, but the pain was getting worse. After x-rays, I was told that I would need further surgery as the socket was wearing out unevenly and in five years I would need a hip replacement, unless I had this reconstruction surgery.

I was utterly amazed when the consultant explained to me the type of surgery I would need, and that it would be a long road to recovery. I had not expected any more surgery on my hips until I had a total hip replacement, probably much earlier than most people would need one, but in my 40's at the earliest. I really thought I would be sent for more physiotherapy and to try and manage the pain. I was now 30 - I was ready to start a family, this was not the time to be having major hip surgery. If I had been prepared for the possibility of more surgery in my late 20's or 30's, I may have decided to try and have my family earlier, or maybe even to delay until my hips were sorted. I often ask my parents if they were ever told that more treatment may be necessary, and they never were.

My surgery took place in October 2002, but it sometimes still feels like yesterday. I was prepared for the surgery to be a major operation and the recovery to take at least a year. Even so, it has been the hardest part of my life to get through. My daughter was just a year old and I was on crutches for 3 months after the surgery. I needed lots of help at home and relatives came in shifts to help look after my daughter and me, as my husband, brilliant as he was, had to keep working. The feeling of loss of control over my life was immense. After 18 months the pins and plate in my pelvis and femur were removed.

My Consultant is extremely good and my daughter and me see the same one. I was obviously concerned about her hips after my history and she was booked for an ultra-sound at six-weeks old. The hip check in the hospital after birth, and the later check by the GP found her hips to be normal, but the ultrasound showed she had a shallow left socket. She wore a Pavlik harness



for 3 months, and this was successful at the time. She is now 6 years old and has another check-up with the clinic when she is 7. Her right hip now shows to be on the margins of dysplasia, and I've been told she may need surgery if the x-ray shows it has got any worse when we go back. The good thing is, she is being monitored and we are prepared for what may happen.

My son was born in 2005, and yet his is a different story. As he was my second baby we were discharged from the hospital on the same day as he was born. All well and good, but if this happens you then need to have a 24 hr baby check by your GP. The day after giving birth, feeling emotional and tired, I had to take myself and my baby to the surgery for this check-up. If this check is done in hospital, I believe this is where the first hip check is done. However, this GP didn't even remove my son from his car seat, just checked his heartbeat with a stethoscope and was about to send us on our way. At this point I asked if he was going to check his hips. Of course I got a blank look and was told this would be done at the six week check. I then asked him to refer Hugo for a hip scan as my orthopaedic consultant had reiterated to me that I should get him scanned by six weeks. I was adamant that I was not leaving until I had an appointment for the scan. I am sure the GP had not realised my history and if he had, perhaps his reaction would have been different, but do many new mothers demand a hip scan just for the sake of it. I doubt it unless they know how important it is with a positive family history. Hugo did have a scan, but at 10 weeks, and thankfully all was fine. The hip clinic reviewed him again with a x-ray at 1 year old just to make sure, and he has now got the all clear.



The thing is, that on paper my surgery has been a success, but I feel that CDH is with me every day. I still walk with a limp, I still have the scars and I still have good days and bad days with pain. I have had counselling for depression, and the time I spent in hospital as a child seems to have been one of the triggers for this.

Returning to the world of hospitals, consultants, surgery, pain and separation from loved ones brought back lots of painful memories that I had buried and not confronted. Now in my 30's, these feelings came back and I found it very difficult to feel positive about what had happened to me, as well as the obvious feelings of 'why me' which made me feel guilty and selfish.

I find it so hard to know that so many cases just like mine are happening now, over 30 years from when my CDH was first diagnosed. How many more will it take before this condition is recognised by GP's, health visitors and midwives. As far as I can see, not much has changed since the 1970's.