



steps

We don't take walking for granted

**Clare** – diagnosed 1974 age 3 Bilateral CDH.

Treatments to date: open reduction, pelvic osteotomy, bilateral femoral osteotomy, triple pelvic and femoral osteotomy.

**Daughter Emily** – diagnosed by ultrasound scan at 6 weeks. Treated with Pavlik Harness. Continues to be monitored.

## Clare and Emily's Story

I was born in 1971 and was not diagnosed with bilateral CDH until I was 2 ½ . My mother 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 she changed GP and he referred me to a specialist. After Xrays it was found that both by hips were dislocated. My parents were told that the condition is harder to diagnose if both hips are affected. At the time I was diagnosed, my parents were told I would need urgent treatment, or face life in a wheelchair from age 12. I then underwent a series of traction, open reduction, pelvic osteotomy and months in spica casts from chest to ankles, all before the age of 6.



At 10 years old I underwent bi-lateral femoral osteotomies. 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 generally found keeping up with my friend's activities difficult.

In my late 20's I started to get severe pain, which I tried to cope with for over 2 years, until finally I was

told 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 – a triple pelvic and femoral osteotomy. This surgery was carried out when my daughter was a year old.

My daughter Emily was born in 2001. I was obviously concerned about her hips after my history and she was booked for an ultra-sound at six-weeks old. This advice came from my orthopaedic consultant, not from my GP, midwife or health visitor. 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 bilateral DDH. 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. We have been told she may need surgery if the xray shows her hips are too shallow. The good thing is, she is being monitored and we are prepared for what may happen.

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. It really does seem that not much has changed since the 1970's.



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