



steps

We don't take walking for granted

**Joanne**

Diagnosed aged 2 Years 10 Months

Treatment to date: see below

## Joanne's Story

My daughter was born in 1992 but wasn't diagnosed until age 34 months with dislocation of the right hip, despite my concerns that she stood and walked on tip-toe.

In March 95, she had her first major operation. She was put into hip-spica, an immobilising plaster from her chest to ankles, on both sides. She was unable to bend or sit up, and as I was 7 months pregnant, things were very difficult. We were told she had to go back into nappies, which she found upsetting and she would be in plaster for 6 months, with changes every 4 weeks under general anaesthetic.

After 4 months, the consultant decided the treatment wasn't working. We were devastated; instead of treatment nearing the end, we were about to start again. We were given 6 weeks for her to 'loosen up' until the next operation.

In September, she had her femur broken and a bone graft. She had to go back into the hip-spica again for another 6 weeks. We found out some months later, that it had again been unsuccessful.

In 2000, we agreed to another operation, after being told that now she was older they wouldn't need to apply the spica and she would be on crutches post op. After the operation,

We were shocked to be told that they had to use a spica because her hip was so unstable. She was age 7 - I will never forget her gripping the iron bed post and screaming Mummy, please, please, help me, while pulling out clumps of her hair with the pain. I swore I could never put her through this again.

She spent her 3<sup>rd</sup> and 8<sup>th</sup> birthdays in a hip-spica.

After this operation, we were sent home by ambulance and told to keep her in bed for the next 6 weeks as they had no wheelchairs to accommodate

her as she couldn't sit up. When the plaster finally came off, she needed physio and was

able to go back to school, mornings only, in a wheelchair until she got back on her feet.

After a while x-rays showed her hip was slipping out again, although she limped, particularly when tired, she never complained and threw herself into all the things she had missed out on. She was desperate to play sport and always tried to participate, even when I could tell it was painful for her, she refused to give in.

At age 12, it was decided that she needed a small op on her 'good leg' to try to equalize her leg lengths. The operation was done in February that year. She was expected to spend 6 weeks on crutches, but in July, she was still using crutches and was admitted in to hospital for a steroid injection into her hip, to try to relieve the pain.

Over the next year, her notes were passed around the country for different experts to give their opinions.

After much consideration, my daughter decided she wanted to go ahead with another operation. She was limping constantly and needing to rely on crutches more and more often.

The operation was scheduled for the beginning of July 2007. This time they didn't apply a spica, she was allowed to use crutches, a walking frame and wheelchair. She began physio, but it soon became apparent that she was in a worse situation than before. The amount of medication she needed to take to enable her to cope with the pain was making her almost zombie-like.

It was decided that she would need a hip replacement as soon as possible – she was only 15.

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It was a complete and total shock to discover my daughter would need major surgery at 3 years old. We went ahead because we were told; if she didn't have surgery she would need a hip replacement in

her 30s. This is what she is now facing at age 16.

It is so hard to see your child in pain every day. If this condition had been diagnosed before she was 6 weeks old, she could have been treated without surgery

### Treatment to Date

1995 - EUA +Arthogram

1995 - Open reduction -Hip spica for 4mths.

1995 - Valgus osteotomy + Salters osteotomy + bone graft (hip spica)

1996 - plate screws removal and Arthogram

2000 - open reduction, varising femoral osteotomy and Pemberton acetabuloplasty (hip spica applied as hip was so unstable)

2003 - arthrogram +EUA

2004 - left distal femoral ephiphysiodesis

2004 - arthrogram and steroid injection +EUA

2006 - EUA and arthrogram

2007 - valgus femoral osteotomy with shelf procedure (shelf started to disintegrate within months)

2008 - removal of metalwork hip replacement specialist attended to plan future THR

Including cast changes - 18 G.A's  
5 major surgeries, MRI SCANS, CTSCANS  
and hundreds of X-rays.

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