

...and baby makes three

by Ellen Bird

My name is Ellen Bird and I have been a member of TAG since it began and came to my first conference when I was about 7 years old.



Chris, Ellen and Callum.

The impact of seeing adults with AMC living normal lives had a hugely positive impact on me and my family but in all the time I was growing up I met very few adults with AMC who had children.

Firstly, let me give you a little bit of background information about me. I am 32 years old and live in Lichfield, near Birmingham with my husband Chris and our son Callum who is nearly 2 years old. I attended a 'normal' school and went on to study psychology and sociology at Oxford Brookes University. I then travelled around the world for 6 months on my own before starting work at the Royal Borough of Kensington and Chelsea back in 2000.

Chris and I married 7 years ago now. We didn't want to start a family straight away but decided that it would be sensible to go for some genetic counselling not long after we got married. We felt that by going when the desire for children wasn't a huge priority for us it would give us plenty of time to think rationally about our options if it was likely that there was a risk of me passing on my disability. Our situation was also slightly complicated by the fact my sister has Down's Syndrome and therefore we wanted to discuss this as well.

Having heard him speak at a conference in the past we decided we would get a referral to Eammon Sheridan at Leeds General Infirmary, which was done relatively easily through our GP.

Throughout our appointment Eammon was absolutely brilliant, he explained to us exactly what he was looking for in my joints and limbs and why he was looking for it. He decided I was a text book case of Amyoplasia and said in his opinion we stood as much chance as anyone else of having a baby with AMC – we were both delighted with this prognosis as we really couldn't have asked for a better result. The Down's Syndrome test was a simple blood test which also showed that my sisters condition wasn't hereditary.

So we decided that we didn't need to explore issues around adoption or any other options further at this stage and put the thought of having children on the back burner.

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over the moon

I found out I was expecting Callum in March 2008 and we were over the moon. I had a rough start to pregnancy as I had extremely bad morning sickness and was hospitalised for 5 days as I couldn't eat or drink anything without being sick. Once on a drip though things started to pick up. We were delighted when we had the 12 week scan and we could see Callum lying on his back with his hands behind his head! Arms and knees bending! The relief was overwhelming and it was an emotional day both for us and our families.

We sailed along then really for the rest of my pregnancy. I had a fall at about 20 weeks but I landed on all fours so no serious damage was done apart from a badly swollen hand. I coped well with being bigger and although I tried to be fairly careful, life carried on as normal.

The midwives were brilliant and weren't overly concerned about my disability. They referred me to the local consultant to discuss my options for the birth. As my other internal muscles were not affected by AMC, she did not feel that my womb would be and was fully supportive in me having a normal delivery.

Callum was due on 26th December 2008 however he decided that wasn't for him and my waters broke a month early at 3pm on a Friday afternoon when I was sitting writing my Christmas cards at home.

Chris 'got the call' at work and we made our way to hospital. They said I was having contractions every 3 minutes but at that stage I couldn't really feel them. They decided to admit me to the ward but said that I probably wouldn't go into labour that night. Again Callum had other ideas.

I was taken down to the delivery suite at about

3am and Chris made another mad dash to the hospital after getting 'the call' for the second time that day! The labour itself went well until the 'pushing' stage and I remember thinking maybe the consultant has got it wrong because things weren't progressing as they should have done. It turned out that Callum had the chord around his neck twice and this was causing the problem. After some technical interventions Callum was born on the Saturday morning at 8.43am weighing in at 6lbs 4oz. It was the proudest and happiest moment of our lives.

he was a bit early

I recovered well from Labour but Callum needed to be kept warm and monitored for a while as he was a bit early. The hospital ward wasn't equipped for me very well and there were no side rooms so I was really relieved when we were finally allowed to go home a few days later.

Then the fun started! I don't want to dwell on negatives but I don't want to give you the impression that this has been an easy 2 years for me or us so thought I would give you a quick snapshot of the problems we have faced – and more positively mainly overcome.

From day one I realised it was going to be physically very tough and that lifting Callum was going to be one of the biggest challenges I would face. I'd got a local occupational therapist lined up to help but she was absolutely useless and wasn't interested in helping at all despite my attempts to work with her as much as possible. I was very anxious in the first few weeks about how I would cope physically with lifting him and had several nightmares about dropping him on his head.

... a TAG members experience



Ellen and Callum.

the lifting got slightly easier

Once he had control of his head the lifting got slightly easier and then got harder again as he gained weight but wasn't fully mobile. Every time I felt we were about to reach a point where I really wouldn't cope Callum got a little bit stronger and started hanging on to me then crawling and walking.

He has been and remains big and strong but I can still carry him now and he literally scrambles up me to be lifted. We did find a few things that helped with the lifting. If anyone

wants to contact me about what I have used and found useful please contact me.

I breast fed Callum whilst we were in hospital and I was living in pyjamas but when we got home getting undressed in public proved impossible and I was very tired from the night feeds so we switched to bottle feeds which meant I could get some sleep and keep my dignity!

Dressing a wriggling baby also proved difficult but by choosing clothes carefully and through strategic use of good old Velcro we have muddled through.

Nappies were ok until Callum realised he didn't have to lie still! I searched the internet and found a changing mat with a harness so now he gets strapped in – once I have caught him and pinned him down that is! Potty training is around the corner and there will be issues there with pulling his trousers up and getting in and out of toilets I'm sure!

Pushchairs, car seats were also awkward but we've found the best the market has to offer in terms of ease of use. It still can take me 20 minutes to get Callum strapped in the car but he can at least now climb into the car seat himself. I have a ready stock of sweets and biscuits in the car so he will climb up and sit still – Is that bribery? Probably!

new set of challenges

As Cal has got increasingly mobile I have a whole new set of challenges to deal with as he can now run away from me and quickly. I have invested in good restraints and a funky back pack with a big handle on the back which enables me to drag him out of danger or move him if he's having a tantrum.

I was still struggling however with fears about

keeping him safe when we were out and about. I had read about Alison Lapper – the lady with no arms who has been followed on the programme ‘Child of our Time’. She had visited a charity in London about helping to control her son with her voice called the Anna Freud Centre. I sent them an email entitled ‘help’ and briefly explained my situation and they called me straight away and offered me an appointment. They gave me really sound advice about letting him be a little boy as much as possible and then using ‘No’ and ‘Be Careful’ type language only when absolutely necessary. This made me feel much more in control and has given me confidence to trust Cal’s judgement about his physical abilities.

There will I am sure be more hurdles to come as he gets stronger and more physical but I think and hope we’ve done the hardest part because the more he understands the more we can negotiate and the more he can do for himself. He will certainly be an independent little boy.

Dealing with the additional challenges on top of being a first time mum has been really hard work. I also put a lot of pressure on myself to prove to the world that we were coping brilliantly and I have had to learn that accepting help does not mean you’ve failed.

What else have I learnt?

- Get a cleaner.
- Make meals as easy as possible and have a thousand stews in the freezer for when the baby arrives.
- Be as prepared as you possibly can in terms of thinking through as many of the

challenges you’re going to face as much as you can before the baby arrives.

- Many of the problems I face with dressing myself have been the problems I face when dressing Callum – buttons, zips etc so think about how you will cope with this.
- Borrow a friend’s baby/buy a doll before you have a baby yourself to try things out but don’t forget your baby will adapt to you.
- Don’t be afraid to accept help – if not with the baby then with the washing or cooking and get as many people lined up to help in place as you can cope with in for when the baby is born.
- Get professionals involved early, ring the health visitor and warn them you’re coming through the system.
- Do a hospital visit before the baby’s born and push for your own room and if possible for your partner to stay with you.
- Finally and most importantly believe from day one that your best is good enough.

I’d just like to finish by talking about my husband Chris. He has been amazingly supportive and has maintained from day one that Callum would adapt to me. He has had unwavering confidence in my ability to cope and has kept me going when the going got tough. I truly couldn’t have coped without him.

The joys of having Callum have by far out weighed the negatives. He is a beautiful little boy who is very happy and confident and one thing I am sure of is that he will certainly grow up with a positive outlook on disability!



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