Limbless Association

Being a Parent with Limb Loss

As a parent of four young children there are always obstacles to overcome. As a parent with no left forearm or hand, there are a few more obstacles to find solutions for.

Napping Changing

My first one was how to change a nappy. How do you keep those feet up when wiping that bottom? How could I lift those feet up out of the way without hurting Cameron (my first)? I came up with a piece of soft fabric that I could fix a slip-knot at both ends, putting his feet in and then resting the middle piece of fabric on my left arm to lift the feet well out of the way. The funny thing is, all of my friends, with two hands, then wanted one, so I have made some for them as well.

After the third child, my husband and I developed this product into a sellable item, "EazyFeet", which is now made from soft neoprene. I was an inventor! Problem number one became a small business.

Bath Time

Then came bath times, how do you hold a baby with one arm and wash them at the same time?
My nan sorted out bath times for me; she found me what could only be described as a towel with a frame. It looked like a slide-shaped frame with a towel that could be threaded on to the frame so the children could lay safely on it, leaving my hand free to wash the baby.

Transport

Then came the car seat. It was impossible for me to hold both straps, and the bottom piece, and put them all together.

Then of course, the pushchair; I needed one that had a continuous handle all the way across instead of two single handles. I also found one that only needed one clip to fold down, instead of one on each side, making things much easier. It was really just a matter of trying lots of things and researching many different products until you find the right one that's right for you.

Being a single-handed mum has not always been easy, but I've learnt to adapt and seek out products that can help. Where there isn't a product, I improvised.

The key thing to note is that not having two hands did not stop me doing anything with my children, it just changed the way I had to do things.

The most important thing about being a mother is caring for your child's needs and welfare. It does not take two hands to love your child with all your heart!

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Being a Parent of a Child with Limb Loss

When we discovered, at our 20 week antenatal scan, that we were expecting a baby with a missing right hand, we were very shocked. We had worried about all sorts of other things but it had never occurred to us that our baby might be an amputee. Looking back, I can see what a tremendous advantage it was to find out at that stage of the pregnancy for two reasons: my husband and I were able to come to terms with the news ourselves, without having to put on a brave face and we had plenty of time to prepare ourselves with information and support.

After hearing the news from the radiographer, we both phoned our offices and said we would not be back for a few days. Still in a state of shock, we drove to my husband's parents' house and broke the news to them, before phoning other relatives. When we had initially been told about Eleanor's missing hand, my husband broke down and I, very surprisingly, did not. Over the following days and weeks, my husband did not (to my knowledge) cry again. I decided I was not going to show my concern, because I felt it was wrong for me to feel like this. It is very difficult to explain the maelstrom of feelings I experienced, the relief of knowing that my child was healthy, the proud determination not to show publicly any sorrow, but to be always robustly positive, and the overwhelming private, solitary grief.

Meeting other families with affected children was tremendously helpful to us in the early days. We had found *Reach* – a support group for children with upper limb deficiencies – before Eleanor was born and had sent for information and an introductory video. We watched it together and 'met' our first amputee children. This was the beginning of a long relationship with *Reach* from which we have drawn tremendous support. We also showed the video to our families who had been anxious (though they had not said anything) about what to expect and how a child would cope with a missing limb. The atmosphere in the room while we watched it was tangible. Our parents had been wonderfully supportive and affectionate, but I remember as if it was yesterday how my sister-in-law sat watching the video with silent tears rolling down her face; how awkward we felt before watching it, and how relieved afterwards when we could talk frankly.

By the time she was born, my concerns had naturally turned to the delivery and how we would cope with parenthood generally. Most people we knew had been told about Eleanor's arm and we were spared the experience of having to break the news when she was born. Nobody can be prepared for the feeling of being a parent, for the first look at a face that you will never forget, for the passionate determination to give your child everything you can. I have always been an emotional person but even I was unprepared for the depth of feeling I had for Eleanor and the need I felt to protect her. The following few months are an emotional blur of sleepless nights, breastfeeding and long sunny walks with Eleanor in her pram.

When Eleanor was about a year old, I confided my true feelings to a friend and realised that it was probably not good that I had kept my feelings to myself all that time, without anyone else knowing. Outwardly, I was keeping up an excellent 'positive outlook' but on the inside I was confused. I took some comfort from literature I found on the internet, and from a piece in the *Reach* magazine about the stages of grief. This helped me to focus on the idea that what I was feeling was part of a process through which I would progress and which I would eventually leave behind. Discovering that other people experienced these same feelings was very reassuring and I began to feel less guilty and more relaxed. The tears became less frequent and the pain less acute.

The stomach-churning anxiety of thinking that she will never be the same as everyone else has turned out to be unfounded. Having an amputation is a very tiny part of what makes her unique and special and her friends rarely notice or make any allowance for it. I am extremely thankful that, despite my private feelings when she was little, I did manage to keep up a positive demeanour, cheerfully intercepting inquisitive children at the park and reassuring their parents that it was quite alright for them to ask me nosy questions (with Eleanor's agreement each time), and helping her to come up with appropriate responses like "'a crocodile bit it off", which amused her tremendously and made her feel proud rather than embarrassed. She generally only shared that bit of information with the most persistent inquisitors, and it never failed to impress. However, this approach did come back and 'bite me' when she announced to a whole room of other Mums (at my first antenatal class with her younger sister), that "my Mummy cut it off because I was naughty". It certainly broke the ice!

I dreaded the day when she would ask me why she had one hand, fearing that I would break down and blow my cover. When it did happen, I managed to keep very calm and explained that we didn't know why, it just happened that way. She accepted it and has not asked again. When I was pregnant with her younger sister, Eleanor asked me if the baby would have two hands or just one like her. I told her that the baby has two hands and she said simply "OK". I had often explained to her that all people are different; some are dark-skinned, some are tall, some have red hair and some have one hand. It was a great surprise to me when her little sister was born with red hair but to Eleanor it was confirmation that, just as I had said, everyone is different.

We actually met another family while I was still pregnant with Eleanor. My midwife put me in touch with a lady who had given birth six weeks before me, to a baby with a missing hand just like Eleanor's (but on the opposite side). They live less than a mile from us and we still get together regularly. We gave birth in the same hospital, with the same midwife, only six weeks apart and yet we were given very different advice by our paediatric consultants. Our consultant was quite frank and admitted that she was not sure how to help us. We sought advice from *Reach* and our consultant referred Eleanor to a limb centre on the basis of that advice. Our friends were told by their consultant that there was little point in attending a limb centre until their son was at least three years old (very outdated advice and completely incorrect). We later learned that anybody can have a referral from their GP and there is no need to go through a consultant, which is what they eventually did.

In our experience, advice from professionals can been patchy. We have had to pursue prosthetic solutions and occupational therapy which weren't automatically offered and ultimately discovered that we need to be selective about the advice we receive. Advice and tips from other families has been very useful, though what works for Eleanor may not be helpful to others and vice versa. We are always ready to try new ideas and we aim to think ahead where possible so that we are prepared. We have never had to say "sorry darling, I don't think you will be able to do that with one hand". If we can't think of a way, then we ask someone who has 'been there' already. We found a lovely piano teacher who writes music especially for Eleanor, so that she plays across both clefs with one hand and we have very close contact with her class teacher so that if anything new is coming up in school (e.g. PE or Design & Technology) we have a plan ready.

Now a confident and outgoing eight year-old with many friends, her current hobbies include playing the recorder (a specially adapted version from *Reach*) and the piano, ballroom dancing (including festivals and competitions) and drama. Eleanor fully intends to become a famous pop star and sometimes when I look at her I think I will burst with pride. Look out for her on Top of the Pops in around ten years from now!

Limbless Association

For parents of young children with upper limb deficiencies the Limbless Association recommends that you contact:

REACH *(registered charity no: 278679).*
Reach Head Office
PO Box 54
Helston
Cornwall
TR13 8WD
Tel: 0845 1306 225
Fax: 0845 1300 262
(calls charged at local rate)
Email: reach@reach.org.uk
Web: www.reach.org.uk

As well as providing a support network for parents and children national events and local branch activities, Reach produces a quarterly newsletter with articles ranging from news of medical advances to 'handy hints' and news from members. Reach also has a bursary fund and a recorder bank, providing specially adapted one-handed recorders on loan.

For parents of young children with lower limb deficiencies the Limbless Association recommends that you contact:

STEPS (*Registered Charity No 1094343)*
Warrington Lane
Lymm
Cheshire
WA13 0SA
Helpline: 0871 717 0044
Admin Tel: 0871 717 0045
Fax: 01925 750 270
Email: info@steps-charity.org.uk
Web: www.steps-charity.org.uk