

# One Mother's experience of Express Feeding

*Sent to CLAPA by Julie Skidmore*

Our first baby had a cleft palate. A cleft of the palate is a gap – for Anna it was just at the back of her mouth where the two sides of the palate hadn't fused together in very early pregnancy. This meant that she couldn't suck as her mouth didn't make a seal to form a vacuum. That was very disappointing as I had never imagined anything other than breastfeeding my child. The very early hours of the morning after my 42 ½ hour labour were spent learning how to express milk with an electric pump and feed her with a special scoop that poured the milk in.

Initially I thought I would express until the operation to repair her palate at 6 ½ months and then hopefully breastfeed her, but I didn't seem to be able to produce enough milk, and as the weeks went by and her appetite increased, Anna needed more and more formula to supplement the expressed milk. I stopped expressing after 14 weeks and although disappointed, was glad not to have to express any more.

I was determined that our second child would not have a cleft palate. Not a huge amount is known about why some children are born with a cleft, but I left nothing to chance, and after visits to a kinesiologist naturopath, plus an organic, whole grain diet for all of us and supplements for months before the baby was even conceived, we were blessed with a healthy girl, nice easy pregnancy and home birth and a baby who could suck strongly from the start.

I breastfed Emily for 20 months and loved it.

Prenatal supplements and the same good diet meant that I was very confident that number 3 would be just as healthy and cleft-free as Emily, so it was a shock to discover by myself 12 hours after his birth that although very healthy like the others, Matthew had a cleft too, despite being given the all-clear by the attending midwife.

Although it was very disappointing at least I knew what to do and we got out the hand pump and sterilized it to get expressing. Matthew had been born at home but our midwife felt that we should get Matthew checked out at hospital and also get an electric pump and the special feeding equipment. We had to go to Carlisle as West Cumberland was closed to admissions and we arrived at the SCBU unit with some freshly expressed milk, and Matthew received his first milk in a feeding cup from a

midwife as I didn't want to spill a precious drop since not much is produced at first.

Matthew checked out just fine, but the midwives didn't seem sure what I should be using to feed Matthew and didn't have any of the special bottles that I'd used last time, so he had to be fed with a cup until the specialist nurse arrived from Newcastle the next afternoon.

Having breastfed Emily, who had fed almost constantly for the first week, I knew that I needed to express much more regularly than I had done first time around, so I embarked on 2 hourly expressing. Matthew was very unsettled that night as basically he wanted the comfort of sucking but couldn't do it effectively. The midwives discouraged letting him try to suck, which seemed odd. The constant expressing was exhausting but I knew I had to get my milk going and just ignored the midwives who told me I was overdoing it.

When the specialist nurse arrived as a representative of the cleft team, she was a revelation. Much had changed in the 5 years since Anna had been born. Specialist nurses to support and advise had not existed then, and the feeding equipment had changed too. We could now use a special orthodontic teat and a squeeze bottle, so we could squeeze the milk in whilst Matthew thought he was doing the sucking himself. Our specialist nurse, Chris, advised that if I wanted to breastfeed after the op. to repair the palate, I should continue to let Matthew try to suck from me whenever possible, both for comfort and to stimulate my milk, but that the priority was to get milk in to him, so not to tire him out with too much ineffective sucking.

In the early days I would try to put Matthew on before feeding him with the bottle, but it was often hard to fit that in with expressing and feeding him as feeds took a long time (at least  $\frac{3}{4}$  hr) After a few days of expressing every 2 – 3 hours I seemed to have plenty of milk for Matthew and was able to freeze the extra. I thought I could ease off on the number of times I expressed but Matthew's appetite soon caught up and I was back to expressing 8-9 times a day ( with expressing taking about 20 minutes each time).

I was really proud when we went for Matthew's initial assessment at the cleft clinic at 3 weeks old, that he had remained on the 75th percentile for his weight and all on my expressed milk.

However, the expressing was beginning to take its toll and I was struggling to keep up with Matthew's demands. We'd

measured him and he was on the 99<sup>th</sup> percentile for his height, so I had a big boy to fill. What was frustrating was that I knew that if Matthew had been feeding normally, he would have stimulated all the milk he needed, but I was finding that even the electric pump (hospital grade) did not work as well as a baby. I kept a chart of how much I was expressing and at 3 weeks Matthew was consuming almost a litre a day, but he was very soon needing a bit more than that, and try as I might – even doing 3 days of 12 expressings a day, I couldn't really boost my output which I'd discovered was about 40ml/hour.

So I kept doing my expressing 8 times in 24hrs, but on Chris's suggestion, I agreed to top Matthew up with formula if he'd run out of my milk at the end of the day.

This generally didn't amount to much, often just an ounce or two, though occasionally it would be as much as 8oz, but what I learnt as the weeks went on was that Matthew's demand didn't increase very much – in fact there would be short spells when what I was producing was more than enough for him, so clearly my milk was changing to meet his needs.

Life wasn't getting much easier and I was feeling exhausted, but I never once thought of stopping.

When I was feeling really tired and hating the expressing I'd ask myself if I wanted Matthew to have only formula milk and the answer was always no, so it was simply a case of getting on with it.

Something that really helped was the Express Yourself bra which someone had recommended at the hospital. It's a special halterneck bra with 2 holes to insert the funnels of the pumps, so that you can be hands-free while expressing. The bra made a huge difference, but feeds were taking a long time, and of course there were two others to look after, so I decided that I would have to try to use my free hands to feed Matthew whilst I expressed. Matthew had a practice suck before most feeds, then I would prop him against one leg as I sat on the floor, attach the pumps, give Matthew some heated up milk from an earlier expressing (what a procedure it all was) and then top him up with some freshly expressed milk from the side that he'd got a little dripping out foremilk from, if he needed any extra. That way I could ensure he got enough hind milk each feed and as much as possible was freshly produced .

All this whilst trying to tend to the needs of my 5yr old and almost 3 year old. Thankfully I had a very supportive husband who helped out lots, and gradually expressing simply became normal life (but I still hated it).

Going out and about was more problematic. If we were driving somewhere I could bring the hand pump and express in the car, and we bought an Avent double electric pump on ebay, which we discovered attached to our in-car adaptor, so on the odd long journey I could actually use the electric pump - all dignity gone of course. (This pump was also quite handy at home, as I could control the suction of the pump with my wrist.) However visiting the baby groups and going to see friends in town was just a bit awkward as feeding/expressing times always seemed to fall when things were on, but my good friends came to me and got used to the sight of the pumps under my jumper and our mad existence.

I did still manage to get to all of the girls' activities (not always punctually) and as the weeks passed I became more confident that if I was a bit late/earlier in expressing due to these activities, it didn't really harm my supply as long as I expressed 40ml x no. of hours since the last express. Matthew was about 4 months old when I stopped expressing in the middle of the night. I was still feeding Matthew, but he didn't really need a huge amount to get him through (having had a big feed at 11pm anyway) so one night I tried just giving him a 'suck' (his 'suck' got stronger as he got older and he could definitely take a bit more milk himself) without expressing afterwards and I still seemed to get almost as much milk in the morning. Overall I did find that the more I expressed, the more I got, but there wasn't a huge difference between 6 and 8 expressings so by 4 ½ months I got down to 6 expresses a day, and the bit of extra free time/sleep made such a difference.

Although I probably should have got tougher when Matthew continued to wake in the middle of the night for a comfort suck, it was the only time that I wasn't rushing to get on with expressing/feeding/trying to get to the next pick-up. It was great for Matthew to snuggle in and we could both pretend he was properly breast-feeding. It might not have done much for my energy levels, but I'm sure that continuing with that comfort suck made it easier to breastfeed Matthew later.

So as we neared Matthew's op at 6 months, I was still expressing 5 times a day with Matthew having his comfort suck in the middle of the night in addition, and a suck before each feed.

Sometimes he was impatient for his bottle as he could look around at the same time, but generally he liked his sucks. The quieter the feed the better - not easy with 2 others - so the night feed was crucial for the practice.

## The operation

At 26 weeks and 4 days, the countdown was finally over, and on 25 July – our 10<sup>th</sup> wedding anniversary - Matthew was booked in for his operation.

Having made it so far, I was very impatient for the op. to repair the palate to be over and done with, however Chris had warned me that Matthew wouldn't be able to suck straight away and that it could be 4-6 weeks after the op. or maybe even longer before the muscles in his mouth had built up sufficiently.

A good thing about still getting breast milk, was that Matthew could be fed much closer to his op. than with formula, as breast milk is more quickly digested, so on the morning of his op. in Newcastle, Matthew didn't have to starve for too long.

The operation was successful but we had a very (understandably) grumpy boy afterwards, who had to wear splints on his arms for 3 weeks to keep his hands and any sharp objects out of his mouth whilst it healed. After initially saying that I couldn't try breastfeeding for 2 weeks for fear that it would damage the repair, the surgeon agreed that Matthew could feed from me again after 24 hours, however Matthew wasn't even interested in his bottle the first day and I had to feed him his milk from a doidy cup. I thickened the milk up with baby rice so that we wouldn't lose too much.

After 2 days of refusing to latch on Matthew finally had a suck, but he wasn't very happy. Clearly both the nipple and the teat were uncomfortable. About a week after the op. was the only time I wondered if breastfeeding was going to work, as Matthew seemed much more interested in his bottle since he didn't have to do any work with that(although he still enjoyed his comfort suck at night).

However, after 2 weeks things started to improve and by 4 weeks Matthew seemed able to take more milk by himself and was therefore much more interested in feeding from me. I had to try to make sure there were as few distractions as possible at feed times, but although Matthew's suck sounded very noisy it was becoming more effective and there was less milk going in to the bottle when I expressed after feeding him. Gradually I began to express fewer times in the day, and at 7 months 11 days (or 5 and ½ weeks after his op) I did my final expressing as I felt that Matthew could just about get enough milk by himself. His sucking still seemed rather noisy, but that has improved over time, and at 9 ½ months the expressing

seems very far away and Matthew loves breastfeeding – especially now that he can just lean back and let me know when he wants to suck. Recently, Matthew has had lots of teeth coming through at once, so I have been very glad to be able to breastfeed him, as when babies are poorly the best comfort they can have is a nice snuggly suck.

The first few months of Matthew's life were very challenging, but I am glad that I stuck with expressing and it is amazing how quickly you adapt to an odd situation. There was very little useful information on expressing and trying to breastfeed a cleft palate baby. I only came across the most useful booklet 5 months in (details below). I discovered that very few people continue with expressing, but with organisation, determination and know how it can be done and really is worthwhile.

***Breastfeeding babies with clefts of lip and/or palate***  
(An *Australian Breastfeeding Association* booklet) which is available to order on the **Association of Breastfeeding Mothers** website.

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