Anke Bauer’s second child was born with a cleft palate, which meant that she had difficulty latching on and feeding from a standard bottle. She shares excerpts from the diary she kept during the 26 weeks she expressed breastmilk for her daughter.

Week 1:
The news that our daughter has a cleft palate came as a shock. She cannot build up a vacuum in her mouth, which is vital for sucking. We spend every free minute online trying to find out as much as possible. The hospital has not been helpful at all—they only referred us to our nearest cleft team after five days. At the end of the week we have someone to call from the cleft team at Great Ormond Street Children’s Hospital (GOSH) if we have questions. I am ‘drip feeding’ Maria from my breast into her mouth and trying different ways of positioning her. Sometimes she manages to get a good latch, but often she has to try 30 times per feed—she is such a patient baby.

Week 2:
After 10 days Maria got too hungry to continue with drip feeding. After trying a syringe, cup, special needs feeder and bottles with various teat sizes, we ended up with special squeezy bottles and teats from the Cleft Lip and Palate Association (CLAPA). As I am keen to help Maria to learn to breastfeed, we do not squeeze the bottle during the feed—I don’t want her to become too used to not having to do anything at all. I am expressing as much as I can. I believe my own milk is so much better for her—building up her immune system, and helping her beat ear infections, which is more prone to because of the cleft. The squeezy bottle has the advantage that other people can feed Maria while I get on with expressing, and so the task of feeding her breastmilk is less overwhelming. I felt horrible yesterday, crying all day, coming to terms with not having a straightforward feeding experience and feeling very tired.

Week 3:
Nipples are a bit sore from all the expressing but lanolin helps. I express more than enough, and always have a little milk store in the fridge, ready for the next feed.

Week 4:
I feel confident I can do longer-term expressing, as I breastfed my son for nearly two years and I never had a milk supply issue.

Week 5:
Having lots of support from friends and family makes it possible to maintain a busy expressing schedule—every three hours day and night, washing up and sterilising the equipment and bottles, keeping track of supply and demand. It’s a bit like running a small company.

Week 6:
I’m feeling the pressure of juggling it all without help: a 2 ¼ year old, nursery drop-offs and pick-ups, shopping, preparing meals, laundry. At the moment it is 50/50—continue or stop expressing?

Week 7:
Crisis. I hate pumping! I don’t know what exactly it is about it—the time it takes, the constant smell of old milk, the never-ending washing and sterilising of equipment and bottles, the sitting and waiting for the milk to be out, or the pain of engorged parts. I called a La Lèche leader who also pumped for her cleft baby. She had similar experiences and it was helpful to share my emotions with someone committed to supporting me in feeding my baby with breastmilk. If I speak to any health professional, they usually tell me that what I am doing is great but I just have to realise that it is too hard and I should stop expressing.

Week 8:
I have got into a routine of expressing at 11am, 5pm, 11pm and 5am. That works around nursery and meal times and does not affect the rest of my routines too much. I have more than enough milk, still freezing about 100ml per day.

Week 9:
Expressing does not affect my life that much any more. The pump has become ‘my baby’ so letdown is quick and the milk just flows. It is routine now. Often I feed my daughter while I pump with her lying across my lap on a pillow.

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Week 11:
I feel less passionate about my goal of starting to breastfeed at six months after my daughter’s cleft repair. Do I want the hassle of teaching her to feed from my breast at six months? Do I want to go through the whole weaning process?

My thoughts now circle around Maria’s developing eczema. I know breastmilk has benefits in preventing allergies, but would it be better for her now to have formula? I think because I eat gluten, dairy and nuts, her skin might be reacting to this, and hypoallergenic formula would have less of that in it.

Week 12:
I am on a dairy-free diet now. By the end of the week, Maria has green slimy diarrhoea, eight times a day. Is she reacting to the soy?

Week 13:
Maria has continuous diarrhoea for over a week now! I don’t know what to eat and I am craving dairy products. The GP was unhelpful. In terms of expressing—no issues, I got lazy, and most days I only express three times. Still enough milk. Maria just drinks what I pump, so there is not much reserve in the fridge any more.

Week 14:
Stressful week. I only pump two or three times a day and by the end of the week I reap the result—my milk is getting less. No problem I think, I’ll just top up this week with the milk I have in the freezer from earlier pumping sessions. Then comes the shock—the eight litres of my milk in the freezer cannot be used because my milk contains an excess of the lipase enzyme, which breaks down the milk fat when frozen, causing the milk to smell and taste bad. All my frozen milk has to go down the drain. I am now faced with the question, ‘Which formula do I use?’
This is complicated by the fact that my daughter’s skin has cleared up after me going dairy-free. Formula that isn’t based on cow protein is only available on prescription. I speak to the dietician at GOSH, he faxes the GP, the GP loses the fax. The stress of all this leads to me getting even less milk out.

Week 17:
Spoke to the NCT breast feeding helpline. I try to make pumping four times a day my priority this week. Having the prescribed formula standing in the kitchen just in case eases the stress and lets the milk flow better. After doing some more research into different formulas I get more motivation to keep up the pumping. The hypoallergenic formula tastes bitter, so it has maltodextrin (sugar) added to it. I’ll keep expressing. It is a joy to see no sign of eczema on Maria’s skin.

Week 18:
I am fed up with expressing. I am tired all the time, get less sleep due to my routine, hate the sitting and waiting for the milk to come out. I don’t like Maria touching my breast – how will I then be able to breastfeed her after her operation? It is tiring having to deal with my conflicting feelings of wanting closeness and wanting to care for my baby in the best possible way, but not wanting to continue expressing or ultimately even breastfeeding. At the end of the week I gave Maria a few formula feeds. She is drinking it fine.

Week 19:
I am reducing the amount of milk on the pumping sessions I intend dropping, the goal being to only express at 9am and 9pm. So in the afternoon I went from 250ml to 200ml, then to 150ml and so on. Now I’m feeding 50% formula and 50% own milk. I decide to slowly stop expressing.

Week 20:
I seem to still have more milk than I thought. The worst thing is that I seem to not let down to the pump any more. I sit and express and nothing comes out – 50ml in 45 minutes. It used to be 300ml in 20 minutes. I need to get the milk out without going back to increasing sessions and thus increasing supply.

Week 21:
I get the milk out with relaxing a bit more about it all.

Week 22:
I’m down to two sessions per day now. Got a new pumping set from the hospital. The valves were worn, and now the milk is really flowing again.

Week 23:
I am now pumping every 16 hours. That is fine; it provides my daughter with a third of the milk she drinks in a day – about 250 to 300ml. We go on a short holiday without the pump. I hand express and that works well.

Week 24:
We hear that our daughter’s surgery will be later than we thought – will I still be expressing then, holding open the possibility that she will eventually be able to feed from me? I’m jumping between joyfully finally being able to stop expressing and wanting to keep some milk going until after the operation so I can breastfeed.

Week 25:
It seems a bizarre decision to stop now, so close to my previous goal of expressing until the operation at 26 weeks. I have to ask myself, why do I want to breastfeed? The answer is because it’s convenient, healthier for her, and because I feel a certain level of closeness is missing in our relationship. Maybe I can achieve this closeness in another way, like carrying her more often in a sling.

Week 26:
Nearly stopped now. Hand expressing every three to four days. I have doubts about stopping now as the operation is in two weeks but after this week’s hormonal turmoil as a result of stopping I really don’t want to restart.

Epilogue:
I stopped expressing after week 26. The operation went well and my daughter’s cleft palate was repaired. No more milk and food through the nose, and the potential for her to learn to speak just like any other child. It has been a struggle, and what an emotional journey. I am happy about each day that I expressed for my daughter, yet I feel no guilt at all for stopping when I did.

Breastfeeding counsellor Kirsty McNicol comments:
For a breastfeeding counsellor, supporting a family when the baby has a cleft palate can be a balance of counselling and practical support. In the Crane database, fewer than half of babies with a cleft were diagnosed antenatally. Anke and her partner had no chance to prepare. If contacted in the crucial early days after birth, a breastfeeding counsellor can ensure that the parents know how to contact their local specialist cleft team, and can provide contacts such as CLAPA so that they can explore options for specialist support and equipment as urgently as required.

The benefits of breastfeeding for cleft babies can be significant, but long-term, highly-individualised support is a key part of both mother and baby getting the most from their feeding journey; a counsellor can play a valuable part.

References