



## 1. Liz – buying a breast pump on Amazon

**“When I got up to the postnatal ward, the staff said "we're really sorry, but it's very busy and we're short-staffed, so we won't be able to give you any help with feeding".”**

Ben was born at the JR after a straightforward labour. The midwife who delivered him was lovely and I held him straight away but she didn't mention breastfeeding or offer me any help to feed him. When I got up to the postnatal ward, the staff said "we're really sorry, but it's very busy and we're short-staffed, so we won't be able to give you any help with feeding".

Luckily, there was a volunteer breastfeeding counsellor helping on the ward that evening and she showed me how to express tiny drops of milk and feed them to Ben by syringe. As my milk increased I needed a breast pump, but there weren't any available on the ward. Staff eventually agreed that I could be discharged from hospital if I managed to buy myself a pump. Luckily my husband and I had smartphones and we got one delivered from Amazon the next day!

I still hadn't had any help to hold my baby comfortably for feeding; every time I tried, I got sore and my baby quickly got tired of our clumsy efforts and fell asleep. It wasn't until about 8 days after Ben's birth that we started going to a Baby Café in Cutteslowe and learned how to feed well. It took about 10 weeks for me to heal fully from the physical damage that occurred during those first few days.

When Lydia was born 4 months ago I was already an experienced mum and didn't need as much support. I had also trained as a Peer Supporter with Baby Cafe and this gave me extra confidence that I could do it. The time I knew to feed her straight away and we found it much easier, even though the help I had in hospital was still very variable.

Parents really need all hospital staff to have the right skills and enough time to spend with them as they learn to feed their babies.

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## 2. Jenny – breastfeeding twins

**In hospital I felt they lacked the time to devote to one mother as they were stretched so thinly, while in the community I felt there was a lack of confidence/knowledge in how to support breastfeeding. In both situations I was pushed to formula feed rather than supported to breastfeed.**

When I knew I was pregnant I assumed I would breastfeed - I was breastfed by my mother at a time when formula was heavily promoted and attending NCT antenatal classes involved a trek half way across the county. Most, but not all, of my friends who already had babies had breastfed enough for me to get the idea that it was the normal thing to do. I went to Abingdon NCT's antenatal classes and the breastfeeding counsellor gave me the confidence that breastfeeding twins was entirely possible. She also made it clear that she would be available to support me and encouraged me to visit Baby Café, which of course I did a couple of times. Sue and the rest of the team made me feel very welcome and they exuded a very infectious confidence that breastfeeding twins would be fine. I went into labour with a deep confidence that there were some very lovely and very capable people out there who would help me to breastfeed. On my antenatal visits to Baby Café I also met for the first time the health visitor assigned to me and unfortunately she didn't inspire the same confidence.

In the JR after my babies were born, we didn't get the hang of feeding immediately and got into a vicious spiral of the babies getting sleepier as they were hungry, so too sleepy to feed. We saw very little of the staff as we were on level 7, but basically healthy, and there were of course many people in greater need of attention. I asked for help with feeding several times and was always told someone would be along when all the crises had been dealt with. I was shown how to express with one of the industrial pumps, which worked quite well. I was shocked one evening when the duty midwife poked her head round my door and asked firmly which brand of formula I would like, presumably having heard my babies crying for some while. I declined and said I would like help with breastfeeding instead. To her credit she came back to me an hour or two later and was actually quite good at helping with feeding, but she was understaffed to deal with the number of mothers and babies in her care. Under these circumstances a new mother less stubborn and assertive than I am would have just given in and gone with the offered formula bottles. I feel sad for the mothers and babies who missed out on breastfeeding simply due to lack of support. We limped through the rest of our ten days in the JR and a couple of the MCAs who seemed to have a little more time did help with feeding to some extent.

At home, we persevered with breastfeeding with help from Baby Café and the NCT breastfeeding counsellor and my babies were getting milk, but evidently not enough as by 3.5 weeks my daughter, the smaller baby, still hadn't regained her birth weight. I was expressing to some extent too. Our Health Visitor had been getting increasingly worried about their growth charts, but offered no practical feeding help.

By 4 weeks I accepted I had to get them stronger to feed better so very reluctantly introduced formula. The Health Visitor warned me that this might very well be the end of breastfeeding. I didn't really see that the two were mutually exclusive and fortunately it was only a day or two until Baby Café and I was able to talk through my options. Once again, the Baby Café team were hugely empowering and put the ball back in my court - how did I want to feed - so I carried on breastfeeding but topping up with formula. We did this intensively for a couple of weeks until they were clearly on a good growth trajectory and then I gradually backed off the formula, only doing the occasional bottle now and then if it seemed they were still hungry after I'd given my all. Up to this point I had largely been feeding the babies separately as getting this sorted seemed tough enough, but to continue long term it was clear we had to learn tandem breastfeeding and here of course Sue came into her own again.

In a nutshell I had fantastic support in establishing breastfeeding from Baby Café and the NCT but rather weak support from midwives in hospital and health visitors in the community. In hospital I felt they lacked the time to devote to one mother as they were stretched so thinly while in the community I felt there was a lack of confidence/knowledge in how to support breastfeeding. In both situations I was pushed to formula feed rather than supported to breastfeed. I recognise that much of this is down to thinly stretched resources as these health professionals have a huge caseload. I'm sure it helped too that the Baby Café and NCT people are quietly passionate about breastfeeding; sadly this passion doesn't seem to be shared by all health professionals.

For us, breastfeeding has been about far more than simply nutrition. It's been about nurturing, comforting, bonding and really enjoying the early years together, not to mention sheer convenience and practicality. I'd have been very sad indeed if I'd had to give up without really starting but it is only thanks to Baby Café and the NCT that this didn't happen. It's almost incidental, but my children had very few minor ailments in the early years, which I like to think is due in part at least to the effects of breastfeeding.

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### 3. Cath – keen to breastfeed second time round

**“When I asked for someone to watch me feed I was told they were too busy dealing with the medical needs of other patients. On day three I transferred to the Wallingford, a Baby Friendly hospital. I went home confident”.**

I was so excited to be pregnant for a second time from IVF. I had 10 year old IVF twins so was an experienced mum, but feeding had not gone well with them and so from my first appointment with my midwife I asked about feeding support.

My twins were delivered at the JR by emergency C section at 38 weeks. After 24 hours Emily had not fed so was taken to SCBU, I could only express 5ml so she was given formula. At 5 days Chloe was weighed and had lost 17% of her birth weight so the paediatrician gave her formula and told me I had to offer formula after every feed. I never managed to get the girls onto exclusive breast feeding and trying to give breast and bottle to two babies at every feed was exhausting. At 2 weeks I gave up offering the breast at night and by 6 weeks I'd stopped breastfeeding altogether.

I was very keen in this second pregnancy to do all I could to build my supply of milk more quickly this time. I was searching the internet, found La Leche League's website and filled out their contact form. A counsellor contacted me by email the same day and we had a series of fantastic exchanges where she sent lots of advice and research links which made me much more prepared going into hospital. In fact it made me realise that most of the practices 10 years ago in the JR had not supported breastfeeding – no skin to skin, babies taken away at night, no-one with time to watch me feed and check the latch was good, no one advising me to check for wet and dirty nappies.

This time I was better informed, and had a birth plan designed to help me successfully breastfeed. Benjamin was due to be born by elective C-section at 39 weeks. In my birth plan I requested skin to skin in the operating theatre and requested that the baby was put to my breast as soon as possible. I also asked for earliest possible transfer to a Baby Friendly hospital to get good breastfeeding support.

In terms of the first request, I had to ask several times, but my LLL counsellor had given me the research to back up the importance of this request so I stuck to my guns. The team on the day were fantastic and supported my request. Post-delivery the midwives were also fantastic in terms of my medical care & post-operative pain relief was much more forthcoming than 10 years ago. However, when I asked for

someone to watch me feed I was told they were too busy dealing with the medical needs of other patients.

On day 3 I transferred to Wallingford, a Baby Friendly hospital. I was given lots of breastfeeding support and left a day later having been shown two positions to feed in and my husband had been taught to latch the baby onto my breast whilst I lay down for night feeding. I went home confident.

However, on day 5 my worst fears were borne out. Benjamin had lost 12% of his birth weight and the community midwife from Wallingford told me to go and buy some formula and offer a top up after every feed. I was so disappointed, I thought that like the twins I was not going to be able to achieve my desire to exclusively breastfeed my baby. She did take the time to watch me feed, and told me he was well latched on, and she offered us the loan of an electric pump from the hospital. This was all great support but going back to expressing and giving top up bottles left me feeling very low.

Two days later a different midwife from Wallingford visited and told me that babies born by C section can lose up to 15% of their birth weight safely and I didn't need to top up or express, just put him to the breast often. She also watched me feed and said that actually he wasn't latching on well and showed me a new position to feed in. She advised that if he couldn't settle in the evening to offer him a bottle, but otherwise to feel confident to just offer the breast. I was delighted to go back to exclusive breast feeding. I offered a bottle at bedtime and he took 1 to 2 ounces, giving me confidence that he wasn't hungry after all.

During these days I spoke by email to my LLL counsellor daily. I couldn't drive so a face to face appointment at a Baby Cafe wasn't possible but the emails were warm, encouraging and full of evidence-based advice and links to further online resources. Feeling well informed and having free access to baby weighing scales at my GP surgery I simply stepped away from the community midwives and health visitors. They were all warm and well-meaning health practitioners, but their advice was inconsistent and I felt I was getting much more reliable and evidence-based support by email from LLL.

With the email support of the LLL counsellor I did manage to get Benjamin back to exclusive breast feeding and at 10 days my milk finally "came in" properly. By 2 weeks he'd regained his birth weight and has stuck like glue to the 50% centile ever since.

**Cath Baillie**

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#### **4. Sam – home birth and a long search for support**

**L was an absolutely fantastic midwife throughout my pregnancy and post birth in all areas other than breastfeeding support. The clinic was always incredibly busy and the midwives and volunteers were completely run off their feet.**

I gave birth to my daughter Indira at home in December 2011. In the few hours between Indi's birth and the midwives leaving I received no breastfeeding support or guidance. I was sitting on the bed attempting to feed her when one of the midwives came in to check on us, saying that she needed to make sure that the baby was latching on before she left. I remember asking how I would know if she was latching on OK, how I made sure that she did. I was told to wait until she opened her mouth wide and then just push her on. That was it.

The next day, my own community midwife came to visit. L was an absolutely fantastic midwife throughout my pregnancy and post birth in all areas other than breastfeeding support. I was asked if Indi was feeding OK. I thought so, she was at the breast sucking a lot but it was incredibly painful. It made me cry every time she latched on. It did get better during the feed, the pain wasn't so intense. But she was probably trying to feed for eighteen hours a day. In between feeds she was unsettled, not sleeping well, very windy; after feeds she never seemed content, was rarely 'milk drunk'. L didn't ask to see Indi feeding; I didn't think to request it.

Somehow, over the New Year period we got 'lost in the system'; no one came to see us. I called the on-call midwives several times to no avail. Eventually, six days after Indi was born a health care assistant came to the house. Breastfeeding wasn't discussed.

So I persevered, watched the DVD that I had been given antenatally, did some internet searching, watched some other videos. When Indi was three weeks old I met up with my NCT group and the natural conversation was birth and breastfeeding. Anecdotally, the post-birth breastfeeding support in hospital hadn't been any better than mine but a couple of the girls had accessed support at the JR breastfeeding clinic and said that I should go.

I think it's important at this point to highlight that I had been given leaflets about Oxford's Baby Cafés by my community midwife antenatally. They sounded great. However, I was unable to leave the house by myself for three weeks after giving birth as I kept fainting and my husband had only had a weeks' paternity leave. We were new to Oxford and so had no friends to call on for help.

I visited the JR breastfeeding clinic a number of times and although my NCT friends sang its praises I don't feel that I was as well supported as they were. The clinic was always incredibly busy and the midwives and volunteers were completely run off

their feet. There were also often lots of very new babies who weren't feeding at all, twins, new mums needing help expressing. I had a very fat baby and wasn't outwardly distressed and I'm guessing that in this very busy environment we weren't a priority. I got some help, but it wasn't enough. It wasn't hands-on enough, time intensive enough, no one sat with me like they did with the other mums. Or that's how it felt.

My husband's mum lives an hour and a half away. She offered to come to the breastfeeding clinic with me and made a point of listening to advice that was being given to others and watching as many babies latching on as she could. Then we went home and practiced, many times. Slowly it got better, less painful; Indi was feeding for less time each feed and in a twenty four hour period but it still wasn't easy. I had trouble getting her into a position where she seemed comfortable and I was comfortable and she seemed really colicky and I read that this could be linked to breastfeeding. I visited one of the Baby Cafés but again, it was busy, we weren't prioritised and I came away having had a cup of tea. That was it. At this point I decided to access the La Leche League and via this medium I finally received the support that I desperately needed.

LLL provided a sympathetic ear and peer support; it's always amazingly useful to hear of others' challenges and solutions. And at LLL meetings I got to watch people feeding who were more experienced. In our society we aren't constantly exposed to breastfeeding and so to be within a group where breastfeeding is very present is one of the best kinds of help. The friends I had made during NCT classes were very helpful in this way too. No one minded anyone else having a closer look to check out latch & positioning and lots of people were happy to pop their baby on and off the breast for real life demonstrations!

Memories aren't perfect but I'd guess that at least the first four months of mine and Indira's breastfeeding relationship were very difficult. With adequate antenatal preparation and perinatal breastfeeding support, this needn't have been the case.

***Sam Leggett***

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## 5. Emily – premature baby and diminishing milk supply

**Some of the nurses really supported me and took time to sit with me and help me to latch him on. However, other nurses disagreed and told me breastfeeding would exhaust him. I had to fight to get the small amount of breast milk I was pumping added to his formula feeds.**

My baby was born at the John Radcliffe hospital in August 2009 by emergency C-section at 30 weeks gestation. Shortly after his birth, a midwife explained how I should hand express colostrum for tube feedings. Later I was shown to a room with a breast pump in for expressing milk. The nurses in the intensive care unit were fantastic at encouraging me to hold my baby skin-to-skin as often as possible, and told me that my breast milk was the best thing my baby could have.

Unfortunately I struggled to express my milk, and despite reassurances that my milk supply would increase as long as I pumped regularly, it did not. My baby was given donor breast milk as the next best thing. The nurses were very busy caring for the babies on the unit, and I didn't feel able to ask anyone to check that I was expressing correctly.

At 33 weeks gestation, a feeding specialist told me to start trying to get him to latch on to my breast. Some of the nurses really supported me and took time to sit with me and help me to latch him on. However, other nurses disagreed and told me breastfeeding would exhaust him and that he might inhale my milk and need to go back on breathing support. They explained that since I could not get much milk through expressing with a powerful pump, that my baby would get even less milk through feeding directly. I was told this would tire him out and he would still need to have the full amount of milk he required by bottle or tube.

I reduced my attempts at breastfeeding him so he could preserve his energy for finishing bottle feeds, which seemed key to being allowed to take him home. It was explained to me that the donor breast milk was now required for smaller, sicker babies and he would need to go onto formula milk instead. I had to fight to get the small amount of breast milk I was pumping added to his formula feeds. When I brought him home from special care aged almost 7 weeks, I was only pumping enough breast milk for one feed per 24 hours.

I was blessed with a health visitor who was very well informed about breastfeeding, and was also referred to the Baby Cafe for practical help. My health visitor, and supporters at the Baby Cafe assured me that I was still capable of fully breastfeeding my baby, although by then I was barely making any milk. I was told I could very quickly increase my supply through regularly feeding my baby directly at the breast. Things changed at this point. I was with my baby day and night. I had practical support in positioning and latching my baby on. I was given reliable information about how milk supply is regulated. I became confident that I could make enough milk to meet my baby's needs. I was also shown that the pump flange I had been



using to express milk was too large, and a smaller one allowed me to finally express my milk successfully. In less than two weeks I was able to completely stop using formula and exclusively breastfed my baby. We enjoyed a wonderful breastfeeding relationship until he chose to stop at 16 months old.

***Emily John***

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## 6. Jayne – postnatal depression after feeding difficulties

**My husband and I travelled to Chipping Norton Maternity Unit for some breastfeeding support. We spent two hours there and this was a wonderful experience where I felt entirely un-judged and supported. As a result, my son fed peacefully for 30 minutes and then fell asleep contented for 2 and a half hours – the only time that he ever did this after a breastfeed**

I had my son in the Horton Hospital Banbury on 31<sup>st</sup> December 2009. Whilst the birth was a straightforward one, it was very stressful as I was not admitted until 10 cm dilated and unable to have the birth that I wanted due to low staffing levels. I had always planned to breastfeed as I felt this was very important to bonding and the health of my son. However, my son had difficulty latching and seemed very fretful and unsatisfied after a feed. I asked for help with breastfeeding but was given none. I was asked if I wanted to express and was given a paper cup and told to use my hand to squeeze my nipples into the cup. I was shocked by this, unable to do it and given no assistance. Eventually, when my baby would not stop crying, an older midwife asked me if I would like to give him some formula. I agreed to this and my son fed then fell asleep satisfied.

After this, I tried again unsuccessfully to breastfeed. As I found my hospital experience so stressful – I was in a room on my own and never visited by midwives unless I rang the bell – at which point I generally got a rather annoyed response. So, despite feeling very low (spending hours at a time crying) and being unable to breastfeed my son, I left hospital the following morning. We were not even checked out by a midwife but by a cleaner (and left with my son incorrectly strapped into his car seat – my fault entirely but I believe they were supposed to check this before I left).

Subsequent to this, once home I had the usual visits which generally focussed on breastfeeding and my inability to successfully do it. I was repeatedly told that all women are able to breastfeed – the implication being that I simply wasn't trying hard enough. On one visit, a week after giving birth, I expressed for 30 minutes, so that the health visitor could see whether I was doing that properly and managed to produce less than an ounce in the 30 minutes. As my son was born at 8.8, (although he lost 10 ounces post birth – due to the insufficiency of my breast milk) he needed 3 or 4 ounces to be full.

Due to my inability to successfully breastfeed and the 'moral' pressure I felt to do so – all of the NHS literature, internet info, even TV adverts for formula (!) were telling me that my son would be healthier with breast milk and that was 'no substitute'!, I became increasingly stressed, essentially stopped sleeping altogether and developed post natal depression.

On a friend's recommendation, on one particular occasion, my husband and I travelled to Chipping Norton Maternity Unit for some breastfeeding support. We

spent two hours there and this was a wonderful experience where I felt entirely un-judged and supported. As a result, my son fed peacefully for 30 minutes and then fell asleep contented for 2 and a half hours – the only time that he ever did this after a breastfeed. Unfortunately, due to the harsh weather conditions and heavy snow, we were not able to go back to Chipping Norton on a regular basis and after several more failed breastfeeding attempts at home, I reluctantly switched to formula.

In short, I suffered from severe postnatal depression for the first 5 months of my son's life; a condition which was extremely harmful to our relationship and essentially 'ruined' what should have been the most wonderful of times. I strongly feel that the lack of 'good' (as opposed to judgmental) support with breast feeding and realistic factual bottle feeding guidance was instrumental in causing this depression. It seems to me now that everybody was so concerned with being seen to follow the latest Government guidelines, that common sense was ignored.

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## **7. Rachel – poor advice and disappointment**

**I had major trouble establishing breastfeeding and after 6 weeks of expressing, I moved on to formula. I am very disappointed that I couldn't give my child the start in life that I wanted to give him.**

My baby was born in June 2011 at the JR and my birth plan clearly stated that I wanted to exclusively breastfeed. When my baby was less than 3 hours old, I was told that it must consume 100ml of milk or its blood sugar levels would drop and the baby may fall into a coma. Also that I would not be able to leave the recovery area until after the baby had consumed this. I therefore fed the baby the 100ml of milk that the worker almost made me feed to the baby. I was made to feel that I would not be allowed to leave the recovery area unless I did this, at my most tired and vulnerable. I felt as if I was being held to ransom in the recovery area.

I have subsequently learnt that a newborn baby of 3 hours old does not require 100ml of milk because its stomach is smaller than the size of a walnut and indeed, that if the baby does not eat for up to 6 hours, this is fine and the baby will not fall into a coma. I would like to know why such bad and incorrect advice is being given out to new mothers.

Nobody helped me to breastfeed my baby when he was born. I was in the delivery room for an hour before being taken to theatre to have my placenta removed. Nobody helped me to breastfeed in that time despite me asking the midwife at least 3 times. The midwife was only interested in the fact that her shift finished at 7am and she needed to finish writing her notes.

I had major trouble establishing breastfeeding and after 6 weeks of expressing, I moved on to formula. I am very disappointed that I couldn't give my child the start in life that I wanted to give him. The care I received at the JR played the major factor in my breastfeeding failure. Not enough is being done at the JR to help new mothers breastfeed. Advice differs from midwife to midwife. One minute you are being told you need to feed X amount of ounces per X hours. The next you are being told to just breastfeed when your baby is awake. There is absolutely no consistency. Most of the advice is actually incorrect.

I got the impression that there was one midwife on duty in the recovery area that morning. There were two very young girls also 'helping out' and indeed, it was these young girls that seemed to be doing all the advising and talking to me. I barely saw the older lady whom I assumed to be the midwife. Such young and unqualified people should not be tending to new mothers when they are in recovery, in their most vulnerable state. Especially when they are giving out incorrect advice and ruining people's breastfeeding journeys before they have even started.

***Rachel Haycock***

## 8. Helen – determined to give her baby mother's milk

**My notes said: "breastfeeding is well established". My nipples were shredded and I was in pain. In the end, I ended up giving formula because I couldn't do it anymore. I did ask the lady who came round to talk about feeding whether she could show me how to use a breast pump and she told me that there was no point as I had now chosen to bottle feed.**

I had my daughter, Sophia, by emergency at the JR in March 2011. I had put in my birth plan that I wanted skin to skin as soon as possible and to be helped to establish breastfeeding. In fact it was three hours after her birth that I realised that I hadn't fed her yet - I was woozy from the spinal blocks. When I tried to feed her I don't think we were very successful but I didn't get much help - they were really busy. When I moved up to the main ward, the "help" I was given consisted of a nurse holding my baby's head to my breast really hard with me having to bite my lip because of the pain. My notes said: "breastfeeding is well established". My nipples were shredded and I was in pain. In the end, I ended up giving formula because I couldn't do it anymore. I did ask the lady who came round to talk about feeding whether she could show me how to use a breast pump and she told me that there was no point as I had now chosen to bottle feed.

When I got home a couple of days later, I was really sad that I hadn't been able to breastfeed, and wished I could have done it just a little, and also had an idea that maybe I could pump just a little so she could have the goodness from my milk. My husband was amazing - he went to the Abingdon midwife centre, which didn't have any breast pumps, then they sent him to the South Abingdon children's centre, again no pumps in stock, but they sent him to Sue Richards, who hired him an industrial Medela pump. This was really great - I had to pump eight times a day to get my supply up but I did this because I was determined! I did try to establish feeding directly from the breast but it was too painful and I could only do it with someone there to help me (Sally and Anthea from the South Abingdon Children's centre were lovely and helpful!). However, I managed to feed Sophia approximately 80% pumped breast milk with one or two formula top ups per day, for six months. I am really proud of myself for doing this as I didn't think I would be able to do it!

I think that the main important points here are that I wouldn't have been able to do this without the support of my husband, and the lovely Children's Centre staff and Sue. I think that the support provided in the community is good but not in the hospital. It's no good telling someone who is still recovering from a caesarean, in a room with no clock, that they can get breastfeeding support at eleven o'clock two floors down! Also, it was great to be able to hire a pump, but this would be difficult for those who couldn't afford it.

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## 9. Megan – sore nipples and help from Baby Café

**They all said the latch looked fine but did not seem confident with supporting me with the process of latching him on. By the 11th day of his life breastfeeding was so sore that I had to use the breathing techniques I had used in labour to get through a feed.**

My son was born in the JR Spires Unit early one morning. I was helped to feed him shortly after he was born and then he slept on and off for most of that day. I stayed in hospital the night after he was born and got some support from the midwives overnight, including being shown how to hand express colostrum and syringe feed it to him. The midwives were very busy so there was not as much support as I would have liked to latch him on, although a midwife did support me with one feed the following morning.

I left hospital still unsure about my latch. I had visits from 3 community midwives over the next 10 days. They all said the latch looked fine but did not seem confident with supporting me with the process of latching him on.

By the 11<sup>th</sup> day of his life breastfeeding was so sore that I had to use the breathing techniques I had used in labour to get through a feed. Feeling very downhearted I went to a Baby Café and received wonderful support and encouragement. By then my nipples were quite badly damaged so the Baby Café facilitator talked me through how to express milk and bottle feed my son to give myself a chance to heal.

For the next 2 weeks I mostly fed my son expressed milk from a bottle. I went to Baby Café every day so that I had support latching him on for at least one feed. Every time I went to Baby Café I was greeted with kindness and encouragement which made all the difference when I was close to giving up. I also appreciated the way the facilitators included my husband in the conversations when he was able to come with me so that he could remind me of tips and keep my spirits up when I was trying to feed at home.

Over time I gradually did more and more of the feeds directly and used fewer and fewer bottles of expressed milk until by the time my son was 5 or 6 weeks old he was breastfed pain free for every feed.

He is now nearly 5 months old and is exclusively breastfed. I am so delighted I have had the opportunity to do this for him, and could not be more grateful to the Baby Café facilitators who made all the difference to me. I think that without their support I would not have been able to establish breastfeeding successfully.

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**10. Katie – “I still feel very angry with myself even though I feel I did everything I could and I'm very jealous of mums who breastfeed”**

**The more bottles he had the harder breastfeeding became. We were told this would be the best thing and would mean we would be home sooner. I was never told about the JR clinic. I felt I had run out of options.**

Here's my story. I was in hospital from 24 Weeks because of placenta praevia and missed all antenatal classes so all talks on feeding. I was naive and thought it would be a natural and beautiful experience. My little boy arrived by emergency c section at 32 weeks. He was in intensive care so I couldn't even hold him for a few days. I was completely out of it but the nurses helped me hand express to produce colostrum then small amounts of milk. By day 3 I was expressing 3 hourly day and night and producing huge amounts of milk. My baby was exclusively tube fed my breast milk for 2 Weeks. I was then encouraged to try him on the breast. It felt very strange, not the amazing experience I was expecting.

Anyway, I persevered during the days as well as expressing and expressed at night and he continued to have exclusive breast milk. When they took his feeding tube out he would have breast milk in the bottle at night. I then insisted I wanted to stay with him around the clock so I could try exclusively breastfeeding. He was sleepy and feeding was very difficult. He was not putting on weight so I felt pressured into bottle top ups, still only breast milk but the more bottles he had the harder breastfeeding became. We were told this would be the best thing and would mean we would be home sooner.

Four weeks later we were discharged, still combination feeding breast milk. The neonatal nurse bullied me into introducing formula top ups because he wasn't putting on weight. I was told weight gain is directly linked to brain development so I was terrified I wasn't doing enough. To cut a long story short, he was very sleepy until his due date and feeding was a nightmare. So more and more bottles were slipping in. I found breastfeeding extremely painful but persevered for 16 weeks as I kept thinking it would get easier. I was desperate to breastfeed but kept getting blisters on my nipples and couldn't get the position or latch right.

I was never told about the JR I clinic. I felt I had run out of options. I was very isolated as I didn't have an NCT group to turn to. I think if I had found someone to support me with the positioning I would have been able to master it. I still feel very angry with myself even though I feel I did everything I could and I'm very jealous of mums who breast feed. I had a very mixed experience. I think the amount of support was great but still more is needed. More needs to be done to support women who miss NCT/ ante natal classes. I can't believe I was never told about the JR clinic!

Thanks for listening to my story. I feel very passionate about this and am more than happy to share my experience with others.

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## 11. **Nia – breastfeeding beautifully after help at Wallingford**

**After a night and very sore nipples at the JR I came back to Wallingford where they were lovely and very helpful with breastfeeding and all round care. I also have great confidence that if I have any issues I can just phone Wallingford whatever time for help.**

After having my little boy at the JR I was very quickly shown how to feed lying down - the nurse just as quickly left (a very busy night) when he came off and I had to put him back on. I didn't really have a clue, which left me with a very sore cracked nipple. But then again in all fairness I was offered antenatal classes which I didn't attend, and I should have read more on feeding beforehand. I suppose I just assumed it would be easier and come naturally.

After a night and very sore nipples at the JR I came back to Wallingford where they were lovely and very helpful with breastfeeding and all round care.

Back home I was struggling when he hit a growth spurt at about one and a half weeks. He vomited blood at about 1am one night (from a bleeding nipple) so I rang them and they offered me to go in - instead I choose to go the breastfeeding drop-in in Berinsfield the next day. Again we went through latching on; I also had a sore lump which they helped show me different positions.

My son is 4 and a half months old now and I'm still breastfeeding him. After I left the breastfeeding drop-in with a bit more knowledge and reassurance I persevered through the soreness, which went away after a week or so. I also have great confidence that if I have any issues I can just phone Wallingford whatever time for help. I also go to weekly postnatal classes run by the health visitors where we can ask anything we want.

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## 12. Lucie – too late to get started with breastfeeding?

**No-one said to me from that stage - get expressing NOW which is probably what should've happened. There wasn't very much encouragement to actually feed from the breast in SCBU - I think they worry that if the baby doesn't get milk from the breast then they tire themselves out trying and so bottle is best**

My daughter Isabel was born at 34+4 last October, it was all very quick and as I'd had a straightforward pregnancy with no indication of going into labour early, I was pretty unprepared! By that I mean I hadn't really given it much thought about feeding, other than I knew I wanted to breast feed, and assumed I just would.

Anyway, Isabel was very well when she was born - great Apgar scores etc. but obviously with a baby who is that early they have to be taken into SCBU immediately to be properly checked and monitored. We had a cuddle with her first and then she was taken away. I then had to get stitched up (ugh!) so I probably didn't lay eyes on her again for another couple of hours. The midwife came in and asked if I wanted her to have donated milk, which I said yes to, but apparently there wasn't any in stock (I suspect there probably was but because she was doing well they chose not to give it to her and save it for the really sickly/early babies, but that's just my suspicion!) so they put her onto formula from the word go.

When I did see her, she was in the high dependency bit of SCBU just being monitored as she was doing really well with breathing/vitals. She was being tube fed formula and there wasn't really any discussion about breastfeeding (and I was probably too out of it to say anything). In the afternoon the nurse who was looking after her did try to get her to latch on but I wouldn't say it was a very serious attempt (I don't mean that horribly as the staff there were amazing, but certainly their priority was to keep Isabel healthy and not to push breast feeding - it does sound mad when you say it as surely the two go hand in hand?! But anyway...) She was in an incubator for the first 18 hours of her life so it wasn't really like there was any opportunity to breast feed anyway. At the same time though, no one said to me from that stage - get expressing NOW which is probably what should've happened. I didn't really feel like my milk had come in at all but there was certainly not much encouragement/support to get it to come in. I'm sure if I had been up on the maternity ward they might have given me more encouragement but I just wanted to be in SCBU with Isabel. It does feel like SCBU and the maternity ward work very independently of each other which is a shame.

Isabel was transferred to low dependency the evening after she was born and was alternately tube fed and bottle fed for the next couple of days. The nurses in low dependency did mention now and again about breast feeding but there wasn't any help given/suggestions for what I could do and I didn't really have a clue, as had been thinking I had 6 weeks left to figure this stuff out! Anyway, I did see the breast feeding lady who works with SCBU but she didn't come to see me until nearly 3 days

after Isabel was born and by then she was in a bottle feeding/tube feeding routine and it just felt like an uphill struggle. She did offer tips to help such as kangaroo care and I did try to express but the facilities are pretty poor and depressing in SCBU and plus going to express meant spending time away from my baby which was the last thing I wanted. In hindsight, maybe I should have tried harder to express but all I wanted was to be with Isabel and that felt like the priority at the time, even if it meant she was bottle fed. There wasn't very much encouragement to actually feed from the breast in SCBU - I think they worry that if the baby doesn't get milk from the breast (which to be fair she probably wouldn't from me as it never really properly came in) then they tire themselves out trying and then won't get any milk inside them at all as will then fall asleep on the bottle, so bottle is best.

Isabel was eventually discharged from SCBU nine days after being born but as I said, by then she was in a bottle routine and it felt like such an uphill struggle to start to breast feed at that point. Once we came home we went to the midwives at Wallingford to get her checked over and I asked about breast feeding but they said it was basically too late and 'better luck next time!' They were probably right but I do think that we maybe could've got breast feeding off the ground when we got home if I had had some more support.

It's a really tricky one because on the one hand, I would've liked to breastfeed but on the other - she was an early baby who needed a regular good supply of milk and I don't know if I could've provided that. The main thing was that she was healthy and thriving, which she was on formula.

I do think there are some things which could be made better/help support and encourage breast feeding though - for example, in SCBU they have two flats where you stay overnight with your baby before being discharged. I wish they had let us stay overnight there with Isabel before she was ready to be discharged as I think if we'd been able to do some proper kangaroo care early on and be together 24 hours a day then we would more likely have been able to breast feed. Also wish that breast feeding/info on what to do had been given to me as soon as I'd given birth as it all just felt like the advice came along too late afterwards.

And they could definitely improve the expressing areas in SCBU to make it easier to do. I think the maternity ward with mothers who have babies in SCBU could do more to support them - I don't know how really, maybe they could have a midwife who does a tour of SCBU once a day to check on the mums? As unless you're physically on the ward you are basically forgotten about by them.

Finally, I wish I had been given more advice/information in my pregnancy about what it's like if you have an early baby - obviously you can't predict if this will happen or not but it didn't really occur to me at all that it might and I think maybe if a leaflet or something could be put together to go into pregnant mums packs about what to do if your baby comes early that might help mums like me feel more prepared if it does happen, and what you can do to help encourage bf if your baby is in SCBU.

I really don't want to criticise SCBU as they are completely amazing and I can't fault the care Isabel got at all but there are definitely things that could be done to help support breast feeding more I think.

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### 13. Hilary – needed support to formula feed

**I went to see the doctor who put me straight back on my medication but told me I couldn't breastfeed any more. That was basically where the support ended for me.... everything came from the packet or from the internet**

I was unable to breast feed my baby (now 7 months). I managed 2 and a half weeks but for the past 3 years have suffered terrible migraines which mean I have to take a low doses of epilepsy medication. I was unable to take this whilst I was pregnant and had a very bad pregnancy. After a very bad attack which left me unconscious in my dinner (luckily at my mum and dad's house so not alone with my child) I went to see the doctor who put me straight back on my medication but told me I couldn't breast feed any more. That was basically where the support ended for me. I had to make my own decision about which formula milk to use, which bottles were suitable, teats, sterilising, how much, how often, best way to make up a bottle... everything came from the packet or from the internet. I know that the Health Visitors are unable to suggest brands but I found this so hard and did feel quite let down.

Since then whenever my baby has had an upset tummy or anything instinctively I assume I made her bottle up wrong, or the water wasn't boiled right, or she didn't agree with the milk. Recently we moved on to the follow on milk; she was so sick and had such an upset tummy. The Health Visitor just said she must be ill. I put her back on the first milk and she's been fine again.

In terms of my experience with breast feeding when in hospital (JR) I can honestly say it was horrible... an hour after my baby was born a foreign lady came in to the room to show me how to breastfeed, I got myself all comfortable to begin and she looked at me and said 'no I can't show you with that breast I have to show you with the other one... too cack handed for me...' so I had to re position myself and then she just grabbed me, didn't ask permission first, just started 'milking' me. At least the midwives and the Health Visitor at the Oaktree were polite enough to ask 'are you happy for me to touch you'.

All in all it wasn't really a great experience for me. And I think there is so much emphasis on breast feeding it might be nice to see a support group for the mums who medically can't. I'm happy to say I gave it a go and I had fully intended to breastfeed for as long as I could. I don't know if this is something that is possible but there is a lot of guilt left behind because I couldn't, rather than chose not to from the start, if that makes sense.

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## 14. Anon – help from Wallingford

**The (JR) staff were lovely but there was no support for anything as they were unbelievably rushed off their feet. I rarely pressed the call button but when I did it would take up to almost hour for them to come. I contacted the Wallingford midwives and went in for some help with breastfeeding.**

Our first daughter was born in August 2009. We planned for a home birth with the support of the Wallingford midwives. Unfortunately there was meconium in my waters which meant a transfer to the JR at the very last minute. I was gutted and desperately didn't want to go which didn't put me the best mood. I had written in my birth notes that I wasn't sure about giving birth on my back but that seemed to be the only position they wanted me in although sometimes I was slightly on my left side. For a few reasons I ended up with a 4th degree tear one of which I believe was due to the position I was in to give birth.

Whilst waiting for surgery, there was a very pro-breastfeeding midwife who helped me to breastfeed. She was a little short with me at times and told me not to be so gentle with my baby! It was clear that they were very busy and everything seemed to be happening at the changeover of shifts but that's not really an excuse. I had a horrendous time in theatre – they couldn't get the spinal block in, gave me medication that caused a reaction despite being told my allergies and there were two flies in the operating theatre and a member of staff chasing them around with a can of Raid. Not what you want to see when you are covered in sticky birth fluids. I kept asking if my husband and daughter could come to the window but nobody went to get them.

After the observation ward, I was transferred to the Spires late at night as the main wards were busy. The staff were lovely but there was no support for anything as they were unbelievably rushed off their feet. Housekeeping had to be called in as there was blood and hair in my bathroom. I spent two full days in the Spires during which the unit was closed to labouring women and one midwife was told shortly after the beginning of her shift to go to Stoke Mandeville to help out. I rarely pressed the call button but when I did it would take up to almost hour for them to come. The midwives and health care assistants (I think that was their job title) were fab and I received some super help for breastfeeding but they were running all over the place trying to help everyone instead of having enough staff to do anything calmly and spend quality one to one time with each mum, which is definitely one of the things a new mum needs.

Our 2nd daughter was born in August 2012 at Wallingford. Everything was much calmer, my birth plan was discussed and the midwife took on board all my concerns from last time. I gave birth in the position I wanted and using only gas/air and a TENS machine. She weighed a whopping 9lb 14oz but I only had a 2nd degree tear. Unfortunately I had quite a bit of bleeding and after the initial cuddles the focus was

on stopping the bleeding so I wasn't able to have skin-to-skin/breastfeed. Due to the bleeding I had to transfer to the JR.

Upon arrival I was put on a drip for 4hrs during which it was extremely difficult to breastfeed as I couldn't really use my left arm and it's not easy to hold/latch on an almost 10lb baby with one hand. It was almost 3hrs after her birth before we began breastfeeding and I was continually becoming more anxious that she wouldn't take to it. The staff were lovely but again very busy. Shortly afterwards I was stitched up, the drip was removed and I showered before moving upstairs to a ward. By coincidence the woman in the bed opposite had been transferred from Wallingford just as I was arriving and we spent a bit of time chatting. We both felt that at the JR there was no support for new mums. I only needed help with breastfeeding but I felt for the other mums who needed help in more areas. I asked for some help with breast feeding but the midwife spent minimal time with me.

Although breastfeeding our eldest went extremely well (I exclusively breastfed for the first six months before gradually replacing breastfeeding with expressed breast milk in a sippy cup and finally stopping all breast feeding/expressing around her first birthday) I needed a few reminders how to get a good latch. I asked to be discharged the following morning at 8am and finally got to go home at 1pm. As a result of the staff having next to no time with each mother we had a few bad latches and I ended up in a lot of pain and my right nipple was actually ripped open leaving a gap about 10mm long by about 4mm wide. I was determined not to give up breastfeeding and carried on even though the pain was so intense I began to dread feeding on my right side.

I contacted the Wallingford midwives and went in for some help with breastfeeding. We were under the care of a student midwife who was fantastic – she took time to watch me feed on both sides and discussed what a good latch was and when my daughter had made a good latch she pointed out how/why it was a good latch so that I could see for myself and know for future feeds. Everything was so calm and peaceful. At home, I began feeding from the left side only and expressing from the right which was much less painful and allowed my nipple to heal. A few days later the pain was quite still intense and I felt like I had been hit by a bus – everything ached. I went to the doctor who said I had an infection and gave me some antibiotics to clear it up. Within 24hrs I felt so much better and slowly everything began to sort itself out. Our daughter is now 9 weeks old and breastfeed is truly a pleasurable and enjoyable experience. I'm definitely glad that I went to the Wallingford midwives to get the help that I needed at that early stage. For the last several weeks breastfeeding our youngest has been as successful as with our eldest and I can confidently and happily breastfeed her anywhere.

Anonymous

## 15. Lorna – perseverance and specialist help

**I was only able to get them breastfeeding after bi-weekly visits to the JR, with help from Sally Inch and 4 weeks of persevering before they latched!**

I had both my boys at Wallingford Hospital, the first in Dec 2007 and second in December 2010. The prenatal and birth care were very good, but the postnatal care in terms of hospital stays/midwife visits was patchy at best and I was sent home with both boys not feeding, unable to latch, and very little midwife visits/contact. I was only able to get them breastfeeding after bi-weekly visits to the JR, with help from Sally Inch and 4 weeks of persevering before they latched!

I found the breastfeeding support provided by Wallingford midwives is probably great if you need help with checking the latch/positioning etc. but no use if you have a baby who won't latch at all. They are very willing initially to try to help but just don't have the time when you need such a large amount of help and I was very lost on who to contact with my first as I knew I really wanted to keep trying to get them feeding.

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## 16. Josephine – “There is no support for those people who can't feed”

**Both times when I mentioned my fears over not being able to feed I was literally laughed at as if this just simply doesn't happen**

Essentially I couldn't breast feed. I simply didn't produce enough for my children to be fed solely from me and the guidance I received with Thomasin was so derogatory that she dropped 8oz in her first week as I tried to feed - my husband had to intervene before I accepted that the advice I was given was wrong. Knowing this I went into Edmund's birth eye open, but again was convinced by a midwife to try again and almost the same happened. There is no support for those people who can't feed and I was made to feel inadequate or that I was doing something wrong.

I'm not sure what I was looking for first time but I was met with nothing but determined midwives who thought I had not persisted enough despite Thomasin's obvious weight loss. There was no question over whether I couldn't feed; it seemed to be my style of breastfeeding or not feeding for long enough or not feeding enough on demand etc.

Both times when I mentioned my fears over not being able to feed I was literally laughed at as if this just simply doesn't happen and so when I was faced with it I was deluding myself about what I could and couldn't do instead of listening to myself. I think in terms of what should have happened is a realistic approach to the possibility that I couldn't feed and perhaps if the midwives had monitored my feeds and weight over 24hrs they might have noticed that not enough milk was being produced or perhaps that it's OK to combined feed.

In summary I'm thinking practical support first and then certainly if you are a first time mum some emotional support when you go home that not everyone can feed and that it's OK to find a feeding suitable to you no matter what that choice is.

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## 17. Asha – tongue tie diagnosed at 10 weeks

**The midwives and nurses at the Horton are not very supportive in regards to breastfeeding. One nurse in SCBU even said to me 'I don't know why you're even bothering' when I brought in my 30mls of expressed breastmilk one morning.**

Oakley was born at 32 +6 weeks. He was rushed straight to SCBU and so I had no skin to skin, and didn't actually get to hold him for 3 hours, and that was only for a few minutes. This was representative of the next few days where we were strongly discouraged from 'handling' him and skin to skin and kangaroo care was not supported.

I was shown how to use a pump and hand express but this was fruitless as I appeared to have barely any colostrum. We were told that Oakley had no suck reflex and so was tube fed for the about the first week. During this time I tried in vain to express milk every two hours, and he was feed donor milk as I could barely express 60ml a day at this point.

After this time his tube was removed, and he put on a bottle, I don't recall if I was asked if I wanted to try breastfeed, but I asked to be shown how. I was still very shell-shocked at this point and feeling very vulnerable.

Oakley was in the SCBU unit at the Horton for 3 weeks during this time I attempted to breast feed but he wouldn't latch. I repeatedly asked for help but there appeared to be little or no support available.

After two weeks someone, I was unsure who, popped in briefly to see me as she had heard I had problems, but they were there only a minute as they were busy. But no one told me who they were or where I could find them for further help. One of the midwives from the ward tried to help me but couldn't.

After ten days Oakley was taken off donor milk without our consent and put on to formula with the addition of my pitiful expressed breastmilk. He struggled even with bottles, and we were told that he wouldn't be able to leave SCBU until he could drink the required amount in the required time, even though there was nothing wrong with him and his temperature was stable.

At this point my husband and I decided that we should focus on getting him out of SCBU as he would be better off at home, and we could focus on trying to breastfeed at that point. Once out of hospital I kept pursuing breastfeeding and pumping, focusing on trying to increase my milk supply, but with no support from my health visitor.

I visited my local 'breastfeeding café' where everyone seemed to be bottle feeding. I asked for help and was taken to one side whilst they watch my attempts to latch, which didn't happen. They tried different positions with me but nothing worked. We kept pursuing at home, but mainly I pumped what little milk I had.

When Oakley was about 10 weeks old, after hearing of my problems my neighbour popped by with a telephone number of a breastfeeding support specialist at the Horton. She obtained this from a friend.

I contacted Naomi and made an appointment for later that week. Within minutes of meeting her she diagnosed Oakley with a stage 1 tongue tie and arranged a referral. She supported me with my low milk supply, advised me on herbal remedies and suggested medication I could request on prescription. I saw her once a week for a month. She helped me continue with the latch using shields and a SNS device.

After Oakley's tongue tie division at 12 weeks he finally started to latch himself, in fact it was amazing as he crawled up me and latched on with no prompting. Although he could now breastfeed, it did not increase my supply. We kept going with nightly feeds on the breast and daily pumping sessions, but the majority of his milk was formula.

At 5 months and after large amounts of herbal supplements and unregulated high doses of domperidone I made the decision to stop taking the supplements and within 24 hours I had no milk and Oakley would no longer latch.

I am still infuriated that none of the nurses, midwives or paediatricians involved with Oakley's early care spotted the very obvious tongue tie. Neither did the health visitors, or local breastfeeding clinic advisors. I feel if this had been found, coupled with skin to skin contact in the early weeks then our story would have been different.

It was only because of my determination to breastfeed that I had sought help. It appears that there is little informed breastfeeding support in the North Oxfordshire region.

The midwives and nurses at the Horton are not very supportive in regards to breastfeeding. One nurse in SCBU even said to me 'I don't know why you're even bothering' when I brought in my 30mls of EBM one morning. (Not the kindest thing to say to a mama who is trying to care for a premature baby).

I really hope that you can do something to improve things in the north of the county as I can only imagine how many new mamas are slipping through the net.

Asha Pearse

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