AIMS For a better birth...

Against the odds: Breastfeeding twins despite NHS errors, and how I found the support I needed

To read or download this Journal in a magazine format on ISSUU, please clickhere

AIMS Journal, 2019, Vol 31, No 3

By Nija Dalal-Small

Photo credit: Michele Selway for her Hidden Mothers Project



My breastfeeding experience was unusual, because I breastfed twins, which is less common than singletons. But, even for a mother of twins, my experience was unique. Due partly to poor advice from the NHS, and partly just bad luck, I had a really hard start to breastfeeding, which led to challenges that took a whole team of people to support me to overcome.

I had a doula, a fantastic doula, who told me a lot about breastfeeding before the babies were born because I wanted to exclusively breastfeed. I was advised to express colostrum before the birth, but I was never able to get anything. I think now that I didn't really have any kind of knowledge of how to do it. I looked online and tried a few times but it just didn't happen. So I wasn't able to express anything antenatally, and then the babies were born by a planned caesarean, because of the position of the babies and various other issues.

I was exclusively breastfeeding them in the hospital and for the first few days when we got home. On the day they were born the hospital said that they both had a mild tongue tie, so we were slightly concerned,

but our doula watched them feed and said they were doing well. By day five, however, the babies had lost too much weight. We went to hospital and they were put on formula top-ups. We fought very hard for donor milk but the staff kept refusing and refusing and refusing and so we had to use formula. The hospital brought me a pump but no one really advised how exactly to make sure that my supply didn't drop, even though I was breastfeeding every three hours. When we were readmitted to hospital on day five they said that the ENT could come and cut the tongue tie. They did it, and it helped a little bit with the latch, but it still wasn't great.

Then, a number of other things happened.

I had severe anaemia and I got very ill. The hospital thought it might be sepsis, and took it very seriously - but luckily, it wasn't that. I got Bell's Palsy on day six, so I was just very, very sick in the postpartum period. In the first few weeks on top of recovering from the caesarean birth, I was feeding the twins through it all. I was so ill, we ended up asking my mother to come to the UK from Atlanta, USA, and move in with us for 6 months. Far from looking after twins by myself after my husband's 6 weeks paternity leave, as I had expected before the birth, we needed an absolute deluge of support.

Our health visitor who came to our home after we got out of the hospital said, "Oh you know, yeah, just let them feed all the time. Just lay back, you rest and let them feed. You won't need to pump because you've got two of them." She also told us to "give them a top-up whenever it seemed like they needed it", which is honestly the most pointless advice to give to two exhausted parents of twin newborns who have just come out of hospital for infant weight loss. How do we know when they need a top-up versus just more breastfeeding? What on earth did she mean? We could not get more information out of her, so we sometimes gave a top-up just to allow me a chance to get half an hour's sleep.

I spent about a week with them like this, just feeding and feeding and feeding and feeding. The feeding situation was that I was on the couch 24 hours a day. Every time they let go and fell asleep, or every time I pulled them off to use the bathroom, they would immediately wake, screaming and wailing until I came back downstairs for more feeding. I was exhausted. We asked the health visitor - who was also on the Infant Feeding Team - to come back and check it was going ok. She said she couldn't come visit us again. And when we described how the babies were feeding, never letting go, even when they fell asleep, she said it was normal and what they expected.

The health visitor and the many midwives who saw us just looked at the babies' latch and said it was fine, none of them noticed that the babies weren't feeding effectively. When I asked if their latch seemed a bit small, one of the midwives said, "Well, they've only got small mouths." Around when the babies were a month old, our doula suggested getting a second opinion, because she finally noticed the babies weren't feeding effectively. She told us about a private tongue tie clinic, Milk Matters in Huddersfield. They told us that their tongue ties had reattached and needed cutting again. The hospital had said that reattachment never happened, not to worry about it at all.

After that appointment, Charlotte, the lactation consultant at Milk Matters, said to me, "Are youpumping

after every feed?" Well, no, I wasn't. I mean, who has the time or energy for that? I'm feeding them**all the time!** When I fed one and they fell asleep, the other woke. One of our babies was feeding, falling asleep, and waking every half hour.

Charlotte put us on a feeding and pumping plan and it was clear. It was inhuman, but super clear. We had told her that our goal was still to exclusively breastfeed the babies. We wanted to get off the top ups. We didn't want to do combi-feeding. Exclusive breastfeeding was the goal. So, she was very clear, this is what we needed to do. She gave us a plan that would eventually get us there - but it was going to be tough. I didn't realise how tough it would be, or how long it would take - or how much help we'd need to be able to do it.

Charlotte advised, essentially, that I feed them both once every three hours for 20 to 30 minutes and the whole time I was feeding them, I should be doing compressions making sure that they're getting let downs and trying to feel how much milk they were getting. At the beginning, I found this very tricky, I remember just really not being able to tell, I could not feel it. I had no sense of it. I couldn't feel let downs.

I very rarely saw a let-down. Some women may see their other breast leak when a let-down happens, but I could never see that, because I was tandem feeding. So I really struggled with having a sense of knowing how much milk they were getting. Charlotte understood, I think, and therefore gave us a plan that didn't rely too much on my sense of a 'great feed' or a 'bad feed' and my doula, Nikki, also helped me to understand how to look at their suck and swallow patterns as a sign of let down and milk transfer.

So the plan was, first breastfeed for 20-30 minutes. Then I (or my husband, mother, mother-in-law, sister-in-law, father-in-law, sister or a doula - so much support!) would give a formula top up. Eventually we moved to informal donor milk top ups, as the babies handled breastmilk better than formula and gained more weight on it. We went with informal donors because we were denied milk from the hospital's milk bank. After the top up, I would wait 40 minutes to an hour and then pump for 20 to 30 minutes. At that point I would get an hour or an hour and a half of sleep. Then, I'd have to get up and feed the babies again because the babies had to be fed every three hours. Eight times in 24 hours. And I needed to pump every three hours; eight times in 24 hours. And one of those pumping sessions had to be a power pump, where you spend an hour pumping - so that was a whole session where I got no sleep at all. I watched many series on Netflix and Amazon Prime and BBC iPlayer. Many, many series. I can recommend The Americans and Parks and Recreation!

We were using all the milk that I pumped to feed back to them as the first part of their top-up and then using formula or donor milk. My boy (I had a boy and a girl) was on insanely big top-ups at first, like a full feed on top of his breastfeed, which was intended to overfeed him, so he'd gain weight quickly and be able to come off top-ups sooner. This carried on, feed, top-up, pump, feed, top-up, pump, eight times every 24 hours, from when we started Charlotte's plan at about six weeks after they were born until they were about four and a half months old.

So, I had a number of months of only getting sleep in one hour, or even just 40 minutes chunks. I pumped

at 2am, 3am, whenever the schedule dictated. Bleary-eyed, staring at the weak blue light emitted by my pump, watching the minutes slowly tick by until I could stop pumping and go back to sleep, always tense in case one of the babies woke crying before I got to sleep in the first place. I remember being so tired, by the time the 6am pumping session came around, I often couldn't face it, and felt horribly guilty for skipping it, even as I fell asleep.

And we had to record everything every day, every feed, as Charlotte tweaked the plan daily, weekly, sometimes on a feed-to-feed basis, based on how well the babies were doing and how my supply was. When did they wake from the last nap? How long did they feed for? How long did we have them on the breast? Was it a decent feed? What time did it start? And how much of their top up did they take? And we just had to keep these charts every day, all day. And there was excruciating anxiety every time we had them weighed, we would pore over their charts, hoping for a sign of success, for a jump in centiles, for something.

We went back to Milk Matters several times over the next few months, to check on how their tongues were healing. Strands kept reattaching and both babies needed quite a lot of cranial osteopathy, which we found helped them to latch and feed in more comfortable positions. I remember wondering if their tongues would ever, ever be ok, if breastfeeding would ever work properly. I asked our doula if we would ever get there, it all seemed so relentless. She reassured me - if she wasn't sure we could get there she would not have encouraged us to keep trying. Through the months of hellish pumping, in the dim light of my heart, I held tight to those words.

The survival through these months is, in hindsight, unbelievable. My 70 year old mum was staying up until midnight or 1am every night, doing the last feed with me, so my husband could get a chunk of sleep. We were sterilising my pump & all the bottles every day. My mother cooked and cooked and looked after the babies, in the mornings when my husband and I were getting some sleep, and throughout the day as I grabbed my 40-minute snatches of sleep.

My mum helped me with my pumping, bringing me food and water, and she helped me through the really quite treacherous emotional side of it. I felt like I'd failed my children, because I wasn't able to feed them exclusively. I felt that it was all my fault for making bad decisions, for not working harder to express antenatally. For not doing things right. I remember feeling chained to the pump, trapped in my house. I felt guilty for not being able to take the babies to baby sensory classes, baby swimming lessons, baby music class. She told me that in India, mothers and new babies stay home for months while they get ready for the world. She said, breastfeeding is important to you and it's good for the babies. That's what they need to have, get that sorted out and then worry about all this stuff that didn't even exist when you were born. She helped me see that it was about deciding what was important, what we would need most. She took care of us all, in a lot of ways.

We also had postnatal doulas come to help out with the feeds or with laundry or just looking after the babies. Sometimes my mom would have one asleep in a sling, a doula would have the other asleep in a sling, so that I could go get some sleep myself.

When I think back, we did top ups in a billion different ways. My boy took to a bottle very quickly in hospital, but my girl wouldn't take a bottle and so sometimes it would take an hour to finger feed her top-ups using an NG tube[1]. Eventually she started taking her top-up well through a bottle. We had to try a few different bottles to get her there, but she started taking it well, and then we worked out how to use an NG tube like a supplementary nursing system. It was an endless headache figuring out how to get the NG tube exactly right, so they were actually suckling and not just sitting there with the tube in their mouths.

When they were around four and a half months old, Charlotte got us onto a much easier pumping routine where I would do a feed for them and then just pump for 15 or 20 minutes straight after. And then I could just go to bed. I didn't have to wait, pump and then go to bed. It was around when the babies were about five months old, I think, when they were being fed exclusively my breastmilk, although I was still expressing and feeding back what I'd pumped. So we had a few days in there where I was actually pumping enough to top up only with my milk. It was about another ten days of pumping to get them to be just breastfeeding, which was so exciting and such a huge freedom, it was amazing.

Then of course, they started eating food at just about six months. We did baby led weaning, so they weren't exclusively breastfed for all that long but we did get to exclusive breastfeeding. I'm proud of that. We're still breastfeeding today and they're over two years old. I'm proud of that, too. Every morning and at various times during the day, they have milk and it helps them through illnesses, and it helps us stay connected. It helps them when they're just feeling a bit grumpy. It's really been beneficial to us but it was definitely super hard going.

We ended up needing so much support. It was really, really tough. I don't know, but if someone had said at the beginning, before I got pregnant, this is what it will be like when you're breastfeeding, I feel like I might have decided right then and there that I wouldn't even try, because it was so hard.

But I guess it's just that thing that happens. You have the kids. And then they teach you who you are. And they teach you what you can do, and what you will do. For them.

Reference:

1) A guide to finger feeding: https://www.ouh.nhs.uk/patient-guide/leaflets/files/11016Pfingerfeeding.pdf