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Breastfeeding with Insufficient Glandular Tissue

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I was never confident that my breasts were 'normal' growing up. I was born blind and never went around feeling other people's breasts so I couldn't be sure, but from the fact that I never filled the top of a bra cup and from comments made by others about different women's breasts, I really began to wonder. I seemed to have very large nipples on the end of small tube-shaped sacks with a large gap between them. I eventually decided to speak to my GP about my concerns, even if it was just to be reassured that all was normal. The doctor took a look and said that he could see what I meant. For me, this was validation that I was not going insane. There was actually a problem.

I was told that I might be eligible for breast augmentation. I saw a plastic surgeon and he agreed. All the way along I told everyone, 'If I ever have children, I would like to breastfeed'. I was told that the surgery would be performed so that the implant was placed under the muscles, away from any ducts, and that the incision would be made on the underside of my breasts, preventing any nipple damage. The surgeon said, 'If you could breastfeed before the surgery, you'll be able to breastfeed after it'. No one had given my condition a name. No one had explained what the shape of my breasts before the operation might mean to breastfeeding.

Time passed, and the day after the surgery came. I remember lying on my hospital bed and the doctor who was on the ward that day came and pulled open the curtains round me. He had a few students with him. He addressed the students and said, 'This is the lady with tubular breast syndrome'. At the time I

thought, 'So that's what it's called' but he offered no explanation.

The surgery improved my self-esteem immensely. I will always be grateful for the GP who listened and the resulting operation. I met my husband and got married shortly after the surgery. I became pregnant in early 2014 and was overjoyed. I told my midwife and health visitor about the name of my condition and the breast augmentation but they didn't seem to think it would be a problem. In December 2014 I gave birth to my first daughter, Karis. She latched on straightaway and I sat there marvelling at my baby and the fact I could provide everything she needed ... or so I thought.

Karis spent a lot of time at the breast. She fell asleep during feeds, and woke immediately to be fed again as soon as she was put down. Despite this, I thought breastfeeding was going well. I had been told that babies fed frequently at this age so I was not worried. Then, the dirty nappies stopped. Karis carried on putting on weight slowly, no one was concerned. After 9 days the dirty nappies resumed infrequently. The midwife discharged us and I was happy. Each time I expressed any concern about my milk supply, I was told that it was fine because I could squeeze drops of milk out. The health visitor was less happy. She disagreed with the midwife and came back 2 weeks later to do another weight check. She found that although Karis had not lost any weight, she had only gained half an ounce in those 2 weeks. She insisted that I should top up with formula. I felt like there was no point feeding her at all, like I was being told that my milk was worthless.

A baby-friendly feeding counsellor was called in and luckily she spotted a tongue tie. It was cut at 8 weeks. In the meantime, I died a little inside every time I gave a bottle of formula. I wished it could have been breastmilk. I expressed after every feed, in the middle of the night and every time Karis slept and I could put her down, but I never expressed more than an ounce at most. I began using a Supplemental Nursing System (SNS)[1] at 4 months. This meant the supplement could be given at the breast, filling the two purposes of stimulating my breast and feeding the baby. This bottle, with its two thin tubes hanging from it, was probably the thing that saved my breastfeeding relationship. Most professionals didn't even know what an SNS actually was and I had to explain it multiple times. This upset me because surely something like this should be the first port of call when a mother is needing to top up but still wanting to breastfeed, and yet so many midwives are unaware of its existence. This is something that I feel should change. Fortunately for me, Karis never lost interest in breastfeeding with or without the SNS.

Time passed, and I continued to see the feeding supporter because I was still feeling so sad for having low supply. We tried dropping the supplements when the tongue tie was revised, but my milk supply only increased slightly. The health visitor asked questions about my surgery, but I explained that they had been so very careful that it would not have affected things. However, the feeding counsellor asked me what my breasts had been like beforehand, and I explained. She then took a look and commented on the large gap between my breasts, and explained that she suspected mammary hypoplasia, otherwise known as insufficient glandular tissue or IGT. I would never make enough milk for my baby. [*Editor's note: Please see the AIMS comment on mammary hypoplasia below this article.*] I couldn't do what I felt that every mother should be able to do for her child. I felt betrayed by my own body, and by the many professionals I'd

shared my story with during and after pregnancy. Surely someone should have known! Someone should have told me! I felt guilty, angry and alone. Many people told me that 'Most women choose to give their baby formula, so why give yourself such a hard time?' but few people understood how heartbroken I felt.

Time passed and I became convinced that Karis was reacting badly to the formula. She was unable to poo easily and was extremely uncomfortable and windy, and she was often blocked up as though she was full of cold. Many of my family have dairy intolerance issues, so I mentioned it to a few of the health professionals that I was still in contact with. My concerns were dismissed as me finding another reason to complain about giving her formula. I was denied the option of receiving milk from a milk bank because most milk banks only supply donor milk to babies who are premature or have specific medical needs. [*Editor's note: Please see the article in this Journal about the Hearts Milk Bank which is working to overcome this issue.*]

At one year I took Karis off the formula and all dairy products. Overnight, I had a different child.

When I became pregnant again with my second daughter, I vowed to do everything in my power to make breastfeeding more successful this time! I researched and researched, joined a support group for women with low milk supply and bombarded them with questions. I took herbs that might be able to make me produce more milk by stimulating the breast tissue growth during pregnancy. I met with an International Board Certified Lactation Consultant (IBCLC) and put a plan together. I expressed from 36 weeks and built up a stash of colostrum for my baby. I convinced myself that this time would be different. I knew that I would have to supplement but thought it wouldn't be as much as last time. I thought that I knew what I was up against and that I was ready to face it.

When Cathy was born, she latched on straightaway, just like her sister. When she wasn't feeding I pumped. By the end of the second day she needed my top-up of colostrum. When this was all used up, she needed the backup ready-made formula I had packed in my hospital bag. From the minute she had the formula she had bad stomach ache and terrible wind. When I got home from hospital I called my IBCLC and she cut the tongue tie which I had already suspected. She explained to me how to express effectively to build up and maintain my supply. This was in contrast to midwives I encountered who were convinced I didn't need to worry and that I just had to have enough milk. I knew that I didn't. I found that I was having to explain my condition more and more to people, and listen to the platitudes of 'Many women worry about their supply, but most of the time it's actually fine, and if you cut out the formula your milk would increase' and 'You see, only a very small percentage of women actually really can't make enough milk, so it's highly unlikely you're actually one of them'.

Constantly having to explain that I had insufficient tissue to feed my baby made me feel like I was actually saying that I was an insufficient mother. I hated going out and having to publicly admit I wasn't enough by feeding my baby a bottle straight after a breastfeed or feeding with the SNS, in case someone asked about it. I'm sure people wondered why I bothered breastfeeding at all but I had learnt from my experience with Karis that it was not just about the milk. I clung to family and friends' reminders that whatever I could give her, no matter how small, was so very important. But still, I constantly totted up the

number of ounces of supplement that day and each time I pumped I'd be discouraged by the pitiful amount in the bottles. I felt judged and was angry and frustrated with my own body and with the inability of anyone to do anything about it!

Formula really did not agree with Cathy. At night I was able to feed her myself and she was a lot more settled. Again, I was told that screened donor milk from a milk bank was not an option. I tried various types of formula but nothing helped much.

I went to my GP in tears and begged for domperidone in the hope that it would increase the little supply that I did have. At the back of my mind was the thought that if I could have produced all the milk she needed, Cathy would have been fine. The guilt was overwhelming. Eventually I asked a close family member who was breastfeeding if she would give me some of her milk. The transformation was almost instant. So then I went online to the Human Milk 4 Human Babies Facebook page[2] and found four other kind women who donated their milk.

Finally, our referral came through and the paediatrician prescribed a hydrolysed formula, which is formula made from cow's milk but with changes made to the protein to make it less likely to trigger a cow's milk protein allergy. This was too thick to pass through the tubes of the SNS, so I had to give bottles again. My heart broke every time I gave a bottle and a little piece of me died every time it was the thing that stopped her crying.

However, Cathy also never stopped wanting to breastfeed. She always asked me for milk first and when the bottle was done would return to the breast. She turned to the breast for comfort, for safety, for a drink after a snack or as a sleep aid. She is still nursing at nearly 15 months old! This continually fills me with joy and humility. It's something that I never thought would happen. I always thought she would give up putting so much effort in for such little reward given that I had stopped taking all herbal and medical remedies and had stopped expressing when she was 9 months old and my supply dropped significantly.

Cathy is a normal breastfeeding toddler and for me the story of our journey has a reasonably happy ending. However, I wish there was more education given to midwives and all people who come into contact with breastfeeding mothers with mammary hypoplasia. Not only about the physical effects and the need to supplement but also about the mental effects on the mother who watches her dream of exclusively breastfeeding crumble into dust in front of her eyes and has to deal with the guilt. There should be the option, for the baby's sake, to receive milk from a human milk bank, instead of having formula pushed at the first sign of trouble. Formula is not the answer to every breastfeeding challenge. Problem-solving with experience and knowledge is.

I am so grateful for my breast surgery, and I don't feel that it has impacted my breastfeeding journeys at all. I know in some cases surgery can have a negative impact, but for me the operation was so well done that it was not the cause of my inability to exclusively breastfeed. It was the shape of my breasts before the augmentation that sealed the fate of my breastfeeding problems. Size doesn't matter, but the shape and structure may do. I urge you, if you're involved with advising or supporting breastfeeding mothers,

please find out about hypoplasia so that you can provide appropriate individualised support or signposting.

Above all, please listen to women! While most milk supply concerns can be overcome, there are women with genuine health issues that cause naturally low supply who need specialist support. Before I found other women online who have hypoplasia I felt like I was the only woman in the world who couldn't breastfeed exclusively. Having to keep explaining hypoplasia to people made it much worse. I was fortunate to have a very understanding and supportive family network which encouraged and supported me to breastfeed as much as I could. Many women don't have this, particularly in this culture where breastfeeding is not normalised or commonly seen in public, so you could be the only person encouraging a struggling mum to carry on when all others are pushing for her to give up. You need to know what you're dealing with.

I wish that more milk banks were able to make screened breastmilk available to mums who need it, such as women with hypoplasia. It's the baby's right to have breastmilk and from my own experience the feelings of guilt increase, knowing that you have to feed your baby a synthetic substitute which may or may not agree with their digestive systems. Surely babies shouldn't be deprived of their right to be fed breastmilk just because they are not sick or premature? It shouldn't be another unspoken statement to the mother with low milk supply that the problem is hers so it doesn't matter.

References:

1) Further information on Supplementary Nursing Systems (SNSs):https://www.laleche.org.uk/nursing-supplementers/

2) Human Milk for Human Babies Facebook page:https://www.facebook.com/HM4HBUK/

AIMS Comment: Hypoplasia (Insufficient Glandular Tissue – IGT)

Hypoplasia is a condition where a mother's milk-making tissue in her breasts – the glandular tissue – has not developed as much as would be required to produce a full milk supply. Women who have hypoplasia may have already noticed, pre pregnancy, that their breasts look different from other women's. Common signs are breasts that are widely spaced, significantly unequal-sized breasts, and a tubular shape, sometimes with a 'bulbous' areola. During pregnancy, women with hypoplasia tend to notice that their breasts have not changed, or have changed very little, and they then find that their milk doesn't appear to 'come in'.

Many women with hypoplasia are able to offer some breastmilk to their baby and, with good support, some may be able to achieve a full or nearly full milk supply – but many cannot. Early intervention and support from an experienced, qualified person such as an International Board Certified Lactation Consultant (IBCLC) is vital to ensure that the maximum amount of a mother's own milk can be produced.

A note on language – the term 'insufficient glandular tissue', with the implication that a mother is

'insufficient' for her baby, can be very distressing. AIMS therefore supports use of the term 'hypoplasia' rather than 'insufficient glandular tissue' or 'IGT'.

More information:

https://kellymom.com/bf/got-milk/supply-worries/insufficient-glandular-tissue/

The Breastfeeding Mother's Guide to Making More Milk, by Diana West and Lisa Marasco:Find this book on Amazon

AIMS comment written by Emma Ashworth, BFC. With thanks to Emma Pickett, IBCLC, for checking this information.