

# Thyroid cancer and Breastfeeding

by Sophie McInnes, ABM Member



Sophie and Katelyn

I never questioned that I would breastfeed our baby. It's better for my baby, better for me, far cheaper and simpler than infant formula, environmentally friendly and makes sense: my breasts evolved for this purpose and would lactate whether I wished them to or not. I concentrated on human biology and cultures during my education, and had been to NCT antenatal classes, so I was primed to go with the norm rather than a fiddly imitation.

That said, Katelyn was not interested in breastfeeding for nearly a day after her birth (a forceps delivery with no drugs bar gas and air) and even then she didn't suckle for long. I did get some advice from the midwives on the antenatal ward, but it was clear they were busy and their suggestions weren't always consistent. To their credit, no one suggested a bottle to tide her over; however none of them suggested that I try to express either. Emotionally I felt a little like a failure, but was so busy dealing with nappies, crying, cuddling and visitors that it became simply something else to improve on.

After we went home, things got better. Rob and I were due to move house four days after Katelyn was born (mental note to self: never again!).

There was no way to avoid this so she and I spent a few days at my parents' home nearby. It was comforting to have Mum around. My father-in-law and his wife were there too, visiting from New Zealand. Mum had formula-fed me (though she did breastfeed my brother), and Ngaire adopted her two children, so neither were entirely helpful when it came to advice. The old chestnuts of "every 4 hours" and "one side at a time" were mentioned several times. Now that things were going well I simply fed on demand and in view of visitors – if they were bothered, they could go elsewhere! My usual stubbornness was kicking in.

A few weeks later, when settled in our new home, I was feeling the agony of sore, bleeding nipples. My husband was great: he had split his paternity leave into two separate weeks and was home at just the right time to keep me going.

It was either week four or six that I finally went to the Bosom Buddies group at Upton. I phoned Julie in advance and she told me to arrive early. Typically, once there, Katelyn latched perfectly! Julie and I talked through my experiences so far, including Katelyn's birth, and she suggested a visit to the nearby chiropractic college after noticing that Katelyn was reluctant to turn her head. This proved to be fantastic advice, as they diagnosed slightly kinked vertebrae – presumably due to the forceps delivery – and proceeded to manipulate them back into place. Everything began to come right again. I continued going to Bosom Buddies. I was making more friends there than at the very busy Under Ones group run by my surgery's health visitors. I also joined a few online breastfeeding communities, for their resources and the support they offer. All of this support reinforced my belief that Katelyn was small, not underweight. She was consistently plotted in the 2% or 9% centiles of the age/weight charts (and not much higher in the



Katelyn, just after birth

WHO version). It also helped me deal with criticism from French relatives in particular, who believed that breastfeeding past three months – let alone babywearing – is foolish and would lead to a spoilt baby. I haven't managed to convince them otherwise, but while visiting them I did learn that "l'allaitement" is very poorly promoted and supported in that area of France.

Then everything came crashing down around us. My mum noticed a lump on my neck when Katelyn was around three months old. Looking back at photos it had been growing for a while, unnoticed. My GP referred me to an ENT consultant, who ordered tests and diagnosed a branchial cyst, which should be removed via surgery in case it abscessed. In hospital, I was allowed to drink water a little longer than usual before surgery, on the grounds that I was nursing (or rather, *expressing*), and my husband was allowed to bring Katelyn in regardless of visiting hours. No one had mentioned that we couldn't bring our steriliser in without a PAT test though, so poor Rob dashed backwards and forwards on his motorcycle for a few days, until the drains were removed from my neck and I could breastfeed without fear of injury. Unfortunately the histology tests on the cyst showed abnormal cells: papillary carcinoma of the thyroid. My mum had had this eight years before – and quite clearly survived – but it wasn't supposed to be hereditary. We clung to the hope that the accidental discovery meant that it had been found early, but even so the news for breastfeeding was bleak. The surgery to remove my thyroid we could manage (even to the point of presenting our



Sophie, after the second operation



The lead-lined room that was Sophie's short-term home

steriliser for PAT testing a week early, to be sure!) but the next step was radioactive iodine. Not just a little bit but sufficient to mean that I would have to spend 2-3 days in a lead-lined room for others' safety; and a few more days sleeping separately from my husband and staying at least 1m away from Katelyn. Daunting, manageable – but what about breastfeeding? It took some time to get the story straight because, as the oncologist put it, "no one's asked me that in 15 years!"

Advice from doctors (both at the hospital and from a specialist in the US who runs an online support group) varied. Some thought I should give up breastfeeding NOW, others closer to the time, one not at all. Another was outraged by the ridiculous idea of relactation. When I showed my consultants the documents found via an online patient support group, they didn't even want to look into it. I suppose they were treating me, not Katelyn, but with all the evidence showing the health benefits of breastfeeding for both mother and child I found it very hard to understand why they weren't taking it into account.

Looking at breastfeeding-friendly resources like Dr Hale's *Medications & Mother's Milk* and contacting the BfN drugline convinced me in the end. It boiled down to this: research shows that the iodine they use to kill remaining thyroid cells (I-131) can also be absorbed by lactating breast tissue. It can then be passed to the nursing child and cause terrible damage to their thyroid. It can also increase the mother's risk of breast cancer – ironic considering the fact that breastfeeding usually reduces the risk! I considered pumping and dumping for a couple of months, but I couldn't find any papers to confirm or deny the safety factor of my particular circumstances.

Another option was to delay treatment, allowing extended nursing but with the risk of secondary thyroid cancer elsewhere in my body. Mailing lists are full of women facing this dilemma because, it



Sophie and her mum in France, October 2009

turns out, women of childbearing age are this cancer's favourite target. It's one of the fastest growing cancer diagnoses in the Western world. The end of my breastfeeding story is that I decided to take the earliest date for radioiodine they could offer me – I was second generation already, after all. I want to see my daughter grow up and have her own children. That said...

The hospital estimated that I would be booked in quickly, so there was time for one last hiccup. In anticipation of the treatment, we had gradually introduced our daughter to formula (while I was attending a peer supporter course – how's that for conflicting emotions?), but were then told that it would be delayed for another couple of months. With the support of Julie, we reversed the process and Katelyn went back to being fully breastfed for a few more weeks.

I was offered a date at the last minute, which I turned down because I needed at least a couple of weeks, if not a month, to switch Katelyn back to formula and take some cabergoline to stop milk production (horrible stuff, in case anyone's interested!).

Incidentally, I had both MRI and CT scans prior to giving up breastfeeding. While the consultants who ordered these knew I was breastfeeding at the time and agreed that contrast dye was unnecessary, they failed to communicate this to the radiology techs in both instances. Sorting this out made my appointments that much longer and more irritating. However, everyone was happy to get me an apparently expensive injection (rarely offered at my hospital) that would remove my need to come off artificial thyroxine and therefore become horribly hypothyroid, prior to radioactive

iodine treatment. Would you like to know why? *Because I was a baby's primary caregiver!* Suddenly Katelyn mattered - because I looked after her, *not because I breastfed her.*

As it turns out, taking the treatment as soon as it became available and not relactating have probably been good plans. I had to go back for a second round of radioiodine 6 months later as one patch of thyroid cells had escaped the first nuking. It was a case of second time lucky. I received the all clear a mere one year after my initial diagnosis, and another year later I'm still well. If I pass medical assessment we'll even be emigrating to New Zealand this year (can I get the ABM mag out there?!).

Much as I don't like the way that Katelyn smiled at her bottle thereafter – and incidentally her weight jumped up to the 25% centile after formula was introduced – I can't help but think that delaying treatment or risking the pump and dump option could have further reduced the risk of me not seeing her grow up. Thyroid cancer is very curable, but it can also be insidious. I've read accounts from long-term patients now suffering nodules in their bones, lungs, breasts... Maybe I'm a wimp, but I couldn't handle that. The only obvious price that I've paid for all this is a scarred neck and the need to take replacement thyroxine every day, which is a lot simpler than the consequences of treatment for many other cancers.

It just irritates me that my body betrayed me right when I was supposed to be giving my daughter the best start in life. ●



Sophie, Rob and Katelyn, Christmas 2009