



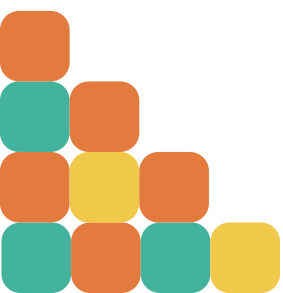
**Positive about
Down syndrome**

The Lived Experience: Breastfeeding a baby with Down syndrome

At Positive about Down syndrome, we work hard to ensure expectant and new parents have access to accurate relevant information.

There are many outdated perceptions and myths around Down syndrome, one being that ‘babies with Down syndrome can’t breastfeed.’ We share the recent Lived Experiences of a number of new mums who are keen that their experiences highlight the reality; and not only educate and empower new and expectant mums, but also the medical professionals who are supporting these women.

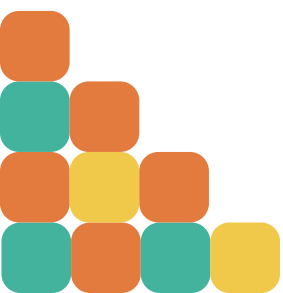
A common thread through the stories is the pivotal role of midwives/breast feeding supporters – those mums who felt well supported and encouraged, went on to achieve their breastfeeding hopes and dreams. We hope that these experiences will inspire and encourage medical professionals to positively and proactively support mothers of babies with Down syndrome who are looking to breastfeed.





Positive about Down syndrome

<u>Dear Future Breastfeeding Supporter</u>	3
<u>Michelle Brophy mum to Harrison</u>	4
<u>Kelly Marshall mum to Betsy</u>	6
<u>Chloe Williams mum to Rosie</u>	8
<u>Lorraine Buckmaster mum to Jaxon</u>	9
<u>Jess Flanagan mum to Frida</u>	11
<u>Rachel Baines mum to Reuben</u>	13
<u>Rachel Gillan mum to Noah</u>	15
<u>Helen Bradley mum to Arlo</u>	17
<u>Rebecca Smith mum to Arthur</u>	19
<u>Emily Vuijk mum to Luke</u>	21
<u>Serena Clark mum to Ollie</u>	22
<u>Stacey McDermott mum to Olive</u>	24
<u>Sarah Empson mum to Wilf</u>	26
<u>Specific resources</u>	28





Positive about Down syndrome

Dear Future Breastfeeding Supporter

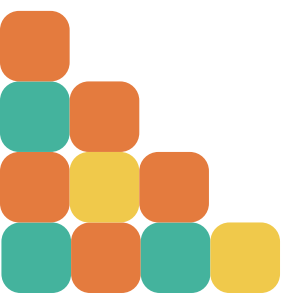


You may be a midwife, a doctor or a peer support worker or one of the many other medical professionals that a new mum comes into contact with. When you have the pleasure of meeting a new family with a baby with Down syndrome, please be supportive and encouraging, no matter what choices they have made to feed their baby. They may want to formula feed and that's fine. However, they may well want to breastfeed and if they do please support them. Be aware that many babies with Down syndrome breastfeed absolutely fine, without any problems at all. Some may need some additional support as of course do some typical babies.

Please don't say things like 'there's no point trying to breastfeed as these babies can't' or 'babies with Down syndrome can't breastfeed' or similar. Not only is it not true but this could potentially put a mum off from feeding the way she wants to try. Yes, some may encounter some difficulties along the way, some of which may be because baby has Down syndrome and some may not; with the right support most problems can be overcome.

I want you to know that when you, a respected professional, tells us that our babies can't breastfeed, it's about more than just the feeding. It's possibly the first time and extremely unlikely to be the last time that we will experience someone putting a limitation on our child, someone telling us what they can and can't do based on their diagnosis and not seeing the baby as an individual. Please look at each baby with Down syndrome as an individual, not defined or limited in any way by their chromosome count. Each is an individual, as unique as any other person and have strengths and abilities in different areas so please give each a chance to show you what they can do!

From Sarah and Zephy Ojar (Breastfed baby with Down syndrome for over 2 years)





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Michelle Brophy mum to Harrison



First of all, I was never a 'breast is best' parent-to-be who was desperate to breastfeed, I was happy to bottle feed or breastfeed, whichever worked out for the best for our child. If I could give any advice from the start it would be to not have any expectations, milk may or may not come in, your child may latch on right away and take the breast, they may not take to it at all. Just try your best and do what is best for you and your baby.

For me, our journey started at 38 weeks in NICU. I was pumping just

hours after birth and the nurses were surprised to see I was already producing milk from both breasts. I continued pumping for bottle feeds throughout our 12-day NICU stay. At this point I never considered breastfeeding (latching baby on). He was in an incubator for some of his stay and on top of this, the nurses and doctors were very strict about measuring how much milk he was getting, and I knew we couldn't measure that if he was to latch on. Within a week I had an oversupply of milk which I later found out was because I was being requested to pump every 3 hours for half an hour. I was producing far more than Harrison needed and this caused me some pain and discomfort from the start. Just be wary of this, if you too have to pump during an NICU stay.

My main focus from the beginning, was just getting milk into Harrison. The first 3 weeks of his life, it would take up to an hour and a half to get anywhere between a 45-60ml bottle into him. It was torture, desperately trying to feed him when he was so weak. It felt like force feeding and it seemed so cruel when he was clearly struggling. However, we were desperate not to rely on feeding tubes when we knew



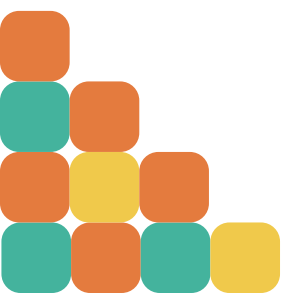
Positive about Down syndrome

he was able to suck and swallow. After 3 weeks, I was sick to death of sterilising and pumping, to then have to feed directly after and repeat. It felt like it was taking up all my time and with my husband taking so many feeds due to me pumping, I felt I was really missing out on bonding time. It was then I decided to try Harrison on the breast. At first, he would thrash about screaming and would not, for the life of him, take the nipple. I would try for less than a minute before giving up and feeding him a ready prepared bottle on standby. I couldn't understand why he wasn't able to latch on. It seemed so simple. I then decided to try offering the breast at a time when he wasn't overly hungry, this started to work.

It meant he wasn't desperate for food and it was far less stressful. However, although he was calm, he was still unable to latch. I kept offering a couple of times a day for the next few weeks. Something in me just told me not to give up.

At one month old, he finally latched on as I laid beside him to offer the breast. I think due to low muscle tone in his neck, this position gave him a lot more support. I cried tears of pure joy at this moment. I was just so proud of him. After reading so many accounts of babies with Down syndrome not being able to breastfeed, I was starting to believe it wouldn't happen for us either and it felt like he had just beaten the first of many odds/challenges! I continued to offer the breast alongside the bottle for the next month and by 2.5 months old, Harrison was almost exclusively breastfed, aside from a night feed with Dad! He would latch on with ease in any position. I feel that this was largely due to improved muscle tone in his neck.

He is now 6 months old and I am still breastfeeding, although he will take bottles while I am at work. I am so so proud of Harrison and myself, we had no support or advice for breastfeeding but between us and with a bit of time to gain some strength we worked it out. It has been one of the most surprisingly rewarding things I have ever done.





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Kelly Marshall mum to Betsy



It never occurred to me that Betsy might not be able to breastfeed. Like many people who receive an antenatal diagnosis I spent hours googling everything and anything Down syndrome related but feeding wasn't something I came across. My breastfeeding journey started before she had arrived. I was asked by one of the midwives if I intended to breastfeed Betsy. She was so supportive and told me how it would be beneficial to her oral muscles and her speech as well as the regular breastmilk magic. She

proactively set up an appointment for me with the hospital's breastfeeding midwives which was again a very positive experience. I never had any success breastfeeding my older girls so was doubting my own abilities to be successful rather than Betsy's. We developed a plan together, the midwife reassured me and encouraged me that I could do this, I felt confident and wanted to be successful this time. She gave me lots of syringes to express colostrum and freeze it, in the scenario should she not be able to feed straight away. We talked about pumping if required from the get-go. I left focused and determined.

When Betsy was born, the biggest sense of pride and excitement was overwhelming, she was here, finally (being very honest) it was the first time I felt happy for a long time, all that sadness, disappointment, anger, denial, wasted emotions, gone, all gone when I saw that little face. Again, the midwives were all aligned, they knew I wanted to feed her. A paediatric doctor checked her over, she was fine. She was put straight on my chest and the midwife grabbed my little bundle and put her straight to the breast firmly. Betsy latched! She fed on and off for hours no more than 5 minutes a time



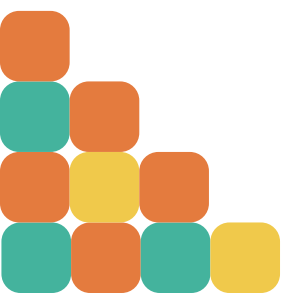
Positive about Down syndrome

but we were doing it. The following day the Breastfeeding midwife came to see us to check her latch and was very happy with it. She encouraged lots of skin to skin, putting her to the breast continually. We only stayed one night in hospital, less than my older girls.

She was sleepy in the early days but I continued to wake her to feed. I made sure I used a good quality nipple cream and applied after every feed. She feeds from both breasts, on demand. She did have slow weight gain and I did feel a bit emotionally pressured to top her up with formula by the community midwives. One did say some negatives things about the quality of my milk but I let it go over my head. This breastfeeding journey I always told/tell myself has a greater good and I wasn't going to stop, I think

that confidence came from those early hospital midwives and their positivity. I also use the dancer hand pose, this is a real game changer for us, it gives more support for her latch, again I was told by the community midwives to use a more traditional position, but I knew what I needed to do to make this happen. As long as baby is latched and it's working it doesn't matter what hold you use. She also feeds laying down at night.

So nearly 13 months down the line... we are still going strong, she is still feeding on demand and there are no signs at the moment of stopping. From someone who struggled so much with my typical older children to breastfeed our beautiful Betsy gave me the gift of experiencing this beautiful journey.





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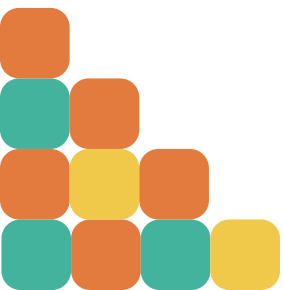
Chloe Williams mum to Rosie



Our journey was relatively straightforward, despite being told by several midwives to bring formula to my delivery 'just in case', I didn't. I knew Rosie would smash it and I was determined to work with her to make sure she did. She did struggle to stay latched at first as she was a very sleepy

baby and I think it was a lot of effort for her. In the hospital we were seen by a breast feeding specialist who didn't really do a lot to help and scoffed that the SALT told us to try nipple shields. As we weren't allowed to go home until Rosie was feeding properly, I demanded they let me pump and sent my husband to Sainsbury's to get some mam bottles.

They said I wouldn't get much to pump as I was only on day 3, even though I told them I breastfed my son until I was 15 weeks into my pregnancy and never stopped producing. They eventually gave me the pump and low and behold, 7oz from both boobs of pure liquid gold! I fed her for the next 24 hours with expressed milk and as soon as we got home, I ordered the nipple shields. They arrived the next day and Rosie went on straight away! She's fed like an absolute boss since then and she even weaned herself off them at about 7/8 weeks and now feeds straight from the boob beautifully.





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Lorraine Buckmaster mum to Jaxon



With baby number 1 I didn't ever try to breastfeed. I was young and had seen a friend and my sister struggle so opted straight for formula. With baby number 2 I decided I would breastfeed. How easy was that! No more worrying you had enough bottles on a day out, no mixing, sterilising and heating. Milk on tap... right temperature every time. Baby number 3 was a bit more difficult. I had a rare breast tumour in my right breast that needed to be removed.

Following surgery, I expressed milk and it was bright red. Half milk half blood. I pumped and dumped but kept getting mastitis so sadly gave up when he was 7 months. Baby number 4 came along, and I decided to trust my instinct. I fed only from my left breast. My right breast produced milk, but I just ignored it! Was told by midwife and health visitor I had to express. I refused. When my baby was about ten days old, I was feeding her one day when suddenly milk poured from my right breast. No more milk was produced - I fed for thirteen months using just my left breast! I had been right all along.

In July 2014 just before my 46th birthday I gave birth to Jaxon. We had been given a high 1:5 chance that he would be born with Down syndrome. We realised at birth he did indeed have that amazing extra chromosome. I put him to my breast, and he started to feed. I was taken to a ward and a bit taken aback when a midwife appeared with a bottle of formula. "I'm breastfeeding" I told her. She replied, "because of his early delivery and because it is suspected he has Down syndrome you need to give him some formula to raise his blood sugars."



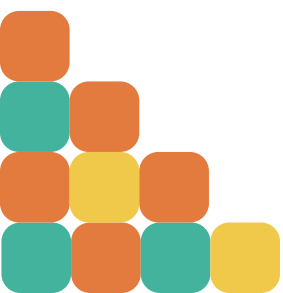
Positive about Down syndrome

I was upset but it gave my daughter an opportunity to experience feeding her new brother and I allowed him to be given the few ounces of formula I was told he needed. Two hours later I struggled to get him to latch on. Again, a midwife appeared “would you like me to bring you some formula?” she offered. “No thank you,” I replied, knowing he was confused by the bottle he had had. By the next feed later that day he was back established on my breast. Again, I was only feeding from my left breast.

That night a bottle of formula was brought to me. I was told I had to give him it! I asked why - was told he needed it to stabilise his blood sugar. But no further blood tests had been done on his sugar levels, so I refused.

He had jaundice and I was again told I needed to formula feed. He was placed under florescent lights and I breast fed him through the night. The next morning the jaundice was gone.

A midwife watched me feed him. Took note of his increasing weight and his wet and dirty nappies. Still the pressure was there to top him up with formula. Eventually a midwife told me I was putting him at risk. If I refused to formula feed him, he would be taken from me and placed in special care, he would be tube fed. So, I lied. I took a bottle of formula and tipped it down the sink. They noted he had had formula and left us alone. We were allowed home the next day. Jaxon was breastfed until 19 months.





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Jess Flanagan mum to Frida



I knew I wanted to breastfeed my babies. Living in Bristol, where there is much more of a liberal attitude towards most things, many mums breastfed publicly and many of my circle of friends fed our first babies until they were well over two years old. I was also lucky to produce lots of milk and fed my first little girl for 2 and a half years. I loved every minute so I went into my second pregnancy as a confident breastfeeder and knew I wanted to do exactly the same for my next child.

When we found out that our second

child (Frida) had a high chance of having Down syndrome I did my reading and research and was stunned to learn that she may struggle to breastfeed. This troubled me because I wanted to - the benefits of breastmilk would be even more important for her, both in terms of supporting her immune system and if she could latch this would be great for her speech and language development. I was determined to make it happen even if it didn't happen immediately. So I prepared as best I could. There were some lovely blogs and articles that pointed out some of the challenges that meant she might not be able to feed immediately but that ultimately and perhaps with a bit of hard work, it would be possible. I bookmarked advice and resources and in my final weeks of pregnancy, got my supply going and collected enough colostrum to keep her going should she need to be tube fed or topped up in the early days, knowing I could express as soon as she was born to keep the supply going!

The moment Frida was placed on my chest (in accordance with my birth plan) she crawled immediately to my boob and she's been there ever since (I initially wrote this piece when she was



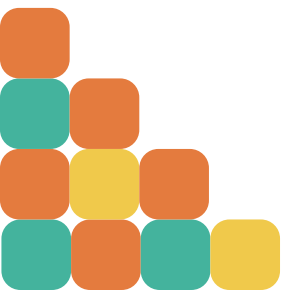
Positive about Down syndrome

2 weeks old and the same goes now at 8 months). Her suckle is strong and her muscle tone pretty good. I was beyond thrilled. When we got back to the ward (we were placed on a step down from NICU, so feeding was something most mums were being supported with and there was an emphasis on keeping an eye on how much baby was feeding) there were no negative comments or suggestions around formula top ups. To be honest, given that she was 9lb1oz, there was probably little conversation to be had.

I put my entirely positive experience down to my confidence in feeding, my strong will and desire to want to do it and Frida's ability to feed well from the off. I also think I have a way of saying things firmly and by getting in first, so if anyone was going to say anything negative, they'd think twice before doing so. I am lucky that Frida is healthy and a good size, that she latched on well and that my milk came

in very quickly and seems to do the trick! I do worry that mums who don't have the right support, experience or confidence to articulate that they want to breastfeed may face more negativity, so I hope that my experience might help you be more vocal and confident about your choices around feeding, whatever those may be.

If you want to breastfeed, believe that you can. It is worth preparing for a situation where you might not be able to immediately as you may need to compromise once your baby is here, but don't be put off before and certainly don't write off the possibility of doing it at some point in the future once your baby has gained the weight they need to! I leave you with the quote from the red book around breast feeding babies with Down syndrome (which you could firmly point to anyone challenging the suggestion): 'Many babies who have Down syndrome feed just as well as other babies'.





Positive about Down syndrome

Rachel Baines mum to Reuben



So, nobody tells you how hard it is to feed your baby, whether breastfeeding, expressing and bottle feeding or formula - it's all so hard initially! Everyone advises you on what they think is best, but no one way is easy!

My gorgeous boy Reuben was born in April 2020, we already knew there was a high chance of him having Down syndrome, which was confirmed soon after birth. He was placed straight on my chest at birth, and they helped me to get him feeding. However, he soon went a bit floppy and struggled

to breathe so was taken up to neonatal. There is a misconception sometimes that babies who have Down syndrome cannot breastfeed, which is not true at all! They might take a bit longer to get there but can (like with everything!) get there in the end.

We spent 3 weeks in neonatal, where Reuben was tube fed to start with, and we attempted breastfeeding whenever we could. He was 4 weeks early so tired easily and had jaundice a few times which also made him sleepy. He gradually woke more and more, his tongue was checked to make sure it wasn't tied, and we had a lactation specialist help us with latching/positioning. All the while I was expressing and tube feeding. It was difficult for him to latch with his NG tube and oxygen tubes all up his nose, and it got to the point where the only thing stopping us going home was his feeding. So, we tried bottle feeding which he eventually took to, and we were allowed home to see Daddy!

I continued to try breastfeeding at home for up to about 8 weeks, but it soon got exhausting. I was attempting to breastfeed for around 30 minutes, (both getting soaked in milk!) then expressing for 40 minutes plus,



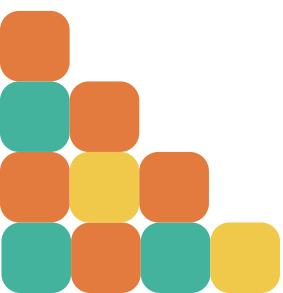
Positive about Down syndrome

sorting/sterilising bottles, changing him them he was hungry again! We were attempting about once a day but that soon just turned into cuddles.

I was happy he was getting my breast milk and was growing, so we continued to express and bottle feed. Reuben has larynomalacia (floppy larynx) and started to cough and struggle with bottles, so we were given a thickener to help him swallow better. This made feeding more of a hassle, having to mix up bottles, and he was now going longer between feeds so we couldn't just take the milk out the fridge and leave it out for the next feed.

Just before he was 12 weeks old, he was hungry while I was expressing so I thought, may as well give it a go while they're out! And he took to it like he'd been doing it since birth! Not long after taking to breastfeeding Reuben started to refuse bottles! But you can't have everything! And it saves so much time on washing and sterilising.

We were lucky enough to have the support of a wonderful breastfeeding nurse who came to see us and make sure Reuben was latching well. It's been a long journey but it's such a rewarding journey. We are 9 months in now and stronger than ever.





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Rachel Gillan mum to Noah



My little boy Noah was born during the first lockdown in the covid pandemic and was diagnosed with Down syndrome shortly after my emergency C Section. So, as you can imagine this was a really scary and very confusing time for me. Especially as he is my first baby and the whole thing was new to me. After Noah was born, he quickly developed some breathing difficulties due to a VSD in his heart and was taken to Neonatal for support on a CPaP machine. Lockdown as we all know meant restrictions in the

hospital were common and the hospital was very protective of the precious babies in the ward. This meant I was only allowed 2 hours per day with him. I can't begin to describe how hard I found this. My instant love and protectiveness of him overwhelmed me and I literally felt that my heart wasn't beating properly when I couldn't be with him. Noah had difficulty latching on when I did get my 2 hours and I was totally defeated and felt hopeless. This played a big part in my feelings of having my opportunity to breastfeed my only child taken away from me, thanks to the pandemic.

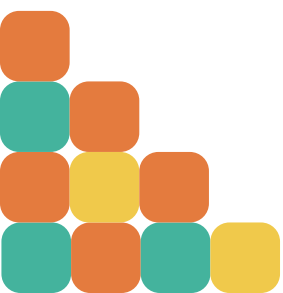
Noah stayed in neonatal for a month after he was born and needed to be fed via NG tube, so ongoing feeding issues were something we had to face at home as well as in the hospital. With this in mind and my feelings of failure, I decided to continue to express and feed him via the NG tube and continue with little bottle feeds just as the nurses had been doing since he was born. As much as I kept telling myself he was getting the best I could offer him, I still felt sad that I never got chance to practice breastfeeding in those early days. I continued to express until he was 6 months old, and this was hard, so much harder



Positive about Down syndrome

than I thought it would be. And having my little boy laid in my arms whilst I expressed using a pump would make me so emotional. It was hard and I truly felt robbed by the pandemic for taking my time with my son away from me. Now though I can see it hasn't affected our bond in any way! He is my baby and I have so far raised a little boy who is growing strong. It's strange that I was so resentful of the pandemic in the beginning but now I know absolutely nothing can break the bond I have with my baby and I am truly one of the lucky few to have a little extra sprinkle of magic in that extra chromosome. That genetic difference that makes my boy mine and no matter how we started out in this life together we will always find a way together to get through anything. I am the happiest I could ever be.... breastfed baby or not he is MY baby and I adore him! I hope my story helps in some way to make another mum not worry so much like I did.

I honestly now believe a fed baby is happy no matter how they are fed, and love is not created through some magic during breastfeeding it's built on and can only get stronger every day.





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Helen Bradley mum to Arlo



After Arlo was born it was a week until we had a Down syndrome diagnosis so I didn't start with any preconceptions about how this might influence our breastfeeding journey. I wanted to breastfeed and was it was really emotional to see him latch on just after I'd given birth. However, during that night and next morning it became clear that although he knew what to do, he wasn't sucking strongly and would tire very easily. He was taken to the Special Care Baby Unit that evening as they also suspected he was having trouble breathing.

Then followed two weeks of pumping round the clock (in hospital for the first week and at home for the second) and taking the, at first tiny amounts of colostrum and eventually larger amounts of milk, across to SCBU for them to feed Arlo through a tube or bottle. I also placed him on the breast at regular intervals. I remember trying to hold him with all his tubes and wires in a position he could latch on while trying to relax and not expose myself to the whole unit - in the end I didn't care who saw my boobs! He was still so sleepy, and I had to tickle his cheek and neck whilst looking out for that all important movement of the jaw to show he was taking in the milk. It was such a long exhausting two weeks full of ups and downs. He was on and off oxygen and his nappies were really varied – it seemed as soon as we tried more breastfeeding and less tube feeding, he'd have more dry nappies and we'd have to go back to tube with top ups of formula. During the two weeks I did come to the decision not to put too much pressure on myself or Arlo and that if it was going to be too difficult for either of us then I would look at other options – I wanted to concentrate on getting him well and that had to be the priority. We had amazing support from the nurses

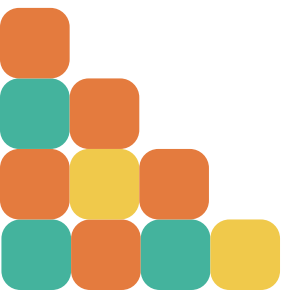


Positive about Down syndrome

in SCBU who not only helped with the practicalities but also supported my strong desire to breastfeed. I remember early on feeling a bit silly taking tiny amounts of colostrum over to SCBU but the nurses treating it like it was gold dust – this was massively important to me and really encouraged me. They spent time giving me advice on positions and latching too which was so helpful (particularly as that was the last physical support we had because of the pandemic).

Eventually Arlo came off, and stayed off, oxygen and over a few days staying in the flat attached to SCBU we both seemed to get the hang of breastfeeding a bit more, the tube came out and we were allowed home. I'd like to say it was happy ever after, but we still had our challenges, finding a position we were comfortable with took a while (and also changed) and feeds could last 45 minutes or longer (thank goodness for box sets!), but after a couple of months it became a lot easier, and we found our groove.

We've just celebrated a year of breastfeeding on Arlo's first birthday. My advice for new parents wanting to breastfeed - get as much support as you can, do what you feel is right for you and your baby, trust your instincts... and enjoy the journey!





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Rebecca Smith mum to Arthur



I had some very clear ideas of what my birth journey and early years of motherhood would look like, and they involved aromatherapy, a birthing pool, organic cotton wool, breastfeeding and washable organic nappies...(!!!)

What the reality looked like at my 38-week scan was an immediate induction, a baby that didn't latch at birth, a possible diagnosis of Down syndrome and heart failure. Not quite the story I had naively set out for myself.

Arthur is my first child, and I quickly realised that I didn't know all that much about babies and I knew nothing at all about Down syndrome. It felt as if my world had just slid sideways and the floor had fallen out from under me. I had never even met anyone who had Down syndrome. Due to his heart failure, he was weak (he had 3 holes in his little heart, and one was 1cm long) so an NG tube was given to him to help

him get the nutrients he needed, and we all had a stay in neonatal.

I was very lucky, (and it will be something that I am always grateful for), that on the day Arthur was born there was an incredible neonatal nurse on duty, and she was assigned to us. The whole world was spinning that day with the unexpected story that was playing out around me, but I do remember in that blur that nurse sitting by me and with her whole being supporting me. She told me that if I wanted to breastfeed my son that they would all help me and that we could both do it. In the world of beeps and tubes and observations and numbers, that felt like there was a part of my old dream that could still be.

I have later found out that I was one of the lucky ones meeting that nurse, her being on shift on that day and her faith in both me and Arthur. I have since experienced so often in Arthur's 20 months of life, the words 'oh he has Down syndrome, so he probably won't be able to do that' and each time he has blown those preconceptions out of the water by achieving each thing set before him. Looking back to his birth, in my fragile state, if I had been told 'oh babies with Down syndrome can't




Positive about Down syndrome

breastfeed' I think I would have given up straight away, not knowing any better and already trying to navigate through so much new information.

It wasn't easy, those first four months of expressing and NG tube feeding (due to his heart failing and him needing to get big enough for the surgery). I often felt very overwhelmed by the cycle of expressing, trying to also establish breastfeeding, then tube feeding, then sterilising and then it was time to start the 3-hour cycle again. However, this hard journey was due to his heart failure and not him having Down syndrome.

Then the moment came when the surgery had been done, and he was on the ward ready to come home. The feeding specialist came to see if after four months he would still be able to breastfeed and to check that it would be safe for him. With everyone around watching us (as I had become so used to in the last four months) he latched on and drank for 10 minutes, we were all in astonishment. Both Arthur and I were then helped to transition from the NG tube to his being solely breastfed. It wasn't all smooth going though, following Arthur's initial feed, we both had to learn again to get it right every time.

One of the most memorable moments for me on this journey was another incredible nurse, a breastfeeding

expert at my local hospital. I heard about her through word of mouth and tracked her down, it was a couple of weeks after the surgery and his latch still wasn't as efficient as it could be. She moved my hand and changed my arm position and that was that – we were off with no looking back. I burst into tears seeing him feeding so well, and the words that came out of my mouth through those tears were 'thank you for giving me my baby back'.

From those pregnancy dreams of a water birth with essential oils and organic cotton wool, it very quickly became a medical intervention, medication and test after test. My baby had become a science experiment, and then here we both were 4 and a half months later, and I had my baby back for the first time, he was mine again.

We went on to breastfeed until he was 18 months old – when he decided to stop himself, and all through that time I loved the fact after my hospital beginning, that now there were no timings to keep to, he fed when he wanted, that we could go out without a whole bag of stuff that I needed to feed him with, that I could help build his immunity and that there were no 3 minute pings of the microwave telling us the steriliser was ready!



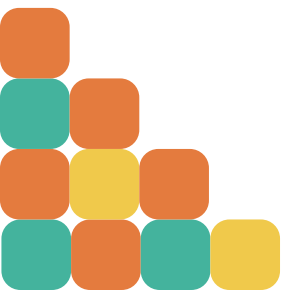


Positive about Down syndrome

Emily Vuijk mum to Luke



When asked to share my experiences of breastfeeding Luke - my baby with Down syndrome, my initial reaction was that I didn't have a story to tell as it was nothing out of the ordinary. But then I got thinking a little bit deeper... do I have a story to tell? The very fact that it's been relatively easy is probably a story in itself and one that deserves to be shared. In summary, he latched on within the first hour after birth and we have so far completed 6 months exclusively on the breast and he is on the 98th centile on his growth chart. Somewhat ironically, breastfeeding Luke has so far been a much easier journey than with my older boy - who doesn't have Down syndrome.





Positive about Down syndrome

Serena Clark mum to Ollie



So, Ollie was born a year ago, a surprise entrance to the world at 36 weeks and a surprise post-natal diagnosis of Down syndrome. After an easy breastfeeding journey with my first, I assumed it would come easy. I didn't know anything about feeding and Down syndrome, we were still waiting for a confirmation of diagnosis. He latched well straight after birth but tired very quickly not managing more than 5 minutes at a time. Due to his jaundice, we were encouraged to add in some formula, which I was reluctant

to do, and he wasn't much better at taking a bottle, but we persevered with both.

I had a wonderful midwife who worked 3 night shifts in a row and she was so supportive of me wanting to breastfeed, she showed me the rugby ball hold and laying down breastfeeding, how to undress him, tickle his feet and switch sides when he got sleepy. Gradually he started breastfeeding for longer and it became easier. I just made sure I had lots of pillows to make us both comfortable. Due to his prolonged jaundice we decided to continue with a bit of formula as well as the breastfeeding, we had a bit of a struggle with bottles for a while and he ended up in hospital once for a while.

We finally settled into a good routine of a bottle mid-morning and late afternoon and breastfeeding the rest of the time. It was especially helpful being able to feed through the night and not have to go downstairs to make a bottle and not worry if we went out without a bottle.

By the time he was 2 months, breastfeeding had become just as easy as with my first, and it was the most wonderful experience. He had good



Positive about Down syndrome

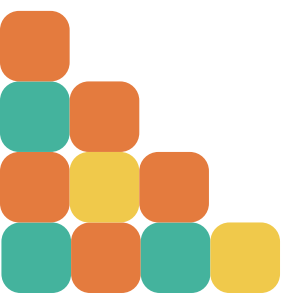
weight gain and no more problems.

I think I probably could have exclusively breastfed at this point but by now we had gone into lockdown and we decided not to change anything when it was working so well and wasn't so easy to get him weighed. I loved being able to comfort him after immunisations and blood tests and hospital appointments as well as providing nutrition.

When he was 9 months old Ollie was in hospital with bronchiolitis for 2 weeks, on high flow oxygen and NG tube fed. I'm so glad I was able to pump throughout to give him at least some breast milk down the NG tube.

It felt like it was the one thing I could do to help him get better and for me to feel less helpless, although I really missed feeding him for 2 weeks. Once they removed the NG tube, he returned to breastfeeding like he had never stopped.

We continued our breastfeeding journey for another 3 months before gradually and naturally stopping just after his first birthday. I would definitely recommend anyone not to assume babies with Down syndrome can't breastfeed, just like anything he took a little longer to master it, but once he got it he was amazing. It was a wonderful way to bond with my gorgeous boy.





Positive about Down syndrome

Stacey McDermott mum to Olive



Before I begin, I just want to emphasise from my own experience that breastfeeding can be hard work, and that applies to all children, not just those with Down syndrome. It can be exasperating trying to establish a good latch, get a good rhythm and feel confident that your child is getting what they need.

Olive had a difficult birth and was intubated for two weeks on NICU and fed breastmilk via a nasal gastric tube. When she was finally extubated, we were warned that breastfeeding would

be difficult to establish as babies with Down syndrome can struggle with feeding owing to low-muscle tone and trouble coordinating suck-swallow-breathe sequences. It's harder for them to maintain a latch and they will often have a weaker suck.

Olive did struggle to latch. We put her to my nipple at every scheduled feed but, after everything she'd been through, she found it hard to stay awake long enough to feed. I pumped milk round the clock and tried lots of different strategies to get her to feed orally, like dipping a dummy in breast milk and getting her to suck on that as we were feeding her through the NG tube, so that she associated the feeling of being full with the taste of my breastmilk. We also gave her lots of opportunities to feed from the bottle so she could practice sucking and swallowing.

I worked with a feeding therapist, to discuss optimal positions for feeding a babe with floppiness, and this made a big difference. Having low tone meant Olive struggled to hold herself in a good position when feeding. I used a good supportive pillow so that she had to do less work and could focus on feeding. Side-lying was another excellent position for us as she could



Positive about Down syndrome

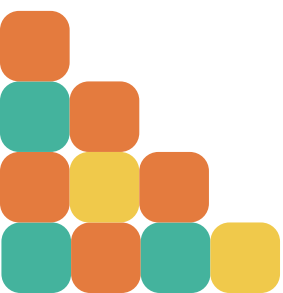
lie comfortably on the bed on a good plane to my body.

She continued to be a very sleepy baby in her first four months of life. We had to wake her every few hours throughout the night and undress her just to get her to rouse enough for a feed, and even then, she could only last for a few minutes. Trying to keep the feeds as regular as possible is so important as children with Down syndrome tend to gain weight at a slower pace. Worth noting that sometimes it was necessary for me to pump a bit after night feeds as she wasn't taking much milk and my breasts often still felt full.

I also had an over-supply of milk (probably from pumping too much when she was on an NG tube) and she often found the flow too fast. She would choke a lot and I had to give her frequent breaks, if it looked like she was struggling.

We encountered more than one health care professional who told us that babies 'like Olive probably wouldn't ever breastfeed'. I am so glad that I didn't allow those comments to prevent me from persevering. With time and patience, a lot of failed attempts, and a bout of mastitis, Olive did successfully transition to breastfeeding, and she went on to breastfeed until she was nearly two.

I want to end by saying, if you haven't been able to establish breastfeeding (and there are myriad reasons why this might be the case, particularly for children with additional needs) you haven't failed. If your baby is eating and gaining weight, then that is all that matters.





Positive about Down syndrome

Sarah Empson mum to Wilf



I'm only just beginning my breastfeeding journey with my son as he's only a few weeks old, but I can't wait to see where the journey takes us. I knew before Wilf was born that I really wanted to breastfeed as I breastfed my daughter until she was just over 2 and loved the journey we shared together. I was warned that breastfeeding may be difficult this time round due to Wilf having poor muscle tone, but I was determined to try and make it work.

After Wilf was born, I needed a lot of patience in the first few days to get

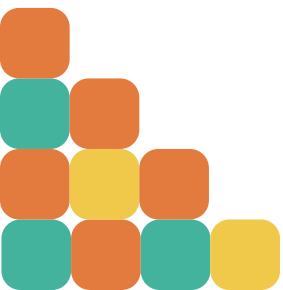
him to latch as his poor muscle tone and long tongue did make it very difficult for him. It would take anywhere between 5 & 15 minutes for him to latch but I remained calm, and he always got there in the end. The effort of feeding meant that he dropped to 11% below birth weight on day 3 so I had to start topping him up with expressed milk to help with his weight gain. After my milk came in (which was slightly delayed due to a caesarean birth) feeding was much easier for him and now we are a few weeks down the line he's not having any top ups and is gaining weight well.

We were in hospital for a week following the birth and I encountered a number of medical professionals who didn't believe that he was feeding well and wanted me to use formula. I stood my ground as I knew he was feeding and that he just needed a little longer to gain weight due to the effort of feeding with his poor muscle tone but that breastfeeding and topping up with expressed milk was enough. I'm glad that I trusted my mothering instincts. My advice to anyone wanting to breastfeed is to remain calm and patient in the early days and seek advice and support from the infant feeding team to help



Positive about Down syndrome

establish breastfeeding. If you are able to establish breastfeeding, then the reward you get back is wonderful. I also love how easy it is as you always have milk available that can be given instantly on demand!





Here are some general and Down syndrome specific breastfeeding resources kindly compiled by Sarah Ojar of chromosomes and curls.

[PADS has a closed Facebook group exclusively for mums of a baby with Down syndrome in the UK.](#)

UK Phone lines:

National Breastfeeding Helpline

0300 100 0212 (calls answered by volunteers trained by the ABM and BFN)

La Leche League helpline

0345 120 2918

NCT Breastfeeding Line

0300 330 0771

Organisations:

The Breastfeeding Network

<https://www.breastfeedingnetwork.org.uk>

Association of Breastfeeding Mothers

<http://www.abm.me.uk>

La Leche League

<http://www.laleche.org.uk>

Specific Down syndrome resources:

<https://juliasway.org>

<http://oakwellbarns.co.uk/breastfeeding-your-baby-with-downs-syndrome/>

<https://kellymom.com/ages/newborn/nb-challenges/down-syndrome/>

<https://www.breastfeeding.asn.au/bf-info/down>

https://www.ndscenter.org/wp-content/uploads/CDSS_breastfeeding_brochure.pdf

<https://www.breastfeeding.asn.au/bf-info/down>

<https://www.lli.org/breastfeeding-info/special-needs/>

<https://www.childrensmn.org/educationmaterials/childrensmn/article/15844/breastfeeding-an-infant-with-down-syndrome/>

<https://chromosomesandcurls.wordpress.com/2018/08/07/how-breastfeeding-can-help-your-baby-with-down-syndrome/>

<https://chromosomesandcurls.wordpress.com/2018/08/01/ten-tips-for-breastfeeding-a-baby-with-down-syndrome/>

<https://themilkmeg.com/breastfeeding-josee-ten-tips-for-breastfeeding-a-baby-with-down-syndrome/>

<https://iamriver.net/2017/07/19/breastfeeding-a-baby-with-down-syndrome/>

<https://www.mattoslactation.com/blog/2019/7/20/breastfeeding-and-down-syndrome-part-one-anatomy>

<https://www.raisingcaleb.co.uk/single-post/2019/05/29/Breast-feeding-a-baby-with-Down-Syndrome>

Other useful websites

<https://kellymom.com>

<https://www.cibii.co.uk>

<https://www.basionline.org.uk>

