



# Breastfeeding a baby with Down syndrome

**The maternity experience**



**Positive about  
Down syndrome**

**This report is not intended to advocate breastfeeding over any other feeding. It is published to raise awareness around the lack of accurate information and meaningful support to women who are expecting, or have had a baby with Down syndrome.**

Survey conducted in July 2021 by 329 mothers of a baby with Down syndrome born in the UK since 2016.

Women were recruited via social media and are from across all regions of the UK.

**34%** of the women were first time mums.

**11%** of the respondents had not planned to breastfeed baby.

Published August 2021.





# Introduction

Positive about Down syndrome (PADS) works hard to ensure expectant and new parents of a baby with Down syndrome, have access to the information and support that they crave - the reality of what living with Down syndrome looks like in modern Britain, as well as ongoing peer support and expert advice when baby arrives.

We have welcomed 125 babies with Down syndrome via our closed Facebook group Great Expectations and currently support over 90 women with a high chance/confirmed result of baby having Down syndrome. We work with approximately 1,000 families of a little one with Down syndrome under the age of 3, so are very immersed in maternity and early care for our families.

We collaborate with maternity units and universities to provide resources and training to midwives and other health professionals, with our training drawing upon the real-life recent experiences of our members together with evidence-based research.

We are passionate about ensuring parents have access to contemporary, relevant, and accurate information as well as positive and meaningful support. This research has been conducted to establish how well informed and supported expectant and new parents are today around breastfeeding their baby with Down syndrome.

The health benefits of breastfeeding are well known, however at PADS we are of the view that the impact on a mother's mental health and well-being should also be considered by medical professionals when considering feeding recommendations.

Around 800 babies with Down syndrome are born in the UK each year. We know from previous research ([Sharing the news: The maternity of experience of having a baby with Down syndrome](#)), that for many new parents, there is all too often a negative outlook and attitude around baby having Down syndrome. ►

# Introduction

Many new parents struggle with the news baby has Down syndrome - compounded with negative attitudes and language by medical professionals, and not being able to breast feed when a mother had planned to do so, can significantly contribute to a negative maternity experience.

Yet we know that when women are well informed and supported, whilst there can be additional challenges for breastfeeding a baby with Down syndrome, that the breastfeeding experience can bring so many benefits – to both baby and mother. Aside from the known health benefits, women report an increase in bonding between mother and baby improving a mother's mental well-being; a feeling of accomplishment and pride for the mother; an increase in a mother's confidence in her ability to meet her child's needs, and satisfaction in the knowledge that the breastfeeding may well improve not only the general health of baby but their oral motor skills and so in time speech development.

We believe, that in general, there is no reason why the majority of babies with Down syndrome cannot be breastfed if this is mother's chosen route.





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**NICU were amazing but that support stopped at 10 days when they came home. There wasn't enough of the right support once we were back home. My health visitor was very attentive and supportive but she was more worried about my mental health (something I appreciated) but she didn't have much experience of babies with Down syndrome.**



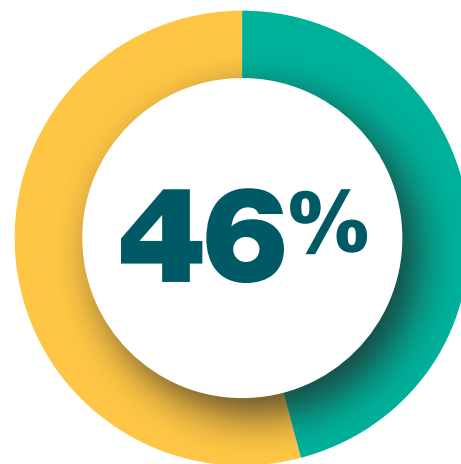
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**It was yet another thing they told me she would never do but she did it. I get that some children with Down syndrome may struggle – plenty without Down syndrome struggle. But the assumption that they knew best was unhelpful and if I had been a first time mum I may well have listened to them.**



## Key findings

**An assumption by medical professionals that babies with Down syndrome cannot breastfeed.**



**46%** of women were advised by a health care professional that they may not be able to breastfeed their infant purely because of baby having Down syndrome.





*Midwives suggested she wouldn't be able to latch and didn't have the strength to suckle' advises Jodie mum to Libby who had been keen to breastfeed her first born.*



*My hopes to breastfeed were not really embraced. I had support whilst in hospital, but no real support afterwards. I received a phone call from a breastfeeding specialist once discharged, but that was all, it wasn't very helpful.*



*One mother who had planned to breastfeed, shares, 'I was told not to breast feed as my baby would not be able to latch on'. As a result, this mum did not attempt to breastfeed her baby.*



*Amy, mum to Connie was advised by a Doctor in NICU that 'it would be unlikely that she would be able to breast feed and not to get my hopes up!!' Nine months on and Amy and Connie are very much enjoying their breastfeeding experience.*



*Mum Linzi has gone onto become an advocate for breastfeeding after she was told that, 'Apparently, due to her heart condition and low muscle tone she most likely wouldn't breastfeed' Two years later Linzi and daughter Matilda are loving their breastfeeding experience.*



*I fed Libby exclusively on breast milk via expressing every two hours for 12 weeks. She never took to feeding directly from my breast unfortunately, and I don't feel I had sufficient support to make it work. if I'd been able to do so.*

## Key findings

**A lack of knowledge and support around breastfeeding babies with Down syndrome.**

**54% advised they did not receive the support they needed around breastfeeding from their midwifery team.**





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*I tried to feed the girls, and was expressing while they were in NICU (preemie babies) but one nurse from NICU said quite harshly to me that I wasn't expressing often enough and I needed to be doing it every 3 hours during the day and night. She just wasn't very nice about saying it.*

*I'd just had my first child (twins), been given a post-natal diagnosis of Down syndrome and they were in NICU. That one person's comments made me quit attempting to breastfeed.*

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*It was so distressing. I wanted so much to feed Alys but she found it hard despite trying, my milk never really came in and I had people just telling me what more I needed to do (tracking amounts, pumping, topping up, hourly schedule) rather than looking at her mouth shape, what she needed to latch, how I could increase supply. I was left feeling like I was letting her down and couldn't feed her. It's left me with a massive trigger around feeding her.*

# For first time mothers, support to establish and continue breastfeeding is essential.

Erica found that when she was struggling with breastfeeding, baby having Down syndrome was part of the discussion of why that might be. Pitched in the sense of “don’t feel bad if you want to stop.”

*‘My daughter was instructed was instructed to be bottle fed due to low glucose levels on birth so direct breastfeeding wasn’t feasible at the start anyway. Some lovely midwives did try to give support with expressing colostrum to add to the formula milk but it was such a struggle to get her to feed already without falling asleep continually, the focus was always on getting the nutrition in and the weight gain rather than breastmilk as a priority.*

*I sought support from multiple sources including children’s centres, health visitors, specialist breastfeeding clinics... variable quality. The best person turned out to be someone who was a mum to a child with Down syndrome herself - but by the time I found her I felt the boat had sailed on my bf journey really.*

*I think the holistic picture should be considered far more - the emotional effects of post-natal diagnosis can play into a woman’s body’s ability to allow let-down of milk and equally perceived “failure” to breastfeed can cycle back into negative mental health. The benefits of properly funded bf support stretch into so many areas beyond direct benefits to the baby.’*





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*I pretty much had to fumble in the dark. I was adamant he would breast feed, he had zero issues latching. And I'm more dismayed at the lack of faith from the medical professionals on what my baby was able to do. It wasn't the most positive experience.*

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*It really helped having a neonatal nurse who had a daughter with Down syndrome on the ward where we were staying who was so kind and supportive of everything.*

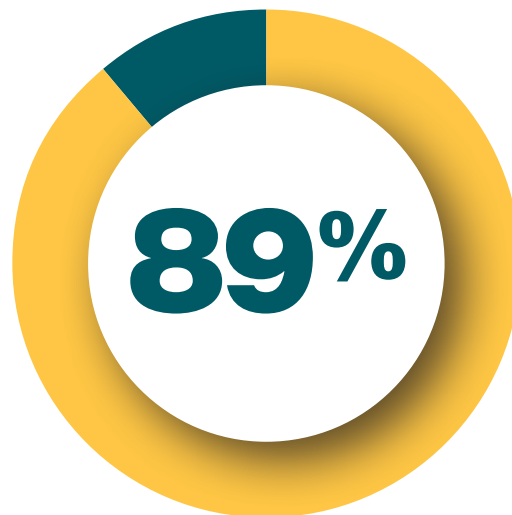
## Key findings

Despite the ignorance and lack of support, most women breastfed/feed their baby with Down syndrome:

**77%**

of women breastfed their baby with Down syndrome

**ONE WONDERS IF WITH THE RIGHT INFORMATION AND SUPPORT MORE COULD HAVE BREASTFED.**



Of the **23%** of women who did not breastfeed their baby with Down syndrome, a staggering **89%** had planned to breastfeed.



*Because he was in NICU and had feeding issues we got told that as they need to monitor his milk intake he had to be bottle feed. I expressed breast milk for 4 weeks until I was physically drained.*

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# Challenges and potential solutions

Whilst babies with Down syndrome can be more prone to hypotonia (low muscle tone), and some will require heart surgery within the first few months of life and as a result may tire quicker, women should be encouraged and supported to try different feeding positions – many of our mothers advocate the use of dancer hold, the biological nurturing position, and the use of nipple shields many advise as a game changer. However, each baby and mother should receive individual support.

For those babies who require support via enteral tube feeding, women should be encouraged to pump so breast milk can be enterally fed and to continue to put baby regularly to the breast, particularly when being tube fed.

## Good practice



Aelene, had breastfed her first child and knew what she was doing in so far as having a simple exclusive breastfeeding journey but hadn't pumped before, and had no experience of combination feeding, nor straw bottle feeding which she went on to use for daughter Mara.

Aelene, advises: *"The hospital had an amazing breastfeeding specialist, without her and her advocacy I would have been lost.*

*It's one of my most proud achievements because it was so unbelievably tough for me but we made it through and I breastfed until 14 months. I also think the idea of her speech and muscle tone improving was a huge motivator for me."*



Kirsty states: *I was offered support from the midwife breastfeeding team who were experienced in supporting breast feeding with babies who have Down syndrome. Everyone was supportive and it was easier to establish than it had been with my eldest who does not have additional needs. I breastfed Rory until he was about 16 months at which point he weaned himself, just like his older brother did.*



Two years on and mum Susan is still breastfeeding. She has received the support and information she needed across her care:

*They were extremely helpful in the early days, while I was still pumping milk and storing it in the fridge to use a syringe to feed it to my daughter while she got stronger. They visited me while feeding to offer help and suggestions regarding positioning, etc.*





# Concerns

Along with the lack of accurate information and support around breastfeeding a baby with Down syndrome, at PADS we are concerned at the number of babies we are seeing being NG tube fed, often against a mother's wishes and we hear time and time again of mother's feeling pressured for baby to have an NG tube, in order that the intake can be measured before baby can be allowed to go home.

For those babies being tube fed, mothers report feeling unsupported, afraid and unsure how to move forward. Most comment that baby is discharged

with no care pathway or advice given about the plan for removing the tube.

*Melissa, wrote, 'they told me we would not be discharged until my son was on a bottle. I asked about impact on my supply and his speech development but was given no answer. At an extremely vulnerable time this was very distressing. Breastfeeding is hard for a lot of mums, but I feel like we were written off in the hospital. Had we had a more positive experience and encouragement I feel this would have given me more confidence to continue at home.'*



## PSYCHOLOGICAL IMPACT ON MOTHER

Aside from missed health benefits, the common concerns that mothers express around not being able to breastfeed either at all or for less time than would have liked are all around a woman's well-being, her mental health.

At time when a woman can feel very alone, potentially disconnected from her baby, struggling to bond and wanting life to be normal, the inability to breastfeed can have significant impact on her mental health.

At a time when women are often struggling with the diagnosis of baby having Down syndrome and are wanting to bond and feed their baby, we believe that the impact on a mother's mental health and well-being should be taken into consideration when determining feeding recommendations.



*I feel cheated and let down by the medical staff, I was told my baby couldn't be solely breastfed when she could have been. Not being able to choose how I fed my baby has had a knock on psychological effect around feeding.*







## Medicalisation of baby

Along with discovering baby has Down syndrome the need for baby to be tube fed leaves many women struggling with and perhaps resenting the medicalised needs of their baby.

## Growth chart

Many parents advise they are not provided with the Down syndrome growth chart and that baby's weight is measured against the standard issued chart.

It is important that the growth chart developed specifically for monitoring the weight of babies with Down syndrome is used from term; with the growth of any pre-term baby born before 37 weeks being recorded on the NICM chart.

## Diagnostic overshadowing

Parents reported a tendency for any feeding issues to be attributed to baby having Down syndrome, before routine issues such as tongue tie or different positions/options were explored.



*I have good days and bad days. Some days are both. Yesterday was a good day because I had a good sleep. Sarah had her newborn baby photo shoot yesterday too, she looked adorable. She pulled out her tube midway through shoot. Deep down I was so happy I loved it. Just for a couple of hours I felt as if everything was absolutely fine she looked so normal without tube. It really does bother me. Outreach soon came though and put a new one down.*



*Breastfeeding was essential to my bonding. It was in stark contrast to the initial medicalised route we were on for the first 4 months. I felt it “gave me my baby back”. I felt confident I was doing all I could for him and his immune system.*

# Conclusions

The evidence shows that the vast majority of babies with Down syndrome can be breastfed in line with Unicef data, two thirds breastfed for more than 6 months and 27% of mothers breastfed beyond 18 months.

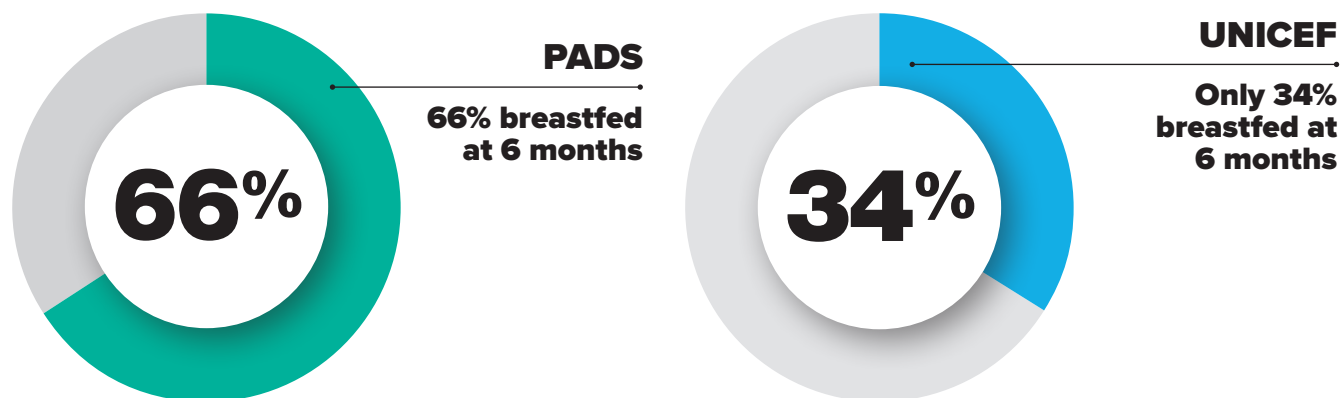
UNICEF's last UK-wide Infant Feeding Survey was conducted in 2010, and reported breastfeeding initiation of **81%**. PADS data shows **77%** of mothers with a baby with Down syndrome initiated breastfeeding.



**77% PADS**

unicef 

**81% UNICEF**



The UNICEF data for the UK showed just **34%** women breastfeeding at 6 months, whilst the PADS data shows **66%** of women breastfeeding their baby with Down syndrome at this age.

## Age at which baby with Down syndrome stopped breastfeeding?



# Recommendations

- ▶ Discussions and plans around an expectant mother's breastfeeding expectations and hopes to be prepared and shared.
- ▶ Discuss harvesting of colostrum with expectant women.
- ▶ For health care professionals to not assume that a baby with Down syndrome will not breastfeed.
- ▶ For the impact on a mother's mental health and well-being to be taken into consideration by health care professionals when determining feeding.
- ▶ Pathways to be discussed prior to discharge with parents of tube fed babies around the plan to remove NG tube.
- ▶ Speech and language therapy to be involved whilst baby is in hospital and prior to baby's discharge, to support baby's oral motor skills development if being NG tube fed.
- ▶ Greater training of, as well as awareness and knowledge of, lactation specialists to signpost women to.
- ▶ For health care professionals to promote the value of family centred care, seeing each baby as an individual and to work with parents to support their unique breastfeeding journey.
- ▶ The Down syndrome PCHR insert developed for babies with Down syndrome by DSMIG to be swapped out in baby's red book.



# PADS Facebook support groups

## ► Great Expectations

A warm welcome awaits any expectant woman in the UK who has had a high chance/confirmed result of baby having Down syndrome.

## ► New parents

One of the most wonderfully supportive and caring groups you will find on Facebook! Parents of a little one with Down syndrome from birth, the youngest age to join so far is 3 hours old, and we welcome parents of little ones through to 18 months.

## ► Dads to be

We realise dads to be can sometimes feel a little overlooked and neglected, so this group is exclusively for those dads in the UK whose partner is expecting a baby with a high chance/confirmed result of having Down syndrome.

## ► Dads

A group exclusively for dads in the UK of a child with Down syndrome aged 0-5 years. A chance for the dads to meet and chat with other dads, to share experiences and perhaps exchange ideas, discuss any worries and celebrate achievements.

## ► Breastfeeding

Several mums who are lactation consultants and others who are very happy to help any mum who would like some support and advice around breastfeeding their baby with Down syndrome.

## ► Grandparents

We know the important role grandparents play in all our lives and so have a wonderfully supportive group exclusively for UK based grandparents.

# Information and support

PADS publication '[The Lived Experience: Breastfeeding a baby with Down Syndrome](#)' provides parents and professionals with an insight into the reality of breastfeeding a baby with Down syndrome, whilst also signposting them to further information

PADS provides ongoing support via our very active and supportive closed [Facebook group DSUK PADS Breastfeeding peer support](#). Members include mothers who have/are still breastfeeding their baby with Down syndrome, and we have trained breastfeeding supporters with the BFN, ABM and F.A.B, as well as an NHS infant feeding support worker.

Here are some general and Down syndrome specific breastfeeding resources kindly compiled by Sarah Ojar of Chromosomes and Curls:

## 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**  
[www.breastfeedingnetwork.org.uk](http://www.breastfeedingnetwork.org.uk)
- ▶ **Association of Breastfeeding Mothers**  
[www.abm.me.uk](http://www.abm.me.uk)
- ▶ **La Leche League**  
[www.laleche.org.uk](http://www.laleche.org.uk)

### Specific Down syndrome resources:

- ▶ [juliasway.org](http://juliasway.org)
- ▶ [oakwellbarns.co.uk/breastfeeding-yourbaby-with-downs-syndrome/](http://oakwellbarns.co.uk/breastfeeding-yourbaby-with-downs-syndrome/)
- ▶ [kellymom.com/ages/newborn/nbchallenges/down-syndrome/](http://kellymom.com/ages/newborn/nbchallenges/down-syndrome/)
- ▶ [www.breastfeeding.asn.au/bf-info/down](http://www.breastfeeding.asn.au/bf-info/down)
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- ▶ [www.childrensmn.org/educationmaterials/childrensmn/article/15844/breastfeeding-an-infant-withdown-syndrome/](http://www.childrensmn.org/educationmaterials/childrensmn/article/15844/breastfeeding-an-infant-withdown-syndrome/)
- ▶ [chromosomesandcurls.wordpress.com/2018/08/07/how-breastfeeding-canhelp-your-baby-with-down-syndrome/](http://chromosomesandcurls.wordpress.com/2018/08/07/how-breastfeeding-canhelp-your-baby-with-down-syndrome/)
- ▶ [chromosomesandcurls.wordpress.com/2018/08/01/ten-tips-for-breastfeeding-ababy-with-down-syndrome](http://chromosomesandcurls.wordpress.com/2018/08/01/ten-tips-for-breastfeeding-ababy-with-down-syndrome)
- ▶ [themilkmeg.com/breastfeeding-joseeten-tips-for-breastfeeding-a-baby-with-downsyndrome](http://themilkmeg.com/breastfeeding-joseeten-tips-for-breastfeeding-a-baby-with-downsyndrome)
- ▶ [iamriver.net/2017/07/19/breastfeedinga-baby-with-down-syndrome](http://iamriver.net/2017/07/19/breastfeedinga-baby-with-down-syndrome)
- ▶ [www.mattoslactation.com/blog/2019/7/20/breastfeeding-and-downsyndrome-part-one-anatomy](http://www.mattoslactation.com/blog/2019/7/20/breastfeeding-and-downsyndrome-part-one-anatomy)
- ▶ [www.raisingcaleb.co.uk/singlepost/2019/05/29/Breast-feeding-ababy-with-Down-Syndrome](http://www.raisingcaleb.co.uk/singlepost/2019/05/29/Breast-feeding-ababy-with-Down-Syndrome)

### Other useful websites

- ▶ [www.kellymom.com](http://www.kellymom.com)
- ▶ [www.cibii.co.uk](http://www.cibii.co.uk)
- ▶ [www.basionline.org.uk](http://www.basionline.org.uk)



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**I believe it was so essential for bonding and boosting baby's immune system. I just wish I had been better supported.**

[www.positiveaboutdownsyndrome.co.uk](http://www.positiveaboutdownsyndrome.co.uk)  
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