

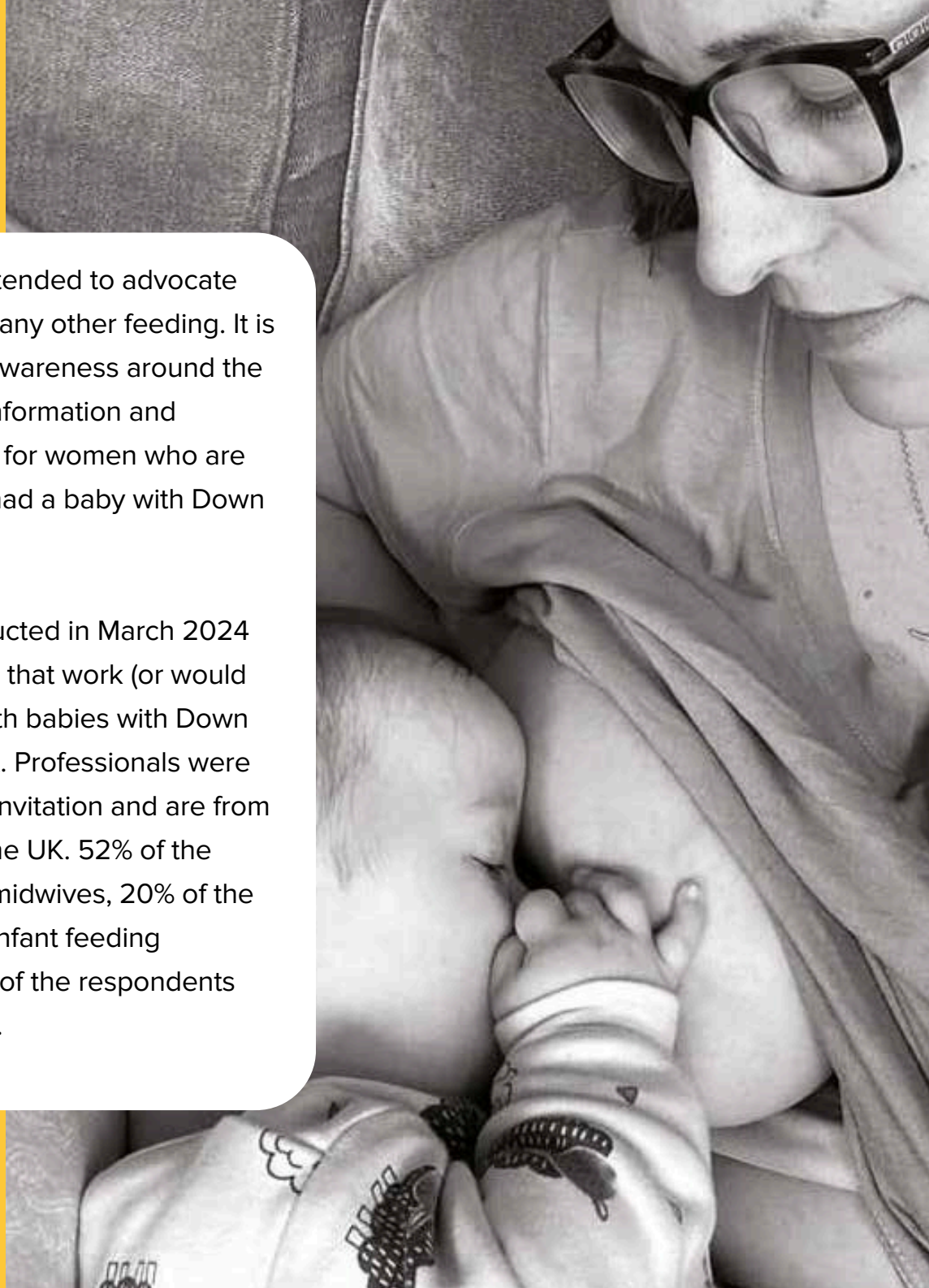
Breastfeeding a baby with Down syndrome

The Professional Perspective

Report 2025

DSUK Down Syndrome UK

Positive About Down Syndrome Community



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

A survey was conducted in March 2024 by 50 professionals that work (or would potentially work) with babies with Down syndrome in the UK. Professionals were recruited via email invitation and are from all regions across the UK. 52% of the respondents were midwives, 20% of the respondents were infant feeding specialists and 14% of the respondents were health visitors.

Published January 2025

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 more than 250 babies with Down syndrome via our closed Facebook group Great Expectations and currently support over 120 women with a high chance/confirmed result of baby having Down syndrome. We work with more than 2,000 families of a little one with Down syndrome under the age of 4, so are 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 and identify how families are being supported in the wider community and how we as a charity can offer support to those professionals who are providing infant feeding support.

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. ▶

Many new parents struggle with the news baby has Down syndrome - compounded with negative attitudes and language by medical professionals, in addition to 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.



I didn’t feel supported and not sure where to turn, the health worker sent generic replies to my questions and suggested reading books and talking to other mums with typical children.



Key findings 1

Almost a third of medical professionals thought babies with Down syndrome cannot breastfeed.

In your opinion, how likely is it that a baby with Down syndrome will breastfeed successfully?



30% of professionals said they weren't sure or didn't think a baby with Down syndrome would be able to breastfeed. The other 70% thought it was likely.

Yet our research shows that **77% of women breastfed their babies, and that at 6 months 66%** of babies with Down syndrome were still being breastfed.



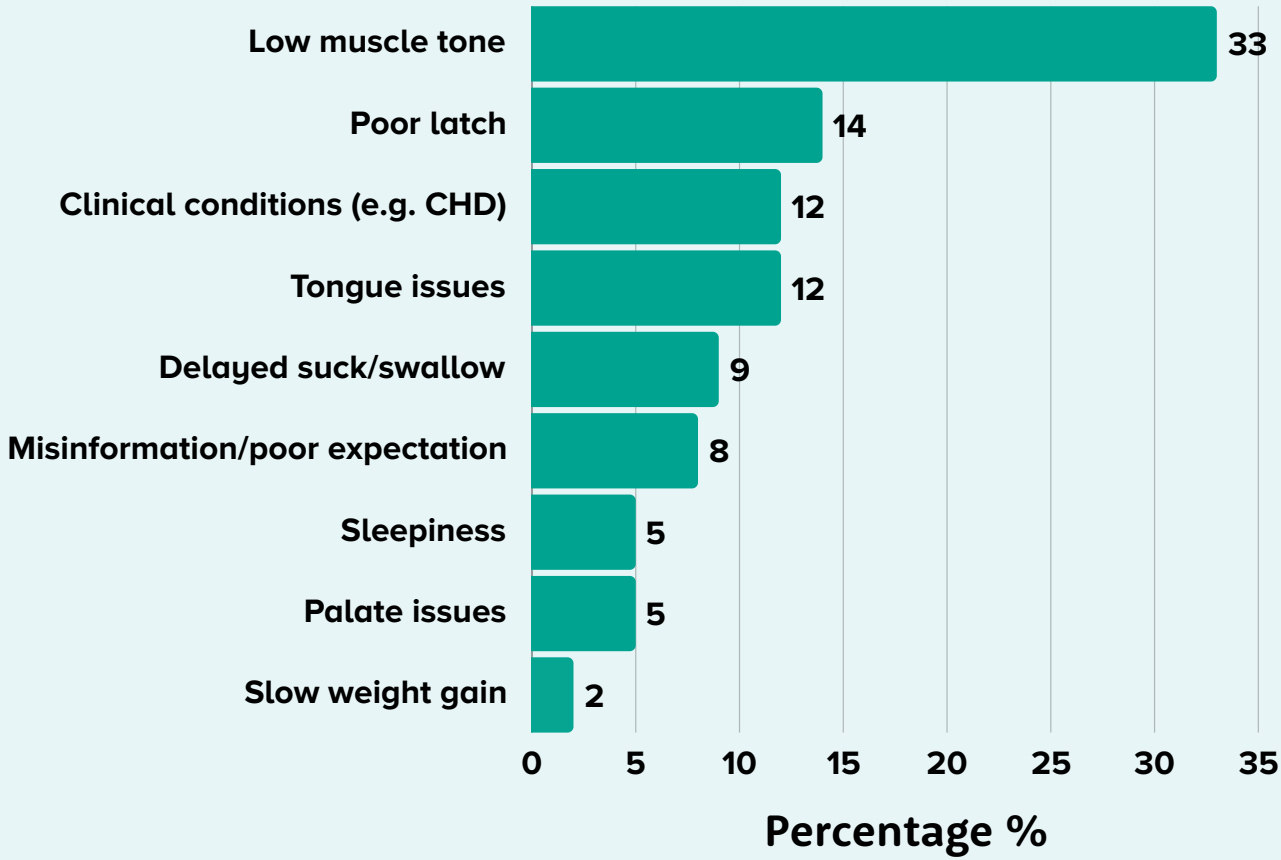
Encouragement and support was crucial to our successful journey. Just being told when I was pregnant that my baby had a great chance of being able to breastfeed meant I went into it hopeful and expectant of a positive outcome.

The lack of knowledge and active support made an already tricky time (post birth diagnosis and poorly baby) even harder to navigate on a daily basis.

Key findings 2

In professional opinions and experience, babies with Down syndrome will face the the following problems...

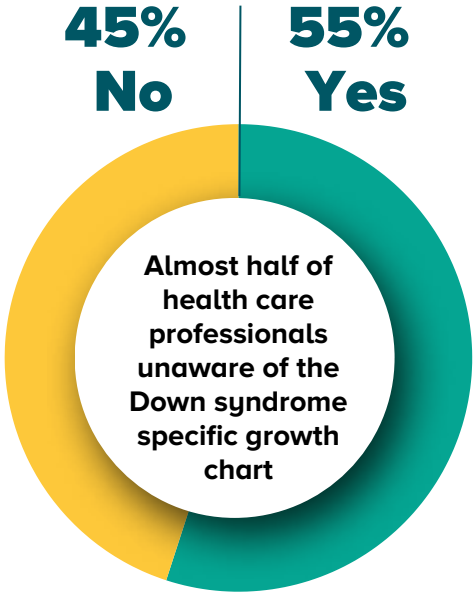
% of number of healthcare professionals



Key findings 3

Awareness of the Down syndrome specific growth chart

Awareness and use of the Down syndrome specific growth chart can be crucial to a successful breastfeeding journey. A baby's weight being plotted on the graph for a typical baby can lead to false concerns over weight gain and lead to an unnecessary feeding plan being introduced including offering expressed breastmilk or even infant formula.

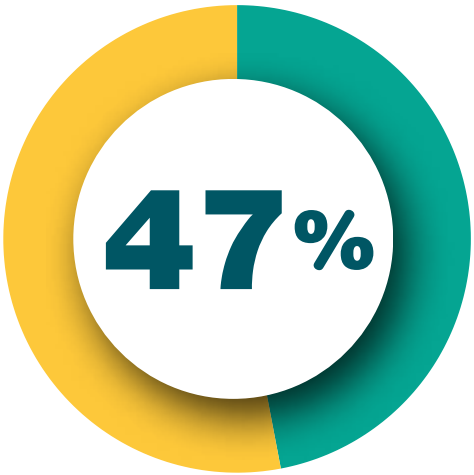


Scan code to download Down syndrome specific growth chart

Key findings 4

Many babies with Down syndrome are coming home from hospitals with an NG tube and some parents are not feeling supported in a plan to stopping its use.

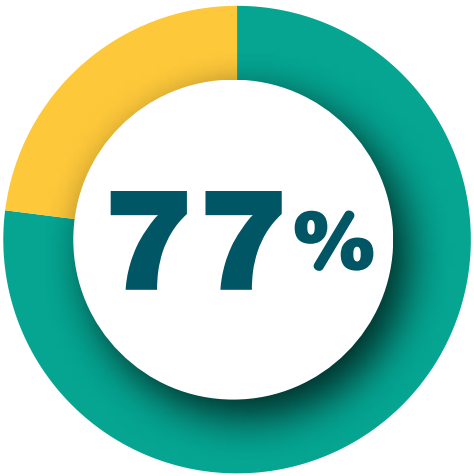
47% of professionals are unaware whether there is a pathway in their trust for weaning off an NG tube.



In our 2022 report, **38%** of babies that required an NG tube came home from the hospital with one. **29%** of parents did not feel informed or involved about when the NG tube would be removed.

Key findings 5

Access to general breastfeeding training vs Down syndrome specific breastfeeding training



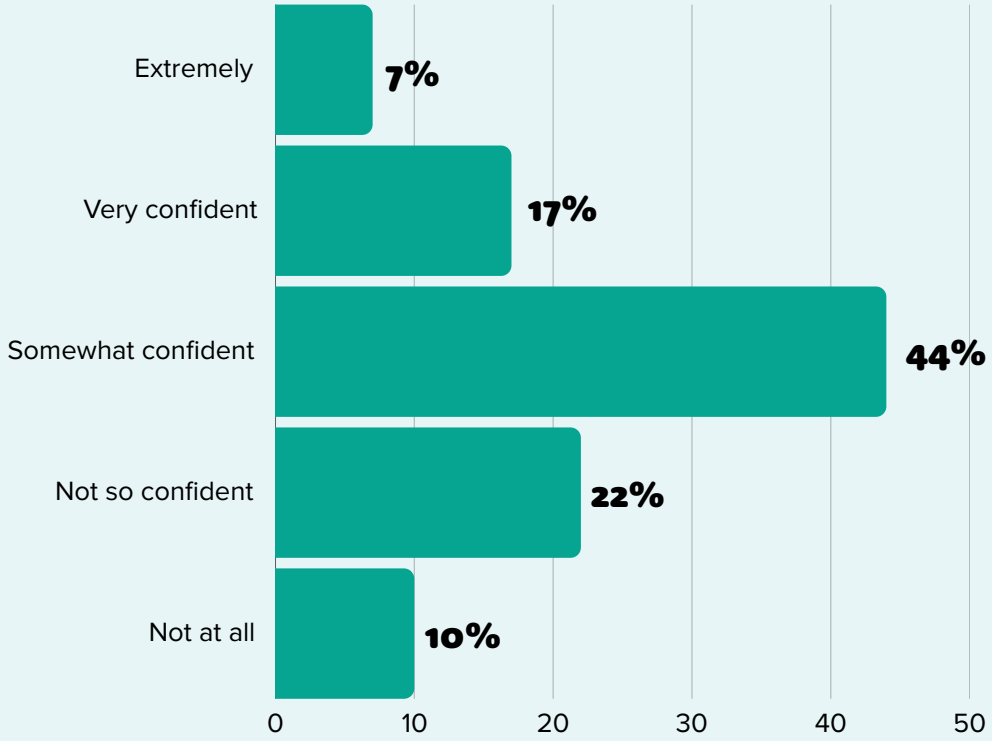
77% of professionals surveyed have accessed general breastfeeding training as part of their job.



18% of professionals have accessed specific breastfeeding training for babies with Down syndrome.

Key findings 6

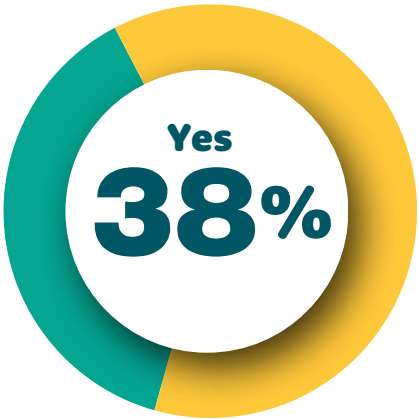
How confident are you supporting a baby with Down syndrome who is breastfeeding?

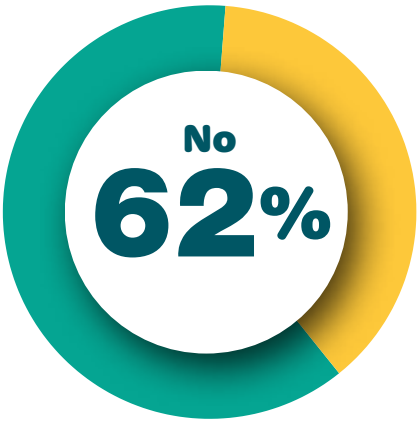


Key findings 7

Experience

Have you any experience supporting a baby with Down syndrome?





Positive Experiences

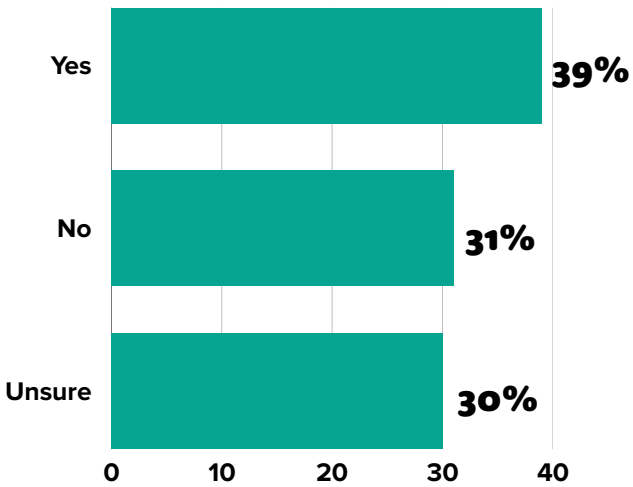
A baby I remember well, my confidence built as the mother became more confident - she went onto breastfeed for more than 9 months.

Over the years I have supported, maybe 10 babies with Down syndrome. They were all different, their mothers brought their own experience, hopes, expectations, cultural, social outlook. Most of them got off to a slow start but breastfed in the end if that was what the mother wanted to do. Only one baby never breastfed, or bottle fed effectively and was NG tube fed until she was over a year old.

Key findings 8

Over a third have access to information on breastfeeding and Down syndrome in their workplace.

In the workplace, do you have access to information and support around Down syndrome and breastfeeding?



Key findings 9

DSUK breastfeeding training sessions are valued

If you have accessed our breastfeeding training, do you feel more confident in supporting babies with Down syndrome when breastfeeding?





Challenges and possible solutions

Whilst babies with Down syndrome can be more prone to hypotonia (low muscle tone), be sleepier in the first few weeks, and some may require surgery which can interfere with the breastfeeding journey, women should be encouraged and supported to establish breastfeeding. Techniques such as the dancer hold and supportive positioning alongside the managing of expectations around expressing, and the observations that it often does take slightly longer to establish feeding should all be part of the support offered to families. Both the physiological and societal challenges should be considered when supporting families.

For babies that are given an NG tube to use, specific support around expressing breastmilk should be offered along with a supportive ongoing plan to establish direct breastfeeding.



Good Practice

The PADs breastfeeding group was the reason I could get her established on the breast due to their advice and support. Thank you.

I have supported all team members to attend the PADS study events and they are valued.

The PADS training materials are excellent, I share your contact details regularly with students

Concerns

Lack of confidence in supporting

Lack of knowledge or access to correct growth chart - if wrong one used impact is that false concerns over weight gain can affect breastfeeding journey

Diagnostic overshadowing

Lack of time and funding for professionals to attend our training

Conclusions

The evidence continues to show that the vast majority of babies with Down syndrome can be breastfed, with many able to breastfeed immediately and continue to do so for many months. However there is an acute lack of support and information, which along with high incidence of NG tube feeding all contribute to a negative impact on the well being of many women.

The training we provide to professionals is valuable and well received by those who attend. It may improve confidence levels in those working with the families of babies born with Down syndrome.

Recommendations

- PADS to continue to promote and offer our breastfeeding training session to professionals.
- Access to our resources including the guide to breastfeeding and recorded webinar.
- 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.
- Ensuring awareness and use of Down syndrome growth chart with the Down syndrome PCHR insert, developed for babies with Down syndrome by DSMIG to be swapped out in baby's red book.
- Greater training of, as well as awareness and knowledge of, lactation specialists to signpost women to.
- Signposting to PADS support groups.
- 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.
- Research to be undertaken to establish if any long term impact around use of NG tube feeding on a child's speech development.
- Better support and information around breastfeeding and weaning babies with Down syndrome.

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 peer supporters 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.

In July 2023 PADS published Breastfeeding a baby with Down syndrome Breastfeeding Research Reports - The maternity experience 2022 and The maternity experience in 2021.

In 2022 PADS appointed Sarah Ojar as Breastfeeding CoOrdinator. As well as supporting mothers of babies with Down syndrome with their breastfeeding journeys, Sarah is keen to collaborate with relevant bodies both in the public and private sectors. PADS has developed a training module specifically around breastfeeding babies with Down syndrome, for further information email breastfeedingsupport@downsyndromeuk.co.uk.

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 FAB, as well as an NHS infant feeding support worker.

In 2025, DSUK PADS is proud to partner with the Royal College of Midwives, to produce a series of iLearning modules: 'Down syndrome: Breastfeeding' and 'Down syndrome: The Importance of Language'. To find out more visit: www.rcm.org.uk/i-learn

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
- **Association of Breastfeeding Mothers**
  www.abm.me.uk
- **La Leche League**
  www.laleche.org.uk

Additional resources:

- juliasway.org
- kellymom.com/ages/newborn/nbchallenges/down-syndrome/
- llli.org/breastfeeding-info/special-needs/
- breastfeedingnetwork.org.uk



My health visitor has always been incredibly supportive and has gone above and beyond to help us get the referrals and follow-ups we've needed.



Hope amazed all the health professionals (and even me) with how quickly and well she latched on. She was breastfeeding effectively 30 minutes after her birth and never had any issues with it at all. We both found it to be such an easy process. Not at all what I was expecting!!

www.positiveaboutdownsyndrome.co.uk
info@positiveaboutdownsyndrome.co.uk
0330 111 2121

/PositiveaboutDownSyndrome/
@PositiveaboutDS
@positive_about_down_syndrome

For further information visit:
www.downsyndromeuk.co.uk

DSUK Down Syndrome UK | Positive About Down Syndrome Community

Registered number 1184564

12682