



# Breastfeeding a baby with Down syndrome

The maternity experience 2022



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 for women who are expecting or have had a baby with Down syndrome.**

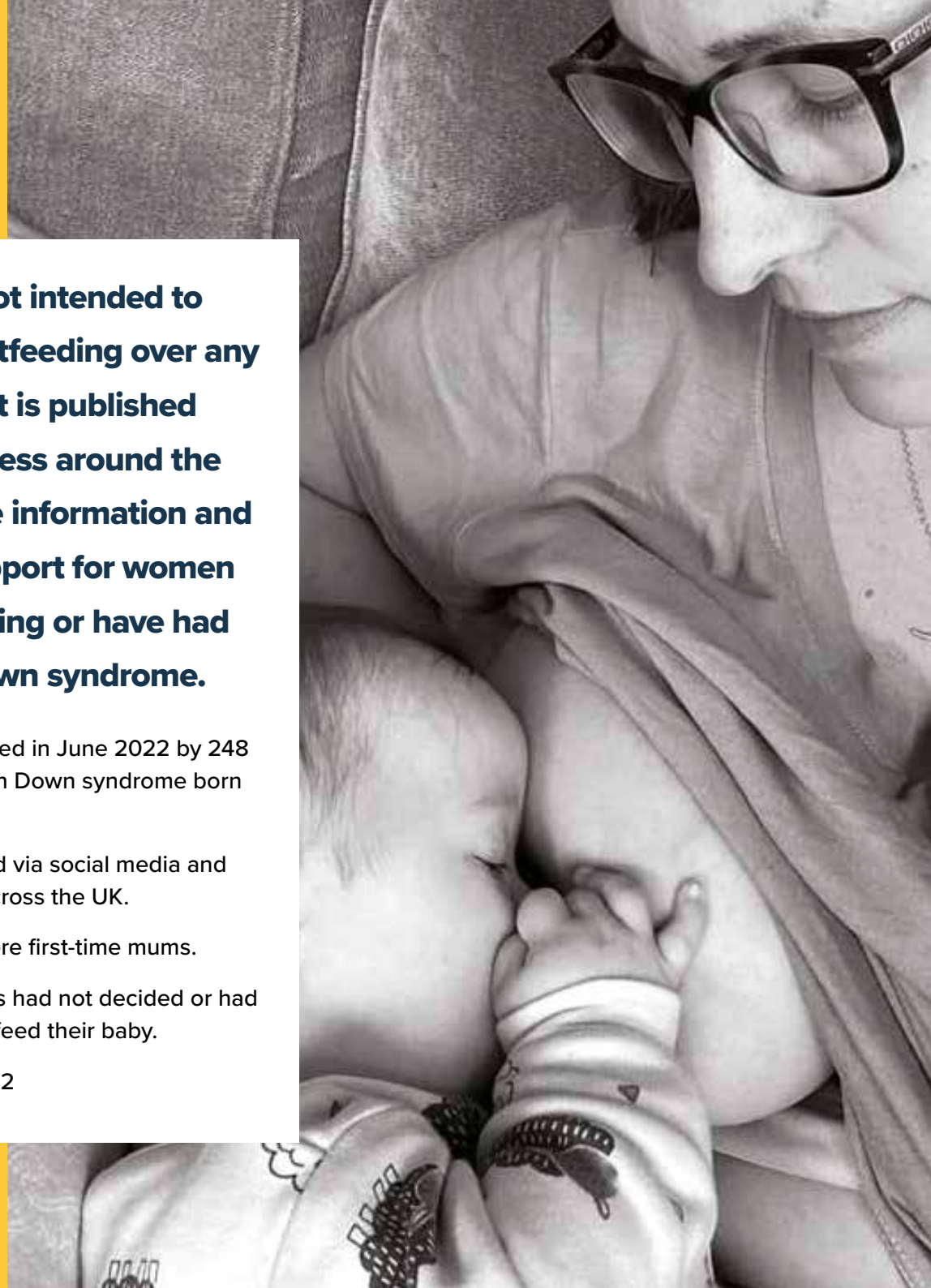
A survey was conducted in June 2022 by 248 mothers of a baby with Down syndrome born in the UK since 2017.

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

**37%** of the women were first-time mums.

**9%** of the respondents had not decided or had not planned to breastfeed their baby.

Published August 2022



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# 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 approximately 1,500 families of a little one with Down syndrome under the age of 4, 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.

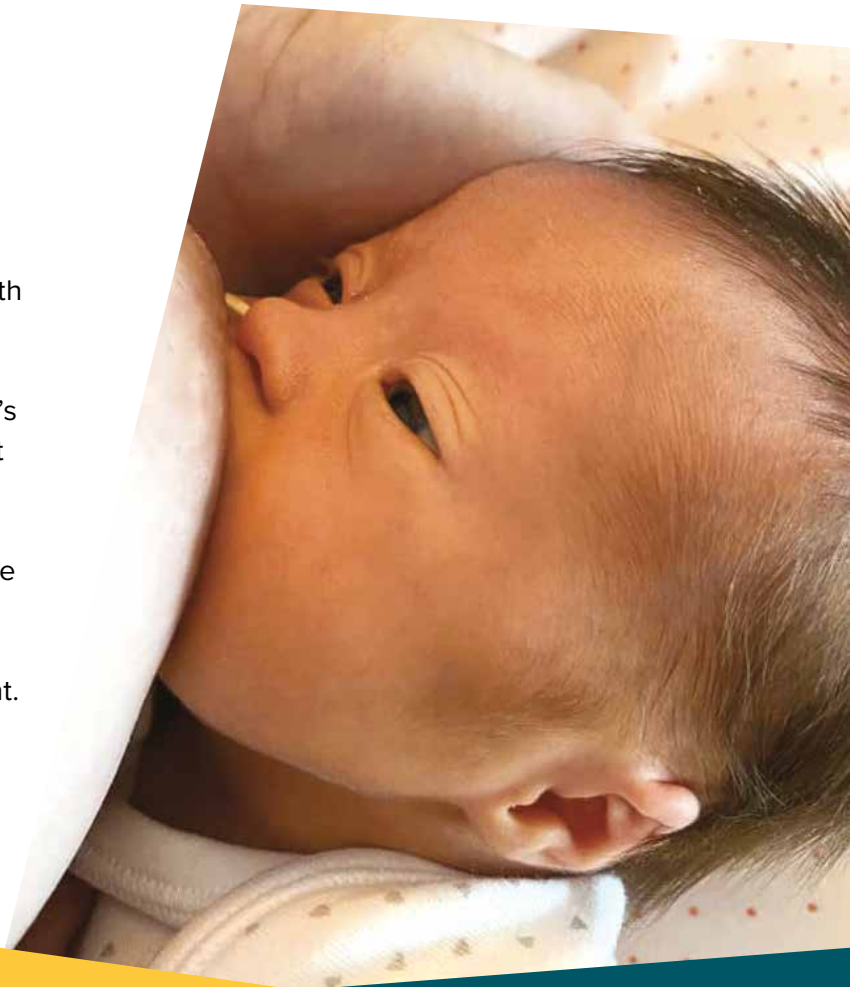
Around 800 babies with Down syndrome are born in the UK each year. We know from previous research ([Sharing the news: The maternity of experience of having a baby with Down syndrome](#)), that for many new parents, there is all too often a negative outlook and attitude around baby having Down syndrome.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

# 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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**I found feeding my child traumatic. It was all about weight gain and ensuring the exact amount of fluid had been taken in a bottle. Eventually (and due to a number of other factors) this led to a complete feeding refusal at 8 months.**



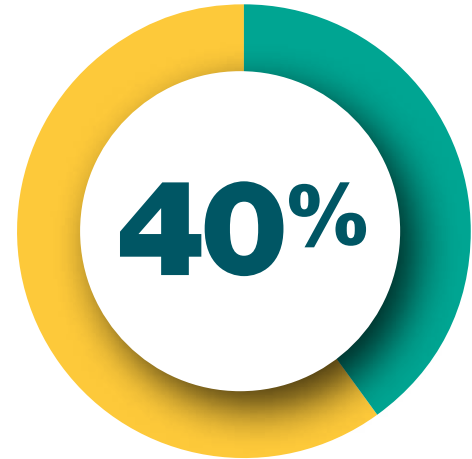
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**I successfully breastfed my two previous babies but was unable to breastfeed my baby with Down syndrome. I exclusively pumped for 3 months but eventually gave up due to exhaustion, lack of support and encouragement.**



## Key findings

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



**40%** of women were advised by a healthcare professional that they may not be able to breastfeed their infant purely because of baby having Down syndrome.

Whilst this is an improvement from our 2021 report, down from 46%, it is still a significant number and indicates parents are being misled.



“

*Consultant said we might be in SCBU for months to establish feeding before being allowed to go home. It was in fact days before we could go home with breastfeeding better established than with my first son.*

“

*I was told that babies with Down syndrome rarely have the tone to latch properly. I wasn't offered any support with trying to breastfeed.*

“

*Nurses were surprised that my daughter was able to breastfeed.*

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## Key findings

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

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**36% advised they did not receive the support they needed around breastfeeding from their midwifery team.**



**36%**





“

*I was pushed towards bottle feeding my baby with Down syndrome because no one had any alternative experience to typically developing babies in cradle or rugby feeding positions. It was only through PADS online support that I knew babies with Down syndrome had a reasonable chance of learning to direct feed later. I had found from online searches that the dancer position might help but because no one had seen it used I couldn't get support from the one enthusiastic nurse. The first time I gave my baby with Down syndrome a bottle I sobbed. I felt I'd failed her and failed to give her the best chance as I was aware there were benefits not only to breastmilk but to direct feeding, especially in speech muscles later down the line.*

“

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

“

*Felt like a failure, conflicting advice. Not much was known about breastfeeding a child with Down syndrome.*

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## Key findings

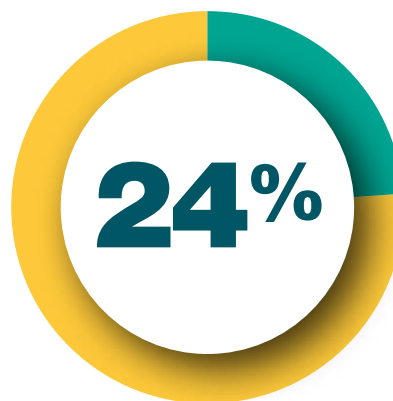
**A significant number of babies breastfed soon after birth.**



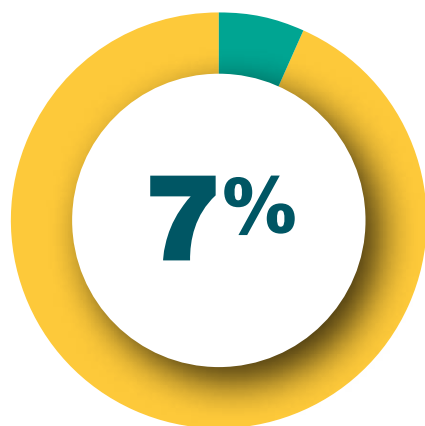
# Despite low expectations from medical professionals, a lack of information and support:



**20%** of babies breastfed immediately.



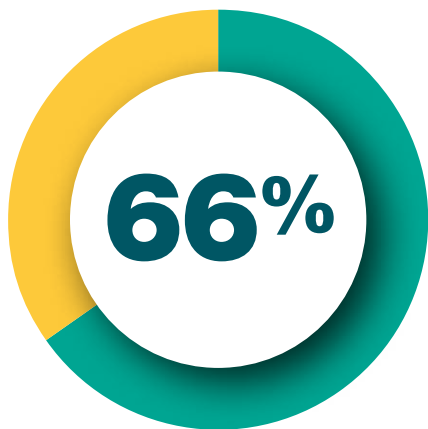
A further **24%** of mothers breastfed within the first week.



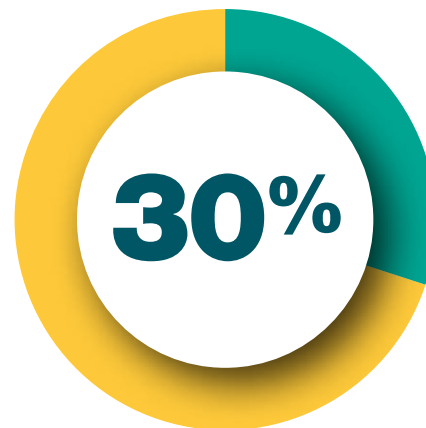
**7%** achieved breastfeeding after baby was more than 12 weeks old.

## Key findings

# Lack of support and knowledge resulting in negative feelings and impact on mental health



**66%** of mothers have felt upset/ disappointed around their breastfeeding experience.



**30%** have experienced a negative impact on their mental health due to their breastfeeding experience.



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*I felt like a failure, feeling like I'm not good enough because I wasn't able to breastfeed.*

“

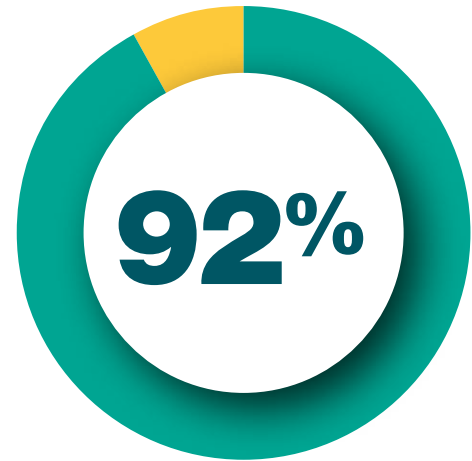
*I feel responsible for her not gaining weight quick enough which makes me feel very guilty and like a terrible mother.*

“

*I found feeding my child traumatic. It was all about weight gain and ensuring the exact amount of fluid had been taken in a bottle. Eventually (and due to a number of other factors) this led to a complete feeding refusal at 8 months.*

## Key findings

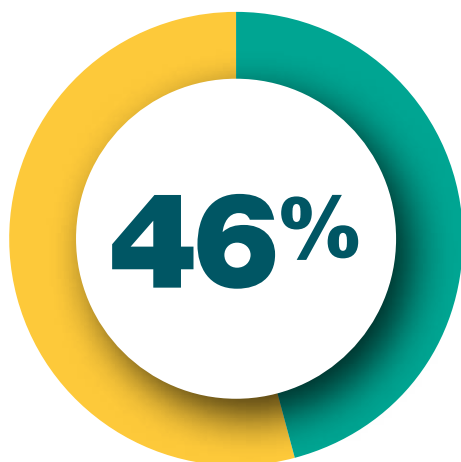
**A high percentage of mothers are expressing breastmilk for their baby with Down syndrome.**



**92%** of women have reported having to express breastmilk for their baby with Down syndrome.

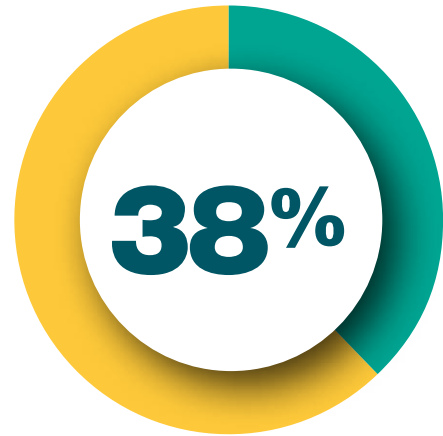


## High prevalence of NG feeding tube and lack of support

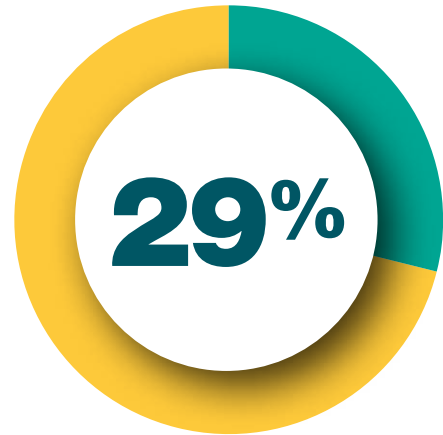


**46%** of babies were given an NG tube post birth.

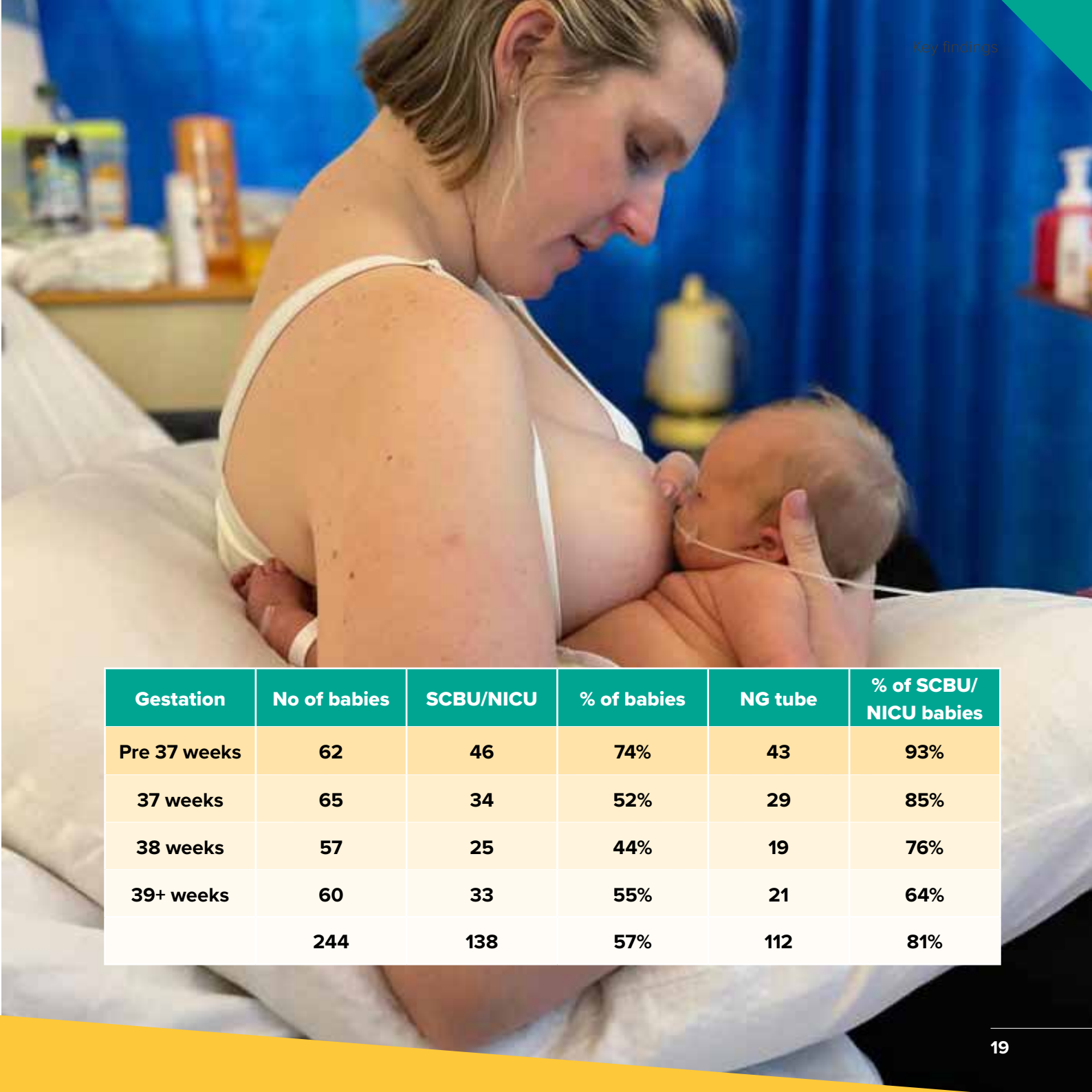
**Many babies with Down Syndrome are coming home from hospitals with an nasogastric feeding tube and some parents are not felt supported in a plan to stop its use.**



**38%** of babies that required an NG tube came home from hospital with one.



**29%** of parents did not feel informed and involved around when the NG tube would be removed.



Gestation	No of babies	SCBU/NICU	% of babies	NG tube	% of SCBU/ NICU babies
Pre 37 weeks	62	46	74%	43	93%
37 weeks	65	34	52%	29	85%
38 weeks	57	25	44%	19	76%
39+ weeks	60	33	55%	21	64%
	<b>244</b>	<b>138</b>	<b>57%</b>	<b>112</b>	<b>81%</b>



*We had no choice at all, we were not informed why, or when it would be removed and were 'scared' by nurses into thinking we'd have to take our daughter home with it and were even told the tube could come out and we'd have to reinsert it ourselves, which was terrifying when we'd seen professionals putting it in nervously whilst she screamed and especially after we were told if it's put in wrong it could rupture her insides.*

*No one ever reassured us. It was always worst-case scenarios or no information at all.*



*It was inserted and kept in with no real effort to take him off it we found. It was very much assumed he needed it but he never had evidence of aspiration. He did have an uncoordinated swallow but they also said he tired too quickly for breastfeeding and didn't really help me to establish that. Initially, the NG tube was supposedly inserted because he had jaundice and needed to be under the lights but it didn't come out until he was 6 months old and we had to fight for it.*



*Tube was inserted against my wishes. I had specifically stated that I did not want an NG tube inserted without prior discussion with me yet when I went down to NICU he had one. Feeds were on a regimented time and volume (expressed breastmilk/colostrum) and I had to beg that these volumes be reduced so he could learn hunger and I could see his cues. This wasn't listened to for a number of days.*

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*There were no formal NHS tube weaning programmes or consideration of how to wean when a tube is placed. In our experience, no one seemed to worry about getting rid of it at all.*

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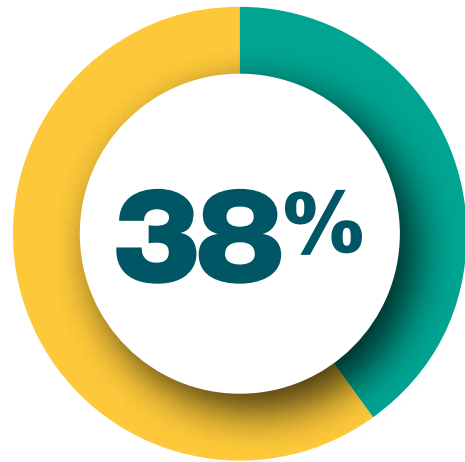
*Felt like it was done as a matter of course rather than supporting me to breastfeed. She struggled because of the tube as it was in her mouth so she couldn't latch well. Conflicting messages were given by medical staff.*



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# Key findings

**Some babies with Down syndrome are experiencing eating aversions and problems when weaning and there could be a link between this and earlier NG tube usage.**



**38%** of babies with Down syndrome have faced an eating aversion or problem when starting solids.



**42%**

**42%** of babies who have experienced an eating aversion when weaning had previously used an NG tube.



**90%**

**90%** of babies with Down syndrome have been weaning using a traditional weaning method.



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





# Challenges and possible solutions

Whilst babies with Down syndrome can be more prone to hypotonia (low muscle tone), can 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 advising that it can take slightly longer to establish feeding should all be part of the support offered to families. Many women advise the use of nipple shields as a game changer. *Both the physiological and societal challenges should be considered when supporting families.*

For babies who require support via enteral tube feeding, specific support around expressing breastmilk should be offered along with an ongoing plan to establish direct breastfeeding including putting baby regularly to the breast. Families also require involvement around the decision and plan around removal of the tube.



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## Good Practice



*I was encouraged to try breast feeding and expressing my milk to go into the NG Tube.*



*They said she might find it a bit more difficult however they wanted to support me to try as I wanted to breastfeed*



*We were told it would be more challenging but actually they wouldn't let us leave NICU until she could breastfeed in case the tube came out and it was needed.*



*I asked for advice from a breastfeeding support worker at the hospital (Kingston Upon Thames) and she was lovely. She advised on harvesting colostrum and how to feed baby when it arrived. She left me her number should I need it post birth and offered support.*

# Prevalence of NG tube feeding

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.

With 46% of babies with Down syndrome having an NG tube inserted at some point whilst new born, we are concerned this is too often becoming a default position.

For those babies being tube fed, mothers report feeling unsupported, afraid and unsure how to move forward. Of these babies, over one third - 38% left the maternity unit to go home with an NG tube, most comment that baby is discharged with no care pathway or advice given about the plan for removing the tube.

Almost two thirds of parents of a baby who had an NG tube (65%), advised they were offered no support from a speech and language therapist around development of oral motor skills.

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.

## Impact of NG tube feeding on weaning and development of speech

We are concerned at the impact long term NG tube feeding has on baby weaning and on their speech development. In this study, we can see that 42% of the babies with an eating aversion had had an NG tube. One wonders at the impact on a child's speech development with long term use of NG tube feeding and/or struggling with solids and this is a topic DSUK is looking to undertake research into.

## Psychological impact on mother

With two thirds of women expressing upset or disappointment around their breast feeding experience, it is no surprise that 30% report a negative impact on their mental health.

The perinatal period is an extremely vulnerable time for all women and for those coming to terms with baby having a genetic condition, and who may therefore be feeling very alone, potentially disconnected from her baby and struggling to bond, the inability to breastfeed can have a significant impact on her mental health.

## Women's needs not being met

90% of women who completed the survey had intended to breastfeed, yet 22% did not achieve this aim.

## 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.

## Parents relying on third sector for support

**Poorest support from Health Visitors and community midwifery teams. Greatest support provided by PADS, local support providers and maternity team.**





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## Support not helpful

Health Visitors	<b>41%</b>
Community Team	<b>35%</b>
Midwifery Team	<b>28%</b>



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## Support helpful

PADS	<b>61%</b>
Local support	<b>50%</b>
Midwifery Team	<b>50%</b>

# 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 to 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 mental well being of many women.

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.

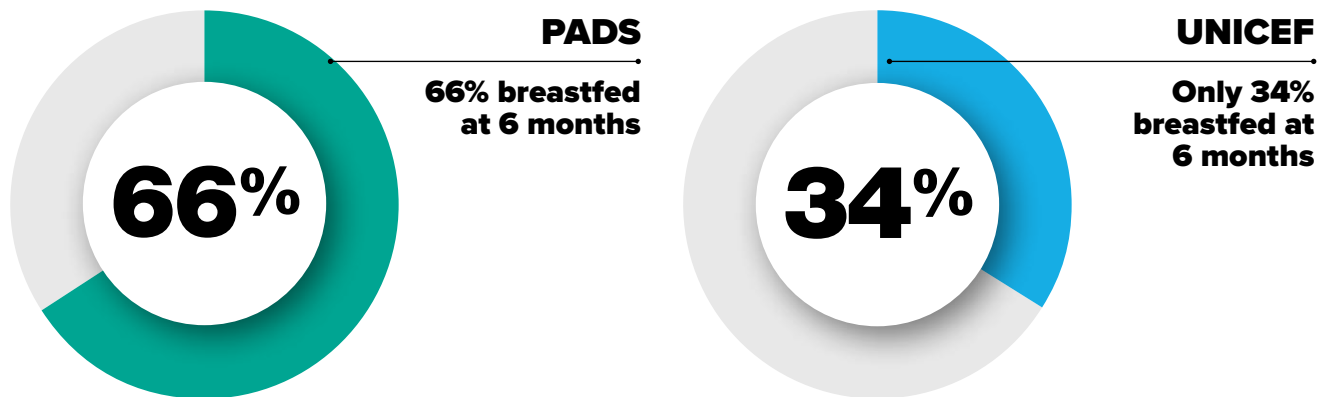


77% PADS



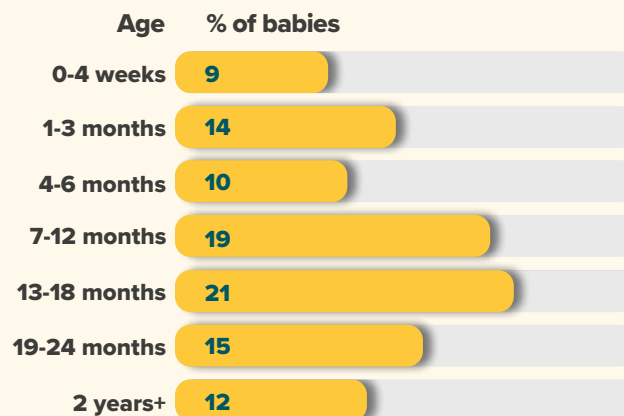
81% UNICEF





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.
- ▶ Awareness training around breastfeeding of babies with Down syndrome.
- ▶ 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 breast feeding 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.

PADS published Breastfeeding a baby with Down syndrome [The maternity experience in 2021](#)

In 2022 PADS appointed Sarah Ojar as our 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 public and private sector. PADS has developed a training module specifically around breastfeeding babies with Down syndrome, for further information email [sarah.ojar@downsyndromeuk.co.uk](mailto:sarah.ojar@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 F.A.B, as well as an NHS infant feeding support worker.

## 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/)
- ▶ [breastfeeding.asn.au/resources/breastfeeding-your-baby-down-syndrome](http://breastfeeding.asn.au/resources/breastfeeding-your-baby-down-syndrome)
- ▶ [ndsccenter.org/wp-content/uploads/CDSS\\_breastfeeding\\_brochure.pdf](http://ndsccenter.org/wp-content/uploads/CDSS_breastfeeding_brochure.pdf)
- ▶ [lli.org/breastfeeding-info/special-needs/](http://lli.org/breastfeeding-info/special-needs/)

### Other useful websites

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





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**I spent the first 6 months expressing for each NG tube feed, until we finally reached our goal to exclusive breastfeeding our little Esther.**





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**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](http://www.positiveaboutdownsyndrome.co.uk)  
[info@positiveaboutdownsyndrome.co.uk](mailto:info@positiveaboutdownsyndrome.co.uk)

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