

A GUIDE TO
Breastfeeding a baby
with Down syndrome

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Introduction

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There are many outdated perceptions and myths around Down syndrome, one being that ‘babies with Down syndrome can’t breastfeed’.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 this guide to give you and your baby the best chance possible to breastfeed successfully. We want to not only educate and empower new and expectant mums, but also the medical professionals who are supporting within the community.

We hope this guide will provide you with all the information you need to enjoy a successful breastfeeding relationship with your baby.



Benefits to breastfeeding a baby with Down syndrome

We hear a lot about all the great things that breastmilk provides babies. Here are some of the ways it can specifically help your baby with Down syndrome. Breastfeeding can be a baby receiving human milk directly from the breast, or via a bottle or tube. Most of the following benefits will apply to all types of breastfeeding but some may be specific to feeding directly from the breast.



1. Immune system support

Babies with Down syndrome may be more at risk of infections, such as pneumonia, due to an underdeveloped immune system. Breastmilk will give their immune system a boost as it contains a variety of substances including antibodies, immune factors, enzymes and white blood cells. These will help protect your baby whilst breastfeeding and in some cases long after your baby has weaned also.

2. Speech

The act of breastfeeding and the repetitive sucking motion and coordination help to strengthen the tongue and other muscles in the mouth which are required for speech. This is of benefit as babies and children with Down syndrome are often delayed in speech and one of the reasons for that is low oral tone.

3. Gut health

Breastfeeding plays an important role in developing your baby's gut health and 'seeding' the infant microbiome with beneficial bacteria. People with Down syndrome are prone to gastrointestinal problems such as constipation, diarrhoea, reflux, obesity, and growth failure. There are studies currently being undertaken, that are looking at the microbiome of babies with Down syndrome specifically and long term gut health and immune system benefits.

4. Brain development

Breastfeeding supports healthy brain development in your baby. There are also many studies looking at the link between breastmilk and cognitive development of the brain. There is extensive research linking physical touch, which inevitably comes with breastfeeding, to a newborn's physical and emotional development.

Immune support - Pisacane, A., Toscano, E., Pirri, I., et al (2003), Down syndrome and breastfeeding. *Acta Paediar* 92(12),1479–1481.

Speech - Dee DL, Li R, Lee LC, Grummer-Strawn LM. Associations between breastfeeding practices and young children's language and motor skill development. *Pediatrics*. 2007 Feb;119 Suppl 1:S92-8. **Gut health** www.ncbi.nlm.nih.gov/pmc/articles/PMC6400986/. **Brain development** www.ncbi.nlm.nih.gov/pmc/articles/PMC565196/



Physical differences breastfeeding a baby with Down syndrome

As babies with Down syndrome are each unique, these may or may not apply to you and your baby. They are however common challenges that have been identified by the parents we support.

1. Low muscle tone (hypotonia)

Babies with Down syndrome can have low muscle tone and, particularly if it's around the jaw, they may have trouble latching effectively to the breast and staying there for a full feed.

2. Delayed suck/swallow coordination

Some babies with Down syndrome, especially if born early, may have difficulty coordinating their sucking, swallowing and breathing. This generally improves with time and practice.

3. Sleepiness

Babies with Down syndrome can be quite sleepy in the first few weeks. This can be more so if your baby has a heart condition or is born early.

4. Clinical conditions and surgery

If your baby needs to have surgery in the first few weeks/months of life then this can have an impact on feeding.

However, from our experience, it is still possible to breastfeed a baby with any/all of these challenges.

Preparing antenatally



If you have received a confirmed diagnosis of Down syndrome during your pregnancy, or even a high chance screening result there are some steps you can take antenatally in preparation for breastfeeding your baby.

It is worthwhile to do some investigation into your local breastfeeding support. If it is an in person group you can pop along for a visit and introduce yourself. You can also make sure you have the helpline numbers for the National Breastfeeding Helpline on hand in case you need them when baby arrives. Watching videos of what good position and attachment looks like can also be beneficial too.

- ▶ **Please join Positive about Down syndrome's closed Facebook group for breastfeeding mothers**

[DSUK PADS Breastfeeding Peer Support](#)



Colostrum Harvesting

This involves hand expressing colostrum in the last few weeks of pregnancy. It is advocated in many NHS trusts so have a chat with your midwife before starting. It is typically advised to begin this after 36 weeks of pregnancy.

Having some expressed colostrum when your baby arrives can provide a form of supplementation if you wish to avoid formula. Colostrum is packed full of vital immunological properties and helps to colonise the baby's gut with healthy bacteria that helps to protect against allergy and disease. It contains the perfect balance of proteins, fats and micronutrients that a newborn baby needs. It can also act as a laxative and so helps with the passing of the all important first meconium stools.

Having some expressed colostrum can help if your baby is having any difficulty with feeding or maintaining their blood sugar levels in the first few days.

It is recommended that hand expression is used at this point rather than a breast pump. Colostrum will be produced in smaller quantities and can be harder to collect using a pump. Your midwife will provide you with small syringes to collect the drops of colostrum.

Try hand expressing for a few minutes 2-4 times a day.





How to hand express

- ▶ Always wash your hands before you begin and sit in a comfortable position.
- ▶ A warm compress or after a bath/shower can help the flow of colostrum.
- ▶ Begin with a gentle massage of the breast stroking from the back of the breast forward towards the nipple. This will encourage a let-down reflex.
- ▶ Cup your breast in a 'C' shape with your thumb above the nipple and your first few fingers below.
- ▶ Use your thumb and fingers to feel a few centimetres back.
- ▶ Press back towards your chest then compress (press fingers together) and release. Repeat this process until you have a rhythm and you will start to gather drops of colostrum.

It can take a few days before you are able to gather up drops of colostrum. If you find it a struggle you can try adjusting your fingers position and placement around your nipple. It is recommended that you try each breast twice in each expressing session.

The colour/texture of your colostrum can vary from thick and yellow to more clear and watery.

You can use the same syringe a few times per day and store in the fridge in between. At the end of the day pop the syringe into a ziplock bag and store in the freezer. Remember to label with the date!

Frozen colostrum can be kept for 6 months in the freezer and once taken out and thawed it should be stored in the fridge and used within 24 hours.

How to breastfeed your baby

Position and attachment

Breastfeeding should be comfortable. How you sit or lie can make a big difference to how well breastfeeding goes and how comfortable it is for you to feed your baby.

Positioning relates to how you hold your baby during feeding.

Attachment refers to how your baby receives the breast and is also known as latching.

The two go hand in hand and better positioning can lead to a more effective attachment.

There are different positions that you can breastfeed in and when breastfeeding your baby with Down syndrome a comfortable supportive position will help you both.

Some of the more supportive breastfeeding positions are cross cradle, rugby, and an upright 'koala' position.

Depending on whether your baby has low muscle tone, and the extent of the low tone, may mean there are some positions that work better for you both than others.

Cross cradle

- ▶ Sit comfortably with your back well supported.
- ▶ Keep your feet flat on the floor or raised up on a small stool or similar to encourage a flat lap.
- ▶ Your baby's body should be in a straight line facing you, especially facing the nipple and breast.
- ▶ Support their neck, shoulders and back ensuring that your baby has the freedom to tilt their head back easily so they can feed. At this point, if your baby has low muscle tone around the neck area and is struggling to support their own head and neck you can give additional support using your fingers or hand on the underside of the cheek/head so that you take some of the weight of the head but do not restrict the neck movement.
- ▶ Bring your baby towards your breast and nipple making sure that your baby's chin touches the breast tissue first.
- ▶ As your baby opens their mouth wide bring them closer to the nipple in a swift movement so they can latch to the breast.
- ▶ Once baby is latched comfortably, you can position a feeding cushion or pillow underneath for extra support.



Rugby position

This position is another really supportive one. It's also great for twins or if you have had a caesarean section.

- ▶ Sit comfortably in a chair with a cushion or pillow along your side.
- ▶ Position your baby on the side you wish to feed from, under your arm, their hips aligned to your hips.
- ▶ Ensure your baby's nose is level with your nipple.
- ▶ Gently support your baby's neck with the palm of your hand and leading with the chin attach your baby to the nipple.



Koala position

- ▶ Sit upright with your back supported.
- ▶ Place your baby vertically and straddling your thigh, facing you.
- ▶ Use your knee to support your baby's bottom.
- ▶ Use your hand from the side baby is sitting on to support the back of your baby's head and use the hand on the opposite side to support and shape the breast if needed to help the baby get a deep latch. This hand can also be used to facilitate the 'Dancer hold' which is a technique for babies with low tone around the mouth and jaw.



Laid back position

This position may not be supportive enough for some babies with Down syndrome but it's worth a try and can be adapted slightly.

It is also often called 'biological nursing'.

- ▶ Lie back semi reclined to whatever feels comfortable for you. Some will lie back just slightly and others almost all the way back. Prop yourself up with a cushion or pillows so you are supported across your neck and shoulders and not lying completely flat.
- ▶ When you feel comfortable, place your baby tummy to tummy or they can be lying to one side (this may give them a bit more support).
- ▶ Make sure you are upright enough to see into their eyes.
- ▶ Whilst giving as much support as your baby needs, gently guide your baby to the nipple and allow them to latch on.

Dancer hold

This is a technique to help babies with low tone around the mouth and jaw to obtain a more effective latch. It can be used in any of the breastfeeding positions but some positions will be easier than others practically. The Koala position works well as it allows access to the jaw at the right angle.

- ▶ Support your breast by placing your hand underneath it.
- ▶ Make a 'U' shape with your fingers.
- ▶ Use your thumb and forefinger to gently hold your baby's chin as they are attached to the breast.
- ▶ Keep your three remaining fingers cupping your breast tissue.
- ▶ Gently press the cheeks of your baby and bring them closer to your breast.
- ▶ Keep your baby in that position until they are finished feeding.
- ▶ Make sure that you aren't restricting any movement and are just giving additional support to the latch already formed.



Tips for a good latch

Obtaining and maintaining a good latch once feeding is really crucial and these tips apply in whatever position you prefer to feed in.

- ▶ When latching, your baby needs to tip their head back and reach forward with their lower jaw to enable their mouth to open wide. As they tip their head back their jaw drops and mouth opens wide so they can anchor their chin and lower lip against your breast. If their chin is tucked in they will struggle to open their mouth wide.
- ▶ Your baby needs a big mouthful of breast tissue rather than latching onto the end of the nipple. Latching onto the end of the nipple can cause compression of the milk ducts which can be painful and hinder the milk flow.
- ▶ Some people find shaping the breast can allow their baby to latch onto more breast tissue. If you do this, make sure the lower jaw fingers are out of the way and do not obstruct the latch.
- ▶ Let your breast rest at its natural level and bring baby to the breast. Avoid the temptation of taking your breast to your baby's mouth.
- ▶ It's easier for your baby to latch onto a soft breast so if your breasts are feeling engorged or hard, you can hand express until the breast tissue is softer.

How to tell if baby is feeding well

You can look out for the following signs as to how well a feed is going.

- ▶ Your baby has a large mouthful of breast tissue.
- ▶ Your baby's chin is touching your breast.
- ▶ Your baby's mouth is wide open.
- ▶ If you can see the darker skin of the areola around your nipple, you should see more skin above your baby's top lip than below their bottom lip.
- ▶ Feed is pain free (after the initial first few sucks).
- ▶ No change in shape or colour of nipple when feed is finished.
- ▶ You can hear and see baby swallowing milk throughout the feed.
- ▶ Your baby has rounded cheeks throughout the feed.
- ▶ Your baby is producing regular wet and dirty nappies.

Signs of effective feeding

- ▶ Baby has a large mouthful of breast tissue
- ▶ Chin is touching the breast
- ▶ Wide open mouth
- ▶ Round cheeks
- ▶ You can hear and see baby swallowing

Watch video





Nipple shields

A nipple shield is a thin, silicone teat that can be placed over a mother's nipple to help a baby who is struggling to learn to breastfeed and latch. Holes at the tip of the teat allow milk to flow through into your baby's mouth. A nipple shield can be used temporarily whilst establishing breastfeeding and enable the breastfeeding relationship to continue. It works by providing a firm stimulus at the roof of your baby's mouth where the soft and hard palate meet. This can help your baby to suckle more effectively.

A nipple shield can also help in circumstances where your baby has a tongue thrust or needs extra stimulus to prompt suckling.

They can also work well if you have flatter or inverted nipples or particularly soft breast tissue.

Expressing

At some point in your breastfeeding journey you might want or need to use some expressed breastmilk. This could be because your baby is still learning to latch to the breast or it could be something you are choosing to do.

Expressing milk can be done by hand or using a breast pump and means squeezing milk out of your breast so you can store it and feed it to your baby later.

Some of the reasons people express their milk are:

- ▶ you have to be away from your baby, perhaps baby is in special care or later on you might have to go back to work.
- ▶ your breasts feel uncomfortably full.
- ▶ your baby is not yet latching well but you wish to give breastmilk.
- ▶ someone else such as a partner is going to help you feed your baby.
- ▶ you want to boost your milk supply.

How to express breastmilk

How often you express your milk and how much you express will depend on why you are expressing. If you are expressing so a partner can give one feed, you will be expressing much less frequently than someone who is expressing a full time milk supply for a baby that is struggling to latch. If you are expressing full time to provide milk for your baby whilst they learn to latch it is recommended that you express at least 8 times a day including at least once overnight.

- ▶ When you sit down to express make sure you are feeling comfortable. It can take a while to get the milk flowing and you can help this by using a warm compress or having a warm shower, having your baby close by, having recently done some skin to skin, or even having a photo of your baby or an item of their clothing close by.
- ▶ If expressing by hand then the process is the same as it is for harvesting colostrum.
- ▶ If using a breast pump there are two types of pump. Manual (hand operated) and electric. You can also get either single pumps where

you will do one breast at a time or a double which enables you to do both. You can also get some pumps that are hands free or use an adapted nursing bra to make a pump hands free.

- ▶ Manual pumps tend to cost less than an electric pump but may not be as fast or convenient. You can also loan or rent electric pumps which are hospital grade pumps so is something to consider if you are having to express a lot.
- ▶ When using an electric pump they usually have a stimulation setting which acts as a massage to get the milk flowing before switching to a pump setting. Always start with a low setting and increase as you go along if you need to.
- ▶ When using a breast pump ensure that the funnel size you use (the part that goes over the breast/nipple) is correct for you. If it causes any bruising or other discomfort to the nipple then try a different size.
- ▶ Make sure that the pump and containers are clean and sterilised.



Storing breastmilk

Expressed milk can be stored out of the fridge for 6 hours.

It can be stored in the fridge for 6-8 days at 4°C or lower.

It can be stored in the freezer for 6 months at -18°C or lower.

Remember to label your milk with the date.

Defrosting breastmilk

It's best to take out breastmilk in advance so it has time to defrost slowly. If you do need to use it straight away you can defrost it more quickly by placing it in a jug of warm water or running it under a tap.

Once defrosted swirl it around to mix any milk that has separated.

Do not refreeze your milk once defrosted.

Once your baby has drunk from a bottle of your breastmilk, it should be used within an hour and then thrown away.

Giving expressed (or formula) milk

There is often an assumption that this method of feeding will be done by bottle. It can be, however there are alternative methods of giving milk.

- ▶ Paced bottle feeding
- ▶ Cup feeding
- ▶ Finger feeding
- ▶ Supplementary nursing system

Paced bottle feeding

If you do wish to bottle feed, this is a method that allows the baby to be more in control of the feeding pace. It slows down the flow of milk into the nipple and therefore the mouth allowing the baby to drink more slowly and take more breaks.

Each feed should take 10-20 minutes depending on volume) as this allows time for the stomach and brain to communicate and along with physical breaks in the feeding, prevents over feeding. It is recommended to use the slowest flow nipple that your baby will tolerate.

Paced bottle feeding requires closely watching your baby and their feeding cues which will indicate if they need more or less milk.

How to do paced bottle feeding

- ▶ Position your baby in an upright position supporting head and neck.
- ▶ Position bottle horizontally.
- ▶ Gently touch the nipple to the baby's lower lip until baby opens their mouth.
- ▶ Advance the bottle's nipple until it reaches the top of the tongue and keeping the bottle flat allows baby to have between 5 and 10 sucks of the bottle.
- ▶ Slightly pull the nipple back keeping it touching the lower lip.
- ▶ Allow baby to pull the nipple back in much as they would during a breastfeed.
- ▶ Alternatively, is after their sucks, tilt the bottle away slightly until baby sucks again.

Cup feeding

Cup feeding is a feeding method that can be used from birth. You can use any clean open cup with a smooth surface.

How to cup feed

- ▶ Hold your baby close to you in an upright position and use your hand or arm to support the baby's head, neck and body.
- ▶ Hold the rim of the cup to your baby's lower lip.
- ▶ Tilt the cup slightly so that the milk just touches your baby's lips.
- ▶ Wait for your baby to use their tongue to lap or sip the milk from the cup. It's important that you do not pour the milk into your baby's mouth.
- ▶ Go slowly and allow your baby to rest in between swallowing but keep the cup touching their lips.
- ▶ Keep the cup tilted enough that the milk stays at the rim of the cup.



Finger feeding

An advantage of finger feeding is that you can use small amounts of milk and you can use your finger to stimulate the suckle reflex if your baby is unable to latch and breastfeed. This method of feeding can help train your baby to feed from the breast and is closer to breastfeeding than using a bottle.



How to finger feed

- ▶ Wash and dry hands thoroughly before and use a sterile tube each time.
- ▶ Hold your baby in an upright position supporting their shoulder and neck.
- ▶ Place the tip of the tube near the tip of your finger and secure with tape.
- ▶ Place the other end of the tube into the milk container.
- ▶ Gently stroke downwards over the baby's lip which will encourage their mouth to open.
- ▶ Once your baby's mouth is open and their tongue is down, place the pad of your finger to the roof of their mouth, ensuring the baby does not gag (remove your finger to the front of the mouth if this happens).
- ▶ Allow your baby to suck your finger and the milk will gradually move along the tube into their mouth.
- ▶ Allow your baby to pause often to control the pace of the feed.



Donor milk

There may be circumstances where you can consider using donor breastmilk for your baby as an alternative to formula. Donor breastmilk is typically used for premature or sick babies. If donor milk is something you wish to consider using you can speak to your hospital/health care provider as the milk they provide is safe and rigorously screened. It is often decided on a case by case basis if a baby is eligible to use their donor milk bank.

Growth charts

When your baby is born, they will be issued with a PCHR (personal child health record) more commonly known as ‘the red book’. Inside those books are standard growth charts used by medical professionals and health visitors to monitor your baby’s weight and height. Your baby with Down syndrome, should be given a green insert which includes a Down syndrome specific chart.

This can have an impact on your breastfeeding journey if the wrong chart is used as it’s very common for babies with Down syndrome to put weight on at a slower rate than a typical baby might. If the wrong chart is used then it can lead to unnecessary worry and feeding interventions. If you do not get given a green insert for your PCHR please ask your healthcare professional or contact us for a copy.

Further Resources

- ▶ [Down Syndrome UK - breastfeeding](#)
- ▶ [PADS The Lived Experience: Breastfeeding a baby with Down syndrome](#)
- ▶ **National Breastfeeding Helpline**
0300 100 0212
- ▶ **The Breastfeeding Network**
www.breastfeedingnetwork.org.uk
- ▶ **La Leche League**
www.laleche.org.uk
- ▶ **Association Breastfeeding Mothers**
www.abm.me.uk
- ▶ **NHS breastfeeding**
www.nhs.uk/start4life/baby/feeding-your-baby/breastfeeding/

PADS is here to help and support you as best we can



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PADS is here to help and support you as best we can. We have wonderful closed Facebook groups, for [expectant mums](#) and [new parents](#). We also have a group for those who are [breastfeeding](#).

Our groups are open and honest, and completely non-judgemental; providing a safe space for you to connect with others, ask any questions, share any concerns or worries, show off your gorgeous babies and celebrate milestones!

We know that it can feel lonely at times, but we are here for you, along with several hundred others who all understand where you are coming from and importantly can share experiences around where you are going!



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