Feeding Your Baby Breastmilk

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lifelong support for those born unable to swallow

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Contents

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Introduction: Feeding Your Baby Breastmilk

This information has been produced for TOFS by Kate Yardley, Registered Midwife. The content has been reviewed by Miss Clare Skerritt Consultant Paediatric Surgeon. It has been endorsed by the National Neonatal Surgical Interest Group (NNSIG) and the Neonatal Nurses Association (NNA). Special thanks to the chair of the NNSIG, Fiona Metcalfe and Education lead, Rhiannon Jones for their scrutiny and input to the document.

Providing breastmilk to your OA/TOF baby has many important benefits, for both them and you. While their initial diagnosis of being born unable to swallow does pose a unique challenge for you both, with the correct support and knowledge, they will still be able to have your expressed breastmilk and progress onto breastfeeding.

How you choose to feed your baby and what works best for you both is a unique choice for **all** mothers and can take many forms including:

- Exclusive breastfeeding
- Expressing breastmilk (EBM) to bottle/tube/enterally feed
- Combination feeding of breastfeeding and giving EBM via a bottle
- Combination feeding breastmilk and formula
- Formula feeding
- Feeding donated breastmilk

The length of time that you choose to give your baby breastmilk depends upon what works best for you both. The World Health Organisation and UNICEF (WHO, 2023) recommends that feeding breastmilk continues until your child is 2 years old and beyond, but it is important to know that any period of providing breastmilk or breastfeeding that you achieve with your baby is a wonderful gift. No matter how long or via what means you choose to feed your baby, TOFS are here to support you.

Feeding breastmilk provides many benefits for both you and your baby. These include:

Benefits for your baby:

- Increased brain development
- Increased immunity
- Increased bonding between mother and baby
- Reduced risk of developing allergies
- Reduced risk of sudden infant death syndrome (SIDS)
- Reduced risk of obesity
- Reduced risk of developing asthma
- Reduced risk of several cancers

Benefits for you:

- Reduced risk of breast and cervical cancers
- Reduced risk of obesity
- Reduced risk of osteoporosis
- Reduced rates of postnatal depression

(NHS, 2023)

Research has found that many of these benefits are particularly important for babies born with congenital disorders such as OA/TOF:

- **Increased immunity** – babies born with OA/TOF are at an increased risk of infections. This is due to the requirement for them to have surgery, the presence of a tracheo-oesophageal fistula and associated tracheomalacia, and the need for them to remain in hospital for a period of time after they are born. Breastmilk contains antibodies which increases a baby's ability to fight infections, protect from inflammation and to build a mature immune system (Camacho-Morales et al., 2021).

- **Improved wound healing** – breastmilk contains healing properties and optimal nutrients and has been shown to decrease wound healing times and complications in infants requiring surgery (Mohamed, 2019).

- **Reduction in pain** – as well as surgery, your baby may be required to have further minor procedures, such as blood tests, vaccinations and heel prick tests, during their time in hospital, all of which may be painful. Research has found that, outside of giving medicines, breastfeeding is the most effective method of pain relief for babies (Koukou et al., 2022).

- **Bonding** – bonding for you and your baby may feel impacted due to their requirement to be transferred to a neonatal intensive care unit (NICU) and undergo surgery. Expressing breastmilk, having skin-to-skin contact once your baby can be held and breastfeeding once your baby can feed, will help you to feel close to your baby and to begin to build a loving, nurturing, intimate attachment. This will also enable you to begin to learn your baby's cues as well as lower stress and promote feelings of calm for both of you; benefits that will also be important for your baby's recovery (Brennan, 2023).

Feeding breastmilk to short gap OA/TOF and long gap OA babies

When your baby is first born, they will be unable to feed until they have had their corrective surgery and recovered sufficiently. During this time, they will be given fluids and nutrition intravenously, containing all of the nutrients they require to grow and heal. The length of time until your baby has their corrective surgery will depend upon the type of OA/TOF that they are born with.

Most babies are born with "short gap" OA/TOF, and undergo a primary repair within the first few days of life. All being well, these babies will then be able to begin having small feeds of their mother's EBM in the days that follow, via a tube known as a TAT (trans anastomotic tube). This is a tube which is inserted via their nose into their stomach and not only helps with feeding, but also prevents the healing tissues of the oesophagus from closing over. They will then progress to feeding orally, which can involve transitioning to breast or bottle feeding, once ready.

Approximately 10% of OA/TOF babies are born with "long gap" OA. These babies have a gap between the upper and lower ends of the oesophagus which is too long to be repaired straight away and therefore corrective surgery must be delayed for weeks to months. During this time, they will be able to receive their mother's EBM, and the many benefits that doing so has to offer, via a gastrostomy feeding tube inserted into their stomach until they have grown enough to have their corrective surgery. It may also be possible to offer "sham feeds", a process which involves a baby feeding orally, via a breast or bottle, and then suctioning out the swallowed milk from the upper oesophageal pouch (The Royal Children's Melbourne Hospital, 2020). This method allows babies to develop their suck and swallow reflexes and learn how to feed orally, readying them for breast or bottle feeding once they have had their corrective surgery (Golonka & Hayashi, 2008).

More information about sham feeding can be obtained from your baby's surgeons, NICU team and speech and language therapists (SALT), who will be able to advise if this is an option for your baby. Progressing onto breastfeeding can be particularly challenging for long gap OA babies and mothers, but it does not mean that it is impossible. If this is something that you would like to do, with the correct support and motivation, this may still be achievable.

Expressing Breastmilk

Colostrum
It will be important for you to begin expressing breastmilk as soon as you can once your baby is born, preferably within in the first 2 to 6 hours following birth, in order to establish a supply of milk and to collect your first milk, colostrum, also known as 'liquid gold'. Colostrum is highly concentrated with nutrients and antibodies which are extremely beneficial for your baby and it will be important for you to begin collecting and storing this so that you have some ready to give to them when they are able to feed. Tiny amounts of "buccal colostrum" (colostrum placed into your baby's cheek) may be able to be given even before they have had their corrective surgery, in agreement with your surgeon, so it is important to begin collecting your milk as soon as possible.

If you are pregnant, you can also begin collecting and storing colostrum before your baby is born, after 36 weeks gestation. You should discuss this with your midwife.

Hand Expression
Hand expressing is the most effective way to begin collecting colostrum and you can use a sterile syringe or cup to do so. Don't be worried if you only produce small amounts to begin with, babies' stomachs are very small (around the size of a marble) and it is not a sign that you will be unable to feed them sufficiently or progress to breastfeeding. Your midwife and NICU nurses will be able to help you with the hand expression technique and storage of your breastmilk. Alternatively, this useful guide and video has been produced by the NHS:

https://www.nhs.uk/start-for-life/baby/feeding-your-baby/breastfeeding/expressing-your-breast-milk/expressing-breast-milk-by-hand/.

It can also be helpful to get your partner to assist you with collecting milk initially, by operating the syringes or holding the cups as it can be fiddly (and may also help to make them feel useful). Alternatively, your midwife or the NICU staff will be able to help.

Breast pumps
After a couple of days your colostrum will change to more mature milk and the volume you express will begin to increase. You may notice that your breasts are fuller and warmer and that your milk changes slightly in colour. At this point you can begin using a breast pump to express your milk. If you do not have a breast pump, an electronic hospital-grade breast pump can be borrowed from your NICU so do speak to the staff about this and how to use it when you are there.

How often should I express?
It is important that you express breastmilk at least 8 times in a 24 hour period. You are trying to imitate a baby's breastfeeding pattern and they will feed roughly every 3 hours. It is also very important that you express at night, as this is when your body produces the most milk-producing hormone, prolactin. It is advised that you express at least once during the night, preferably between 2am and 4am (NHS, 2019). Although it can be tiring, this routine will help you to be ready to breastfeed your baby should you wish to, in a way that responds to their needs, as babies are hardwired to feed throughout the night.

How long should I express for?
You should express for as long as your milk is flowing well rather than being guided by a set amount of time. Every woman is different, but for most, expressing takes around 15-20 minutes. Once your milk is not flowing as freely and begins to slow to drips is when it is time to stop.

How much should I feed my baby?
The NICU team will be on hand to guide you with how much milk your baby should have whilst you are there. In the early days, this will be dependent upon a number of factors such as your baby's weight, how well they are tolerating feeds and if they are also receiving other fluids. This will be reviewed regularly and, if required, a dietitian may also be involved to ensure that your baby is getting everything that they need. When you are discharged, if you are still feeding your baby expressed milk, you will get to know how much is right for them by reading their cues and observing if they are content after feeds, having wet and dirty nappies and gaining weight. Your GP, health visitor, midwife or NICU team will be monitoring this closely and will be on hand if you have any queries.

Supporting your milk production
Having a baby that is unwell and admitted to NICU can be a very stressful time and this can affect the amount of milk that you produce. When we are stressed the level of oxytocin, the hormone which releases milk from the breast, is inhibited. It is therefore important to find ways to relax while expressing in order to encourage the "milk ejection reflex". Making sure you are comfortable, listening to music, having low lighting and ensuring privacy are some ideas for helping you to feel calm when expressing. Being next to your baby and looking at them or touching them in the early days can also help. If you are away from them or using a pumping room located in the hospital, looking at pictures or videos of them and having one of your baby's bonding squares or blankets nearby or to smell can also be beneficial. When your baby is well enough, having **skin-to-skin contact** with them will also help to support your milk production.

Skin-to-skin contact, also known as "kangaroo care", involves holding your baby naked against your bare chest under a blanket and can be enjoyed whether you intend to progress to breastfeeding or not. The practice can benefit expressing mothers as it initiates strong instinctive behaviours, stimulating your body to release hormones including oxytocin, which in turn encourages the production and release of breastmilk. Skin-to-skin contact can also benefit you and your baby by:

- Regulating your babies breathing, heart rate and temperature
- Reduces your baby's levels of stress hormones, particularly after painful procedures
- Builds your baby's immunity by enabling colonisation of your baby's skin with your friendly bacteria
- Helps you to develop a close and loving bond with your baby
- Calms your baby when they are upset and helps them to build a strong attachment to you

(UNICEF UK, 2024)

It is also important to ensure you are eating and drinking enough to support your breastmilk production. Breastfeeding requires an extra 500-700 calories per day to fuel the milk making process (La Leche League, 2024). Having snacks and a water bottle to hand whilst you are in NICU, enquiring about hospital meals and enlisting the help of family and friends to make sure you are eating and drinking well are top tips.

What to do if expressing is painful

Expressing breastmilk should not be painful. Pain can interfere with your goal to provide breastmilk for your baby so it is important to address it as soon as possible. Slight discomfort, especially as you first begin to express breastmilk, can be normal, as the collagen fibres in your nipples begin to stretch and you first start to experience "let downs", which can feel tingly or like pins and needles (Children's Minesota, 2024). Anything more than slight discomfort should be discussed with your midwife, NICU team or health visitor straight away.

Non-nutritive sucking and breastmilk

Research has proven that non-nutritive sucking (NNS), which involves giving your baby something in their mouth to suck such as a dummy or your finger, encourages the development of sucking and swallowing reflexes which is especially important for OA/TOF babies (Sherwood Forest Hospitals, 2020). It is important to discuss NNS with your baby's SALT team and surgeons before commencing, to ensure that it is safe to do so. Your baby in time may then be able to progress to dummy/finger dips (dipping a dummy/your finger into your EBM for them to taste), which can help them to begin to learn the taste of your breastmilk ready for when they start to feed orally. Research has shown that doing so can reduce the length of time it takes to establish breastfeeding and can also decrease levels of stress hormones and pain (Orovou, 2022). It may also be possible to offer an "emptied" breast (a breast that has been recently fully expressed) to your baby as a method of providing NNS, but this will need to be discussed with your SALT and surgical teams beforehand to establish how appropriate this will be for your baby.

Other benefits of EBM

EBM can also be used in providing mouth care, or buccal care, to your baby, in agreement with your NICU and SALT teams. This involves putting tiny drops of your EBM into your baby's mouth and onto their lips and it can be beneficial to begin doing so within the first few hours of life. Breastmilk's unique antimicrobial and moisturising properties can help to keep your baby's mouth and lips healthy and improve comfort, especially as your baby may be receiving many oral procedures such as suctioning and intubation. (The Northern Neonatal Network, 2017). Using your milk can also support the development of your baby's taste and smell senses until they are able to feed (Aoyama, 2010). Spending time doing these small tasks for your baby can help you to feel closer to them and reassured that you are making an important contribution to their care even though you may not be able to hold or breastfeed them just yet.

Transitioning to feeding at the breast

Once your NICU, surgical and SALT teams are happy that your baby has recovered sufficiently from their corrective surgery and is tolerating tube feeds of your breastmilk well, if you would like to progress to feeding at the breast this is something that you may now be able to begin working towards. It is important to note that transitioning to breastfeeding for OA/TOF parents and babies is not a "one-size fits all approach" and can be challenging. Every OA/TOF baby's prognosis differs and the support that they will require to be able to breastfeed, and length of time that it will take for them to get there, will be unique to them. At this point in your baby's feeding journey, it could be helpful to talk to the hospital breastfeeding support team to get some guidance about you and your baby's individualised pathway to breastfeeding and what steps this might include. They will also be able to talk to you about the correct positioning and attachment technique or alternatively this helpful guide and video has been produced by the NHS:

https://www.nhs.uk/conditions/baby/breastfeeding-and-bottle-feeding/breastfeeding/positioning-and-attachment/#:~:text=When%20your%20baby%27s%20mouth%20is,mouth%20should%20be%20wide%20open.

Skin-to-skin contact and transitioning to breastfeeding

Skin-to-skin contact is a great place to begin the transition to feeding at the breast as it not only possesses a number of important benefits as discussed above, but also stimulates your baby's digestion and interest in feeding, encouraging pre-feeding behaviours such as rooting, nuzzling, smelling and licking.

You should try to have as much skin-to-skin contact with your baby as possible if you are wishing to progress to feeding at the breast, so that your breasts become a familiar environment to them. This familiarisation process is important and can take some time – it can require more than one session of skin-to-skin contact for your baby to want to attach to your breast and begin to try to feed. It is important not to rush this process and to remain patient and confident that you and your baby will be able to breastfeed, even if they don't get it straight away. Remember – your baby has never done this before and even if you do have experience of breastfeeding an older sibling, every baby's feeding journey is very different so it can take some practice for you both.

Feeding cues

When initiating breastfeeding, it is important that your baby is ready to feed and is hungry, otherwise they will make little effort to latch and suckle when held to the breast (and instead will probably just curl up and go to sleep on you!). This can be tricky as it is likely that your baby is continuing to be tube fed regularly (usually every 3 hours) whilst breastfeeding is being initiated. You will know if your baby is hungry by reading their feeding cues, which you will learn as you both spend more time together, and you should attempt to get your baby to latch if they show these even if they are not due a feed according to their schedule.

These signs may include:

- Stirring
- Mouth wide open
- Sucking their fingers
- Fists in their mouths
- Crying (a late sign of hunger)

(Just One Norfolk, 2024)

If your baby is showing little interest in attempting to latch or suckle whilst having skin to skin, and is not showing any feeding cues, it may be that they are not hungry or that they are very tired from practising feeding at the breast as well as recovering from their procedures. **TIP** – when your baby's next tube feed is due, before it is given, gently wake them, strip off their clothes, talk to them and perform their daily cares (changing nappy etc) to rouse them. This will help them to be awake enough and ready to breastfeed, instead of remaining warm, sleepy and uninterested. You can then attempt to breastfeed them. You could also discuss slightly lengthening the amount of time between your baby's tube feeds with your NICU team so that they are a little hungrier when they are put to the breast.

Tube feeds whilst establishing breastfeeding

Early on, your NICU and SALT teams may suggest that your baby then has their tube feed of your EBM whilst they are having skin-to-skin contact and attempting to latch to your breast, so that they begin to associate the feeling of filling their tummy with breastfeeding. In this case, it will be important for you to express beforehand to "empty" your breast so that if your baby does manage to latch successfully, they don't become overwhelmed by having too much milk. This could lead to a negative experience for them which could delay successful breastfeeding. It should however be noted that there is no such thing as a completely "empty breast", your baby will continue to get small amounts and little tastes of milk when latched so you should just try to express as much as possible.

Signs your baby is feeding effectively

As you and your baby continue to practice breastfeeding together, your team will continually assess how effective this is. **Emphasis will be placed on the quality of a feed rather than the quantity of a feed**, as it will take time for your baby's oral skills and strength to gradually develop to a point where they can exclusively breastfeed (Thompson et al., 2019). If you are both progressing well, your team will begin to reduce the amount that your baby receives via their tube and you can begin to reduce the amount that you express before each feed until your baby is exclusively breastfeeding from you. It can take a little time to strike the right balance here so it will be important for you and the team to continually assess the signs that your baby is feeding effectively at the breast and to remain patient, as, unlike bottles, there is no way of gauging exactly how much they have taken during each feed. Signs your baby is breastfeeding effectively include:

- **Your baby is having wet and dirty nappies** – roughly 6-8 heavy wet nappies every 24 hours when your baby is small is usually expected and is a great sign that they are

hydrated. Any less than this may be an indication that your baby isn't getting enough milk and could be dehydrated.

- **Your baby is calm and content during and after feeds** – this is a sign that your baby is satisfied that they are getting enough milk and that their tummy is nice and full after they've fed. If your baby seems agitated, frustrated or upset each time they feed it may be because they are not managing to get enough milk.

- **The length of time that your baby feeds for** – although there is no "right" amount of time and every baby will feed for different durations, your baby may only be able to manage short amounts in the beginning, perhaps just 1 or 2 minutes, as it can be very tiring for them while they are small and can take some practice to coordinate their breathing and new-found swallowing ability, particularly if they also have associated tracheomalacia. Each NICU will have a different policy to guide them, but if your baby can only manage a few minutes to start with, a **top-up feed** via their tube may be suggested. **TIP** – take a note of the time you begin feeding during the early days so that you can accurately calculate how long your baby has fed for instead of trying to guess. This will enable your NICU team to accurately calculate the amount of top-up feed required, if any.

- **Feeding does not hurt** – this is a sign that your baby has a good latch to your nipple and is therefore feeding effectively. If you have nipple pain, speak to your midwife, breastfeeding support team or health visitor as soon as possible so that they can help you with the correct positioning and attachment techniques and prevent any nipple trauma. Pain can interfere with your goal of breastfeeding your baby so it is important to address it as soon as possible.

- **Your breasts feel "emptier" or softer after each feed** – this is an indication that your baby is effectively removing milk from your breast. However, if your breasts don't feel emptied, and are instead hard, painful, swollen after feeds or become engorged, it may be a sign that your baby isn't managing to remove enough milk. It is important to speak to your midwife or breastfeeding support team if you do experience any of these symptoms in order to prevent it worsening and leading to mastitis. More information about this can also be found at:

  https://www.nhs.uk/conditions/baby/breastfeeding-and-bottle-feeding/breastfeeding-problems/breast-pain/#:~:text=Breast%20engorgement%20is%20when%2C%20for,need%20feeding%20little%20and%20often

- **Your baby is gaining weight** – this is a sign that your baby is receiving enough milk and nutrients they need to grow. If your baby loses weight this *could* be a sign that they are not getting enough milk when they feed and you may be referred to a dietitian. However, they would not be expected to put on weight quickly as they will be using a lot of calories to recover from their procedures and it should also be noted that it is normal for newborn babies to lose a little weight in the first few days after birth, as they adapt to life outside the womb and to feeding orally. Try not to be disheartened

if your baby's weight gain is slow, it is normal for babies' weight to fluctuate as they grow your NICU team or health visitor will be monitoring this regularly.

- **What you can see and hear when your baby feeds** – when a baby is feeding effectively, you should be able to see that their cheeks are round and that they are periodically swallowing, and you should also be able to hear them suckling and swallowing quietly. It can be normal for OA/TOF babies to make some noises when feeding, especially if they also have associated tracheomalacia and/or a TAT in situ (as this can take up a lot of space in their oesophagus), so it will be important to establish if what you can hear is a cause for concern or not with the help of your surgical, NICU and SALT teams.

If you have concerns about any of the above, talk to your midwife, NICU, SALT or breastfeeding support team as soon as possible. It may be that a few simple adjustments that they can suggest might make a lot of difference.

Potential issues when breastfeeding your OA/TOF baby: Things to watch out for!
If your baby's feeding and swallowing sounds change or you notice them becoming worse, and are accompanied by your baby displaying any of the following symptoms, it may be a sign that there is an issue such as a stricture or dysmotility, or a difficulty co-ordinating swallowing. In any of these cases you should contact your baby's surgical or NICU teams as soon as possible:

- Swallowing which is very noisy, "raspy" or "wet"
- Swallowing which is very slow
- Coughing when feeding
- Baby visibly struggling or stressed – eyes wide, fingers splayed, back arching, appears in pain
- Disengaging from the breast
- Crying
- Laboured, noisy breathing/gasping
- Change in heartrate/oxygen saturations if on a monitor
- Loss of tone
- Colour changes to face, lips, nose or finger tips

A stricture, also known as an "anastomostic stricture", is a narrowing of the oesophagus at the point where it was joined (anastomosis) as it heals and are a common feature of OA/TOF following repair. If your baby experiences any of the above symptoms, along with slower feeding, not finishing feeds, taking longer than normal to feed or not finishing feeds when they normally would, it may be an indication that milk is struggling to get past the stricture and is "pooling" behind it.

- **Mild stricture** - your baby may experience some of the above symptoms for a few seconds and then find that it eases with a short break from feeding and being held upright, allowing the milk to move past the stricture. This may happen more at the start of a breastfeed, especially if you have a fast "let-down reflex", which could overwhelm your baby with milk. This may then ease as the reflex subsides and the

flow of milk begins to slow, allowing your baby to cope with the volume that they need to swallow. They may then be content to carry on with the feed without further issues.

- ✓ You should let your NICU team know about these symptoms or, if at home, contact your surgical team and describe what has happened as best as you can and they will be able to advise you further. They may suggest that your baby is admitted for a procedure called an **oesophageal dilatation**.

- **Severe stricture** - if your baby struggles throughout the whole of a feed, experiencing symptoms after very few suckles or chokes and brings milk back up, it may mean that little or no milk is able to move past the stricture which will have now become very tight and therefore requires urgent medical attention.
  - ✓ **Stop** the feed and do not give your baby anymore in case they choke
  - ✓ Tell your NICU/surgical team straight away or attend A&E if you are at home and it is safe to do so
  - ✓ If your baby goes blue or stops breathing, seek emergency help immediately

If your baby develops a stricture, it does not mean that you have to stop breastfeeding them in the long run. You may however have to temporarily express breastmilk to maintain your breastmilk supply and prevent engorgement or mastitis whilst your baby's stricture is addressed.

Note - these symptoms can also be exacerbated if your baby has a TAT/feeding tube in situ as this will be taking up a significant amount of space in your baby's oesophagus. The tube will however offer a safe, temporary, alternative means of feeding your baby until their stricture has been addressed. **TIP** – it may be useful to learn how to safely feed your baby via their TAT if they are going to be discharged with it in situ, so that you can feed them using it should the need arise.

Dysmotility in OA/TOF babies is a result of poor nerve supply to the oesophagus below the repair site, and thus peristalsis, the wave-like motion of the oesophagus muscles tightening and relaxing when we swallow, is usually absent in the lower oesophagus below the repair (Loma Linda University Health, 2024). This means that food and fluids do not pass easily. For babies with dysmotility who breastfeed, swallowing can be slow and a feed can take much longer than normally expected. You may notice that your baby's swallowing becomes progressively slower, that the duration of feeds takes an increasingly longer amount of time and that they begin to display some or all of the symptoms outlined above over time. Your SALT team will be able to guide you if you have any concerns about dysmotility. Ask your surgeon or NICU team for a referral if you would like a SALT assessment. If you have been discharged from hospital and do not have a SALT team, an online self-referral service may be available in your area, or your midwife, health visitor, or GP may be able to refer you.

There are several ways in which you can help your baby to cope with their dysmotility when breastfeeding, including:

- Offering shorter and more frequent feeds (if your baby is agreeable), so that they don't become too tired when feeding

- Ensuring your baby is in an optimal upright breastfeeding position, with their head and neck slightly extended
- Ensuring that your breasts are not too full before commencing a feed as a large volume of milk, particularly if you have a fast let down reflex, may be even more difficult for your baby to swallow
- Take your time, do not rush a feed and try to ensure there aren't too many distractions for you and your baby so that you can both concentrate on feeding effectively. Being somewhere quiet so that you can hear their swallowing sounds can also be helpful

Tracheomalacia and breastfeeding

Tracheomalacia affects almost all babies diagnosed with OA/TOF to some degree (Baxter et al., 2018), and is defined as the collapse of the airway when breathing due to the malformation of the rings of cartilage in the trachea, at the point of the tracheo-oesophageal fistula (TOF) (Boston Children's Hospital, 2024).

Babies with tracheomalacia who breastfeed may struggle to coordinate their "suck, swallow, breathe" activity when feeding, causing them to work harder when they are at the breast which can be very tiring, especially in the early days. You may notice that your baby takes frequent pauses when feeding in order to breathe, has noisy breathing (also known as stridor) as they feed, and comes off the breast in order to catch their breath (Johnson, 2024). **If your baby has tracheomalacia, you can still breastfeed,** but you should assess the signs that your baby is feeding effectively (as outlined above), and talk to your surgical, NICU, SALT teams or GP if you are concerned, so that your baby can be assessed and managed appropriately.

There are several ways in which you can also help your baby to cope with their tracheomalacia symptoms when breastfeeding, including:

- Offering shorter and more frequent feeds (if your baby is agreeable), so that they don't become too tired when feeding
- Ensuring your baby is in an optimal breastfeeding position, with their head and neck slightly extended, and that their nostrils are not covered by your breast tissue
- Ensuring that your breasts are not too full before commencing a feed as a large volume of milk, particularly if you have a fast let down reflex, may overwhelm your baby further
- Take your time, do not rush a feed and try to ensure there aren't too many distractions for you and your baby so that you can both concentrate on feeding effectively. Being somewhere quiet so that you can hear the presence and/or degree of any stridor can also be helpful

Your baby's NICU team or health visitor will closely monitor your baby's weight gain to ascertain if their tracheomalacia symptoms when feeding are affecting their growth. If any of your baby's symptoms or their growth are of concern, your surgical team should be informed so that they can assess your baby and involve other healthcare professionals as needed.

It should also be noted that the symptoms of tracheomalacia when feeding may become worse if your baby has a cold. In this case it will be important to closely assess the signs that your baby is feeding effectively, as outlined above, and seek further advice if concerned.

Responsive feeding

Responsive feeding, also known as "feeding on demand" and "baby-led" feeding, is instinctively feeding your baby when they are hungry or when you want to instead of following timings or a schedule. When you begin establishing breastfeeding with your baby, it will be important to move away from feeding at set times, as will have been the case whilst they were tube fed in the early days, and begin reading their feeding cues to know when they are hungry. Responsive feeding not only allows your baby to feed little and often in order to fulfil their nutritional needs, but also supports a milk supply which is in-sync with your baby's appetite (UNICEF, 2016). It is important to note that you cannot overfeed or "spoil" your baby by breastfeeding them as often as they want to and that feeding responsively is a significant source of love, comfort and reassurance for you both (UNICEF, 2016).

Advice for partners

Your partner may have been involved in feeding EBM to your baby when they were tube fed in the beginning, and you might both now be wondering how they can remain as involved as you transition to breastfeeding. There are in fact lots of helpful ways in which your partner can support you and your baby with breastfeeding, including:

- Conducting your baby's daily cares, such as changing their nappy and bathing them, just before they breastfeed – this allows time for your partner to continue to build a bond with your baby and gives you a little time for yourself
- Ensure your privacy needs are met whilst breastfeeding – this is especially important whilst your baby is in hospital and can involve drawing curtains and blinds, putting up signs, keeping you both covered if that's what you'd prefer and ensuring you are not disturbed
- Provide you with emotional support – praise and encouragement can help you to feel more confident with breastfeeding and motivated to continue
- Providing practical help – making sure you are both comfortable and that you have a drink and snacks to keep you well nourished, being on hand to get you things you may need and entertaining your older children if you have them
- Seeing to administration - such as paternity/compassionate leave, organising hospital parking and hospital meals etc.
- Safeguarding yours and your baby's time together and ensuring you're not overwhelmed with visitors, especially in the early days

Gastro-oesophageal reflux disease (GORD) and feeding breastmilk/breastfeeding

Reflux during or following a feed is common in all babies, but GORD, a chronic form of reflux, is particularly prevalent in OA/TOF babies and adults. This is due to the nature of the OA repair.

Emma Sidebotham, MD FRCS in The TOF Book, says, "Repair of oesophageal atresia pulls the lower oesophagus upwards into the chest to a varying degree.

- This shortens the length of intra-abdominal oesophagus, opens the angle of His and can stretch the hiatus in the diaphragm. These changes combine to reduce the efficacy of the lower oesophageal sphincter and increase the tendency to reflux.
- The longer the gap at the time of the repair, the greater the risk of this happening.

The muscular wall of the normal oesophagus squeezes sequentially from top to bottom to push swallowed solids from the mouth to the stomach. This process is called peristalsis.

- When reflux occurs into a healthy oesophagus stomach contents are rapidly pushed back into the stomach by this peristaltic wave.
- Following repair of oesophageal atresia, the oesophagus below the anastomosis peristalses poorly. When stomach contents reflux up, they will clear much more slowly and cause more irritation."

GORD causes stomach acid to regurgitate into the oesophagus which can lead to inflammation and pain, sometimes described as "heartburn" in adults. Signs and symptoms observed in infants may include:

- Frequent "spit up", during or following a feed
- Frequent gagging, choking, coughing, burping and/or hiccupping
- Only taking small amounts of feed
- Crying and irritability
- Appearing in pain or discomfort
- Being uncomfortable when lying flat and sleeping poorly when doing so
- Arching back when feeding
- Wheezing and chest infections
- Reluctance/refusal to feed

(East Sussex Healthcare, 2013)

Some of the symptoms of GORD are similar to those of a stricture or dysmotility in OA/TOF babies, so it is important to discuss any concerns you have with your baby's surgeon or NICU team in order to gain a clear understanding of the cause and receive appropriate treatment. If your baby does have GORD, they can still have your **EBM or breastfeed**, but they may require medication to help to treat it (Martin & Crabbe, 2016).

If your baby has GORD, as well as medication, the following tips may help to alleviate some of the symptoms when feeding breastmilk/breastfeeding:

- Using positions when feeding that keep your baby's head higher than their tummy, such as having them diagonally across your chest in a cradle hold, to prevent stomach contents from travelling back out of the stomach into the oesophagus. Avoid positions where they are lying flat, such as having them lie next to you in your bed whilst feeding.
- Giving shorter, more frequent feeds (if your baby is agreeable), to reduce the amount of milk that they have in their tummy at one time
- Keeping your baby upright and avoiding too much movement for 15-20 minutes following a feed to allow milk to digest. This could be achieved by leaning back with your baby on your chest for a cuddle or whilst having skin-to-skin contact
- "Burping" your baby at the end of each feed
- Feeding your baby in the bath when they are more calm is also a great way to enjoy time having skin-to-skin contact
- Non-nutritive sucking can help to encourage the stomach to empty
- Gently rolling your baby from side to side when changing them, rather than lifting their legs up higher than their stomach, can also reduce stomach contents from moving back up into the oesophagus

(La Leche League International, 2024).

Deciding to move on from feeding breastmilk or breastfeeding

Deciding to move on from feeding your baby your breastmilk or breastfeeding them can be a really difficult and emotive decision. For whatever reason it may be that you decide to move on, know that you **did** do it, no matter how you did it or how long you did it for and that this is a wonderful gift to give your baby which you should be proud of.

If you do decide to stop, you and your baby can still continue to enjoy the many benefits of having skin-to-skin contact and feeding responsively.

It may be helpful to talk to your midwife, NICU team or health visitor about stopping to get support with this, especially if you have established a supply of breastmilk already as it is very important that you do so gradually to avoid any complications such as mastitis. If you would still like your baby to receive some of the benefits of breastmilk, you could also talk to your NICU team about the possibility of them receiving donor milk.

Additional resources and support

Where to get support

Breastfeeding or feeding breastmilk to **any** baby can be challenging, but particularly when your baby is born unable to swallow. Anxiety and worry around whether you are doing the best thing for your baby and you is expected, especially in the early days, and it can be normal to experience feelings of pressure, helplessness, grief, loss, jealousy, anger and frustration surrounding the reality of your new feeding journey. Many sources of support are available to help you during this time including:

- Your midwifery team
- Your NICU team
- Your health visitor
- Becoming a TOFS member – gives you the opportunity to talk to other parents as well as giving you access to a range of literature, the 'CHEW' newsletter and the members only areas on our website
- TOFS Local Contacts (TLCs) - we operate a network of volunteers who are mainly parents of OA/TOF children, who are available to offer support. You can book a TLC call here
- TOFS UK Facebook group – a closed group for parents/carers of OA/TOF children to openly discuss experiences and ask questions of one another
- The Association of Breastfeeding Mothers (ABM) - a group of trained volunteers who support breastfeeding mothers and their families. You can call them on 08444 122 949
- The Breastfeeding Network (BfN) - a helpline, online chat service, and information and support for families who are breastfeeding. You can call them on 0300 100 0212
- La Leche League GB (LLLGB) - a helpline service, and trained breastfeeding counsellors who can provide local and face-to-face support. You can call them on 0845 120 2918
- Breastfeeding the Brave – Supporting breastfed medically complex infants and children
- Your GP

We hope that this guide provides information which will support you and your baby on your feeding breastmilk journey, whatever that may look like. Remember, however you feed your little person, you are amazing.

Additional Resources

About OA, TOF and VACTERL - this leaflet is a useful introduction to OA and TOF, explains why surgery is necessary for these conditions and outlines the likely course of events after surgery. It also includes basic information about VACTERL association, of which OA and TOF may be features.
https://tofs.org.uk/oa-tof-information/resources/about-oa-tof-and-vacterl/

Introducing solids, following repair for OA/TOF – when you and your baby are ready to begin your weaning journey, this leaflet provides information to help guide you through the processes and challenges you may face.
https://tofs.org.uk/oa-tof-information/resources/introducing-solids-following-repair-for-oa-tof/

About the author

Kate Yardley began her career in healthcare in 2014 as an Adult Nurse in the British Army. A passion for providing care to women and reproductive health saw her transfer her skills to midwifery and civilian life, completing a Post Graduate Diploma in Midwifery at the University of Hull in 2020. Since then she has worked as a Registered Midwife within Gloucester NHS Foundation Trust, providing all aspects of antenatal, intrapartum and postnatal care to women and babies at Gloucester Royal Hospital's Central Delivery Suite.

Kate has a little boy, Ted, with her partner Tom, a British Army Officer, and in March 2023 they welcomed their daughter, Primrose, who was born with undiagnosed OA/TOF. Primrose received her care at Bristol's St Michael's Hospital and Bristol Royal Hospital for Children. Primrose was born with short gap OA/TOF and had her corrective surgery when she was a day old. Unfortunately her surgery was unsuccessful and required an emergency repair when she was 1 week old resulting in a very persistent anastomostic stricture requiring multiple oesophageal dilatations.

During this time, Kate and Primrose managed to successfully breastfeed and continue to do so. However this was not a straightforward journey and was at times very challenging, despite one of Kate's main roles as a midwife being to provide breastfeeding support to women and babies and although she has the experience of breastfeeding her son for 16 months. This led Kate to contact TOFS and work with us to improve the support and information available to OA/TOF babies and families, surrounding feeding breastmilk and breastfeeding.

Kate plans to complete her MSc in Midwifery in September 2024 by furthering this work and undertaking a piece of research into the experiences of mothers who breastfeed OA/TOF babies.

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