

Breastfeeding your baby with a diagnosis of cleft lip (with or without palate involvement)

When a cleft is diagnosed, either at an antenatal scan or following birth, you may wonder if breastfeeding is possible for you. The answer is yes. Most babies with a cleft lip only can feed well at the breast. Babies with a cleft in the palate (gap in the roof of the mouth) will find it more challenging to exclusively skin-to-skin breast feed. They may need some of your expressed breast milk supplemented in a specialized bottle or feeding tube. The World Health Organization (WHO) recommends exclusive breastfeeding for the first six months of a baby's life. The Cleft Team understand that it is important for you to feel supported and listened to regarding your choice for feeding your baby.



Why is breast milk important?

- It offers the perfect balance of nutrients and is easier to digest than formula.
- It can help the digestive system mature.
- It contains antibodies that help fight infections.
- It helps to minimize your baby developing allergies.
- It can lower the risk of Sudden Infant Death Syndrome (SIDS).

Extra benefits for babies with cleft

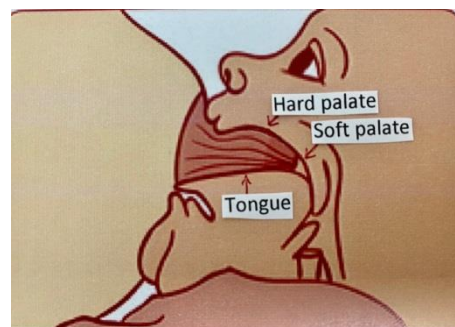
- Breastfeeding can protect against ear and chest infections.
- Breast milk may be less irritating if leaking through your baby's nose as it's a natural body fluid.
- Babies who are receiving breast milk do not have to fast for as long as formula fed infants prior to surgery.

How does a cleft affect breast feeding?

- Babies with a cleft lip only, and little or no involvement of the gum or palate, can usually breast feed well. Some may have difficulty making a lip seal around the breast, thus reducing suction and delivery of milk. Advice on positioning at the breast from your midwife or lactation consultant might be helpful.
- The majority of babies with palate involvement have good sucking action but it is not strong enough. The cleft makes it difficult for your baby to block off the roof of their mouth which limits the suction during feeding. They have to work very hard during feeding, similar to sucking through a straw with a hole in it. They may successfully get your fore milk but tire and fall asleep before your fat-containing hind milk is delivered. Weak suction and not fully emptying the breast will also lower your milk supply. If exclusive skin-to-skin breastfeeding is difficult with a cleft then you could consider combining it with expressing your milk. Expressed breast milk is an excellent choice for your baby for all the reasons detailed above, and can be offered in a specialized cleft bottle.

Breastfeeding challenges with a cleft: (depending on the cleft type)

- Trouble keeping a good seal on the breast
- Gagging & spluttering with milk let-down
- Milk leaking out of the nose
- May prefer to feed on the side without a cleft
- Tiring on feeding, long feeds and small weight gains
- Swallowing too much air
- Weak suction causing a low milk supply



There are ways to help you get around these challenges (please see following section). You will also be supported by your maternity hospital and cleft team.

What can I do to help my baby breastfeed/feed with breast milk?

- Keep an open mind regarding breastfeeding. Seek breastfeeding advice from your maternity team / lactation consultant / cleft team as soon as the diagnosis is made.
- If the diagnosis has been on a pregnancy scan discuss the possibility of expressing breast milk before your baby's birth with your maternity team. Milk expressed can be frozen and stored so that it's immediately available for your baby after birth.
- Hold your baby skin-to-skin to breast feed as soon as possible after birth.
- You may need to experiment with different holding positions at the breast.
- You may need to hand express some milk onto the nipple to get your baby sucking.
- Mothers may need to hand express milk into their baby's mouth to compensate for an absent suction and to stimulate the let-down reflex. You may also need to pump after feeds to empty the breast and stimulate milk production.
- Your midwife/lactation consultant will advise you on hand expressing/pump expressing.
- Expect to breastfeed +/- express every 2 to 3 hours (8 to 12 times in 24 hours) for adequate supply.
- Keep an open mind regarding breastfeeding. Any amount of breast milk is beneficial whether given by breast or bottle, before contemplating formula milk.
- Breast milk in the first few days is called colostrum and is very rich in antibodies and nutrients for your baby. If you are undecided about breastfeeding you might like to consider offering your baby some colostrum initially? Small amounts can be offered, with the guidance of your team, by oral syringe or in a specialized bottle.

How do I know my baby is getting enough milk?

- Remember: many mothers and babies experience some difficulties with breastfeeding, regardless of a cleft diagnosis. This is YOUR baby and YOUR choice; the cleft team will guide you on what's possible with your baby's cleft type.
- Offer frequent feeds i.e. 2 to 3 hourly during the day and night.
- Watch out for wet nappies at changing times.
- Look at the dirty nappies. The stool should change from greenish black to yellow soft & seedy by day 5 of life.
- Babies should not lose more than 10% from their birth weight in the 1st few days of life. They should be back to birth weight by 2 weeks of age and then gain steadily. Your baby's doctor or public health nurse can monitor weights locally after discharge from the maternity hospital.
- Your baby should be content between feeds but not over-sleepy.

How can I access further information on breastfeeding?

- Some of the health professionals that can offer advice are: Maternity hospital staff, midwives, lactation consultants, dieticians, speech & language therapists, public health nurses, cleft team coordinators and cleft nurse specialists.
- Enquire about breastfeeding support groups in your local area.
- Contact other parents of children with a cleft by accessing the website or Facebook page of the Cleft Lip and Palate Association of Ireland.



Useful websites:

www.mychild.ie HSE site with breastfeeding section and 'ask the expert' question options

www.coombe.ie/breastfeeding Breastfeeding advice with videos

www.cleft.ie/?page_id=33 Breastfeeding advice from Irish cleft site

www.clapa.com/treatment/feeding/breastfeeding/ Breastfeeding advice from UK cleft site

www.intermountainhealthcare.org/ckr-ext/Dcmnt?ncid=522574921 USA Factsheet - breastfeeding

Feeding equipment	Supplier details
<u>Breast pumps</u> Various brands are available to purchase or hire to support a mother's milk production when exclusive breast feeding is difficult. If a mother needs to fully express all feeds then rental of a hospital grade double pump may be recommended e.g. Medela Symphony Breast Pump, Ardo Carum Breast Pump. Electric pumps are best for the 1st few weeks until a good milk supply is established. Once home you can choose to continue renting or purchase a breast pump for ongoing expressing. Remember to keep receipts for pump hire or purchase as they can be claimed with your tax returns at www.revenue.ie	Please discuss with your midwife or Lactation Consultant in your Maternity Hospital for their recommended products, suppliers and price list.  www.medicare.ie For Medela pump www.breastisbest.ie For Ardo Pump www.inha.ie For information on reduced hire breast pumps for mothers of babies who are premature or hospitalized. General HSE breastfeeding advice available at: www2hse.ie/babies-and-toddlers/breastfeeding/
<u>Breastmilk supplementation with a Haberman Special Needs Feeder</u> Available in some maternity hospitals. The long teat requires squeezing as the baby feeds. There is a special valve mechanism inside the teat. The parent/caregiver delivers the milk into an infant's mouth by gently squeezing the teat during sucking. Your health professional will show you how to put the bottle together and how to use it correctly.	Medicare: (01) 2014900 Email: info@medicare.ie www.medicare.ie  Most pharmacies can place an order for you. Can also be purchased on Amazon & EBay sites. Information on: https://www.medela.com/en/breastfeeding-pumping/products/special-feeding-needs/specialneeds-feeder?productId=1007
<u>Breastmilk supplementation via Mam Soft Bottle</u> Available in some maternity hospitals. Simple, soft and squeezable bottle. The parent/caregiver delivers the milk into an infant's mouth by gently squeezing the body of the bottle during sucking. Lower cost than other bottles, with bottle & teats ordered separately. The Mam vented newborn (size 1) teat is recommended for use with newborn babies. An all ages (size 2) teat is available for babies older than 3 months if needed. Standard NUK latex, or SMA latex, (size 1) for narrow neck bottles also fit the Mam bottle (remove yellow collar and replace with the white collar of the Mam bottle).	No Irish based supplier. Order teats/bottles from UK: www.clapa.com  The Irish Cleft Association: www.cleft.ie can supply a starter pack (2 bottles/4 teats) if contacted. SMA size 1 teats can also be used <u>once yellow collar</u> is removed and replaced with the Mam white collar. Online bulk orders: https://lirpharmacy.com/products/sma-anti-colic-teats-100?srsId=AfmBOooyOV2oPgcGcLghhIWUAspk9bG31Y7EqGq22cAKwy9itygrEnMb https://onlinepharmacy.ie/pages/search-results-page?q=sma%20hygienic%20teats 

Feeding equipment	Supplier details
<u>Breastmilk supplementation with a Dr. Brown's Specialty Feeding Bottle</u> Presently Cleft teams advise trialing this bottle 1st, if available in the Maternity Hospital. This Dr Brown's bottle has a special blue valve that allows milk to be delivered to the baby when the baby presses on the teat with their tongue and gums. This means that a strong suck is not necessary for baby to get the milk. The idea is that the baby can self-pace their feed (no squeezing is required by the parent or caregiver). It can be used with a variety of teat sizes. Your SLT/nurse/cleft team should be able to advise which teat size is best for your baby. Some newborns may need a preemie or transitional (T) size teat before being able to manage the flow on a size 1 teat. Size 2 teats not recommended under 3 months of age. Requires instruction for use by a health professional. Important: this bottle is not to be confused with standard Dr Brown's bottle available nationwide. The bottle for cleft conditions has a special blue valve. However, this blue valve can be added to a standard Dr Brown's bottle to make it a specialized feeding bottle.	No Irish based shop supplier presently, but can be ordered from McCabe's Online Pharmacy at www.mccabespharmacy.com (size 1 & 2 teats) NB order the Dr. Browns <u>Hospital Special Bottle</u> Also available to order from the UK on: www.clapa.com (preemie to size 4 teats) For information on use & assembly, see feeding dropdown section on www.cleftcareireland.ie  Online product name: Dr. Brown's Zero-Resistance Specialty Feeding System or Dr. Brown's Specialty Feeding Bottle https://drbrownsbaby.com/products/dr-browns-specialty-feeding-system-8oz-240ml-2-pack
<u>Other options</u> Some parents have reported success with cheaper soft bottles sourced from pharmacies, supermarkets or discount shops that, by the nature of their material, can be squeezed. Various shaped teats and spoons have been used by parents with limited success reported. Enlarging or cutting a hole in a teat is not recommended as it may be unsafe for feeding.	Feeding advice and feeding assessments are available by contacting your local cleft team. Further information on cleft: www.cleftcareireland.ie www.cleft.ie www.clapa.com It is important that if parents find a bottle that works for them and their baby, that they ensure replacement bottles can be sourced during the 1st year of life

Remember your cleft team are happy to help you and your baby with any feeding difficulties that come up. They can offer specialized advice and direct you to your local supports and care teams. For further information please contact your linked Cleft team at either CHI Temple Street or Crumlin locations.

