

Breast feeding 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 breast feeding 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 breast feeding 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 lowers the risk of Sudden Infant Death Syndrome (SIDS).

Extra benefits for babies with cleft

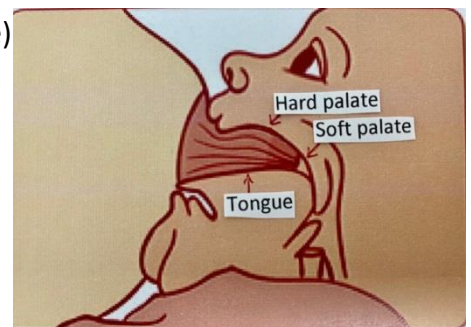
- Breast feeding can protect against ear and chest infections.
- Breast milk may be less irritating if leaking through your baby's nose as it's a natural body fluid.
- Babies who are receiving breast milk do not have to fast for as long as formula fed infants prior to surgery.

How does a cleft affect breast feeding?

- Babies with a cleft lip only, and little or no involvement of the 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.

Breast feeding 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 gain
- 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 breast feed/feed with breast milk?

- Keep an open mind regarding breast feeding. Seek breast feeding advice from your maternity team / 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 breast feed +/- express every 2 to 3 hours (8 to 12 times in 24 hours) for adequate supply.
- Keep an open mind regarding breast feeding. Any amount of breast milk is beneficial whether given by breast or bottle, before contemplating formula milk.
- Breast milk in the 1st day or two is known as colostrum and is very rich in antibodies and nutrients for your baby. If you are undecided about breast feeding you might like to consider offering your baby some colostrum initially? Small amounts can be offered with an 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.
- 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 breast feeding?

- Some of the health professionals that can offer advice are: Maternity hospital staff, midwives, lactation consultants, speech & language therapists, public health nurses, cleft team co-ordinators and nurse specialists.
- Enquire about breast feeding 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 breast feeding section and 'ask the expert' question options

www.coombe.ie/breastfeeding Breast feeding advice with videos

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

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

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

Feeding equipment	Supplier details
<p><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 a hospital grade double pump e.g. Medela Symphony Pump may be recommended. Other pump options work well if full milk expression is not required.</p>	<p>Please discuss with your midwife or Lactation Consultant in your Maternity Hospital for their recommended products, suppliers and price list.</p> 
<p><u>Breast Milk supplementation via Haberman Feeder</u> Readily available in most maternity hospitals. Recommended by Dublin Cleft Teams. The long teat is squeezed as the baby feeds. Valve mechanism inside the teat. Although relatively expensive it is successful with most babies. Your health professional will show you how to put the bottle together and how to use it correctly.</p>	<p>Medicare: (01) 2014900 Email: info@medicare.ie www.medicare.ie</p> <p>Most pharmacies can place an order for you. Can also be purchased on Amazon & EBay sites.</p>  <p>Information on: https://www.medela.com/breastfeeding-professionals/products/feeding/special-needs-feeder</p>
<p><u>Breast Milk supplementation via Mam Soft Bottle</u> Available in some maternity hospitals Recommended by Dublin Cleft Teams. Simple, soft and squeezable bottle. Lower cost than other bottles with bottle & teats ordered separately. Works best with a Mam vented newborn (size 1) or all ages (size 2) teat. Standard NUK latex (size 1) for narrow neck bottles also fit. Requires instruction for use by a health professional.</p>	<p>No Irish based supplier.</p> <p>Order teats/bottles from UK: www.clapa.com</p> <p>Extra NUK teat supply from Maternity Unit or online: https://teat.shop/teat-latex-medium.html</p> <p>The Irish Cleft Association: www.cleft.ie can supply a starter pack (2 bottles/4 teats) if contacted</p> 
<p><u>Other options</u> Some parents have reported success with cheaper soft bottles sourced from 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.</p>	<p>Feeding advice and feeding assessments are available by contacting your local cleft team.</p> <p>Further information on cleft: www.cleft.ie www.clapa.com</p> <p>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</p>

Feeding equipment	Supplier details
<p><u><i>Dr. Brown's Specialty Feeding Bottle</i></u> Relatively new bottle introduced from the USA for babies with cleft. The milk flow can be a little fast for some babies when they are very young. Reported by parents to be a successful option for babies who are a few weeks' old and already established feeders. No squeezing required as the baby's tongue & gum action, rather than sucking, causes the milk to flow from the bottle. The idea is that the baby can "self-regulate" a feed but it may not work for every baby. Middle range cost. Teats come in different sizes. Advise to contact your cleft team before ordering.</p>	<p>No Irish based supplier.</p> <p>Order from UK: www.clapa.com</p> <p>Also available on: www.amazon.com</p>  <p>Information online: http://www.drbrownsbaby.com/medical/products/new-dr-browns-speciality-feeding-system</p> <p>Also available on: www.amazon.com</p>
<p><u><i>Vital Baby Nurture Bottle</i></u> Squeezable bottle system. Use with caution when your baby is very young as the flow can be fast at times. Parents have sourced this bottle independently from supermarkets and pharmacies with varied success reported to cleft teams. Price varies. Advise to contact your cleft team before ordering.</p>	<p>Available from selected supermarkets and pharmacies.</p> <p>Information on: www.vitalbaby.com</p>  <p>(Search for Silicone Vital Baby Nurture range)</p>
<p><u><i>Nuby Bottle</i></u> Squeezable bottle system. Use with caution when your baby is very young as the flow can be fast at times. Parents have sourced this bottle independently from supermarkets and pharmacies with varied success reported to cleft teams. Price varies. Advise to contact your cleft team before ordering.</p>	<p>Available from selected supermarkets and pharmacies.</p> <p>Information on: www.nuby-uk.com</p>  <p>(Search for Nuby Natural Touch range)</p>

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.

