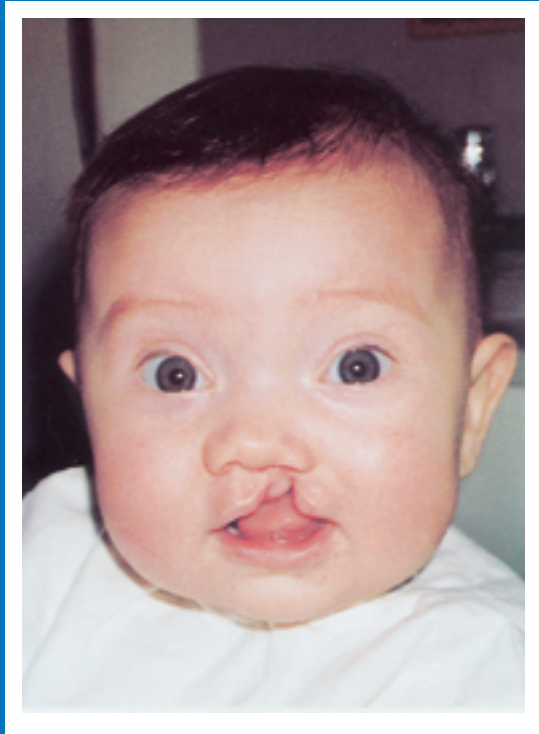


CLAPA 
Cleft Lip & Palate Association



Help With Feeding

This is a guide to some of the ways your baby with a cleft lip and/or palate may be helped with feeding so that you enjoy this special time together.

It is not intended to replace the help you and your baby should receive from the maternity staff, Cleft Nurse Specialists, or other members of the team looking after your baby.

HELP WITH FEEDING BABIES BORN WITH A CLEFT LIP AND/OR CLEFT PALATE

Babies spend most of their early weeks feeding and sleeping. As well as satisfying hunger and thirst, feeding is a time of social interaction when a baby is most alert. Unless your baby has other issues, you should not need to be separated from your baby in the early days following delivery.

To feed, babies use a collection of reflexes which are present at birth in full-term babies. For effective feeding, they need to be able to form a vacuum inside their mouths and to position the tongue properly. A vacuum is formed by sealing the lips around the nipple or teat and closing the back of the mouth using the soft palate.

A combination of the correct reflex action and a vacuum result in milk being drawn out of the bottle in bottle feeding, and correct positioning and maintenance of the nipple on the back of the tongue in breast feeding. Babies born with a cleft may have difficulties combining reflex actions with attempts to form a vacuum. Babies born with Pierre Robin Sequence have a small lower jaw (mandible) and a tongue which, in the early months, is positioned at the back of the mouth. This can affect breathing and swallowing for the first 3-5 months of life.

Ways of helping may include:

- Taking a different approach to breast feeding, which your feeding specialist will be able to advise you on.
 - Using a differently shaped teat with enlarged or newly positioned holes.
 - Using a different bottle for bottle feeding. E.g. a soft squeezable bottle to help the flow of milk.
 - Very occasionally, a thin feeding tube may be passed into the stomach through the nose or mouth to help those babies who also have a small jaw.
- Babies with a cleft palate and other difficulties may need extra help. If a baby is fed by tube for any length of time it is helpful for the Cleft Team to be aware of this, as some teams feel it is important not to delay sucking unless there is a medical reason for doing so.
- Babies with a cleft may swallow more air than normal during feeding, especially if the flow of milk is either too slow or too fast, and may show this by having a blue 'moustache', being extra sleepy, or bringing up some of their feed. If this happens, stopping two or three times during the feed to burp the baby may be helpful.
- All babies can lose up to 10% of their birthweight but usually regain it in two to three weeks. If a baby is having five to six wet nappies a day and regular motions, is healthy and alert, these are indications that he or she is being fed sufficiently.

Every mother and baby is unique, so it is not possible to give hard and fast rules to follow. Some babies feed easily, and others take more time to find the way which suits them, even if they have the same type of cleft. Try to give yourself time to sit comfortably and be relaxed. Make sure your baby is given enough time with one method of feeding before trying alternatives. Always contact your Cleft Nurse Specialist if you have any concerns.

Babies with a Cleft Lip

Breast feeding

A baby with a cleft lip can usually breast feed. Sometimes there is difficulty in forming a seal between the breast and lip but, depending on the type of cleft, the breast can usually mould to the gap. A hissing sound usually means air is entering the mouth, so reposition the baby on the breast. To maintain the nipple position onto the back of the tongue, it may be useful to help the baby by holding the breast into the mouth. Small changes in the vacuum will result in the nipple slowly moving towards the front of the mouth resulting in ineffective feeding. You may need to try your baby in different positions and seek support from those experienced with feeding children with clefts. A good flow of milk helps and this can be encouraged by massaging the breast or using a breast pump. Your midwife will be able to help you with this. Remember that some babies without a cleft will also have difficulties breastfeeding. There are some booklets written specifically for mothers who wish to breast feed their baby with a cleft (see Other Help on page 8).

Bottle feeding

Again, the seal is required at the lips in order for a baby to feed efficiently. Some babies feed well with an ordinary bottle and a soft teat, although the hole may need to be enlarged or a new one made using a sterilised needle. You can sterilise a needle by holding it in a flame until it is red hot - do this for at least one minute so the natural carbon which forms on the metal during heating is burned off.

It is important that assisted feeding using a soft bottle (such as the MAM bottles) only happens when the baby is sucking. Squeezing the bottle during rest periods may cause the baby to cough. Your Cleft Nurse Specialist will help you identify the frequency of help that your baby needs.

Winding

All small babies require winding and your baby will usually let you know when he or she is uncomfortable. If the milk flow is correct, your baby will not have more wind than normal. If your baby appears to be windy, try stopping 2 or 3 times during the feed to burp the baby.

After a lip operation

Following surgery, you can usually feed your baby by breast or bottle as you did before. In some cases you may be told to use a 'cup and spoon' method for a while. You may also be advised to not allow your baby to suck on a dummy while the wound is healing. Ask for the advice of your Cleft Team so your baby can get used to any changes before the operation.

Babies with a cleft palate or cleft lip and palate

A cleft in the palate means that your baby may have difficulty in sucking effectively as they are unable to create a good vacuum inside the mouth and correctly position the tongue. Babies born with a cleft palate only may be more difficult to feed than those born with a cleft lip or cleft lip and palate. Very occasionally, it may be necessary to use a combination of naso-gastric tube feeding and teat/breast feeding during the first two months following birth.

Plates

Not all cleft teams are agreed on the benefits of using feeding and orthopaedic plates from birth, so do ask if and why a plate is considered necessary for your baby. Some teams use a small feeding plate for the baby to wear in the roof of the mouth. This may be made by your orthodontist to:

- Assist with breast feeding
- Protect the delicate tissue in the roof of your baby's mouth
- Keep the baby's tongue out of the cleft

A special orthopaedic plate may be used to begin to apply pressure to close and align the cleft prior to surgery. Plates (obdurators) need to be checked and adjusted or renewed at intervals, so the orthodontist will want to see your baby regularly.

Milk escaping down the nose

If the flow is too fast, milk may pass into the nose and cause sneezing, or some milk may come down the nose if your baby is being sick. Your baby will normally clear this, but have some tissues or a bib handy!

Oral hygiene

Babies do not produce very much saliva during the first 2 months of life. Formula fed babies may require 2/3 teaspoons of cooled boiled water after a feed to ensure that any milk is removed from the nasal airways. Formula milk left in the nose may result in a snuffly baby. This is not necessary for babies fed on breast milk, as breast milk leaves no deposits in those areas.

Breast feeding

Breast feeding a baby with a cleft palate is possible and works best when the cleft is small or narrow. The breast needs to be held well into the area where the palate is intact so the baby can get a good grip and work at the breast with the tongue. A baby born with a cleft palate will need help in achieving a good 'latch on'. A nurse specialist will be able to help you with this.

If your baby is allowed to practice on the soft breasts in the early days, it will be easier for you to find a position that is comfortable for both of you. Your baby will also benefit from the valuable colostrum. At about 2-4 days after delivery when the breasts fill it will be natural for them to have more difficulty in breast feeding.

It is helpful to have a good flow of milk, as your baby may not have a strong enough suck to stimulate the flow. The flow of milk can be encouraged by massaging the breast or by using a breast pump. Your midwife will be able to show you how to massage your breast and hand express the milk when a breast pump is not available. The breasts need to be expressed after feeding to ensure they receive enough stimulation.

Your baby will satisfy their thirst on first suckling, and hunger on the hind milk which contains more calories. Feeds may need to be supplemented using expressed breast milk with an alternative feeding method, as your baby may not get enough milk through suckling.

If your baby is unable to suckle at the breast before their palate is repaired, it is possible, with commitment, for him to taste and lick milk expressed onto the nipple and be fed with expressed breast milk by another feeding method. Many parents feel very satisfied having done this.

There are several alternative 'cup and spoon' methods, cup feeding, and a supplemental nursing system. Breast pumps can be hired and the baby given mothers milk. Do talk to your midwife, cleft team feeding advisor or CLAPA Parent Supporter about this. Take it a week at a time and review the situation, deciding whether to continue for another week.

Breast milk does not irritate the delicate tissue in the nose and throat as much as formula milk and can help to reduce the risk of ear problems developing.

There are some booklets written specifically for mothers who wish to breast feed their babies born with clefts (see Other Help on page 7).

Bottle feeding

Many babies will need extra help to get enough nourishment in a reasonable time, say 30-40 minutes. You need a teat on which your baby can grip well and a good flow of milk. This can be achieved with an ordinary bottle, though the hole or holes in the teat may need to be enlarged or extra ones made (see page 4).

If your baby is feeding slowly, you may need to experiment with different teats, as some manage better with one sort, such as an orthodontic shaped teat. If using an orthodontic shaped teat, the hole is best placed on the non-cleft side and slightly towards the tongue so that the milk is aimed downwards and away from the cleft.

Others need a soft bottle that can be gently squeezed as the baby sucks to help the flow of milk, such as the MAM bottles. This may give you more control than an enlarged hole. Nursing your baby in the normal cradling position is possible in most cases. Babies born with a cleft palate alone may be nursed and fed on their sides. Some babies may not have the energy to suck from a teat, and here a cup and scoop method may be helpful. Feeding from a scoop attached to a soft bottle requires less effort from a baby.

Feeding after a palate operation

The timing of the palate operation will vary from hospital to hospital, depending on the type of cleft and operation that your surgeon performs. This may mean that your baby is weaned, but still using a bottle for milk or other liquids.

Ask your team how they recommend you feed your baby after surgery, as you may need to get your baby used to a spoon bottle or short spouted trainer cup before the operation. The same may apply to a dummy.

Weaning

The usual time to start weaning babies is at about 6 months of age. The exact time will depend on your baby, and it is no different for a baby with a cleft than for one without. The texture of the food needs to match your baby's stage of development. Do ask your specialist nurse for help if you have any questions or concerns around this. As with milk, food may pass into the baby's nose and cause sneezing. This may be distressing at first, but it is nothing to worry about - just have a bib or some tissues handy to catch the mess! Your baby will soon learn to cope with this. Finish meals with a drink to help clear any food from the cleft area.

When introducing a **trainer beaker**, you may be advised to use one with a soft or a short spout which won't disturb a healing palate repair. It may be hard for your baby to suck from a non-spill beaker - a small hole drilled in the lid will help.

General Advice

A cleft in the lip may extend into the gum and bone of the jaw where teeth develop. This can lead to some front teeth coming into the mouth twisted and misplaced. It is important that your baby grows up with strong teeth, as future treatment may be needed to straighten them. You can do this by limiting sugar, avoiding syrupy drinks, and giving sugar free medicines or supplements at mealtimes.

Other Help

Booklet on breastfeeding:-

Nursing a baby with cleft lip or cleft palate (leaflet No. 122)
La Leche League
PO Box 29
West Bridgeford
Nottingham NG2 7NP
Tel: 0115 9455772

Feeding Bottles and Teats

CLAPA can provide special bottles and teats, including a free 'Welcome Pack' for family in the UK. See overleaf for details.

Help from Other Parents

Read stories and suggestions about feeding from other parents by visiting:
www.clapa.com/treatment/feeding

Get one-on-one support from a trained parent volunteer with our Parent Supporter service. Call 020 7833 4883 or visit www.clapa.com/need-to-talk/ to ask for a Supporter to get in touch.

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A free catalogue and price list is available on request.
Visit our online shop at www.clapa.com/shop to find
out more about and purchase any of our specialist
bottles and teats, or call us on 0207 833 4883.

For details of other CLAPA literature and
local support groups contact the above
address or visit our website.

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