

# Cleft Lip and Cleft Palate

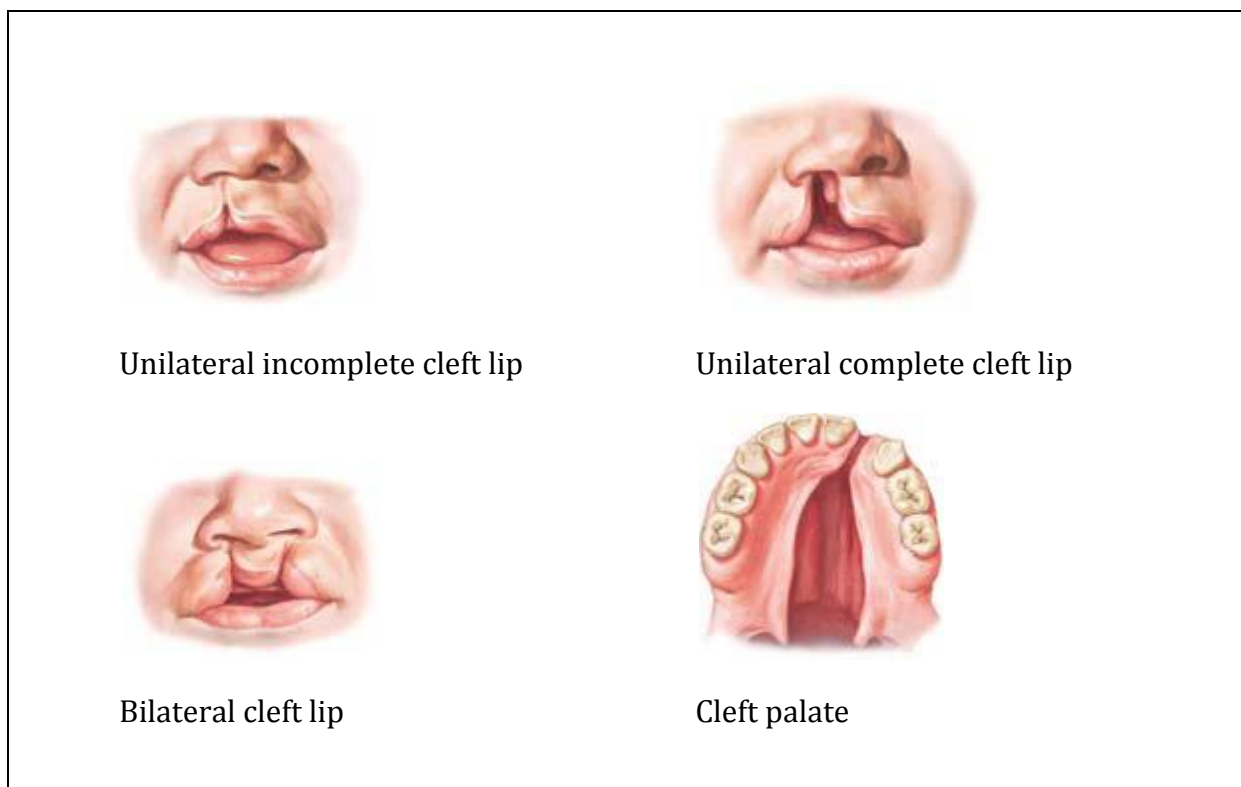
## How do cleft lip and cleft palate occur?

Each of us has a cleft or gap of the lip and palate during the early weeks of development in our mother's womb. Normally, the tissues that form the palate (the roof of your mouth) and the upper lip come together in the middle and join (fuse). You can see the lines of fusion in the "Cupid's bow" under your own nose, and feel the ridge and line in the middle of your palate. If your baby has a cleft, this fusion did not happen when he or she was developing.

## Why does fusion of the palate fail to happen?

In most cases we simply don't know why lip and palate do not fuse. About 1 in 700 babies has a cleft lip or cleft palate.

In some families, clefts appear in several family members, so heredity is important. Sometimes substances in the environment, called teratogens, may be associated with clefts. But most babies with clefts have no known relatives with clefts and no known exposure to teratogens. A few babies with clefts also have other abnormalities.



## **Did we do anything wrong?**

We don't know what causes most clefts. Even if it is hereditary in your family, it is still not your fault.

## **What happens now?**

Remember that cleft lip and palate are not dangerous to your child. The surgery to repair the cleft can be done when the child is the right size and in good enough general health to tolerate surgery.

Surgery is done in several stages. Parents are usually eager to have at least the visible cleft lip repaired early; this is usually done when the baby is at least 12 weeks old and weighs 4.5 kg. The palate is repaired later, usually when the baby is at least 9 months of age.

## **How will my baby's feeding be affected?**

Infants with only a cleft lip can often breast-feed. Infants with only a cleft of the soft palate may have difficulty learning to breast-feed. Infants with a cleft lip and palate cannot usually breast-feed as they cannot create enough suction. They may also have difficulty compressing the nipple. This can make feeds long and tiring and the baby may not get enough milk for growth.

Even if breast-feeding is not possible you can still feed your baby breast milk by expressing your milk and using a bottle or feeder. Along with your midwife, a lactation consultant and a speech pathologist will help you to work out the best way for your baby to feed.

Special teats and bottles are used for either expressed breast milk or formula. They are specially designed to regulate the flow rate of the milk so that your baby can feed comfortably. Several types of bottle and teat are available and the speech pathologist or midwife will trial them with your baby to see which one best suits him or her.

The Monash Children's Cleft Unit most commonly use the SpecialNeeds® (Haberma)feeder

<http://kidshealth.schn.health.nsw.gov.au/fact-sheets/medela-special-needs-feeder>

and the Pigeon® Cleft Palate Teat

<http://kidshealth.schn.health.nsw.gov.au/fact-sheets/using-pigeon-cleft-palate-teat>

## **How will my baby talk?**

If your baby has only a cleft lip, he or she should have no major problems learning to talk. If your baby has a cleft palate it may take a little longer than usual to learn to talk. Speech therapy is usually helpful and the speech pathologists that are part of the Monash

Children's Cleft Unit will monitor your baby's speech development. They will work with you and your child to develop the correct sounds for speech.

## **What other problems is my baby likely to have?**

**Ears:** Children with cleft palate are at increased risk for hearing loss. It is therefore important that hearing is regularly monitored. The first diagnostic assessment is usually done after the newborn hearing screen, in the first few weeks following birth.

Hearing loss in relation to cleft palate is usually due to a build-up of fluid in the middle ear. This is often called 'glue-ear', 'middle ear effusion' or 'otitis media with effusion'. The middle ear normally stays aerated and healthy because air can pass in and out from the nose and mouth via the sinuses and Eustachian tubes. In most cases the Eustachian tubes of children with cleft palate cannot open effectively. This can cause the middle ear to fill with fluid resulting in hearing loss and an increased risk of middle ear infection.

The degree of hearing loss in children with cleft palate varies but is usually mild or moderate. This is likely to affect the development of speech and language of the child.

Insertion of grommets is usually the recommended treatment for middle ear fluid and/or middle ear infections. Grommets are tiny ventilation tubes which are inserted into the ear drum and allow an alternative air passage into the middle ear cavity. They are usually inserted at the same time as cleft palate repair at about twelve months of age. Depending on the degree of hearing loss, a hearing aid fitting may be recommended before twelve months, at least until the child is old enough to be treated.

**Teeth:** Your child will need to see the dentist often. From an early age, it is important to develop a good relationship with your family dentist as preventive care for both baby teeth and permanent teeth is critical. Children with a cleft may be missing some teeth or may have extra or overcrowded teeth. This will be treated in the teenage years. The Monash Children's Cleft Unit will monitor dental development as part of your regular visits and can provide specialist orthodontic care as well as oral and maxillofacial surgery when required.

**Social:** Many children with a cleft lip and palate have no concerns psychologically however some parents naturally worry about their child's ability to make friends and the difficulties they may have to face in the future. It is very important to spend as much time as possible with your baby, cuddling, talking, playing and so on. Later on, when your child is older and is making friends outside the family, it is important for you to make your home a safe place for your child.

If you are worried about any problems with growth and making friends, you should talk to your doctor. You may also want to talk to a psychologist or a psychiatrist.

## What is all this going to cost?

If you are eligible for Medicare Australia all surgery and outpatient visits are free through the Monash Children's Cleft Clinic at Monash Medical Centre, Clayton. In the future you may wish to register for the Medicare Cleft Lip and Palate Scheme. This scheme covers you for treatment from recognised dentists and orthodontists.

## Will it happen again to my next child?

It may, although chances are your next child will not have a cleft. If cleft palate appears in a family, the risk of it happening again goes up. If several family members are affected, the risk of clefts is higher in all children born in the family. Your doctor may send you to a genetic counsellor.

### References

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Please note: The information in the document is meant to support not replace consultation with your doctor. Children should be assessed individually as not all conditions are present in all children. Care will be planned according to the individual needs of each patient.