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## Cleft palate and cleft lip

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### Summary

- A cleft palate or cleft lip is a birth condition caused by failure of the mouth parts to join up during early fetal development.
  - The cause is unknown, although genetic factors sometimes play a role.
  - Surgery can repair most clefts so that appearance and speech develop normally.
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A cleft palate or cleft lip is a birth condition caused by the baby's mouth parts not joining up during early fetal development. The two halves of the palate or the lip don't fuse properly, leaving an open space or 'cleft'. This can occur on one side of the face only (unilateral) or on both sides (bilateral).

One in every 600 to 800 babies is affected by cleft lip or cleft palate. The cause is unknown, although it is thought that genetic factors play a role in a small proportion of cases.

Surgery can repair most clefts so that the child's appearance and speech develop normally.

### How a cleft palate or cleft lip develops

Late in the first month of pregnancy, the baby's mouth develops in two halves, which are growing closer together. Somewhere around the sixth to eighth week of pregnancy, the two halves of the baby's hard palate fuse (join) together to form the roof of the mouth.

Next, the fusing seam travels forward and backward to seal the lips and the uvula (the teardrop-shaped tissue that hangs at the back of the throat). By the tenth week of pregnancy, the mouth is fully formed and the nose has developed its familiar structure and location.

In a child with a cleft palate or cleft lip, the two halves of the palate or the lip do not fuse properly. Other areas that may not properly join up include the soft palate, located at the back of the roof of the mouth, and the nostrils.

Cleft conditions vary in severity and extent, with variations including:

- Cleft lip only
- Cleft palate only
- Cleft lip and palate
- Microform cleft (notch or scar)
- Unilateral cleft (one side)
- Bilateral cleft (both sides)
- Cleft involving the soft and/or hard palate.

### Causes of cleft palate and cleft lip

The causes of cleft palate and cleft lip are unknown, although hereditary factors sometimes play a small role. Around one in three babies born with a cleft palate or a cleft lip may have a relative with the same or similar condition, or an associated chromosomal or genetic condition. A parent who was born with a cleft has a small chance of passing on the condition to their child.

Around two thirds of cases occur spontaneously, with no family history or known cause.

Current research indicates that the actions or behaviours of the mother or father during pregnancy have no bearing on whether or not the child will develop a cleft palate or lip.

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## **Cleft palate and cleft lip – feeding your baby**

A suckling baby uses its tongue to push the nipple or teat against the roof of its mouth. The muscular motions of the jaw and soft palate at the back of the mouth allow suction to draw the milk.

Depending on the location and severity of the cleft, a newborn baby may have difficulties with sucking. A cleft palate or a cleft lip makes it hard for the baby to seal its mouth properly over the nipple or teat. This can prevent the formation of the vacuum necessary to draw milk out of the breast or bottle.

It may be necessary to try a variety of different feeding methods before you find the combination that works best for your baby. Swallowing air is likely and babies with a cleft palate or cleft lip need thorough burping.

Bottle feeding is often easier for a baby with a cleft palate or cleft lip than breastfeeding, but be guided by your doctor, surgeon or healthcare nurse.

A maternal and child health nurse, breastfeeding specialist or another parent of a child with a cleft palate or cleft lip may help you to find a solution.

Suggestions include:

- Try expressing with a breast pump and feeding your baby from a bottle.
- Use both breastmilk and bottled formula to make sure your baby is adequately nourished.
- Press your baby's cleft lip against your breast to help seal the mouth when breastfeeding.
- Use soft bottles that can be manually squeezed to push milk into your baby's mouth. There are bottles and teats designed especially for use by babies with cleft conditions. (CleftPALS Victoria can supply these bottles to parents of babies with a cleft palate or cleft lip in Victoria.)
- You can use a special supply line that 'supplement feeds' your baby by tube while you breastfeed them.
- Breastfeeding a baby with a cleft palate is extremely difficult. Try not to be too surprised or upset if breastfeeding isn't possible.

## **Treatment for cleft lip**

Cleft lips are often more a cosmetic than a functional concern. Usually, an altered nose is associated with a cleft lip. A cleft lip can be surgically corrected at around three months of age.

## **Treatment for cleft palate**

Cleft palates have to be surgically repaired before the baby is ready to speak, usually between six months and one year. During the operation, nearby mouth tissue is used to close over the cleft.

Some children will require further operations, such as pharyngoplasty, to help seal the mouth from the nasal cavity. Some children born with cleft palates will have speech difficulties after surgery. Speech pathology can help overcome this.

Children born with a cleft palate have a greater tendency to develop recurring ear infections, such as 'glue ear'. This will need ongoing attention from their ear, nose and throat surgeon.

Depending on the location and severity of the cleft, other treatments might include:

- Follow-up surgery on the hard palate at a later stage
- Jawbone realignment prior to surgery, using elastic braces
- Bone grafts for the upper jaw at around 10 years of age
- Ongoing dental and orthodontic care
- Subsequent cosmetic operations – may be necessary as your child matures.

Your child may need some or all of these treatments, depending on their condition. However, location and severity

are just part of the picture. Treatment needs and success will depend on a range of factors. A severe cleft does not always need complex treatment.

### **Support for parents of children with a cleft palate or cleft lip**

Having a child with a cleft palate or cleft lip birth condition can be traumatic. Parents need to be supported, particularly in the first few days when feeding is difficult and there are unanswered questions.

There are various organisations that offer information and advice. It is important to remember that clefts can be repaired, and children who were born with a cleft palate or cleft lip go on to lead normal, happy lives.

CleftPALS Victoria offers support and information for Victorian, Tasmanian and South Australian families, young people and friends of affected children. Volunteers are mostly parents and adults who themselves have had a cleft palate or cleft lip, who understand what you are going through. Regular updates, play dates, family fun days and assistance with ordering feeding equipment are available.

Cleftstars, a youth support group run through CleftPALS Victoria, offers young people the opportunity to meet each other and share experiences face-to-face and online. Structured and fun sessions are planned throughout the year, and there is a closely monitored Cleftstars Facebook site.

The Medicare Cleft Lip and Cleft Palate Scheme helps families to meet treatment costs for specialised services for cleft lip and cleft palate conditions.

### **Where to get help**

- **CleftPALS** Victoria Support Hotline Tel. 0425 784 130
- **CleftPALS** Victoria Feeding Equipment Hotline Tel. 0425 784 136
- **Monash Children's Cleft and Facial Anomalies Unit**, Monash Medical Centre Tel. **8572 3833**
- **Plastic surgeon**
- Department of Plastic and Maxillofacial Surgery, **Royal Children's Hospital** Tel. 9345 6582
- **Paediatrician**
- **Ear, nose and throat** surgeon
- Your **GP (doctor)**
- **Speech pathologist**
- **Dentist**
- **Orthodontist**
- **Clinical geneticist**
- **Medicare Cleft Lip and Cleft Palate Scheme** Tel. 132 150 or 1300 652 492

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