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## Cleft palate and cleft lip

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### Summary

- A cleft palate or cleft lip (or both) is a birth condition in which parts of the mouth do not join up during early fetal development.
  - The cause is unknown, although genetic factors sometimes play a role.
  - Cleft conditions vary in severity and extent.
  - A cleft lip or palate can be repaired through surgery.
  - Surgery can assist with the development of a child's face and speech.
  - A baby with a cleft lip can usually breastfeed or bottle-feed well.
  - A baby with a cleft palate needs a specialised approach to support feeding.
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A cleft lip or cleft palate (or both) is a birth condition in which a baby's mouth parts do not join up during early fetal development. The two halves of the palate (the roof of the mouth) or the lip don't fuse (join) 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 number of cases.

Surgery can repair a cleft lip or cleft palate. Surgery aims to support the child's appearance and speech development.

### How a cleft lip or palate develops

Late in the first month of pregnancy, the baby's mouth develops in two halves that grow 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 lip or cleft palate (or both), 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, which is located at the back of the roof of the mouth, and the nostrils.

Cleft conditions vary in severity and extent. Variations include:

- 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 hard palate
- submucous cleft palate (under the mucous membrane of mouth).

### Diagnosis of cleft lip and palate

A cleft lip is often detected on ultrasound at 20 weeks gestation, however a cleft palate can be more difficult to detect at this time. A prenatal diagnosis provides an opportunity for parent education, counselling and support. A

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thorough examination of a baby's face and mouth at birth is required to diagnose the type and severity of the cleft.

### **Causes of cleft lip and cleft palate**

The causes of cleft lip and cleft palate (or both) are unknown, although hereditary (genetic) factors sometimes play a small role.

A cleft lip or cleft palate (or both) is not caused by anything the parents did or did not do during the pregnancy. Even the healthiest, well-planned pregnancies can result in a cleft, and this is no one's fault.

Around one in three babies born with a cleft lip or a cleft palate may have a relative with:

- the same or similar condition
- an associated chromosomal condition
- an associated genetic condition.

A parent who was born with a cleft lip or a cleft palate has a small chance of passing on the condition to their child. But around two thirds of cases have no known family history or cause.

To find out more about what caused your or your child's cleft lip or cleft palate (or both), see your cleft team coordinator about arranging genetic counselling and testing.

Read more about what causes a [cleft lip or cleft palate](#).

### **Cleft lip and cleft palate – genetic counselling and testing**

If your child has a cleft lip or cleft palate (or both) it could be associated with a genetic condition.

A cleft lip or cleft palate may exist in isolation, or it may be part of a 'syndrome'. This is when lots of different symptoms happen together. One of these symptoms can be a cleft lip, a cleft palate, or both. There are over 400 conditions and syndromes for which a cleft lip or palate can be a symptom.

To find out if your child's cleft lip or cleft palate is linked to or part of a genetic condition, or if you know that a genetic condition runs in your family that may cause cleft lip or cleft palate, it can be helpful to speak to a genetic counsellor.

Genetic counsellors are health professionals qualified in both counselling and genetics. As well as providing emotional support, they can help you to understand a condition and what causes it, how it is inherited (if it is), and what a diagnosis means for your child's health and development. Genetic counsellors are trained provide information and support that is sensitive to your family circumstances, culture and beliefs.

If a genetic condition runs in your family, a genetic counsellor can explain what genetic testing options are available to you and other family members. You may choose to visit a genetic counsellor if you are planning a family, to find out your risk of passing that condition on to your child, or to arrange for prenatal tests.

**Victorian Clinical Genetics Services (VCGS)** provides genetic consultation, counselling, testing and diagnostic services for children, adults, families, and prospective parents.

The **Genetic Support Network of Victoria (GSNV)** is connected with a wide range of support groups throughout Victoria and Australia and can connect you with other individuals and families affected by genetic conditions associated with cleft lip or cleft palate (or both).

### **Feeding a baby with a cleft lip or cleft palate**

Babies born with a cleft lip alone are usually able to feed well. But babies with a cleft palate often have difficulty with creating enough suction during feeding to draw milk from the breast or a regular bottle. They tend to need bottles and teats specially designed for babies with cleft palate.

If your baby is not able to feed directly from the breast, you can still feed your baby your expressed breastmilk. Talk to a midwife, lactation consultant, maternal and child health nurse, paediatrician or paediatric speech therapist with experience working with babies with cleft lip and cleft palate about how you can do this.

Breastmilk protects your baby against infections and other common health problems. Breastmilk is beneficial for all babies, but it is particularly beneficial for babies with a cleft palate because:

- Babies with a cleft palate can be more susceptible to ear infections than other babies.
- Protection from infection is very important for babies who may need surgery.

The **Australian Breastfeeding Association** provides information on the benefits of breast milk for babies with a cleft palate, and helpful information on managing feeding.

### **Breastfeeding – cleft lip only**

Babies born with a cleft lip alone usually breastfeed (or bottle-feed) well. Some babies breastfeed better with the cleft facing upwards. The breast tissue usually fills the gap caused by the cleft and allows efficient feeding.

Your hospital health care team will give you a referral to a lactation consultant and a paediatric speech pathologist to provide support regarding positioning and maximising feeding efficiency.

### **Breastfeeding – cleft lip and palate**

Babies with a cleft palate usually have difficulty creating enough suction to draw milk from the breast or bottle. This is because air leaks from their nose to their mouth. The degree of difficulty depends on the location and severity of the cleft palate.

If a baby has a cleft lip **and** a cleft palate they may not be able to compress the breast or teat well enough to push milk from the breast or bottle.

Babies with cleft palates usually require special bottles and teats to be able to feed well. It is important to get help to find what works best for you and your baby.

Help is available through lactation consultants, hospital midwives, maternal and child health nurses. They can:

- help you learn how to express breastmilk to feed your baby by bottle
- provide support and advice regarding positioning and maximising feeding efficiency.

Your hospital health care team will give you a referral to a paediatrician and paediatric speech pathologist for further support and review.

### **Bottle-feeding**

A number of bottles are available for babies with **cleft lip and cleft palate** [], including:

- the SpecialNeeds® feeder
- the Pigeon cleft palate teat and soft squeeze bottle
- the Chu Chu teat and soft squeeze bottle.

These bottles can be purchased from some pharmacies, the **Equipment Distribution Centre (EDC)** at The Royal Children's Hospital, the Therapies Clinic at Monash Children's Hospital or **CleftPALS**.

Tips for bottle-feeding your baby with a cleft lip and cleft palate include:

- Before feeding, practise squeezing the bottle and compressing the teat to be familiar with the rate of flow and pressure required.
- Hold your baby in a **semi-upright position** to minimise the nasal regurgitation of milk.
- Squeeze the bottle rhythmically only when your baby sucks (every two, three or five sucks). If you are using the SpecialNeeds® Feeder, squeeze the teat rather than the bottle. A squeeze every three to four sucks is usually enough, but all babies are different. You may need to experiment a little with the rate of pulsing or squeezing.
- Have several breaks for burping.
- Keep each feed to 20 – 30 minutes. Longer feeds mean your baby will use too much energy during feeding. This can make weight gain difficult.
- Watch a **video demonstrating how to use the SpecialNeeds® feeder**.
- Watch a **video demonstrating how to use the Cleft Pigeon teat or bottle**.

### **Tube feeding**

In most cases a baby with a cleft lip and palate can be fully bottle fed. In some rare cases, if the baby is unable to feed successfully using a bottle, they may require a short-term naso-gastric tube for feeding. This is a tube that passes from the nose into the stomach.

If tube feeding is necessary for your baby, your hospital team will help you. If you need to continue tube feeding your baby once you leave hospital, your hospital health care team will help get you established with the appropriate support network – such as registering you for a home enteral nutrition (HEN) program.

Read more about feeding a baby with a [cleft lip or palate](#).

### **Management of cleft lip and palate**

Babies born with a cleft lip or cleft palate (or both) will need care from a multidisciplinary team of specialists from a 'cleft and craniofacial anomalies service'. This is also known as a cleft clinic or cleft team. Your baby will be referred to a cleft team at birth or soon after. A 'cleft coordinator' will help guide you through the process of seeing these specialists and caring for your baby.

If your baby's cleft lip or palate was detected during pregnancy, they can also be referred to a cleft team before birth.

Referrals to a cleft team may be provided by your GP, ultrasound specialist, obstetrician or maternity team.

A cleft team may include the following specialists:

- audiologist
- clinical nurse consultant
- dental specialist
- ear, nose and throat surgeon
- orthodontist
- paediatrician
- plastic surgeon
- paediatric speech pathologist.

### **Treatment for cleft lip**

A cleft lip can be treated with lip repair surgery. This usually happens when the baby is around three to six months of age. Often, an altered nose is associated with a cleft lip. Cleft lip repair involves reconstructing the shape of the lip and the nose and joining the tissues that were not joined before birth.

When having cleft lip repair surgery your baby will be placed under general anaesthetic. This means they will be asleep during the surgery.

Read more about [cleft lip repair surgery](#).

### **Treatment for cleft palate**

Cleft palates have to be surgically repaired before the baby is ready to speak, usually between nine 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
- rhinoplasty surgery to improve breathing and nasal symmetry
- subsequent revision surgery – this 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 lip or palate**

Having a child with a cleft palate or cleft lip at birth can be an anxious time. You may find it particularly challenging in the first few days when feeding is difficult, and you have unanswered questions.

Support is available. There are various organisations that can offer you information and advice:

- **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. CleftPALS will put you in touch with a contact parent whose child has a similar condition or who lives near you.
- **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.

It is important to remember that clefts can be repaired. Children who are born with a cleft palate or cleft lip (or both) go on to lead normal, happy lives.

### **Where to get help**

- Your cleft team
- **CleftPALS** Victoria Support Hotline Tel. **0425 784 130**
- **CleftPALS** Victoria Feeding Equipment Hotline Tel. **0425 784 13**
- **Monash Children's Cleft and Facial Anomalies Unit**, Monash Medical Centre Tel. **(03)8572 3833**
- **Plastic surgeon**
- Department of Plastic and Maxillofacial Surgery, **Royal Children's Hospital** Tel. **(03) 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**
- Lactation consultant
- Hospital midwife

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