

## Cleft palate and cleft lip

A cleft is a birth defect caused by the failure of the mouth parts to join up during early foetal development. The two halves of the palate and/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 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 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 separated itself into its familiar structure and location.

In a child with a cleft defect, the two halves of the palate and/or the lip fail to fuse properly. Other areas that may fail to properly join up include the soft palate, located at the back of the roof of the mouth, and the nostril.

A child may be affected by one or both of these conditions:

- Cleft lip only – around 25 per cent
- Cleft palate only – around 25 per cent
- Both cleft lip and palate – around 50 per cent.

### The cause is unknown

The causes of cleft lip and cleft palate are unknown, although hereditary factors sometimes play a small role. Around one in three babies born with this abnormality may have a relative with the same or similar condition or an associated chromosomal or genetic problem. Around two-thirds of cases occur spontaneously, with no family history or known cause.

A parent who was born with a cleft has a small chance of passing on the condition to their child. However, 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 lip or palate.

### Feeding problems caused by cleft palate

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. The cleft makes it hard to seal the mouth properly over the nipple or teat, preventing the vacuum necessary to draw milk out of the breast or bottle. Swallowing air is likely and babies with clefts need thorough burping.

Bottle feeding is often easier for the baby than breastfeeding, but be guided by your doctor, surgeon or health care nurse.

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

It may be necessary to try a variety of different feeding methods before you find the combination that works best for your baby. A maternal and child health nurse, breastfeeding specialist or another parent of a cleft child may help you to find a solution.

Suggestions include:

- Try expressing with a breast pump and feeding the baby from a bottle.
- Use both breast and bottled formula to make sure the baby is adequately nourished.
- Feed the baby with the cleft pressed against the breast to help seal the mouth.
- Use soft bottles that can be manually squeezed to push milk into the 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 cleft babies in Victoria.
- You can use a special supply line that 'supplement feeds' the baby by tube while you breastfeed them at the same time.
- Breastfeeding a baby with 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 of a cosmetic, rather than functional problem. Usually, a nose abnormality is associated with a cleft lip. The 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 born with cleft palates will have speech difficulties after surgery. Speech pathology can help overcome this.

Some children will require further operations, such as pharyngoplasty, to help seal the mouth from the nasal cavity. 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.

### **Other treatment options**

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

- Follow-up surgery on the hard palate at a later stage
- Jaw bone 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 – these may be necessary as the 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 and a severe defect does not always need complex treatment.

### **Support for parents**

Having a child with an abnormality at birth can be traumatic. Parents need to be supported, particularly in the early days before surgery. There are various organisations that offer information and advice. It is important to remember that most clefts will be repaired and many children have no noticeable speech difficulties after surgery.

CleftPALS Vic offers support for Victorian families and friends of affected children and information about the cleft condition. Volunteers are mostly parents and cleft-affected adults who understand what you are going through. Regular updates, play dates, family fun days and assistance with ordering feeding equipment are available.

The Medicare Australia 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 Vic Support and Feeding Equipment Hotline Tel. 0425 784 130
- Your doctor
- Cleft Lip and Palate Clinic, Royal Children's Hospital, Melbourne Tel. (03) 9345 5391
- Paediatrician
- Ear, nose and throat surgeon
- Speech pathologist
- Dentist

- Orthodontist
- Plastic surgeon
- Clinical geneticists
- Medicare Australia Tel. 132 011 or 1300 652 492

### **Things to remember**

- A cleft is a birth condition caused by failure of the mouth parts to join up during early foetal 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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CleftPALS Victoria Inc.

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