

## Cleft Lip and Palate

### Living with a cleft lip and/or palate

A cleft is an **unusual opening** through the lip and into the roof of the mouth.

It is the most common **facial difference** babies are born with.

In Australia, clefts are usually surgically repaired in the first 12 months of life. Even though they are repaired early, clefts can still have long-term effects.

### About clefts

Clefts occur when parts of the face do not join early in pregnancy.

Clefts can develop in one or both sides of the face and be big or small.

Around 30% of babies are born with clefts that are part of known genetic conditions, like 22q11 deletion syndrome. These clefts are called **syndromic clefts**.

The other 70% are non-**syndromic**. These clefts may be caused by things such as genes and environment. We are still researching this area.

### The effects of a cleft

Clefts affect people differently at varying stages of life, depending on the type and extent of their cleft.

#### Feeding

Babies with clefts might have difficulty sucking and swallowing. Children or adults may sometimes have food or liquid come through their nose when they eat and drink.

#### Hearing

People born with a cleft might also have trouble hearing, particularly while in the preschool and early school years.

#### Teeth and jaw

Clefts may also be linked with dental defects like crowded or rotated teeth. Top and bottom teeth may also not align correctly when the jaw is closed.

#### Facial difference

Even after repair, a cleft can affect the appearance of a person's face and nose.

#### Communication and learning

Most commonly, a cleft can affect speech clarity, making it difficult to speak clearly and be understood in conversations. This can pose challenges in social situations. Sometimes, children may also have difficulties with language, reading, spelling and learning at school.

#### Social difficulties

People with clefts can also experience behavioural and social difficulties such as anxiety. This can affect relationships, learning and daily activities like public speaking.

#### Syndromic clefts

People born with syndromic clefts might also have additional needs according to their specific condition.

### Where to get support

The three common places people with clefts go to get support are:

- in hospital – most surgical procedures, early feeding, hearing and speech management are done in hospital settings. People with clefts usually have regular appointments with health professionals from birth through to early adulthood
- in a community setting – in some areas, children with clefts can access community services like speech pathology. Eligibility varies from state to state
- in a private setting – families can also access most of the above services privately.

You can also get help from national and state-specific support groups, such as CleftPALS.

### How speech pathologists help

Speech pathologists help people with feeding, speech, language and literacy challenges.

They will work with you depending on your needs at different times.

People with clefts may work with different speech pathologists at different times.

In **hospital settings**, speech pathologist help with early feeding and cleft-related speech difficulties.

In **community and private settings**, they can usually provide more regular and long-term support in the above areas.

### Find out more

Some ways to find out more include:

Better Health Channel fact sheet: <https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/cleft-palate-and-cleft-lip>

Royal Children's Hospital early communication fact sheet for children with cleft palate:

[https://www.rch.org.au/kidsinfo/fact\\_sheets/Cleft\\_lip\\_and\\_cleft\\_palate/](https://www.rch.org.au/kidsinfo/fact_sheets/Cleft_lip_and_cleft_palate/)

CleftPALS support groups:

- Victoria: <https://www.cleftpalsvic.com/>
- New South Wales: <https://cleftpalsnsw.org.au/>
- Queensland: <https://www.cleftpalsqld.org.au/>
- Western Australia: <https://www.cleftpalswa.org.au/>