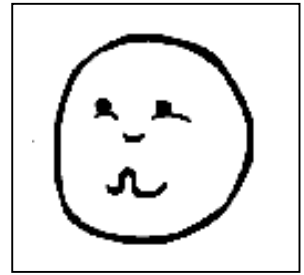


# CLEFTPALS VICTORIA

The Cleft Palate & Lip Society Inc.

## FACT SHEET



- One in every 600 - 700 babies in Australia is born with a cleft making it one of the highest incidences of birth defect. In about one third of families there is a relative also born with a cleft. For the remainder there is no family history.
- A cleft occurs when the lip and / or the palate fail to fuse.  
**A cleft lip** is a split in the upper lip. The lip is formed when two tabs of skin unite from the sides of the face at around 4-6 weeks of gestation, and a failure to fuse results in a cleft lip.  
**A cleft palate** is a split in the roof of the mouth, resulting in an opening between the mouth and the nose. Tissue grows in from the sides of the upper jaw and joins in the middle to form the roof of the mouth (palate), during the first two months of pregnancy. Failure to fuse results in a cleft of the palate.
- Babies can be born with a cleft of the lip **OR** a cleft of the palate **OR** a cleft of the lip & palate. The cleft can affect one side (uni-lateral) or both sides (bi-lateral) of the lip and / or palate.
- Detection ~ many clefts are now being diagnosed by ultrasound. Those that are not detected this way will usually be diagnosed at or soon after birth.
- Up to 23 years of treatment can be required by cleft patients.
- Clefting is associated with over 250 syndromes. The most common is Robin sequence (Pierre Robin syndrome).
- Feeding.  
When a baby with a cleft is born there are usually feeding problems. Feeding problems can occur with any cleft type but more so when the cleft affects the palate. The severity of the cleft doesn't necessarily determine the degree of difficulty with feeding.  
Babies born with a cleft of the lip only can usually be breastfed; it often requires positioning the baby in a way that the cleft is filled with breast so that a seal is created.  
A cleft of the palate interrupts normal suction, as a seal cannot be created. A baby with a cleft involving the palate or lip & palate requires special feeding.
  - Breastfeeding may be achieved (although not in the traditional sense) by expressing the milk into the baby's mouth and allowing the baby's jaws to "milk" the breast. We recommend seeking advice from the Breastfeeding Assessment Service at the Royal Women's Hospital for those with a strong desire to breastfeed.
  - Expressing breastmilk and feeding it through a bottle.
  - Formula fed through a bottle.
  - Special bottles and teats are usually required and CleftPals has information on these.
- Surgery to repair the cleft
  - a cleft lip is usually repaired between 0-6 months
  - a cleft palate is usually repaired between 6-12 months of age
  - different hospitals have different timing schedules
  - timing of repair can be dependant on many factors
    - child ➡ baby's growth / health / tissue growth / severity of the cleft
    - hospital ➡ timing schedule / availability of beds and surgery time

*CleftPALS Victoria Parent Information Package*

*This information is intended as a guide only. It is not intended to be a substitute for professional advice and no liability is accepted.*

- Ear Problems

The palate operates the opening and closing of the Eustachian tube (which drains fluid from the ears), so if you don't have a palate, this function does not occur. Many children with a cleft involving the palate have repeated ear infections and a condition called "Glue Ear". The constant fluid in the ears means many of these children don't hear properly. Grommets are often required to treat this problem, and will usually be inserted at the time of palate repair if required. Throughout early childhood grommets may be required repeatedly until the Eustachian tube matures and begins to function on its own.

- Speech Problems

Children who have had fluid on the ear resulting in hearing loss often have delayed speech. This combined with the fact that these children have been fed differently (meaning their jaw muscles are often not as well developed), and have a palate that may not function "normally" means some will need speech therapy. Some children with a cleft require no therapy at all, others require a little help with pronunciation, and others require intensive work and sometimes surgery to correct problems also.

- Orthodontic Treatment

A child with a cleft may have mis-shaped teeth, missing teeth, extra teeth, or a crooked arch, and may require orthodontic treatment (straightening of the teeth) at some stage.

Where the cleft has affected the gum and hard palate, a bone graft may be required to create a spot for the teeth to come through.

Every person with a cleft, whilst under the age of 22, is entitled to extra Medicare benefits for dental and orthodontic treatment.

## SPECIALISTS

WHO MAY BE INVOLVED WITH A CLEFT CHILD

Paediatrician  
Plastic Surgeon  
Lactation Consultant  
Paediatric Dentist  
ENT Specialist  
(Ear, Nose, Throat)  
Orthodontist  
Speech Therapist  
Maxillofacial surgeon  
Genetic Counsellor  
Cleft Coordinator

## SURGERIES

THAT MIGHT BE REQUIRED BY A CLEFT CHILD

Cleft lip repair  
Cleft palate repair  
Grommets  
(tubes in the ears)  
Fistula repairs  
Pharyngoplasty  
Scar tissue reviews  
Bone graft  
Jaw surgery  
Rhinoplasty

It is important to note that **not all** specialists are required by each cleft patient. **Not all** cleft patients will require all surgeries either.

The cleft type and severity of the cleft do not always determine the degree of difficulty in treatment.

Outcomes for the cleft patient are dependant on many factors.

## CLEFT CLINICS

Cleft Clinics involve a team of specialists that treat children with a cleft condition. Clinics are run at the following hospitals

- ♥ MONASH MEDICAL CENTRE (CLAYTON)  
Ph. 9594-2380
- ♥ ROYAL CHILDREN'S HOSPITAL  
Ph. 9345-6582
- ♥ BARWON HEALTH (GEELONG)  
Ph. 5226-7279

CleftPals Victoria Ph. 9887-1773