The Melbourne Cleft Lip & Palate Centre





**Royal Children's Hospital** 

A BOUT ONE IN 600 infants are born with either a cleft lip, a cleft palate, or both. Nowadays, with modern ultrasound examinations during pregnancy, the diagnosis is often made before the birth of the child. This can allow parents to develop an understanding of the condition and the treatment their child will need after birth.

In the past 20 years or so, there have been remarkable advances in the treatment of clefts, and parents can now expect their children to end up with very acceptable appearance, teeth and speech.

Because the cleft involves facial development, hearing, speech, teeth and palate function, a dedicated and expert cleft lip and palate team of specialists is required. The Melbourne Cleft Lip and Palate Centre has a large and experienced team with expertise in all the specialist treatments that are required and, therefore, can work together with parents to provide the child born with a cleft with the most up-to-date management.

## **An Overview**

The amount of treatment required for a child with a cleft depends on how severe the cleft is at birth. For instance, a minimal cleft may just require one surgical procedure early in life and nothing else, whereas a child with a severe bilateral complete cleft lip and palate may require a number of procedures. As facial growth is a major factor, those patients with more severe deformities will not complete their treatment until growth has ceased, usually in the late teenage years. While the prospect of such long-term treatment may be daunting to parents, it is important to realise that even with severe cleft children the operative procedures are now relatively minor and usually only require a maximum of two to three days hospitalisation.

To provide an understanding of the overall management involved in the more severe clefts it is helpful to examine the issues that occur at various stages of development. The Melbourne Cleft Lip & Palate Centre

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## At Birth

The diagnosis is confirmed at delivery and a detailed assessment is made. A member of our team will usually visit you and your child in hospital if you live in the metropolitan area. During the early days the child may experience some feeding difficulties because of inability of the lips to make a seal, or for the palate to close off the mouth from the nose. We can assist you and the staff of the maternity unit on appropriate feeding techniques, and we are keen to preserve breast-feeding where possible.

## **The First Year**

During this time the surgical correction of the lip and the nose takes place. The timing of this depends on the severity of the cleft and the health of the baby. The palate repair is usually performed some time later (usually after six months) when the components of the palate have grown to a reasonable size and before the baby starts to develop speech patterns.

Also, during the first year (usually at about four months) there can be problems with hearing. The child with a cleft frequently experiences problems with normal drainage of fluid from the middle ear cavities, into the throat. This causes build-up of fluid behind the ear drum which can result in pressure and a degree of hearing loss. Your child will be routinely tested for this and may need small tubes placed in the ear drum to drain the fluid and equalise the pressure. Continued monitoring of hearing in the early years is necessary. However hearing improves with growth and, by the end of primary school, may present no further problems.

## **The Preschool Years**

During this time the major concerns are maintenance of good teeth and the development of speech. A small percentage of children who have had their palate repaired cannot speak properly without some air escaping out the nose and mouth – the palate is a trap-door between the mouth and nose and it may not be able to close properly. Detailed speech assessments are made in the preschool years and, if necessary, an extra palatal operation may be done to ensure proper closure. During this time a child should see a paediatric dentist and become registered on the Federal Government cleft lip and palate scheme.

## **School Age**

The orthodontist usually becomes involved with the child's management when the secondary teeth start to appear. Where there is a cleft in the gum or palate, the secondary canine teeth may not be able to erupt. In most children a bone graft is inserted into the gum to stabilise the situation and to allow teeth to erupt. This is usually done somewhere between eight years of age and puberty, depending on the individual child's tooth development. If there is insufficient upper jaw growth, some patients may require surgical correction to balance the jaws.

## **Puberty and Beyond**

During puberty there is a rapid growth phase for the child and this includes the facial structures. Parts of the face in a child with a cleft may not have the growth potential of a normal child, which are accentuated during this period. Virtually all cleft children have a nasal deformity that is well-corrected at the original lip operation during the first year of life. However, there are residual growth discrepancies and these are often made worse by the child also developing the 'family nose'. Most children will require further nasal correction after puberty and may even need minor lip revision.

More importantly, in some children with severe clefts the mid-part of the face does not grow forward as much as one would like. For these children, in the later teenage years the jaws can be moved with incisions inside the mouth to create optimal facial harmony and normal dentition.

Naturally, not all children with clefts will require all the treatments mentioned above. It really depends on the severity of the cleft.

A cleft lip or palate is a problem that usually requires long-term management by a team of specialists. Our cleft lip/palate team is dedicated to working with parents to provide the child with the best possible surgery, dentistry, speech pathology, school planning and emotional support.

In this booklet, members of our team have tried to answer a series of questions most frequently asked by parents. We hope that this information will provide a better understanding of the situation and what can be done for your child in the years ahead. Because techniques are forever evolving, advances in management may mean that some aspects of treatment will be different for your child in the future. However, having your child's problem managed by a major cleft team will ensure that recent techniques are always available for your child.

A cleft lip or cleft palate need not be a disability for your child.

## **Questions Frequently Asked by Parents**

## What causes clefts of either the lip or the palate?

We do not know the cause or causes. Some children born with clefts have one or more relatives with the same condition, while in other cases there is no family history.

Although many studies have been undertaken, there have been no factors identified that can be avoided. In other words, X-rays, tablets, minor illnesses or injuries do not seem to influence the development of a cleft.

## What are the chances of having another child with a cleft of the lip or palate?

The chances are about four per cent or 1:25, but there are many factors involved and your surgeon or a geneticist would rather discuss this matter with you in more detail. Ask your surgeon or a member of the team if you would like to arrange an appointment with the genetics clinic.



## What is a cleft lip?

A cleft lip is a split in the upper lip. Normally the lip is formed by the union of two tabs of tissue that grow in from the sides of the face with a central tab that grows down from the tip of the nose. This fusion should take place in the fourth to sixth week of the formation of a baby. If the union is not complete, the baby is born with a cleft lip.

## Does a child with a cleft lip always have a cleft palate (split in the roof of the mouth)?

A cleft lip may be associated with a cleft palate. However, many children with a cleft lip do not have a cleft of the palate.

## What can be done for my child with a cleft lip?

Lip surgery helps restore the lip to 'near normal', both in function and in appearance, and also helps correct the deformity of the nose. Restoration is never perfect, but in most cases the results are very good.

## When will the operation be done?

We usually operate when your child is around three months of age, although there is now a tendency to operate at a younger age. This decision varies from case to case and depends on the individual patient and the surgeon. The most important thing is that the baby must be in good health at the time of surgery.

## Will my child look 'normal' after the operation?

No. After the operation the lip will be slightly swollen and the scar will be red. Appearance will be greatly improved, but the scar will take from 6-12 months to soften and fade. It will never completely disappear, but in time it may be hard to see.







**Fig 1.** Types of cleft lip. Unilateral incomplete cleft lip (A), unilateral complete cleft lip and palate (B) and bilateral complete cleft lip and palate (C).

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## The Nose

There is frequently a nasal deformity associated with a cleft lip, and a cleft lip and palate.

The nose is usually operated on at the time of lip repair, resulting in significant improvement. However, further nasal surgery is required – sometimes during the primary years, but often after facial growth is completed in adolescence.

## The Alveolus

If the lip cleft involves the alveolus – the bony gum margin (of the upper jaw) – or if there is a complete cleft of the lip and palate, the alveolus is repaired at the time of lip repair. However, this can only be a soft tissue repair and the bony aspect of the upper jaw will need to be joined together by a bone graft, with bone taken from the hip at 8-9 years of age. Sometimes this small gap in the gum allows fluid to leak into the nose, causing some return of fluids through the nostrils.

How long will my baby be in the hospital after the lip operation? Approximately 2-3 days.

## May I remain with my baby during the hospital stay?

Yes. Parents are encouraged to stay with their baby and assist in the child's care as much as possible. Discuss accommodation requirements with the nursing staff when you arrive at the ward.

## How should I feed my child before the operation?

If the cleft in the lip is incomplete, and the palate is intact, the baby can breast-feed or use a normal bottle and teat. Please refer to the Feeding Information Sheet for Parents.

## Should we use a special formula?

No. The amount and type of food provided is the same as for a baby without a cleft. Your paediatrician or Maternal and Child Health nurse will advise you what to give.

## What about breast-feeding?

Breast-feeding is usually not a problem with just a cleft lip. If the cleft of the lip is quite wide you may need to round the lips around your nipple or the teat.

#### How should I feed my child after the lip repair operation?

It should be possible for your child to return to the method of feeding that was used before the operation quite soon after surgery.

If you were breast-feeding before the operation and your surgeon does not think this would harm the repair you should be able to resume breast-feeding.





How can I keep my baby's fingers away from the mouth after lip surgery? We will provide you with special arm splints and instructions on how to use these restraints.

## **Dummies**

Dummies cannot be used for one month after lip surgery and one month after palate surgery.

## What is the best sleeping position?

Babies under 12 months should be placed on their backs or their sides and learn to sleep in this position, both to minimize the risk of Sudden Infant Death Syndrome and to prevent the newly-repaired lip from rubbing on the sheets.

Will a child with a repaired cleft lip have difficulty talking? Speech is not affected if only the lip is involved.



## What is a cleft palate?

A cleft palate is a split in the roof of the mouth. In the first two months of pregnancy, bone and tissue normally grow in from the sides of the upper jaw to join in the middle, thus forming the roof of the mouth (palate), which is also the floor of the nose. Failure of this union results in an opening between the mouth and nose.

## Are there various kinds of cleft palate?

The palatal defect varies in width and length depending on when and where the growth process stopped. The palate is composed of a bony part (hard palate) and a muscular part (soft palate). There may be a cleft of the soft palate alone or a cleft of both the soft and hard palate.

Usually the split in the palate is clearly visible. However, sometimes it is covered by mucous membrane, which we call a submucous cleft palate. Often a bifid uvula, a split in the uvula, is a sign that the palate may not be intact. This type of cleft is often difficult to detect and may not be suspected until speech begins to develop.

A small split in the uvula may not be associated with any other problems and is the most minor form of cleft palate, usually requiring no treatment.

## Why is the palate important?

The palate separates the oral cavity from the nasal cavity. It prevents food and fluids from entering the nose when eating and drinking, it's very important in speech, and it stops air escaping into the nose when talking. If air does escape through the nose, and if the muscles of the palate and pharynx are not working efficiently, speech will sound nasal.

#### Is cleft palate always associated with cleft lip?

No. A baby may be born with a normal lip but still have a cleft palate.

#### How should I feed my baby with a cleft palate?

If the palate is cleft, the baby cannot suck properly and other forms of feeding are required. In most cases a polythene squeeze bottle will be necessary. The soft Pla squeeze bottle is available from the Royal Children's Hospital Equipment Distribution Centre, or through the Cleft Palate Parents Support Group and should be fitted with a Chu Chu teat (the Haberman feeder is another suggestion). Please refer to the Feeding Information Sheet for Parents.

Return of fluids through the nose is very common, especially in the early stages of feeding, and may persist after the palate repair.

#### Is my baby likely to swallow a lot of air this way?

This does happen initially, so burp your baby frequently during feeding.

#### What about breast-feeding?

This is usually very difficult, both in regard to satisfactory nourishment and infant fatigue because suction is impaired. If mothers wish to consider this option as supplementary feeding, advice can be obtained either from nursing staff in the Plastic Surgery ward, the Nursing Mothers Association, a lactation consultant, or the Cleft Pals Parents Support Group.

## What can be done for my child with a cleft palate?

The defect can be closed by surgery. The surgeon frees two flaps of tissue from the existing parts of the palate and uses these to close over the defect, thus creating a hard and soft palate which will function, in the majority of cases, as well as a palate already closed at birth. (This closure may require more than one operation). Muscle repair is carried out at the same time as this closure.

## When should the operation be performed?

Palate surgery is usually performed between six and twelve months of age, before your baby starts to make the first attempts at speech.

Fig 2. Palate defect before closure.



Fig 3. Palate after surgery.



## Why do you operate at this age?

It is preferable to close the palate before the child has started to talk. Speech development will then proceed in a more normal way, unhampered by an open palate.

## Is this a dangerous operation?

It is serious, as any operation is, but it is not considered dangerous.

#### How long will my child be in the hospital?

If the operation goes well and healing is normal, the child usually returns home about the third post-operative day.

#### What can I feed my child at home after the operation?

In hospital your child will receive fluids for the first 24 hours following the operation, then graduate to a soft diet. Continue this diet at home until you have seen your surgeon for the first post-operative visit.

### Can my child suck or use straws?

Do not let your baby use straws, suck lollies or place hard objects in the mouth – such articles can damage the repaired palate. Be sure that other children, family or friends do not give your child any of these objects.

## How can I prevent my child from putting fingers or objects into the mouth after the operation?

Your child will be sent home from the hospital wearing an arm splint. These are restraining elbow cuffs to be worn at all times, day and night, until your surgeon advises that they can be left off. You will need to set aside several periods each day when the child is held in your lap, the cuffs removed, and the elbows exercised.

## Can I let the baby cry?

Crying will not harm the baby's palate, even while in hospital. If the baby seems fussy and demanding after leaving hospital, remember that there has been a big change in routine, that there have been unusual and often unpleasant experiences, and that there must be some readjustment to the routine at home. Your baby is just like any other baby who requires a special feeding routine, but needs also the same care, support, interaction and affection as other babies.

## Speech

## Will my child talk like other children?

Most children who have undergone repair of a cleft palate have speech which is normal or very close to normal. This is often achieved through careful cooperation between the family and various professional members of the team. A high percentage of children develop normal speech, just as any other child does, with parental stimulation and the presentation of good speech models.

## How does the palate work for speech?

When the palate is repaired the aim is to close the gap in the roof of the mouth, to repair the muscles in the soft palate and to lengthen the muscular part of the palate as much as possible so that it can reach to the back of the throat (the pharynx).

The palate needs to alternate between these two positions:



Fig 4. Soft palate at rest (above), and soft palate during speech (below).

In the open position, the palate muscles are relaxed and the air can pass into the nose and through the mouth. This enables production of nasal consonants m, n, and ng.

In the closed position, the palate shuts off tightly with the back of the throat to make a seal, preventing air from entering the nose. This means that the nose and mouth are completely separated and oral pressure can be built up in the mouth to produce all consonants apart from the nasal sounds. This ability to close off the nose from the mouth by the action of the muscles of the palate and pharynx is called velopharyngeal function and is a basic prerequisite for clear, precise speech.

## Will nasal sounds during speech and fluid escaping from the nose be eliminated after the operation?

Perhaps not immediately. It takes time for muscles to heal and become strong and flexible enough to close and open the normal airway that connects the nose and throat, and to do this effectively for normal speaking. When we first start to talk we must learn to lift the soft palate towards the back wall of the throat in order to direct the breath through the mouth for speech (see Figure V). Talking is really the best exercise your child can have – so as speech continues to develop, voice quality becomes clearer. In most cases the 'hypernasality', or nasal speech, will gradually lessen. Nasal emission of fluid should lessen and finally stop several weeks after surgery.

Sometimes a small hole or fistula may remain in the hard palate, often just behind the upper teeth (this is usually closed at the time of the bone graft at 8-9 years of age). The hole may be responsible for return of fluids through the nose and if it is larger it may cause distortion of, or difficulty in producing, some consonants.

## How should I help my baby before palate surgery so that he will speak as well as possible later?

A baby with a cleft of the palate needs speech models, enjoys your voice, looks for your smile and likes you to talk, play and laugh with him. A baby with an unrepaired cleft may not make the same sounds as a baby with a palate that is intact, but this does not matter. It is his attempts to produce sounds that are important.

#### How can I help my child to speak clearly after palate surgery?

Just as you would with any other infant or toddler. Keep presenting speech models clearly and simply – use single words initially, with much repetition, then move on to short sentences and phrases. Respond to your child's early attempts to talk with praise and encouragement. Learning to understand and use words and sentences shows that language is developing normally. Children learn very quickly that talking is fun, effective and important.

## Will certain sounds be especially difficult?

Most children take a little time to develop normal articulation (sound) patterns. They need correct models and frequent practise. Sounds such as s, sh, ch and j, may be difficult, especially for those children who have a cleft of the lip and palate and where there is some degree of poor teeth alignment and bite discrepancies.

## When will I see the speech pathologist?

You can ask to do this any time you wish, but an appointment for the first speech assessment is usually arranged somewhere between two and three years of age.

## Will my child require speech pathology?

Some children may need a little help with their speech from time to time, but a large percentage speak well without the need for speech therapy.

## Will further operations on the palate be necessary?

In a small number of children the palate does not work properly so further surgery in the form of a pharyngoplasty may be necessary. Speech and voice quality are carefully monitored and, if appropriate, an operation will be suggested. A reliable assessment can be made only after the child's speech is fairly well developed. This means that the second operation on the palate (pharyngoplasty) is not usually carried out before four or five years of age. If the indications for surgery are not clear we prefer to wait and pursue a policy of regular review. Once a decision for surgery has been made it is carried out as soon as possible in order to avoid the negative effects of impaired communication.

A pharyngoplasty is an operation that narrows the space at the back of the throat and helps reduce air escaping through the nose and hypernasality (nasal speech). After this type of surgery it is normal for snoring to occur for a few months. Occasionally it may persist longer.

If this operation is necessary you will be given a Parent Information Sheet and the opportunity to discuss the procedure, the operation and the postoperative treatment with your surgeon and your speech pathologist.

#### Are there other problems that I should be aware of?

Yes. Middle ear problems and hearing difficulties are likely to occur in many children born with a cleft palate.

## Hearing – Audiology

Because children born with cleft lip and palate risk hearing problems, it is important that hearing be assessed early and then at regular intervals throughout your child's hospital program. Hearing can be assessed from birth and is usually done within the first 10 weeks of life. These early tests can usually only be conducted at specialised centres, including this hospital but later tests can be arranged through your Infant Welfare Centre, at a local Hearing Centre or here at the hospital.

Audiologists can do a number of specialised tests and will provide information and guidance about ways of managing hearing loss if this is present. Satisfactory hearing is essential for the development of language and learning skills.

## Ear, Nose and Throat (ENT) Problems in the Cleft Palate Child

Muscles of the palate control opening of the eustachian tube, which is responsible for allowing air to fill the middle ear space and also enables drainage of secretions from the middle ear. The child with an unrepaired cleft palate will have impaired eustachian tube function and, as a result, the middle ear will frequently be filled with fluid. This may continue for the rest of childhood even after the palate has been repaired. Fluid in the middle ear (otitis media) causes temporary hearing loss, which is usually mild in severity. Nonetheless, this can be responsible for delayed speech development, behavioural problems and, in the older child, difficulties with schooling. It is also often associated with middle ear infection.

#### What are drainage tubes (grommets)? Why are they necessary?

Otitis media predisposes the child to frequent ear infections. Medical management of otitis media may involve the use of antibiotics and the insertion of tympanostomy tubes (grommets) which are tiny drainage tubes inserted into the ear drums. The effects of hearing loss at an early age when the child is learning language skills can be quite severe, particularly in the cleft palate child and, therefore, insertion of tympanostomy tubes is generally performed at the same time as the palate is repaired. The first set of tubes usually lasts six to nine months. While the tubes are in place, the child may experience episodes of discharge through the tubes, particularly in association with upper respiratory tract infections. If the discharge persists it can be treated by either oral antibiotics or antibiotic ear drops. The ears should be protected from water, which could enter the middle ear directly through the tubes and also cause discharge – this is usually only necessary if the child's head is placed under water, as is the case with swimming. The ears can be plugged by cotton wool and Vaseline, Blu Tack, ear putty, or fitted ear plugs.



Fig 5. Basic anatomy of the ear.

#### Should we have regular check-ups?

Follow-up is very important. Once the tubes have come out, approximately half the children will go on to have further episodes of otitis media, requiring reinsertion of tubes. It is difficult to predict which child will have

ongoing problems, therefore regular follow-up by an ear, nose and throat surgeon, together with hearing assessment, is important. When tubes need to be reinserted, larger tubes that function for a longer period of time are generally used. However, the longer the tubes remain in the ear drum, the higher the incidence of a perforation or hole in the ear drum developing. If a hole develops it may, in fact, be beneficial because it performs the same function as a tube. However, once the child has outgrown their predisposition to otitis media, the hole can be repaired. The age at which otitis media settles is generally around eight years of age, but in a cleft palate child, otitis media may continue well beyond this time.

## What do we need to know about tonsils and adenoids?

Another aspect of ENT problems in the cleft palate child is management of problems related to tonsils and adenoids. Removal of the adenoids in a cleft palate child may cause nasal escape, resulting in unclear speech. However, if the child is experiencing significant obstructive breathing, particularly while asleep, removal of the adenoids could be considered, but this decision must be made in consultation with the plastic surgeon and speech pathologist. Removal of the tonsils can generally be done safely without impairing speech.

## Teeth

## How important are my child's teeth?

Every child's teeth are important, but your child's teeth are doubly so. A child with a cleft lip, and sometimes the child with an isolated cleft palate, may have misshapen teeth, missing teeth, extra teeth or a crooked arch, and will require orthodontic treatment (straightening of teeth) at some stage. Therefore, it is important to learn about and practice good diet and oral hygiene, so that the teeth can be maintained in the best possible condition.

#### Are my child's first teeth important?

First teeth are necessary for proper chewing and to save space so that permanent teeth can come into line without crowding. Teeth are also important in making some of the speech sounds. It is imperative to keep the first teeth as long as possible, therefore your child should visit the local dentist or paediatric dentist (specialist in the care of children's teeth) regularly.

#### Are my child's teeth more likely to decay than other children's teeth?

A child with a cleft palate generally has teeth that are of as good quality as those of other children except, perhaps, the teeth at the site of the cleft. However, since the teeth may be far out of alignment, they may not receive the natural cleansing action of the saliva, lips, cheeks and tongue and may, therefore, develop cavities more readily. Conscientious tooth-brushing and a good diet with a minimum of sweets and starches will help a great deal.

#### Are sugar-containing foods harmful to a child's teeth?

The child who is given sweets, chocolate, sweet foods and soft drinks will probably suffer, not only from bad teeth and toothache, but poor nutrition as well, since these may be eaten to the exclusion of good body-building food. Restrict these foods to a 'treat' once a week. Remember there is a lot of 'hidden sugar' in breakfast cereals, biscuits and most 'fast foods'.

#### Should my child receive a fluoride supplement?

Yes, if you live in a community that does not have water fluoridation. Your paediatrician can prescribe fluoride in liquid or tablet form, which will increase the resistance to decay of both deciduous and permanent teeth. The greatest benefits from fluorides are derived when the teeth are being formed, so they should be given as early as possible. You can also ask your dentist to recommend a fluoride supplement.

## Should my child's teeth be brushed or painted with fluoride?

If you live in an area with fluoride in the water, the use of a fluoride toothpaste provides all the surface fluoride necessary if teeth are brushed thoroughly at least twice a day. However, if you live in an area without water fluoridation the application of fluoride to the tooth surface in the form of a gel brushed on at home, or a gel or varnish applied by the dentist, may be necessary. Older children can use fluoride mouth rinses, which are useful if your child requires orthodontic treatment or braces.

#### Are there any other ways to prevent decay?

Yes. All first permanent (six-year-old) molars, possibly some first teeth and other second teeth should have 'fissure sealants' placed in the grooves. This is a quick, simple and painless 'paint on' treatment, protecting the vulnerable surfaces of these teeth from decay.

#### When should I take my child for his first visit to the dentist?

Good dental care should start from birth – your dentist can advise you about diet, maintenance of oral hygiene etc. You should take your child to a dentist for examination and further advice as soon as the first teeth appear at six to nine months of age. The dentist you choose should be experienced in the treatment of children with clefts of the lip or palate and be aware of the specialist care required.

#### Will it be necessary for my child to have orthodontic treatment (teeth straightened?)

It is usual for the clefting defect to also involve the bone of the upper jaw in the area where teeth are forming. This usually results in the absence of the tooth in the line of the cleft but with poorly formed extra teeth that require removal. Those teeth next to the cleft are often rotated and tilted. Orthodontic treatment is required to correct these problems and to restore the normal curve of the upper arch of teeth. Treatment is usually initiated between the age of 6 to 8 years and involves an appliance attached to the upper teeth to expand the arch form prior to surgical closure of the bony cleft. Further treatment to straighten the teeth may well be necessary later (around the age of 14) particularly if more jaw surgery is required.

## Will further dental treatment be required?

Often there is a missing lateral incisor in the region of the jaw cleft and this can be permanently replaced either with a dental bridge where a tooth is attached to the adjacent two teeth or by a dental implant. The implant is suitable for some patients and is a titanium threaded post that joins with the bone over several months and then supports a crown to replace the absent tooth.

## Will I have to pay for all the dental treatment?

No, you will only have to pay for certain aspects of dental care. The federal government have a Cleft lip and Palate Scheme. You should ensure that your child is registered as soon as possible on this scheme. Your plastic surgeon can register you, as can an orthodontist or a paediatric dentist. This scheme covers your child for 3 dental check ups per year, most xrays and orthodontic treatment up to the age of 21. It does not cover them for routine dental care such as fillings, fissure sealants etc., nor will it cover the costs of any crown or bridge work. For further information please contact the dental department at the Royal Children's Hospital on 03 9345 5344.

## What Further Surgery Will My Child Require?

# Closure of the bony gap (alveolar cleft) and fistula (hole between the mouth and the nose)

Although the gap is difficult to see, closure of the bony cleft with a graft, allows normal tooth eruption, restores the proper contours to the base of the nose and allows for a more normal gum contour. It also provides bone for future dental implants to replace any missing teeth.

The bone graft is taken through a small incision over the hip and is placed into the gap to restore normal upper jaw continuity. At the same time, any abnormal communications between the mouth and nose are closed. This surgery takes place when the permanent teeth are growing between 8 and 12 years of age and after orthodontic expansion of the upper teeth. The hospital stay is for one or two days with some swelling of the upper lip for approximately one week. During this time a soft diet is required.



Fig 6. Grafting of cleft and closure of fistula.



Fig 7. Before and after jaw and nose surgery.







Fig 8. Before and after jaw and nose surgery.









#### Will my child require further surgery?

In up to 50% of children who have undergone a cleft palate repair, the upper jaw does not grow forward proportionally. This results in a poor bite as the normally growing lower jaw and front teeth move in front of the upper front teeth. This usually causes some difficulty in chewing, results in extra wear of the back teeth and affects the balance of the facial profile. Surgical advancement of the upper jaw is undertaken routinely in these situations but only after growth has ceased. This is usually by the age of 16 years in females and 18 years in males. Correction of the position of the upper jaw (and sometimes the lower jaw) is performed following further orthodontic alignment of the teeth that is often started 2 years earlier. In some patients, a preliminary minor operation is undertaken to allow a quick form of upper jaw expansion as part of orthodontic treatment.

When the final jaw surgery is scheduled, records are collected in our department and include photographs, xrays and dental models. These are used to plan the detail of the surgery. During the surgery, miniature bone plates are used to stabilize the jaw(s) which heal over four to six weeks. The teeth are not locked together during this time, but a soft diet is required.

Facial swelling is variable but maximises between two and three days following the surgery and there is surprisingly little pain postoperatively.



Fig 9. Repositioning of upper and lower jaws to correct the bite and provide facial balance.

Finally, if there are any scars or irregularities of the lip or nose that your surgeon thinks may be improved with surgery, the option of having a final 'touch-up' operation will be offered. This may be anything from a small scar revision to a full rhinoplasty (reshaping of the nose). These procedures are usually left until all other surgery has been completed, but if the problem is significant they may be considered at a much earlier age. Appearance is often a sensitive issue, especially in the late primary and early adolescent years. Because it takes time to complete treatment frank discussion and a realistic understanding and acceptance of the situation can help you and your child to remain confident and to work towards long-term goals.

## **Psychological Aspects**

## How will my child feel about having a cleft?

With continued help and guidance from parents and other advisers most children accept and cope with their cleft very well. However, there are periods of stress, such as changing schools or during the early teenage years. There may also be some comments or teasing. Some children become very sensitive, others are less bothered, but all will be helped by frank discussion about the cleft and, above all, by your acceptance of the problem. The prospect of later corrective operations will help the child adjust to any residual scars.

# How Can I Know When and Who to Ask Concerning These Special Problems?

At the Royal Children's Hospital a group of specialists - plastic surgeons, oral and maxillofacial surgeons, ENT (Ear, Nose and Throat) surgeons, audiologists, paedodontists, orthodontists, otolaryngologists, speech pathologists, social workers and nurses – combine to form the Cleft Palate Team, all working together for you and your child and providing information and assistance when required. Please feel free to ask any members of the team about problems or queries that occur to you during the course of treatment.

## **Your Role as Parents**

You are vitally important in this management program: firstly, by providing support and helping your child to understand the reasons for treatment and in dealing with the cleft; secondly, by maintaining regular contact, keeping appointments and working with the team to achieve the best possible results.

## **Parent Support Group**

As parents you need support, too. Cleft Pals is a parent group that offers support and information to families. Members of this group are happy to visit new parents in hospital, they provide telephone contact, and are available at any time. The group also arranges regular meetings and sends out a newsletter to members. There is a branch of Cleft Pals in each state – the Victorian contact telephone number is listed under 'C' in the white pages telephone directory.

## **Telephone Contact Numbers**

Plastic & Maxillofacial Surgery Secretary:	(03) 9345 6636 (03) 9345 5347
Interpreter, Royal Children's Hospital:	(03) 9345 5026
Equipment Distribution Centre, Royal Children's Hospital:	(03) 9345 5325
Cleft Pals:	(03) 9467 5259

Feeding Information Booklet for Parents can be obtained from: Cleft Pals Victoria, Child Health Information Centre, Royal Children's Hospital, Neonatal Unit, Royal Children's Hospital