



CLEFTPALS VICTORIA

THE CLEFT PALATE & LIP SOCIETY

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CLEFT LIP AND PALATE OVERVIEW

It is vitally important that your baby be given the best possible start in life. This requires, amongst other things, that you as parents understand as fully as possible what is required to be done for your child. You are naturally worried by your baby's cleft condition. But there is surgical, dental and other treatment available nowadays in special clinics which will help your child grow up to live a full and satisfying life.

The Baby's Palate:

Parents may not understand what is meant by the word 'palate' as it is used in this information.

The palate is the roof of the mouth arching above the tongue. It is made up of a hard, or bony, palate and a soft palate.

The normal hard palate is the front part bordered by the upper gum pad and later by the teeth. The soft palate runs across the back of the mouth joined invisibly to the back of the hard palate. The uvula is a soft round piece of tissue which hangs down from the centre of the soft palate above the back of the tongue and throat.

The twin breathing passages of the nose are above the hard palate. They open into the throat above and behind the soft palate.

You might also keep in mind that the tonsils are glands which lie on each side of the throat near the ends of the soft palate. The adenoids are normally hidden from view above the soft palate at the sides of the nasal passages. The soft palate, including the uvula, normally moves upward and backwards during speech. This movement is the method by which we can close off the nasal passages and direct a flow of air out through the mouth. It is important to be able to do this properly during speech, blowing, and eating.

Types and Causes of Clefts of Lip and Palate:

Firstly, you will understand that we use the word 'cleft' to describe a split or gap which divides the baby's lip or palate into two or more parts. The cleft opens from the mouth towards the nose.

The term 'hare-lip' is often used to describe a cleft lip. It dates back to medieval times, when it was believed a mother gave birth to a baby with a cleft lip because a hare had jumped across her path. 'Cleft Lip' is a more meaningful term to describe the condition today.

A number of conditions, including cleft lip and cleft palate, present when the baby is born and are called 'congenital'. 'Congenital' means literally, 'born together', and indicates that the particular medical condition arose during the formation of the baby. The lip and palate are formed during the first ten or twelve weeks of pregnancy and clefts arise during this period. Cleft lip and cleft palate may occur separately, although they are often connected.

Clefts often occur on one side of the nose and mouth and are called 'unilateral'. A left side cleft occurs more commonly than a right side cleft. We do not know the reason for this. Sometimes facial clefts form on both right and left sides and are called 'bilateral' clefts. Cleft lip occurs by itself in approximately 25% of affected infants, cleft palate in another 25%; and combined cleft lip and cleft palate affects the remaining 50% of cleft infants. There are all grades of defect, from quite small clefts of lip or gum pad, or clefts of the uvula and the soft palate, up to complete clefts of the lip and palate.

We can expect an infant, with any form of facial cleft, small or complete to be born once in every 1000 births.

In about 20% to 30% of cases there may be a relative who was also born with a cleft lip and/or cleft palate.

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

In a few cases, an illness early in pregnancy (such as German Measles) or some other factor may cause the cleft, but a clear connection is rare. In most cases no obvious cause can be found. Clefts of the lip with cleft of the palate, affect boys more than girls, whereas more girls seem to have a cleft of the palate alone, without clefts of the lip. There is no certain explanation yet for these known facts, in spite of a great deal of medical research on this problem.

Simply put, the cause or causes of facial clefts of newborn infants are unknown.

Nursing Care:

The first year of a baby's life is very important in establishing qualities in his/her personality which will help him in later life. A great deal of a mother's time during this year is devoted to feeding her baby. He/she gets to know their mother and develops a feeling of security and well being from the warmth and love she gives him at this time. A child needs to feel satisfied and secure in order to grow up and eventually develop a mature personality.

Some babies with clefts of the palate have difficulty in sucking at a nipple. Help may be necessary to find the method most suitable and satisfying for each particular baby.

Your baby should be fed in as nearly normal a way as possible, sucking being encouraged whenever feasible. This not only makes the baby feel well inside, but also lays a good foundation for later speech development. In this respect, a pacifier, or dummy, may be of assistance early, but will have to be discarded at the time of the operation.

Early Treatment:

Everyone concerned with your baby is naturally anxious for treatment to commence as early as possible. This includes the surgeon who will close the cleft and reshape the lip, and the nose if necessary.

It is understandable that some cleft conditions are more complex than others and present difficulties in repair even to a surgeon especially skilled in this work. In some of the more severely affected infants, it is a help to the surgeon if an orthodontist, who is concerned with connection of malpositions of children's teeth, first alters the shape of the cleft before operation, with dental plates carefully fitted over the infant's gum pads. On occasions, a small sucking plate is made to cover the gap in the baby's palate and this helps him to feed more normally. It has been found that the best time to commence this treatment, where it is considered it would be helpful, is very soon after the child is born.

Further Surgery:

When clefts that occur on one side only are repaired by a skilled surgeon, little (if any), additional surgery is required for the child, except perhaps for surgery on the nose in the teens. However, sometimes the original repair of the lip may be improved, and any remaining distortion of the nose may be corrected, especially for those children with bilateral cleft of the lip.

Also, after later orthodontic treatment, the gap in the gum will need a small bone graft, so that the orthodontist can rearrange the child's teeth to achieve a natural row of teeth.

In general, these surgical procedures are left until the child matures (6-11 years) and the face is fully grown, but some may be done before the child starts school.

Speech:

Speech is a skill that we learn, but the development of good speech can depend on other things besides having a normal-looking palate, which appears to move properly.

A baby only gradually learns to speak, starting with a babble of sounds, slowly developing a small vocabulary of words. He comes to learn by listening and watching and copying that certain sounds have meaning, which make it possible to respond to and get responses from people around him. Many children by their first birthday will say a few words in their own baby way, such as "Mum", and "Dad", "drink", etc. Other children may not start until later but it is important that whenever these words come, they are recognised and responded to. This is a baby's biggest achievement so far, and he will feel discouraged if no-one pays attention to his early attempts to communicate.

If a baby with a cleft palate starts to talk before his palate operation, his baby words may sound a little different, and perhaps a little more nasal. Some sounds will be hard for him to say; for instance, "dad-da" may sound like "nan-na" and "bub-bub" like "mum-mum". However, after your baby has had his palate repaired, he will have an excellent chance to learn gradually to make correct speech sounds. He cannot learn these sounds, or learn to join them together in words overnight, anymore than a child without a cleft palate. But he must be allowed to experiment and play about with sounds. Other activities and play where people talk to him will be a great help. It is best if you can give him gentle, warm and joyful encouragement with his early attempts to speak. This is also important for the general well-being and happiness of any young child.

Each child develops at a completely individual rate in all ways, including speech, although some general patterns can be seen. Some sounds are easier to say than others, and although some children may speak very clearly at the age of three or four, many children do not master the difficult sound such as 's' and 'r' until the age of five or six years. Girls seem to develop speech a little earlier than boys do, though of course there are exceptions.

Lip Repair Surgery:

The lip, nose opening, and upper gum pad:

At this operation the surgeon will join the lip, reshape the nostril and close the front of the palate. The surgery is normally carried out when the baby is gaining weight well and is a few weeks old. It is remarkable how quickly following surgical connection, the tissues heal, the scar becomes less distinct, and the lips and nostrils take on a natural appearance. Sometimes at this early stage a small piece of bone is grafted into the cleft between the gum pads. But in most cases this procedure is left until a later time, usually 6-11 years, and even then such a graft may be judged unnecessary. A decision about a later bone graft may depend upon the result of orthodontic treatment and the reshaping of the upper dental arch.

While your baby is in hospital he/she will need all the love and support than you can give him and will be greatly helped and much happier if you can stay with him/her.

You may need to accustom him/her to being fed with a Rosti bottle in the week before he/she goes to hospital as he/she may be fed this way for two weeks after the operation. Those children that are breast-fed may continue to do so if your surgeon agrees.

Palate Repair Surgery:

Because the cleft of the palate allows connection between the nasal passages and the mouth, food and liquid may enter the nose. This is a source of inconvenience to the child, but more importantly, it may lead to infection being carried into the middle ear, which are connected with the back of the nasal passages by natural tubes. Infection of the middle ears may cause discomfort, as well as pain and deafness. One reason why it is important to repair the soft palate early is that shape and movement of the soft palate play important parts in the formation of speech sounds. If the cleft of the soft [palate is allowed to remain while the child is attempting to learn to speak, poor speech and 'bad' speech habits may develop which will be difficult to overcome later on.

A further reason for early surgical repair is to help the child to develop other normal functions of the mouth, such as chewing and swallowing, as well as normal breathing through the nose. These functions are very important for stimulating better growth of the upper jaw and parts of the face affected by the cleft.

Your baby will need to be able to drink from a cup and to feed from a spoon by the time he goes to hospital for the surgery on his palate. He will remain in hospital about 3-7 days. Once again he/she will feel much happier if you can stay with him/her.

Children who have had a cleft palate seem to be more prone to recurrent infections of the throat and ears than those children who have normal palates. Sometimes these infections are treated by removing the child's tonsils and adenoids. However, it has been found in the case of the child with a cleft palate that this operation can sometimes create more problems for the following reason. The adenoids are situated at the back of the nasal passages, somewhere above the soft palate. When the soft palate moves during speech it comes into contact with the back wall of the throat and adenoids. This contact prevents air from entering the nasal passages during speech. Sometimes when adenoids are removed, it can leave a space too large for the palate to close off the nasal

passages from the mouth. This allows air to escape through the nose and a nasal sound results, where previously speech may have been very good. Hence, if the problem of removing tonsils and adenoids even arises, you should contact your surgeon and discuss this matter with him.

Very few children who have had their cleft palates repaired early need direct help with their speech, either by speech therapy or further surgery. Parents may contact a speech therapist if they are worried about their child's speech, no matter how young the child may be. Often little problems develop into bigger problems if they are not attended to, and a discussion with a speech therapist may be helpful in dealing with present troubles, perhaps preventing future ones from developing.

Dental Treatment:

As we noted earlier, a dentist, or orthodontist, may be called in to help the infant very early, even before surgery for the lip.

These children with clefts of lip and palate can have dental problems, just as any other child can, but generally the problems have some particular features. It might be easier to consider these if we think of the development of the teeth and dental arches in three stages:

- *the deciduous dentition period between 6 months & 7 years
- *the mixed dentition period (where there are both deciduous and permanent teeth present, between 7 & 23 years
- *the permanent dentition period beyond 12 years (where no deciduous teeth are remaining).

The Deciduous Dentition Period:

The upper deciduous (or first teeth), are not greatly affected, although the teeth just next to the cleft or clefts may be slightly displaced into the palate, or may be very slow in erupting or coming through the gums. Occasionally one or other of these teeth may not form.

Behind the cleft of the gum pad, one or all of the teeth (which are the deciduous canine and two deciduous molars) may turn inwards towards the palate, and the bone, which holds them, may, as we say, "collapse". This is generally not a serious problem and may be readily corrected by orthodontic treatment when the child is about 4-6 years. It is difficult to prevent such "collapse" at an earlier stage. If there is only minor collapse, orthodontic treatment may be deferred until the child is 8 or 9 years old.

A very important point to note is that the orthodontist mostly uses the teeth to hold appliances with which the upper dental arch is reshaped and repositioned. For this reason, special care must be taken of the teeth, with attention to diet, eating habits, and tooth-brushing. Otherwise no orthodontic treatment can be given, and the child's malocclusion (meaning 'bad locking together of the teeth') will always become worse, never better.

If the front deciduous teeth are displaced because of the cleft, it is not always possible, or very helpful, to correct them, as this may not sufficiently help the position of the permanent front incisor teeth which appear later.

Mixed Dentition Period:

It is during this stage that we see the permanent incisor teeth appearing, and we must anticipate that they may not be as well positioned as the first teeth were.

However, as long as the teeth continue to be well looked after, the orthodontist can use appliances to improve their positions. It must be understood that a plate or other dental device may have to be worn by the child to hold the corrections. Such devices are a source of worry because they must be kept scrupulously clean, otherwise the teeth against which they rest may decay and the gums may become unhealthy.

The Permanent Dentition Period:

All the deciduous teeth are replaced by permanent teeth by about the age of 12 years, although sometimes the canine tooth near the cleft does not appear for quite some time after this.

While these teeth are forming and appearing, the child's jaws are continuing to grow. The teeth move around and adjust their positions during this growth, although they do not improve their positions. This is why it is almost

always found necessary to carry out a final orthodontic correction between 12-14 years. This treatment is usually done with bands and arch wires which are fixed to the teeth for a period sometimes longer than 12 months.

Sometimes one or two permanent teeth may not form in the child with a cleft lip or cleft palate. For this reason, after orthodontic treatment a partial denture is made to fill the empty space in the dental arch. When the child is grown beyond adolescence the denture might be replaced with a fixed dental bridge, or implants.

If the crown of a front incisor tooth near the cleft happens to be slightly malformed, the dentist may be able to cover it with naturally shaped and coloured porcelain.

Ear, Nose and Throat Conditions:

It has already been noted that the repair of the child's palate is important for the health of the upper air passages, that is, the nose and throat. However, children who have a cleft palate, even though it has been repaired, are more likely to be troubled with ear, nose and throat problems than other children.

In particular, most children with cleft palates tend to have fluid formed behind their eardrums, in the middle ear. This is a condition called "Glue Ear" because of the thick, sticky nature of the fluid. This fluid tends to make the child slightly hard of hearing and this may upset general development and schooling.

Children with 'glue ears' should have the thick fluid removed. Often very small plastic tubes, called 'grommets', are inserted through the eardrums to keep a flow of air to the middle ears, and to prevent further collection of the fluid. This procedure may have to be repeated several times throughout the early life of the child.

In some children there may be distortion inside their nasal passages, which may produce blockage and recurring or persistent infection. This distortion may need to be corrected.

The adenoids and tonsils can become infected causing tonsillitis. But, as you now know, the size and position of these glands help some children to speak better. Therefore, the tonsils and adenoids should not be removed without first asking for specialist opinion.

The Cleft Palate Clinic:

Where you have any doubts about your child's health, particularly where you even suspect ear or throat troubles, hearing loss, poor speech, difficulties with schooling, problems with eating, malocclusion and tooth troubles, seek advice as soon as possible from your surgeon or the nearest hospital centre which has a team of specialist devoted to the care of children with clefts of the lip and palate.

Reminders To Parents Of The Child With A Cleft Condition:

1. You can and should seek advice as soon after birth of the child as possible, (or as soon as possible after an ultrasound diagnosis).
2. There is a specialist service to which you may be referred by your obstetrician.
3. If you have any queries regarding this information please speak to your plastic surgeon.
4. Different hospitals repair clefts at different ages, for various reasons. If you have any queries, speak to your surgeon.

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