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CLEFT LIP AND CLEFT PALATE*

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 lip or cleft palate. But there is surgical, dental and other treatment available nowadays in special clinics which will help the child to 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 booklet.

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 one 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 and blowing.

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.

A number of conditions, including cleft lip and cleft palate, present when the baby is born 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 12 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 800 births.

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

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 clefts of the palate affect boys more than girls, whereas more girls seem to have clefts 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 new-born infants are unknown.

Nursing Care

The first year of a baby's life is very important in establishing qualities in his person-

*Information and advice for parents as prepared by the Cleft Palate Clinic, Royal Alexandra Hospital for Children, Camperdown, New South Wales. Reprinted by permission.

ality 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 gets to know his 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 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 nose.

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 correction 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.

The First 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 correction, 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 many cases this procedure is left till a later time, maybe as long as 12 or more 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 will need all the love and support that you can give him and will be greatly helped and much happier if you can spend much of the day with him.

You will need to accustom him to being fed with an eye-dropper in the week before he goes to hospital, as he will be fed this way for two weeks after the operation.

The Second Surgery

The palate — the remaining part of the cleft inside the mouth:

It is desirable to carry out this surgery as early as possible, which is usually at about the child's first birthday. It is difficult to complete this work much earlier than this time because of the small size of the baby's mouth for such intricate 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 ears, which are connected with the backs of the nasal passages by natural tubes.

Infection of the middle ears may cause discomfort, as well as pain and deafness. This is an important reason why surgical repair of the palate should not be delayed. Another important reason is that the shape and movement of the soft palate play important parts in the formation of speech sounds. If the cleft of the 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 effected 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 14 days. Once

again he will feel much happier if you spend as much time as possible with him.

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 clefts of the lip.

Also, after later orthodontic treatment, further reshaping of the bone, may be carried out with the help of a small bone graft where the cleft penetrates the gums between the front teeth.

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

Speech

Speech is a skill which 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," "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 at about one year of age, 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, any more 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 sounds such as "s" and "r" until the age of five or six years. Girls seem to develop speech a little earlier than boys, though of course there are exceptions.

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 the cleft palate that this operation can sometimes create more problems than it removes, 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 ever 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 six months and seven years of age: the mixed dentition period where there are both deciduous and permanent teeth present, between seven years and 12 years; and the permanent dentition period beyond 12 years of age, when there are no deciduous teeth remaining.

The Deciduous Dentition Period

The upper deciduous or first teeth are often 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 four to six years of age. 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 eight or nine 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 toothbrushing. 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 at between 12 and 14 years of age. 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.

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 had 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 ear drums, in the middle ears. This is a condition called "Glue Ears" 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 ear drums 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.

As you can understand, several of the above-described conditions can be of great importance to the health and well-being of the child. It is essential that these conditions be treated by an ear, nose and throat specialist who works in the team of specialists looking after children with cleft lip or cleft palate, and who is aware of the special problems.

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 specialists devoted to the care of children with clefts of the lip and palate.

Reminders to Parents of the Child with Cleft Lip or Cleft Palate

1. You can and should seek advice as soon after birth of the child as possible.
2. There is a specialist service to which you may be referred by your obstetrician.
3. Once surgical repair of the lip and palate is completed, help will usually be needed from a speech therapist and dentist.
4. The child with a cleft of lip or palate should be treated as much like any other child as possible. All children need parental love and attention. They need the right kinds of food, and hygiene. All this will help ensure nomal development.
5. Special attention must be given to protecting the teeth and keeping them.
6. Ear, nose and throat should be periodically checked.
7. Once you have established contact with a hospital cleft palate centre, you will find that the staff of the centre are there always to advise and help you and your child.