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Understanding cleft lip and palate

The birth of a baby with a cleft is often a difficult time for parents and family. This booklet provides information for parents about the types of cleft lip and palate and the different treatments that are available. The leaflet shows that it is possible to treat all the related aspects of the cleft. As result, the new baby, like any other child, should grow to be a healthy adult.

A cleft of the lip and/or palate occurs in about one in 700 births. It occurs in all ethnic groups and in both boys and girls.

**Why does this condition occur?**

A baby’s face develops during the early stage of pregnancy at about 9 weeks. The upper lip is made up from three parts, as is the palate. When these parts do not join, clefts (gaps) are formed. There are no parts missing.

There is still no proper explanation for the clefts forming, except when there is a family history of clefts. Often, the cause of the cleft is a mystery. However, the plastic surgeon might be able to give you some idea of why it happened to your baby.
How are parents’ feelings affected by the condition?

Sometimes a cleft shows on a scan during pregnancy. If this is so then the parents will have the opportunity to know what to expect. However, whether parents know or not the birth of the baby is a stressful time. Parents are often unprepared for what to expect and the birth of a baby with a cleft will have an effect on the family and friends.

Parents have many different reactions and feelings towards the baby with a cleft. These feelings can range from shock, distress and anger to disappointment and embarrassment. Parents often feel loss and sadness because this is not the baby they had hoped for, or they might feel guilty that they had done something wrong. Sometimes, parents are very hurt and find it hard to believe that this is their child.

All these feelings, which are difficult for parents to have about their new baby, are very normal.
It is often a good idea and helpful for parents to speak to a counsellor on the cleft team. The counsellor can help with:

- Understanding your own confusion and uncomfortable feelings. For instance, “Did I do something wrong?” “Why isn’t my baby normal?” “What will my family say or think?” “How can I possibly show this baby to its brothers and sisters?”
- Sharing difficulties you might have in bonding with the baby. “Will I ever be able to love this baby in the same way as his/her brothers or sisters?”
- Getting support for how to be prepared with all the questions that siblings, family, friends and other children will ask.

These are just some of the worries that parents can share with a counsellor. Some parents need help immediately and others after a little time. Every parent responds differently.

However, the baby with a cleft will have to have a number of operations and might have hearing, speech and dental problems. This means having to visit the hospital many times and you can expect some visits to be stressful.

It is important that you feel free to ask for advice and get support from the cleft team whenever you need to.
What are the major cleft types?

The above diagrams show the nose, lips, hard and soft palate and the alveolus (gum). The ridges at the sides of the ‘philtrum’ show where the three parts of the lip have joined. The ridge in the middle of the palate shows where the parts of the palate have joined.

There are three major types of clefts. Each type will require a number of treatments.
Cleft lip

A cleft of the lip may be complete or incomplete and involves either one side (unilateral) or both sides (bilateral). This type of cleft sometimes includes the upper gum (alveolus) and the nose.

Cleft palate

A cleft palate involves some or all of the soft palate and can extend into the hard palate up to the back of the alveolus. Occasionally some children may have a split (bifid) uvula; this is where the muscles beneath the lining of the mouth and the nose (mucosa) are not joined (submucous cleft palate).
Cleft lip and palate

A cleft of the lip and palate involves one (unilateral) or both (bilateral) sides of the lip, base of the nose, gum and palate. Occasionally, the lip and palate are cleft but the nose and alveolus (gum) are intact.
Fluid moves during infant feeding because of changes in pressure. The lips form a seal around the nipple/teat. The nipple/teat is held between the tongue and the hard palate. The tongue compresses the nipple/teat against the hard palate and “pushes” the milk out. The soft palate lifts to close the nose to create a vacuum, and suction “draws” milk out of the nipple/teat.

The combination of compression (pressure) and suction (vacuum) make up the action of sucking.

However, babies born with a cleft of the lip and/or palate often have difficulties with sucking from the breast or bottle.
It is common for feeding to take extra time. Babies can often work too hard and become exhausted. Careful assessment and monitoring can prevent this and a suitable feeding method and pattern established.

There are a number of methods available for feeding babies born with a cleft. Parents should be encouraged to try to find the best method for their own baby.

**Babies with a cleft lip only**

These babies can often breastfeed successfully. Placing the baby in an upright position with the cleft covered by the mother’s finger or breast tissue can aid attachment and reduce air intake. The secret is to create a seal where no air passes through.

When the cleft is more than 1cm wide or is bilateral then poor lip seal can make breastfeeding more difficult.
Babies with a cleft of the palate only

Occasionally, babies with a cleft of the soft and/or hard palate can breastfeed if the cleft is quite narrow. They are usually unable to “draw” out of the teat/nipple and therefore are unable to suck properly. They take a long time to feed and get tired. As there is no closure of the soft palate, the infant can often take in large amounts of air and will need repeated ‘winding’.

Assisted feeding with a soft “squeeze” bottle is very successful. As the baby sucks, the carer squeezes the bottle and delivers the milk into the mouth for the baby to swallow. Cup or spoon-feeding is also effective, but more spillage may occur, so always give a little extra amount of milk!

Babies with a cleft lip and palate

These babies have difficulty with attachment and sucking and need to be fed with a squeeze bottle, a scoop or a spoon. In some centres, an orthodontic plate may be fitted. This will cover the opening in the hard palate. However, the baby will continue to have difficulty “drawing” milk out from the teat/nipple. In this case, use a “squeeze” bottle, cup or spoon. The hole in the teat can be enlarged so that milk can be “pushed” out by the tongue against the palate.
Treatment options

Surgical repair of the lip

The only way to repair a cleft lip is by surgery.

The lip repair is usually done between 3 and 6 months after birth. Plastic surgeons carry out this operation under general anaesthesia. Part of the operation involves stitching the skin of the lip together. The operation may also involve improving the baby’s nose. If the baby also has a cleft palate, some surgeons might close the front part at the same operation.

Usually, a blood sample and other tests are taken to make sure that the baby is fit enough for the operation. On the day of the operation, your baby will not have any food for a few hours beforehand to reduce the chance of being sick (vomiting). Sometimes, a calming medicine (pre-med) is given by injection or as a drink before the operation.
Afterwards you might see some bleeding from the mouth. There will be some stitches, swelling and crusting on the lip. If the nose was involved in the operation, a small piece of foam might be used to hold its new shape. You might find that splints are on your baby’s arms to prevent touching the stitches. The baby’s scars often become red and swollen afterwards, but usually only for a short time.

Be prepared for your baby to look different after the operation.

Use a dummy to pacify your baby only when necessary, as some surgeons are concerned about their effect on the wound healing following the operation. Take advice on whether to breast-feed, bottle or spoon-feed immediately after the operation.
Surgical repair of the palate

Most surgeons repair the palate from about 4 months to 12 months of age. It is thought that repairing the palate before the child learns to speak will help in speech development.

The palate is usually repaired in layers, with as little surgery to the upper jaw and hard palate as possible. The muscles of the soft palate are reconstructed so that it can work properly during speech and swallowing. Sometimes, the gap in the upper gum area is closed at this stage and sometimes later, depending on the surgeon.

A blood sample and other tests will be taken to make sure the baby will be fit enough for the operation. On the day of the operation, your baby will not have any food for a few hours beforehand to reduce the chance of being sick (vomiting). A calming medicine (pre-med) is given by injection or as a drink.

As with the lip repair, you might see some bleeding from the mouth. There will be some stitches in the palate. If the nose was involved in the operation, a small piece of foam might be used to hold its new shape. You might find that splints are on your baby’s arms to prevent touching the stitches.

Use a dummy to pacify your baby only when necessary, as some surgeons are concerned about their effect on the wound.
healing following the operation. Take advice on whether to breast feed, bottle or spoon-feed immediately after the operation.

In some cases, the repair is unable to withstand the pressure of bottle or breast-feeding and holes can open in the palate. Most often, these holes are small and contract in time and close on their own or become very small.

**Adjustment surgery**

Occasionally further surgery is required to adjust the original repair. A small hole (fistula) might remain in the palate and might need to be closed if it affects speech or allows food or drink to enter the nose.

About 1 in 5 children with repaired clefts might need further surgery to improve speech (pharyngoplasty).

The timing of this surgery varies from patient to patient and depends on the assessment of the cleft team.
Hearing

Children born with clefts sometimes suffer hearing loss because of the cleft. This is usually due to fluid in the middle ear (glue ear) and sometimes corrects itself as the child grows up. If the glue ear does not clear up with medication it might be suggested that grommets are put in. This involves an operation to insert a small tube into the eardrum to allow air to enter the middle ear.

Rarely, the middle ear is not fully developed and the resulting hearing loss might be permanent or further damaged by glue ear.

Your baby should be assessed for hearing and speech and referred to an audiologist or otologist when necessary.

Poor hearing can affect the baby’s language development and should be managed as early as possible to avoid further loss.
Dental aspects

Dental decay is avoidable. Follow correct diet right from birth. Avoid sugar as much as possible. Feeding children on formula food with added sugar or drinks with added sugar will affect their taste for such foods. Trying to wean a child off sugar once the teeth have erupted into the mouth can be extremely difficult.

Drinking from a baby’s bottle/feeder prolongs the contact of liquid with the teeth and even children who have milk only develop dental decay when using the bottle for long periods.

If your child is regularly prescribed medicine in a syrup form you should ask the doctor for a different form of prescription. Children on long-term medication in syrup form develop more dental decay.

Fruit drinks, even the non-sweetened variety, contain fruit sugars and fruit acid that are damaging to the teeth. Give these only when diluted and only at meal times.

Eating sweet things in between meals causes the most damage.

Start a tooth brushing routine as soon as the first teeth are in the mouth.

We recommend fluoride drops or tablets in some areas. These help to strengthen the enamel of the teeth and make them more resistant to decay. Get advice from your team.

Dental decay is often difficult to treat in young children. A number of extra visits will be required in addition to those to the surgeon and other specialists, thereby adding extra time to the overall treatment. If the decay progresses too far your child might need a general anaesthetic just for dental treatment.
Orthodontics: Correction of the position of the teeth

It is common for children born with clefts to have crooked or irregular teeth. The “baby teeth” are not as affected as the permanent teeth. Proper maintenance of the baby teeth is important as they act as a support structure for the permanent teeth that are developing in the jaws and under the baby teeth. Early loss of the baby teeth can create or complicate orthodontic problems.

The cleft might result in a gap in the gum and bone of the upper jaw. The teeth either side of the cleft can be twisted or in the wrong position. There might even be extra or missing teeth either side of the cleft.

Children born with a cleft lip only or a cleft of the palate only do not usually need special orthodontic treatment.

Orthodontic treatment is usually limited to two or three treatment stages.
First stage:
• When the first permanent front teeth come into the mouth and are in “cross bite” (when the upper teeth fit inside the lower teeth), a short course of treatment can be started to straighten the teeth and correct a minor cross bite.

Second stage: (Not necessary in all cases)
• When the child is about 9 years of age, and has a gap in the gum, a bone graft can be used to close the gap. It might be necessary at this stage for the orthodontist to widen the upper arch of teeth to an ideal shape before having the bone graft.

Third stage:
• When most of the permanent teeth are in the mouth the final stage of orthodontic treatment can start. This stage usually takes at least two years, during which time you will need to see the orthodontist almost every month. The treatment is a gradual process where the teeth are moved with metal brackets attached to the teeth and with wires and elastics applying gentle pressure.

We do not recommend orthodontic treatment for baby teeth because small children do not tolerate the braces and there is little lasting benefit from early treatment.
Bone graft

If the cleft has involved the gum (alveolus), a bone graft operation might be suggested at about 9 years of age. Dental x-rays will be taken to assess the development of the teeth in the jaws. From these x-rays the orthodontist can tell if an eye (canine) tooth needs more bone to erupt through.

The operation involves taking some bone usually from the hip and inserting it into the cleft. Before the operation, the child should see the dentist to make sure that he/she is dentally fit for the operation. Any infection from abscessed teeth can affect the success of the operation. An antiseptic mouthwash should be used for a few days before and after the operation. Often after the operation small fragments of bone come out. This is normal.

The operation will help stabilise the upper alveolus and provide bone for the teeth to grow into. It is not required for every patient with a cleft.
Speech and language

Children should be monitored as early as possible even for first sounds, babbling and words.

A good seal between the mouth and the nose is required for correct speech. Movement of the soft palate and the muscles in the throat create the seal. The soft palate must make contact with the back of the throat. Babies born with a cleft of the palate with or without a cleft of the lip may have speech problems. Sounds of the consonants (/p b// t d//k g// ch// and s//) can be difficult. Sometimes, air escapes through the nose when making these sounds and the voice has a nasal quality. A speech therapist needs to see these children routinely to assess and help improve the speech. If necessary, the speech therapist can develop exercises to help in making the correct sounds.

It is sometimes necessary to assess the muscle activity during speech. This is done with a moving x-ray called fluoroscopy/video fluoroscopy, or by nasopharyngoscopy, which involves a small fibre optic being passed into the nose so that the surgeon can watch the palate and the sidewalls of the throat.
in action. If the results of the tests show that the muscles do not close the nose properly during speech your child might need an operation to help improve speech and remove the nasal quality. The operation is called a pharyngoplasty.

You will usually see the speech therapist at every visit to the clinic. In this way, the language development and speech can be monitored and special programmes developed for your child as the needs arise.
The team

At your child’s birth and during his/her progress you should expect to see a whole team of people, these include:

The paediatrician/
a medical specialist for children

The plastic surgeon/
surgically repairs clefts

The specialist “feeding” nurse/
counsels and oversees feeding
The speech and language therapist/monitors speech and language development

The paediatric dentist/advises on prevention of dental disease and manages dental care

The orthodontist/monitors growth, development and fits braces to straighten the teeth

The audiologist/tests children’s hearing
The otologist/ENT surgeon/treats hearing difficulties

The clinical geneticist/advises on the chances of inheritance of the cleft

The psychologist/counsellor, provides counselling

The maxillo-facial surgeon/surgically corrects jaw-related growth problems
The members of the team work together to provide the best possible care for your child and correct the cleft and it’s related affects. You should expect a number of hospital visits and visits to the team as your child grows up and you should ask to see any of these specialists if you yourself think your child needs their attention. With their help and assistance it is possible for your child to grow up with few long-term effects and, like any other child, become a successful confident individual.
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Contacts

Local support group

Paediatrician

Plastic surgeon

Speech therapist

Specialist nurse/dietician

Orthodontist

Dentist

Therapist/counsellor

Audiologist

ENT surgeon

Geneticist