CLEFT PALATE REPAIR

INFORMATION FOR PARENTS

What is a cleft palate?

A cleft palate is a gap in the palate (roof of mouth) which prevents the palate from working properly. Cleft palate can occur on its own or in association with a cleft lip. If your baby has a cleft palate but does not have a cleft lip it may not be obvious in the beginning that there is a problem. It is usually the paediatrician (doctor) who first notices the gap and at this stage the baby is referred on to the cleft lip and palate team.

Cleft lip/palate is amongst the most common of congenital abnormalities occurring in approximately 1 in 600 live births. About 90 new patients with cleft of lip and or palate are born each year in Ireland. Cleft of lip and or palate can result in a wide variety of disabilities.

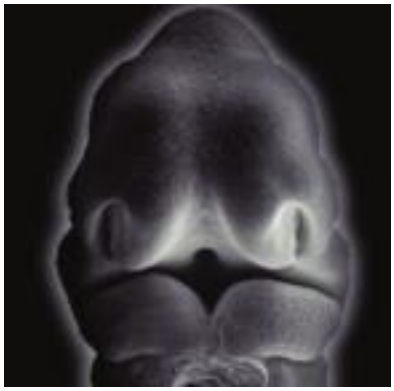
Cleft palate can occur in isolation or associated with cleft lip. There is also a condition called submucous cleft palate which may look normal, but the muscles of the palate do not meet in the middle and children with this condition may also need a cleft palate repair.

Clefts may affect:

- breathing and feeding in newborn babies
- speech
- hearing
- facial appearance
- facial growth
- teeth
- psychological and social adjustment

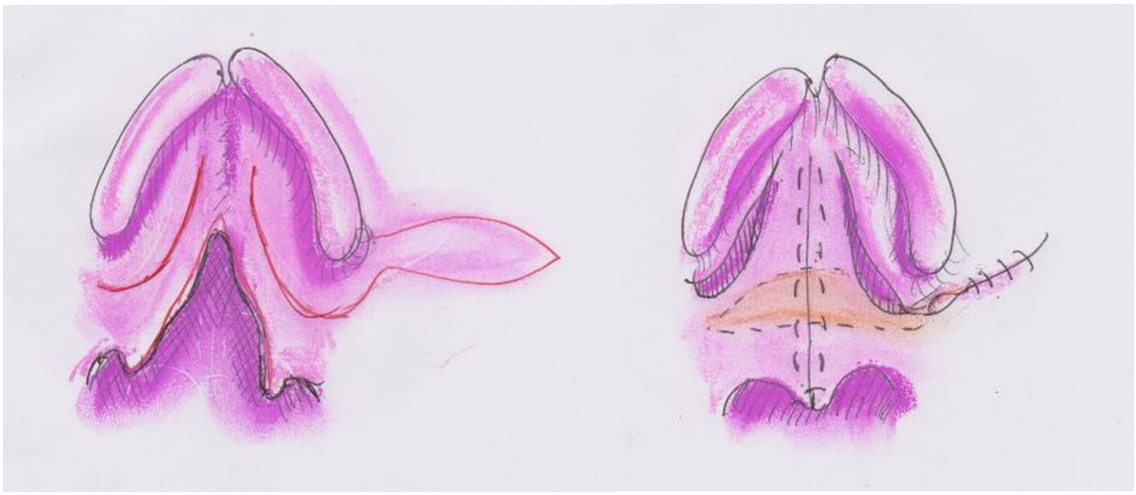
Why does cleft lip/palate occur?

The face and the palate forms during the early stage of pregnancy (from the 4th to the 8th week post conception). At week 5, all faces have clefts (gaps) and the palate is in two halves. The gaps then close over the next few weeks. If the two halves of the palate do not fuse, the result is a cleft palate. It is not understood why parts of the palate do not fuse properly. In some cases there is a family history of clefts. In most cases there is no single cause and the reason is never discovered. Having a first-degree relative (ie mother, sister, daughter) increases the risk of clefts by about 40 times.



What does surgery involve?

We usually repair isolated cleft palates at six to seven months of age. The operation involves repair of the hard palate and of the soft palate. The most important part of the operation is joining up the palate muscles in a more normal position.
Children with a cleft lip as well as a cleft palate may have their hard palate repaired at the same time as their lip repair (Vomerine flap) at 3 months and need to return for a second operation at 9 months or 1 year to have the soft palate repaired.
Sometimes, the operation involves making some cuts along the sides of the palate to allow the two halves of the palate to be brought together.
The following diagram illustrates a cleft palate repair technique used in this unit. It also shows a cheek flap (buccal flap), being used to add to the nasal layer. The cheek flap is only necessary in very wide clefts.



What happens before the operation?

You will receive information on how to prepare your baby for the operation in your admission letter. You will need to bring your baby to the ward the day before the operation is due, so that all the preparation can be done to allow an early start the following morning. Your baby will need to have a medical check up and blood test to check everything is fine before the operation. The doctors will also need to see you to explain the operation again, discuss any worries you may have and ask you to sign a consent form. If your baby has any medical problems, such as allergies, please tell the doctors. If your baby is on any medications, please bring these with you. An anaesthetist will also visit you to explain your child's anaesthetic in more detail.

Is there anything that I should do before the operation?

Where possible, it is advisable to keep your baby away from children or adults who have colds, 'flu or other infections, to reduce the chances that your baby's operation will have to be postponed because he or she is not well.

Ideally soothers (dummies) should be avoided in babies with clefts and we would prefer that babies with dummies are weaned off it before the operation. However, each baby is different if this is not possible it is not a major cause for worry.

How long will the operation take?

Your baby will be off the ward for two to four hours, depending on the extent of the cleft. The procedure itself takes about one and a half hours.

Who performs the operation?

The operation is performed by the cleft specialist plastic surgeon on the team.

What anaesthetic is used?

The baby is given a general anaesthetic by a consultant anaesthetist who specialises in giving anaesthetics to babies and children. One parent will be able to go with the baby to the anaesthetic room for the beginning of the anaesthetic. This usually involves the baby breathing some anaesthetic gas until sleepy. Later, a tube is passed into the wind pipe (trachea) to safeguard breathing during the operation. A drip is put in a vein and usually left in place for a short time after the operation. Fluids can be given to your baby through the drip during the operation and afterwards if necessary.

How the operation is performed

The operation involves joining the parts of the palate which have not joined before birth. The surgeon does this under magnification to allow the small structures to be accurately joined. It is not always possible to completely repair the palate in one go. Sometimes it is better to close the hard palate using an operation called a Vomerine flap. This is allowed to heal and settle and when everything is ready about 3 – 6 months later the remaining soft palate can be repaired. The important part of repairing the soft palate involves teasing out the muscles of the soft palate which are usually in the wrong position. The muscles on either side of the cleft are then re-directed and stitched to each other across the midline. These muscles will hopefully allow the palate to move and close the gap at the back of the throat as happens normally during speech and swallowing. The lining of the palate is repaired with dissolvable stitches.

When can I see my baby after the operation?

Your baby will go to the recovery room after the operation and one parent may go to be with the baby as he or she is waking up. Because local anaesthetic is injected into the area while your baby is asleep, your baby will probably not be feeling any pain at this stage. Your baby may be distressed however, this is mostly due to hunger. There may well be a little blood around the face but do not be concerned about this. Occasionally, a tube will have been placed through one nostril to help the baby to breathe.

When can my baby feed?

We are happy for your baby to feed as soon as he or she is awake after the anaesthetic. The first feed may be difficult, partly because of the numbness of the mouth.

What happens afterwards?

At first there may be some bleeding from the mouth, but this usually stops quickly. Only very rarely will any further measures be necessary stop the bleeding. The corners of your baby's mouth may become sore after the operation but this will improve within a few days.

When your baby has returned to the ward, the regular diet of milk and puree food may be offered in the normal manner as soon as he or she is awake. If your baby is not happy to drink from the bottle, fluids may be taken more easily from a spoon, syringe or beaker. If your baby is reluctant to drink it may be necessary to give extra fluid through the drip. The drip will be removed once the baby is drinking well again. It is important to give your baby some sterile water after each feed to keep the wound clean.

Your baby will have a sore mouth after the operation and so may not feel like eating or drinking much. Various medicines can be given at regular intervals to help ease the pain and make feeding more comfortable.

A course of antibiotics will be prescribed to reduce the risk of infection. You will need to continue giving this medicine for a few days after leaving hospital to complete the course.

When you get home… … ..

By the time your baby goes home he or she should be getting back to the normal feeding pattern. The stitches in the roof of the mouth will gradually disappear but for as long as they are still there you should continue to clean your baby's mouth with cooled boiled water each time after eating, drinking or taking medicine.

Try to stop your baby putting his or her fingers or any toys into the mouth as this could damage it. Most babies will not but their fingers into their mouth during this time but if there is concern, we can wrap the baby's hands to prevent him/her from using them. Try to avoid using a dummy for the first two or three weeks.

You should call the ward or the cleft team if:

- You are concerned in any way about your baby's operation
- Your baby develops an infection in the mouth
- Your baby has a raised temperature of 37.5° and paracetamol / Calpol does not bring it down
- Your baby is irritable and does not feel like feeding
- Your baby is in a lot of discomfort and pain relief does not seem to help
- Your baby's mouth starts to bleed
- Sometimes it may appear that a hole has appeared where the palate has been joined. This may close by itself and in general we would not need to be told about it, but if you have any special concerns contact us

The next few months

After your baby has had a cleft palate operation, he or she will need to come back to the hospital for an outpatient appointment the following week and about three months after the operation. These appointments will either be arranged on discharge or sent to you in the post.

Hopefully, when the initial discomfort settles, your baby's feeding should improve and he or she should start babbling and beginning to produce hard sounds such as "b" and "d".

What are the risks of surgery?

1 bleeding postoperatively:
Usually there is some minor bleeding after the operation, but this stops after a few hours. More significant bleeding is uncommon but would require a trip back to the operating theatre. Bleeding occurring 5-6 days after the operation is very rare and may be a sign of infection. Should this occur, bring the baby back to the hospital straight away and inform the on-call plastic surgery team.

2 Infection
If the palate becomes red, and the baby is irritable, not feeding well or has a temperature, it could be a sign of infection. Call the team and/or GP as a change of antibiotics may be required.

3 Repair breakdown
This is rare and usually occurs as a result of infection. It is usually not possible to re-stitch the Wound. The palate may need to be repaired again at a later date.

4 Fistula
Sometimes a hole develops in the repair. Food may come out the nose; nasal regurgitation. If it is a large hole, the palate may need to be re-repaired.

5 Poor growth
Surgery to the palate, particularly to the hard palate may cause adverse scarring which may restrict local growth. This can result in very crooked teeth and even restrict growth of the upper jaw /midface. Poor growth in this area causes problems for dental occlusion requiring orthodontic treatment. In severe cases orthognathic surgery may be required

6 Poor palatal function, poor speech
Sometimes, despite repair, the palate is too short or scarred to work properly and air leaks up the back of the palate into the nose during speech. This may also need further surgery such as a pharyngo plasty when the child is 4 to 5 years old.

7 Anaesthetic problems, chest infection, Air way issues.
Babies can be very irritable after an anaesthetic, but this settles after a day or so. They may have a sore throat or even develop a chest infection. It is very rare for the upper airways to swell and cause problems but this would be an emergency. Babies are closely monitored with an oxygen probe for the first night to alert the team to an airway problem. Sometimes the baby might need an inhaler or have the breathing tube reinserted should this problem arise. Fortunately, this situation is rare.

If you have any questions, please call:

Baby or Children's surgical ward
Cork University Hospital
Switch; 0214546400

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Secretary to Mr O'Broin
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Plastic surgical Registrar on call
Cork University Hospital
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Cork cleft service 2019

NURSING INSTRUCTIONS Post Op post palate repair / Vomerine flap

- Feed as soon as possible using whatever bottle / teat the baby is used to.
  If this is problematic and baby is refusing to take a teat try spoon or syringe.
- IV fluids should be maintained until taking sufficient orally.
- Clean with sterile water or wash around suture line with a syringe of sterile water after every feed to avoid deposits of milk getting stuck to the suture line.
- Sats monitor for 12 to 24 hours and Apnoea monitor subsequently.
- Supplementary O2 if dropping sats in early post op period and nurse with head to one or other side
- Watch for excessive bleeding particularly after vomerine flap which creates a raw area that can bleed.
- Routine obs
- Analgesia and Antibiotics for 5-7 days