Patient

View this article online at: patient.info/ears-nose-throat-mouth/cleft-lip-and-palate-leaflet

Cleft lip and palate

Cleft lip and palate are facial abnormalities which can affect babies at birth. They are common worldwide and can affect the lip, the palate or both. If untreated they can lead to feeding difficulties early on, and psychological difficulties as your child grows up. However, modern treatment begins early in the baby's life, with surgery to correct the defect, and continues as the baby grows. The expert nature of modern surgery means that the health, development and appearance of a baby with cleft lip and palate should not be affected.

What are cleft lip and cleft palate?

The word cleft means a a gap or split. Clefts can be in the upper lip, the roof of the mouth (palate), or sometimes both.

In the womb (uterus) a baby's face is formed of several parts coming together, like petals of a flower. Cleft lip and palate (CLP) occurs when the upper areas of the central face do not quite join together properly, leaving a gap in the palate, the upper lip, or both.

How common is cleft lip and palate?

CLP is the most common facial birth defect in the UK. It affects about one in every 700 babies. The type of cleft and its severity vary considerably. It may affect the lip, the palate, or both. Nearly half of all affected children have a cleft palate. Around a quarter have a cleft lip alone and about a quarter have both a cleft lip and palate.

One-sided cleft lip is more common than the two-sided type, which affects only about 1 in 10 children with cleft lip. One-sided clefts are more commonly on the left side.

Who is most often affected by cleft lip and palate?

About two thirds of cases occur in babies with no other medical problems. Boys are affected by CLP slightly more often than girls. However, clefts of the palate alone are more common in girls.

CLP is most common in people of Asian and Native American descent. It is least common in people of African ethnicity. The condition is becoming less common.

Can cleft lip and palate be detected before birth?

Lip clefts may be detected by antenatal scans (ultrasound) at around 20 weeks of gestation. A prenatal ultrasound is a test that uses sound waves to create pictures of the developing baby (fetus). However, many are not noticed on these early scans, so not all parents are forewarned. Palate defects alone are not usually seen on ultrasound scan.

If ultrasound shows a cleft, your doctor may offer further tests - usually a procedure to take a sample of amniotic fluid from your uterus (amniocentesis). The fluid test is to find out whether the fetus has inherited a genetic syndrome that may cause other birth defects. However, most often no genetic cause is found.

See the separate leaflet called Pregnancy Screening Tests for more information on this.

What problems can cleft lip and palate cause?

As CLP may be very visible, it can be a shock to new parents. CLP can sometimes affect the way a mother initially bonds with her baby. However, some mothers say they quickly came around to accepting their baby's unusual appearance, so that after a short time it no longer seems strange.

CLP can affect early feeding. Babies can usually manage breastfeeding but may struggle with bottle-feeding without help, because this is more difficult if the lip or palate has a cleft. Normally, when babies feed they breathe through their noses and produce a vacuum in their mouths to suck. When there is a cleft in the palate or lip babies can't make this vacuum. Babies with CLP can also have difficulty managing to breathe and feed at the same time. Simple devices are available to help babies with CLP feed before corrective surgery takes place.

Once it has been corrected, CLP should not affect a baby's health and welfare.

In places where healthcare resources are poor, babies with CLP may fail to feed well. This can affect their health and even their survival. Children with uncorrected CLP may also have considerable problems in later life. This is due to society's lack of acceptance of a facial abnormality and to the poor self-image that they develop. They may also have problems with speaking and hearing. There are now a number of organisations offering CLP surgery in developing countries, since this operation can change children's lives.

What causes cleft lip and palate?

The exact cause is not known. It is thought to involve a mixture of genetic and environmental factors affecting the baby in the womb (uterus). 'Genetic' means that the condition is passed on through families through their genes.

The failure of development of the upper lip and palate occurs early in pregnancy, between the fifth and ninth weeks.

What are the genetic factors in cleft lip and palate?

If both parents are unaffected but have a baby with a cleft, the chance of the next child being affected is around 1 in 40. If one of the parents has a cleft, the risk of a cleft in their baby is about 1 in 20 for each pregnancy.

What medical conditions make cleft lip and palate more likely?

There is some evidence that women diagnosed with diabetes before pregnancy may have an increased risk of having a baby with a cleft lip with or without a cleft palate.

There is some evidence that babies born to obese women may have increased risk of CLP. palate.

Do medicines, drugs or smoking cause cleft lip and palate?

Researchers are still trying to identify things which may contribute to the failure of the facial sections to close together properly in babies with CLP.

- Some types of medicines, if taken during early pregnancy, are known to increase the risk. These include some epilepsy medicines such as phenytoin, isotretinoin, and sodium valproate. They also include benzodiazepines and steroid tablets.
- Smoking around the time of conception and in the first ten weeks seems to increase the risk.
- Alcohol use in the first twelve weeks of pregnancy, particularly if you are binge drinking, also increases the risk.
- Researchers are unsure whether a shortage of folic acid, of other vitamins, and of zinc are important, and whether cholesterol levels may be important. See the separate leaflet called Diet and Lifestyle during Pregnancy for further information on antenatal care.

At the moment much of this is uncertain. If you have epilepsy and are taking antiepileptic medicine then, if possible, you should talk to your specialist about your medication before you try to get pregnant. They may recommend changing you to a more modern medicine that is not thought to increase the risk of CLP. The downside of a change in medicine is that, if your epilepsy is controlled and you have a driving licence, you will have to give it up for a time.

What are the types of cleft lip and palate?

CLP usually involves only the upper lip and/or palate. Very rarely other parts of the face are also affected.

Cleft lip and bilateral cleft lip

If the cleft affects the lip only and does not affect the palate it is known as cleft lip.

Clefts of the upper lip are 'off-centre' - they may be just on one side, or the clefts may be on both sides of the centre of the upper lip (bilateral cleft lip means cleft lip on both sides).

There may be a small gap in the lip (complete cleft) with the split running from the point on a 'cupid's bow' lip (the philtrum) to the nostril. Or there may just be an indentation (partial or incomplete cleft). A partial cleft may be very small.

Cleft palate (with or without cleft lip)

Cleft palate occurs when the two plates in the base of the skull which form the roof of the inside of the mouth (the hard palate) fail to join together The cleft is central in the palate. Most commonly, cleft lip is also present.

A complete cleft palate involves both hard and soft palates.

A partial cleft can affect just the soft palate, forming a hole in the roof of the mouth. The dangly piece of tissue at the back of the throat (the uvula) is usually also split. Submucous cleft palate is a very slight cleft palate which involves only a split uvula, a furrow on the soft palate and a notch on the back of the hard palate. The hole in the roof of the mouth connects the mouth (oral) cavity to the nose (nasal) cavity. As a result, if the hole is not closed, the voice is affected.

What will a baby with a cleft lip and palate be like?

There may be an obvious gap in your baby's lip. Doctors will examine your baby's mouth to see if there is also a hole in the palate.

Your baby may have difficulty bottle-feeding, although most babies are able to be breastfed. Special teats and bottles are available to help your baby feed. A further option is to use a dental plate to seal the roof of the mouth.

Some babies with CLP gain weight very slowly at first, but they usually catch up by the age of 6 months.

Do babies with cleft lip and palate have other abnormalities?

Most babies with CLP have no other conditions. However, all babies with CLP are carefully examined by a children's doctor (paediatrician) to look for rare conditions that can be associated with CLP. Your baby may also have chromosome tests (blood tests which can detect some genetic conditions) performed. Some of the rare conditions which can have CLP as a part of a group of other symptoms include:

- Apert's syndrome.
- Goldenhar's syndrome.
- DiGeorge syndrome.
- CHARGE syndrome.
- Pierre Robin syndrome.
- Edwards' syndrome.
- Patau's syndrome.
- Trisomy 15.
- Van der Woude syndrome.

What other problems might cleft lip and palate cause?

If CLP is corrected the chances of ongoing problems are small.

If CLP is left uncorrected, psychosocial problems are likely to occur. These include problems with self-image, behaviour, anxiety and depression. There are many charities working in the developed world to correct CLP in babies who might otherwise grow up to experience these difficulties.

What is cleft lip surgery?

Children with CLP are managed by a multidisciplinary team. This is usually in a specialist CLP centre, of which there are nine in England and Wales, with separate specialist networks in Scotland and Northern Ireland.

The team approach includes cosmetic surgeons, craniofacial surgeons, ear, nose and throat surgeons, speech and language therapists, dentists, orthodontists, psychologists and specialist nurses. They provide support and treatment until growing is complete at around the age of 18 years.

Surgery is the main treatment. A series of operations will be required as the child grows.The first lip closure is usually performed at three months after birth. Palate closure is performed at 6-12 months. Further operations are performed to improve appearance and tooth growth.

The goals of treatment are to improve your child's ability to eat, speak and hear normally and to achieve a normal facial appearance

Following the initial cleft repair, your doctor may recommend follow-up surgeries to improve speech or improve the appearance of the lip and nose.

When is cleft lip surgery performed?

These surgeries begin early, in your baby's first few months of life. He or she will be given a general anaesthetic, so he or she won't feel pain or be awake during surgery. Several different surgical procedures are used to repair CLP, reconstruct the affected areas and prevent or treat related complications.

Cleft lip repair

This is usually performed within the first 3 to 6 months of age. To close the separation in the lip, the surgeon makes incisions on both sides of the cleft and creates flaps of tissue. The flaps are then stitched together, including the lip muscles. The repair should create a more normal lip appearance, structure and function. Initial nasal repair, if needed, is usually done at the same time.

Cleft palate repair

This is usually performed well before the age of 12 months. The separation is closed and the surgeon will aim to rebuild the roof of the mouth (hard and soft palate). The surgeon makes incisions on both sides of the cleft and repositions the tissue and muscles. The repair is then stitched closed.

Follow-up surgeries may be needed between age 2 years and the late teen years.

Ear tube surgery

For children with cleft palate, ear tubes (grommets) may be placed to reduce the risk of build-up of chronic ear fluid, which can impair hearing and therefore language. Ear tube surgery involves placing tiny bobbin-shaped tubes in the eardrum to create an opening to allow drainage.

Surgery to reconstruct appearance

Additional surgeries are sometimes needed to improve the appearance of the mouth, lip and nose. This kind of surgery can improve your child's appearance, quality of life, and ability to eat, breathe and talk.

What non-surgical treatments are offered?

Other help is offered, if and when your child needs it. This can include:

- Feeding strategies, such as using a special teat device.
- Speech therapy to help speech development.
- Orthodontic adjustments to the teeth and bite, such as having braces to straighten teeth.
- Monitoring by a paediatric dentist.
- Monitoring by an ear, nose and throat specialist

What other problems might affect a baby with cleft lip and palate?

CLP affects the shape of structures around the mouth and nose. This includes the tubes from the throat to the middle ear (Eustachian tubes) and the teeth. As a result, children who have been born with CLP are more likely to experience several conditions which are (in any case) common in unaffected children too. These include glue ear, hearing difficulties and dental problems (caries and misaligned teeth).

How do I support my child with cleft lip and palate?

- Your child may need extra support with feeling different, particularly if they need a lot of surgery, or develop additional problems with hearing or speech.

- Focus on them and not their condition.
- Don't feel that you've failed them.
- Point out positive qualities in others that don't involve physical appearance.
- If teasing or self-esteem issues arise at school, talk to your child and to the school about this.
- Consider joining child and parent support groups such as CLAPA.
- If your child is distressed it may help them to talk to a school counsellor, or to specialist nurses on the CLP team who may work with many young people.

What is the long-term outlook for children with cleft lip and palate?

Your baby should achieve a normal appearance, and normal speech and eating habits very early in the process.

Can cleft lip and palate be prevented?

Until the causes are absolutely understood, this remains unclear. Pre-pregnancy planning seems to reduce risk, involving good diet and avoidance of alcohol, cigarettes and certain medicines. Research continues into other things which may affect the risk.

Dr Mary Lowth is an author or the original author of this leaflet.

Further reading

- Orofacial Cleft 1, OFC1; Online Mendelian Inheritance in Man (OMIM)
- Cleft Lip and Palate Association (CLAPA)

Last updated by: Dr Mary Elisabeth Lowth, FRCGP 18/09/2018	
Peer reviewed by: Dr John Cox, MRCGP 18/09/2018	**Next review date:** 17/09/2023

View this article online at: patient.info/ears-nose-throat-mouth/cleft-lip-and-palate-leaflet

Discuss Cleft lip and palate and find more trusted resources at Patient.