

Cleft lip and palate

A cleft is a gap or split in either the upper lip or the roof of the mouth (palate), or sometimes both. It occurs when separate areas of the face do not join together properly when a baby is developing during pregnancy.

The face and upper lip develops during the fifth to ninth week of pregnancy. Most cleft problems can either be picked up at the routine 20 week scan or soon after birth. However, a submucous cleft, where the cleft is hidden in the lining of the roof of the mouth, may not be detected for months or even years.

A cleft can lead to feeding, speech and hearing problems, ear infections, dental decay, jaw development problems and psychosocial issues.

What causes cleft lip and palate?

The exact cause of clefts is not known, although evidence suggests they are caused by a combination of genetics and environmental factors, such as smoking and drinking in early pregnancy and a lack of folic acid in the mother's diet.

Cleft lip and palate can occur on its own (non-syndromic) or can sometimes be part of a wider series of birth defects (syndromic).

Who is affected?

A cleft lip and palate is the most common facial birth defect. One in every 700 babies is born with a cleft. The type of cleft and how severe it is can vary widely between children.

Approximately half of all affected babies are born with a cleft lip and palate, a third with a cleft palate only, and 1 in 10 have a cleft lip only or a submucous cleft.

A cleft lip or combined cleft lip and palate are more common in boys, but a cleft palate on its own is more common in girls.

Outlook

Surgery is the usual treatment for cleft lip and palate, with good results. After treatment most children have a normal appearance, with minimal scarring and normal speech.

All types of treatment for cleft lip and palate are available on the NHS. A long-term, structured care plan from a team of cleft specialists is usually needed to help children born with clefts. Ongoing or follow-up treatment that lasts for up to 20 years is often required.

Symptoms of cleft lip and palate

There are two types of cleft lip:

unilateral cleft, where the cleft occurs on one side of the lip

bilateral cleft, where the cleft occurs on both sides of the lip

The appearance of the cleft lip can be anything from a small notch in the lip (incomplete cleft) to a wide gap that runs all the way up to the nostril (complete cleft lip).

The appearance of a cleft palate can range from an opening at the back of the soft palate towards the throat, to an almost complete separation of the roof of the mouth.

As well as affecting appearance, a cleft lip and palate can also cause associated symptoms which are outlined below.

Hidden cleft palate

Cleft lip and palate is visible at birth. However, a type of cleft palate called a submucous cleft palate can be hidden by the lining of the roof of the mouth.

You should take your child to see your DOCTOR if they develop the following symptoms:

milk frequently comes out of the nose when feeding

an inability to suck through a straw or blow out candles

nasal-sounding speech

These symptoms may indicate a submucous cleft palate.

Causes of cleft lip and palate

A cleft lip or palate happens when the structures that form the upper lip or palate fail to fuse together properly when a baby is developing in the womb.

In most cases the exact cause is unknown, but it's thought to be a combination of genetic (internal) and environmental (external) factors.

Inherited genes

Research indicates that the genes a child inherits from their parents make them more vulnerable to developing a cleft lip or palate. A number of genes have been identified that may be responsible.

In some cases there is a family history of clefts, although most children of parents with clefts will not develop them.

Environmental risk factors

A number of things have been identified that may increase a child's chance of being born with a cleft lip or palate. These are outlined below.

Lack of folic acid during pregnancy

All pregnant women are advised to take a daily supplement of folic acid during the first four months of pregnancy. Folic acid helps reduce the possibility of birth defects. One study found that the risk of having a child born with cleft lip or palate was more than four times higher if mothers did not take folic acid in the first three months of pregnancy.

Smoking

A mother who smokes during pregnancy increases her baby's chance of being born with a cleft. The risks from passive smoking are not fully known, but it is a good idea to avoid breathing in high levels of secondhand smoke.

Alcohol consumption

Some studies have shown a link between a mother's alcohol consumption during pregnancy and the development of a cleft lip or palate in her baby.

Obesity and nutrition

Mothers who are obese have a higher chance of their child being born with a cleft. Poor nutrition during pregnancy can also increase the risk.

Medications during pregnancy

It has been suggested that some medications taken during pregnancy may increase the risk of cleft lip and palate. These include:

methotrexate, a medicine used to treat cancer, arthritis and psoriasis

isotretinoin, a medicine used to treat acne

anti-seizure medicine

Speak to your DOCTOR or midwife if you are concerned about any medication you are taking during your pregnancy.

Pierre Robin syndrome

Pierre Robin syndrome is a rare condition where a baby is born with an abnormally small lower jaw, which causes the tongue to fall backwards in their throat (glossoptosis). This can result in obstruction and breathing difficulties.

Most infants with Pierre Robin syndrome will also have a cleft palate.

The cleft can usually be repaired with surgery, although treatment may be delayed if there are continuing issues with airway obstruction. The lower jaw usually has some 'catch-up' growth later and orthodontic treatment can further help the bite

Diagnosing cleft lip and palate

Clefts in unborn babies are often picked up with an ultrasound examination during the routine 20 week antenatal appointment. The cleft nurse specialist will then normally be in contact with you and arrange to meet you.

If cleft lip and palate is not detected during the scan, it is nearly always diagnosed soon after birth. However, some clefts – such as a submucous cleft palate, where the cleft is hidden by the lining of the roof of the mouth – may not be detected for several months or even years, when speech problems develop (see symptoms of cleft lip and palate).

Specialist cleft team

As soon as a cleft has been diagnosed, you and your child will be referred to a cleft team. An arrangement can also be made for a specialist nurse to visit you to help with feeding and answer any questions you have. The specialist nurse will liaise with other healthcare professionals involved with your child's care.

Treating cleft lip and palate

In this section, the term cleft refers to a cleft lip, cleft palate, or a cleft lip and palate. Specific types of cleft are only referred to when necessary.

Cleft clinics and treatment teams

In England, all children born with a cleft are referred to a specialist cleft clinic. Specialist cleft clinics are dedicated medical centres that provide ongoing support to children and parents.

The cleft treatment team is made up of healthcare professionals from different specialist backgrounds who work closely together. The team includes:

a specialist cleft nurse, who will provide initial advice about feeding and act as your first point of contact

a cleft surgeon, who will carry out the repair of the cleft

a paediatrician, a doctor who specialises in treating children

an audiologist and an ear, nose and throat (ENT) surgeon, who will both assess and treat hearing conditions

a speech and language therapist, who will assess and treat speech problems

a paediatric (children's) dentist, who will help prevent dental decay

an orthodontist, who specialises in dental and jaw development and will straighten the teeth with braces

a restorative dentist, who specialises in replacing missing teeth

a psychologist

The core members of the team will be available at the outpatient cleft clinic appointments to give you advice and answer any questions you may have.

Care plan timetable

Most children with clefts will receive the same type of care plan tailored to meet their individual needs. A typical care plan timetable is described below:

birth to 6 weeks: counselling for parents, hearing test and feeding assessment

3 months: surgery to repair a cleft lip

6-12 months: surgery to repair a cleft palate

18 months: speech assessment

3 years: speech assessment

5 years: speech assessment

8-11 years: bone graft to the cleft in the gum area (alveolus)

11-15 years: orthodontic treatment and monitoring jaw growth

18 years+: if needed, jaw surgery, lip and nose revision surgery, and final replacements for any missing teeth

Once the initial care plan has been completed, your child will attend regular outpatient appointments at the cleft clinic so that their condition can be monitored closely and any problems can be dealt with.

Important records are taken at key stages of development at age five, 10, 15 and 20 years to monitor how treatment has progressed over time.

Feeding

If your baby has a cleft, their feeding will need to be assessed so that problems can be resolved. Many babies with a cleft palate have problems breastfeeding due to the gap in the roof of their mouth.

If your baby has difficulty feeding, your specialist cleft nurse can advise on alternative feeding methods. Some babies respond better to alternative feeding methods than others.

One method that works well for some women is expressing breast milk and using a specially made flexible bottle for feeding.

Lip repair surgery

Lip repair surgery is usually carried out when your child is three months old. Your child will be given a general anaesthetic (where they are unconscious) and the cleft lip carefully repaired, including underlying muscles. The nose is usually reshaped at the same time.

The operation usually takes about an hour, although it can take longer if the cleft is severe. The surgery usually leaves a slight scar, but the surgeon will attempt to line up the scar with the natural lines of the lip to make it less noticeable.

Palate repair surgery

Palate repair surgery is usually carried out when your child is six months of age. The muscles and the lining of the palate are rearranged and usually no extra tissue is needed to complete the operation.

The operation usually takes about one-and-a-half hours and is carried out under general anaesthetic.

Additional surgery

In some cases, additional surgery may be needed to improve the appearance and function of the lips and mouth. For example, if there is a cleft in the gum, the surgeon will perform a bone graft operation when the child is between nine and 12 years of age. If the jaws have not grown equally, they can be corrected by braces and jaw surgery at the end of growth, at approximately 18 years of age.

Your cleft care team can tell you whether further surgery is required.

Hearing

Children with a cleft palate are more likely to develop a condition called glue ear. If hearing is significantly reduced, the ENT surgeon may recommend inserting a tiny plastic tube called a grommet into the eardrum. This lets out the sticky secretions and allows air in. Sometimes, a hearing aid may be recommended.

An audiologist (hearing specialist) will assess your child's hearing at birth and a second hearing assessment will take place once your child has had

reconstructive surgery. Your child's hearing will also be regularly assessed during their outpatient appointments.

Speech and language therapy

Repairing a cleft palate will significantly reduce the chance of future speech problems. However, approximately half of all children with a repaired cleft palate still need some form of speech therapy. Further corrective surgery may be required for a small number of children who have increased airflow through their nose when they're speaking.

A speech and language therapist (SLT) will carry out an initial assessment after surgery, followed by a further assessment once your child is three years old. If the assessment reveals problems with your child's pronunciation and use of language, the SLT will teach you speech exercises to help your child's development. They may also carry out a number of one-to-one exercises with your child. Children born with cleft lip only do not normally need further therapy.

The SLT will work with your child for as long as they need assistance. Therapy is not usually needed after the age of seven, though specialist investigations may be necessary.

Dental care

When the cleft involves the gum area, it is common for teeth on either side of the cleft to be tilted or out of position. Often a tooth may be missing, or there may be an extra tooth. The paediatric dentist will monitor the health of your child's teeth and recommend treatment when necessary. It is also important that you register your child with a family dentist.

Orthodontic treatment, which helps improve the alignment and appearance of teeth, may also be required. Treatment can include using braces or other dental appliances to help straighten the teeth. Orthodontic treatment will also monitor the development of the jaws and the bite during growth.

Children with a cleft are more vulnerable to tooth decay, so it is important to encourage them to practise good oral hygiene.

Problems related to a cleft lip and palate

Giving birth to a baby with a cleft can have a profound psychological impact both on the parents and the child.

It is common for parents to feel guilty, angry, shocked, helpless or disappointed.

It is important to realise that in most cases a cleft cannot be prevented and that you are not to blame. Some parents may worry that they will be unable to bond with a child who has a cleft, but there is no evidence that this is the case.

Your cleft care team will be used to supporting parents during the difficult time that can follow the birth of a baby with a cleft. Take this opportunity to express any concerns and worries you have and ask as many questions as you want.

Some parents find that learning as much as they can about the condition helps them cope better. Talking to other parents in similar circumstances can also help reduce feelings of anxiety and isolation.

Psychological impact in children

A cleft can also have a psychological impact on a child, particularly as they get older and begin to mix with other children.

Experts advise explaining the condition to your child as soon as they are old enough to understand. Treat it as a normal topic of conversation. The clinical psychologist in the team will be able to give further support with this.

It is best to be realistic about the possible length of treatment your child might require and its likely outcomes. Ongoing treatment lasting for up to 20 years is usually required for most children with a cleft. Although this can be upsetting, giving your child false hope and unrealistic expectations could be more damaging in the long run.

You can also help strengthen your child's independence by involving them in the decision-making process about their treatment and their life in general.

If you are worried about your child's social or psychological development, speak to your specialist cleft nurse. They can arrange an assessment and any necessary counselling and support.

Feeding problems

Babies with a cleft may have problems feeding, particularly if the cleft includes the palate, as the baby may not be able to suck adequately. However, feeding can usually be established quickly with assistance and sometimes the use of a special bottle.

Hearing

Children with a cleft palate often develop a condition called glue ear, where sticky fluid collects in the middle ear behind the eardrum. This may reduce their level of hearing and can sometimes cause ear infections. It is therefore important that all children with a cleft palate have their ears and hearing checked regularly by an audiologist.

Speech and language problems

The roof of the mouth (palate) plays an important role in helping your child form sounds for speech.

If a cleft palate is not repaired with surgery, it will lead to speech problems when the child is older. The cleft palate is therefore carefully repaired before speech development starts and in many cases the child goes on to develop normal speech.

About half of all children with a repaired cleft palate will need speech therapy, and a small number may need further surgery. Over time, a specialist speech and language therapist will monitor the child's speech development.

Dental health

A cleft lip and palate can cause changes to the structure of the mouth and lead to problems with the development of teeth, making children more vulnerable to tooth decay. It is therefore important for the child to have their teeth checked regularly.

Tooth decay

Children with clefts are more likely to develop tooth decay. This is partly due to crowding of the teeth, which makes it more difficult to keep them clean. The advice below may help reduce your child's risk of developing tooth decay.

Your child should have a dental check-up at least once every six months.

Encourage your child to brush their teeth after every main meal. When they are at school, you could put a small tube of toothpaste and a toothbrush in their lunchbox.

Using a fluoride mouthwash once a day will help protect your child's teeth against decay.

Limit the amount of sweet and sticky food and drink your child consumes, especially between meals, as these foods increase tooth decay.

Limit the amount of starchy foods such as crisps, white bread and biscuits that your child eats, especially between meals, to lower the risk of tooth decay.

Preventing cleft lip and palate

In many cases, it is not possible for a cleft lip and palate to be prevented. However, pregnant women can lower the risk of their child being born with a cleft lip and palate by following the advice below.

Avoid smoking and drinking alcohol while pregnant

During pregnancy, maintain a healthy lifestyle and avoid smoking and drinking alcohol. Ensuring you have a healthy pregnancy will help lower the risk of your baby developing a cleft.

See the pregnancy and baby guide for more information and advice on how to have a healthy pregnancy.

Folic acid supplements

The Department of Health recommends that all women take a daily supplement of 0.4mg of folic acid before they conceive and for the first 12 weeks of pregnancy while the baby's spine develops.

Taking folic acid is known to cut down on other birth defects and there is increasing evidence that taking folic acid in early pregnancy cuts the risk of

cleft lip and palate births. One 2012 study of 11,000 babies born in Ireland found the risk was more than four times higher for mothers who did not take folic acid in the first three months of pregnancy.