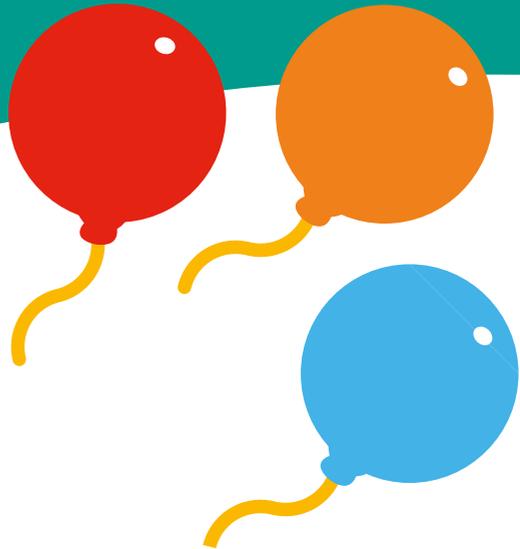


Cleft palate

Information for parents



Leeds children's
hospital

caring about children



The Northern & Yorkshire
Cleft Lip & Palate
service

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The Northern and Yorkshire Regional Cleft Lip and Palate Service have produced this booklet to help you understand what a cleft palate involves and how it will affect you and your child. The aim of this booklet is to answer some of your questions and concerns that you may have during the first weeks.

The care of your baby involves several specialists from different backgrounds who work together as a Cleft Team. Your baby will be seen regularly by members of this team in order to plan future treatment, observe your child's progress and monitor future growth and development.

If you still have any questions at the end of this booklet then you may contact either your Specialist Nurse or any member of the team regarding their input.

The Cleft Lip and Palate Team

Specialist Nurse	Supports parents at home, helps with feeding
Speech and Language Therapist	Monitors and treats speech and language problems
Cleft Surgeon	Repairs the clefts
Geneticist	Looks into why the cleft happened
Paediatric Dentist	Children's Dentist
Orthodontist	Dentist who positions teeth with braces
Ear, Nose and Throat Surgeon	Monitors and treats hearing problems
Paediatrician	Doctor looking after children
Clinical Psychologist	Offers chance to talk through any difficulties with you or your child
Anaesthetist	Puts child to sleep for operations

Clefts of the palate are not uncommon and about one in every 700 babies born each year in the UK will be born with a cleft of one type or another.

Your baby has a cleft palate and initially you may feel upset and worry about coping, especially during the first few weeks. At the very outset we would like to reassure you that skilled help is available to assist you and your baby. Our aim is to provide you and your child with the highest standards of care and so obtain the best possible outcomes from treatment.

Initially it is not uncommon for parents to feel distress and to be overwhelmed at first. These feelings usually begin to fade as you begin to understand more about cleft palate, meet the specialists involved in the care of your baby and plan for future treatment. However if these feelings continue, further help and support is available from the professionals within the team.

The most important people in the team are
you and your baby

Please feel free to ask questions at any stage. Any of the specialists will be happy to discuss your child's treatment or arrange for you to talk with one of the other team members if this is felt to be more appropriate.

What is a cleft palate?

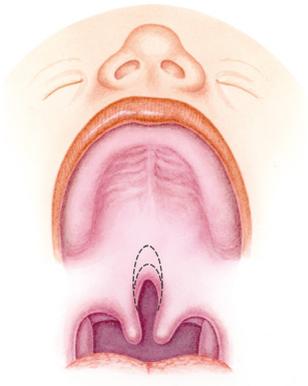
The word **cleft** means a gap between two sides. A **cleft palate** is a gap within the roof of the mouth. The palate separates the mouth and the nose.

The area behind the teeth and gums is called the **hard palate** and the muscular area at the back is called the **soft palate**. The cleft may extend from the soft palate into the hard palate.

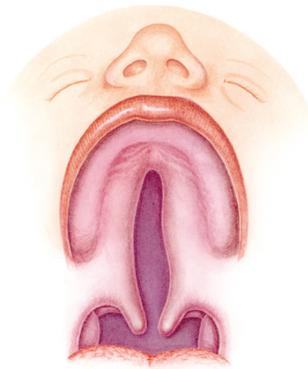
In some children the palate may look complete, but the muscles are not joined together. This is called a submucous cleft palate.

View looking inside the mouth

Cleft of the soft palate



Cleft of the soft & hard palate



How does a cleft palate occur?

The palate forms during the early stages of pregnancy. Initially it forms as separate halves that join together in the middle. If this joining does not occur then a gap (cleft) will be left.

Why did it happen?

It is not fully understood why this happens. As parents it is unlikely that you could have done anything to prevent this.

Sometimes there may be a genetic or inherited link and possibly a family history of a cleft. We may ask a doctor who looks at inheritance patterns (the Geneticist) to look into this further.

Occasionally parents may experience feelings of anger or guilt. Such feelings are often part of the necessary coping or adjusting process. Whilst these feelings vary in degree, they are all natural reactions and as such are understandable.

In time these early feelings usually pass as you become more confident in looking after your baby and become closely involved in the development of a future plan of care and treatment.

How will I feed my baby?

Some babies born with a cleft palate may have difficulty sucking effectively because air leaks into the mouth from the cleft. The wider the cleft in the palate, the harder it will be for your baby to create the suction needed in order to get the milk. Babies with cleft palate can appear to be sucking well, but the extra effort needed may lead to tiredness and poor weight gain.

With support and guidance from the Specialist Nurse, initial feeding difficulties can usually be overcome. Our experience shows that babies with a cleft palate can feed successfully and move on to a weaning diet at the correct age.

It is your choice how you would like to feed your baby, either by breast or bottle. Breast-feeding a baby with a cleft palate may prove more difficult, but it may be possible. However, your baby will need to have extra milk given from a special bottle. This can be your own breast milk or formula milk. If you are bottle feeding your baby, we will describe the specialist bottles available to overcome the problem caused by the cleft.

Your specialist nurse will provide some bottles and teats, and show you how to use them.

In our team, the Cleft Surgeons prefer the babies not to suck on a teat, immediately following their operation. So a free flow beaker should be encouraged at this time.

Extra feeding bottles can be ordered from CLAPA (Cleft Lip and Palate Association).

When you go home from the maternity unit you will continue to get support and advice from your Specialist Nurse, who will visit you at home.

When will the cleft palate be repaired?

The Cleft Surgeon is likely to operate on the cleft palate when the baby is between eight and nine months old. However, if your baby was born early or there are other medical conditions, then these times may change.

The operation is carried out under a general anaesthetic in hospital. Your baby will be given pain relief both in theatre and on the ward to keep them comfortable. Recovery is generally quick in babies and feeding is started shortly after the operation. The stay in hospital is usually between two to three nights. If you wish you can stay overnight with your baby. If you have other children it is understood that this can sometimes be difficult.

To prevent damage to the mouth after the operation, feeding should continue from a free flow beaker for at least four weeks. To keep the palate clean, you will need to give your baby water after each feed.

Dummies or pacifiers are not allowed either during this time. We also ask for your baby to wear small arm splints. The splints are to stop the baby putting things into their mouths, but do allow the baby to move their arms and grasp toys.

Will the cleft palate affect speech?

Many children born with a cleft palate will develop normal speech and language without the help of a Speech and Language Therapist. Problems can arise when the soft palate is not working properly and does not make a seal between the mouth and nose. Air can then escape into the nose when speaking. This can make speech less clear and have a nasal sound.

Some children may have difficulty in making certain speech sounds even though the palate is working well. The Speech and Language Therapist will monitor your child regularly, so that any problems can be picked up early and therapy offered if necessary.

Will the cleft palate affect hearing?

A cleft of the palate can affect the middle ear and lead to a build up of sticky secretions - a condition sometimes referred to as **glue ear**. This condition is quite common in all children, however it is more common when a cleft palate is present. Glue ear can lead to impaired hearing as such it is recommended hearing is monitored and treated if necessary.

If glue ear becomes a problem the an Ear Nose and Throat (ENT) Surgeon will make further assessments and advise if treatment is required.

The most common treatment currently in the UK is an operation to correct this by draining the sticky fluid and placing very small tubes into the eardrums. These are called grommets.

Increasingly glue ear is also being treated with hearing aids. Most treatments for glue ear are for a few years until the child grows out of it.

After the cleft palate has been repaired will any other operations be required?

In a small proportion of children, speech and language therapy is not enough to correct continuing speech difficulties and a further operation may be necessary.

The need for any additional surgery will be discussed with you and your child during your visits to the cleft clinic.

Is it possible to meet other parents who also have a child with a cleft?

Yes, your Specialist Nurse will know other families in your area and can introduce you to them.

The parent support group CLAPA (Cleft Lip and Palate Association) will also provide local contact with other families. Your Specialist Nurse can provide you with the details of CLAPA and a contact person for your area.

Compliments and complaints

We welcome feedback on our service. This can be sent directly to your team or problems can be raised through PALS (Patient Advice and Liaison Service). PALS is led by matrons and managers, who aim to sort out problems as quickly as possible.

Contact PALS via your hospital switchboard.

Contacts

Northern Area:

Newcastle Cleft Lip and Palate Team,
Royal Victoria Infirmary,
Queen Victoria Road,
Newcastle, NE1 4LP
Tel: 0191 282 0750

Yorkshire Area:

Leeds Cleft Lip and Palate Team,
Clarendon Wing
The General Infirmary at Leeds,
Great George Street,
Leeds, LS1 3EX
Tel: 0113 392 5115
<http://www.leedsth.nhs.uk/a-z-of-services>

CLAPA (Cleft Lip and Palate Association)

Tel: 020 7833 4883
www.clapa.com

Reference: Royal College of Surgeons (2001)
'The Treatment of Cleft Lip and Palate - A Parents' Guide'.
Jameson Press. Cheshunt, Hertfordshire.
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What did you think of your care?

Scan the QR code or visit bit.ly/nhsleedsfft

Your views matter

