Introduction

The Northern and Yorkshire Regional Cleft Lip and Palate Service have produced this booklet to help you understand what a cleft lip and 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.

Will the cleft lip and 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 if not picked up, monitored and treated if necessary.

The Ear Nose and Throat (ENT) Surgeon will examine the ears and arrange for hearing tests. If glue ear becomes a problem then the ENT surgeon may advise an operation to correct this by draining the sticky fluid and placing very small tubes into the eardrums. These are called grommets. With monitoring and where necessary treatment, your child should develop normal hearing.

Will the cleft affect my child’s teeth?

As the cleft involves the gum area (alveolus) in the top jaw, there may be an extra or missing tooth. Sometimes teeth near the gap may be twisted or may come through later than usual. The Orthodontist will carefully monitor how the teeth come through and bite together.

It is important that your child grows up to have healthy teeth. Regular brushing and avoiding sugary foods and drinks will help this.

The first teeth are very important as they help to guide the second or permanent teeth into the best position. If the
If you wish, a visit to the ward can be arranged before admission, to meet the ward staff and see where you will be staying.

**Will the cleft lip and palate affect speech?**

Many children born with a cleft lip and palate will develop normal speech 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 makes speech 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 see your child regularly, so that any problems can be picked up early so therapy can be offered if necessary.

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**The Cleft Lip and Palate Team.**

- **Cleft Surgeon**  
  (repairs the clefts)
- **Orthodontist**  
  (Dentist who positions teeth with braces)
- **Speech and Language Therapist**  
  (monitors and treats speech and language problems)
- **Ear Nose and Throat Surgeon**  
  (monitors and treats hearing problems)
- **Specialist Nurse**  
  (supports parents at home, helps with feeding)
- **Paediatrician**  
  (Doctor looking after children)
- **Geneticist**  
  (looks into why the cleft happened)
- **Clinical Psychologist**  
  (offers chance to talk through any difficulties for you or your child)
- **Paediatric Dentist**  
  (Children’s Dentist)
- **Anaesthetist**  
  (puts child to sleep for operations)
Clefts of the lip and palate are not uncommon and about one in every 700 babies born each year in the UK will have a cleft involving part of the lip and palate (roof of the mouth).

Your baby has a cleft lip and 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 anguish and to be overwhelmed at first. These feelings usually begin to fade as you begin to understand more about cleft lip and 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 aspects of your child’s treatment or to arrange for you to talk with one of the other team specialists if this is felt to be more appropriate.

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. Extra feeding bottles can be ordered from the Cleft Lip and Palate Association (CLAPA). Details can be found at the back of this booklet.

When will the cleft lip and palate be repaired?

The Cleft Surgeon is likely to operate on the cleft lip and part of the palate near the gum (hard palate), when the baby is between three and four months old.

The rest of the palate (soft palate) is then repaired when the baby is between six and nine months old. However, if your baby was born early or there are other medical conditions then these times may change.

The operations are 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 three and five days. If you wish you can stay overnight with your baby. If you have other children it is understood that this can sometimes be difficult.
How will I feed my baby?
Some babies born with a cleft lip and palate may have difficulty sucking effectively because air leaks into the mouth from the cleft. The wider the cleft in the palate the more difficulty your baby may have creating the suction needed to get the milk. Babies with cleft lip and 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 lip and palate can feed successfully and move on to a weaning diet at the correct age.

It is up to you how you would like to feed your baby, either by breast or bottle. Breast-feeding a baby with a cleft lip and palate may prove more difficult, but it may be possible. However your baby may 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 generally advise an orthodontic teat and a soft plastic bottle. The bottle can be gently squeezed to help the baby get the milk, overcoming the problem caused by the cleft. The flow of milk is matched with your baby’s sucking, so squeezing stops as your baby pauses to rest. This method is called ‘assisted feeding’.

Your Specialist Nurse will provide these bottles and show you how to use them.

What is a cleft lip and palate?

The word **cleft** means a gap between two parts. A **cleft lip and palate** is a gap within the upper lip, the gum (alveolus) and the roof of the mouth. The cleft of the lip may be complete, involving the full length of the lip from the red margin to the nose or it may be incomplete, involving only a part of this area. The cleft may affect one side of the upper lip, gum and palate (a unilateral cleft), or may affect both sides (a bilateral cleft).

If you wish to see some photographs, your Specialist Nurse will be able to arrange this. Here are some diagrams showing this.
How does a cleft lip and palate occur?

The lips and the palate form during the early stages of pregnancy. Initially they form as separate halves that join together. If this joining together does not occur then a gap (cleft) will be left in the lip and palate. If this happens on one side then a unilateral cleft develops or if both sides are affected then a bilateral cleft is formed.

Why did it happen?

It is not fully understood why this happens, so as parents it is unlikely that you could have done anything to prevent this. Sometimes there may be a genetic or inherited link with possibly a family history of a cleft lip and palate. We may ask a Doctor who looks at inheritance (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.
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.

Information on Cleft Lip and Palate

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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 details of CLAPA and a contact person for your area.

Contacts:

Northern Area:
Newcastle Cleft Team, Tel: 0191 2820750
Royal Victoria Infirmary, Queen Victoria Road, Newcastle NE1 4LP

Yorkshire Area:
Leeds Cleft Team.
Clarendon Wing
The General Infirmary at Leeds, Great George Street, Leeds.
LS1 3EX
Tel: 0113 3925115

CLAPA (Cleft Lip and Palate Association)
Tel: 020 7431 0033
www.clapa.com


Illustrations by permission, Diane Mercer, Medical Illustrator.
first teeth are lost early due to decay then it is more difficult for the Orthodontist to straighten the permanent teeth later on.

From an early age (as soon as first baby teeth appear) you should begin to take your child along to your Dentist who will be able to offer advice on caring for the teeth and gums, as well as providing any necessary treatment. Our own team will also check your child’s teeth and arrange any special help they may need.

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

As the cleft also involves the gum then a further operation is often required around 9 to 11 years of age to repair the gum to help with tooth eruption.

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 during your visits to the cleft clinic.