

Cleft Lip

Information for parents



Leeds children's
hospital

caring about children



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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 lip 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 lip 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 or palate (roof of the mouth).

Your baby has a cleft lip 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.

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 lip, meet the specialists involved in the care of your baby and plan for future treatment. However, if these feelings continue, further help 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 to arrange for you to talk with one of the other team members if this is felt to be more appropriate.

What is a cleft lip?

The word cleft means a gap between two sides. A cleft lip is a gap within the upper lip and may involve the gum (alveolus) area. The cleft of the lip may be complete, involving the full length of the lip from the red margin up 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 (a unilateral cleft), or may affect both sides of the lip (a bilateral cleft). If you wish to see some photographs, your Specialist Nurse will be able to arrange this.

Here are some diagrams showing a cleft lip.



Incomplete cleft lip



Complete cleft lip
(alveolus (gum) not involved)

How does a cleft lip 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. If this happens on one side then a unilateral cleft lip develops or if both sides are affected then a bilateral cleft lip is formed.

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 lip. 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 will 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?

It is your choice how you would like to feed your baby, most babies who have a cleft lip should be able to feed normally by breast or bottle.

Some babies may have difficulty sucking effectively because air leaks in to the mouth through the cleft. The wider the cleft in the lip, the harder it will be for your baby to create the suction needed in order to get the milk.

These babies can appear to be sucking well but the extra effort needed may lead to tiredness and poor weight gain. When breast-feeding, minor adjustments to the feeding position may be needed. If you decide to bottle feed, changes to the teat or type of bottle may be required.

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

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 lip be repaired?

The Cleft Surgeon is likely to operate on the cleft lip when the baby is between three and four 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.

If your baby has a unilateral cleft lip the repair may be carried out as a daycase. If the cleft is bilateral the hospital stay is usually between one and two 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.

After the operation the same method of feeding will continue. To keep the lip and mouth 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 affect my child's teeth?

If 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 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 has been repaired will any other operations be required?

If the cleft involves the gum then a further operation may be required around 9 to 11 years of age to repair this area, to help with tooth eruption. The need for any further 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) can also provide local contact with other families. Details can be found at the back of this booklet. Your specialist nurse can also provide you with 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.

Contact details

Northern Area:

Newcastle Cleft Lip and Palate Team

Royal Victoria Infirmary, Queen Victoria Road, Newcastle.
NE1 4LP.

Tel: 0191 2820750

Yorkshire Area:

Leeds Cleft Lip and Palate Team

Martin Wing, Leeds General Infirmary, Great George Street
Leeds LS1 3EX

Tel 0113 392 5115

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. Illustrations by Diane Mercer, Medical Illustrator.



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Your views matter



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