



# Children Born with Cleft Lip & Palate

A Guide for Parents and Carers

**cover photo:** *Jasmine at 5years old*

# CLAPA

The Cleft Lip and Palate Association (CLAPA) is a registered charity set up to give information and support to all those affected by cleft lip and/or cleft palate. The support we offer complements the professional treatment provided by specialist health professionals. CLAPA staff and volunteers are not medically trained but often have personal experience of cleft lip and/or palate.



*Emma at 6 weeks with her parents.*  
photograph courtesy of Nottingham City Hospital

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## Introduction

This booklet is written for parents of children born with cleft lip, cleft palate, or both cleft lip and palate. Some of the information will be relevant to anyone caring for a child born with a cleft.

Parents are often distressed when they find out that their baby has a cleft and does not look as they had expected it to. Life can suddenly feel overwhelming and filled with worries and unanswered questions: Is it their fault? What is a cleft lip? What is a cleft palate? What can be done for their new baby?

It may be helpful to remember that to feel like this is absolutely normal.

You may want to talk to someone about what it is like for you and your family to have a child born with a cleft. You should be referred to a specialist cleft team within 24 hours after your baby's cleft has been diagnosed at antenatal scan or once he or she has been born. The health professionals on the cleft team will always be happy to talk to you about the diagnosis and about your child's specific needs. You could also call CLAPA or visit our website [www.clapa.com](http://www.clapa.com), to find out how to contact other parents of children born with cleft lip and/or palate in your area. Many people find it helpful to speak to others who have been in similar situations and who are familiar with the same cleft team.

We hope that this booklet will help answer some general questions about cleft lip and/or palate, tell you what it might mean for you and your baby, and perhaps also set any fears you might have to rest.

# What is a cleft lip and what is a cleft palate?

**Cleft** means 'split' or 'separation'. During early pregnancy separate areas of the face develop and then join together. If some parts do not join properly the result is a cleft, the type and severity of which can vary. Cleft lip and palate can occur separately or together.

**A cleft lip** can range from a slight notch in the coloured part of the upper lip to complete separation in one or both sides of the lip, extending up and into the nose. A cleft on one side is called a *unilateral cleft*, a cleft on both sides is called a *bilateral cleft*.

**A cleft palate** occurs when the roof of the mouth has not joined completely. The back of the palate (towards the throat) is called the *soft palate* and the front (towards the mouth) is called the *hard palate*. If you feel the inside of your mouth with your tongue, you will be able to notice the difference between the soft and the hard palate. A cleft can affect either the soft palate, or both the soft and the hard palate.

## How does it happen?

Although about 1 in 700 babies is born with a cleft in the UK (that's about 1,000 each year), the cause of cleft lip and palate is not really understood. While we know *what* happens, we don't know *why* it happens. Sometimes clefts run in families and sometimes a baby is born with a cleft without anyone else in the family having one. Your cleft team will have more information on current research.

## Is my baby healthy?

Some people are worried that a cleft lip and/or palate might be associated with learning difficulties, heart conditions, or other disorders. Though this can be the case, it is very unusual. If you have any worries about this, please do not hesitate to talk them through with someone on your cleft team.

Most babies born with cleft lip and/palate are perfectly healthy. You can expect your child to suffer from the usual 'childhood ailments' sooner or later; these can be addressed in the usual way, and are not related to cleft lip/palate.

## Will my baby need treatment?

Your baby will need some treatment by members of your **Cleft Lip and Palate Team**. You should be told which hospital to attend as soon as you know your child has a cleft. If you are unclear about this, you could ask someone on your maternity unit. The specialists on the cleft lip and palate team will work with you to ensure that your child receives the treatment that he or she needs. A cleft lip is usually repaired within the first 6 months of a baby's life. A cleft palate is usually repaired a little later, probably by the time a baby is a year old. If there is a gap in your baby's gums, this will be repaired as his or her second teeth are coming through. The treatment of cleft lip/palate is described in more detail on page 12.

# What do I need to know about how the condition might affect my child?

**A**lthough a cleft is not a condition which is likely to affect your child's general health, there are a few areas where he or she may need more encouragement and support than other children. These are summarised below:

## feeding

Most babies with a cleft lip feed very well, though some need a little help. If your baby has a cleft palate, he or she might have some difficulties to begin with. Your cleft nurse specialist will be happy to give you advice, and may be able to visit you and your baby at home to help you find the best way of feeding your baby.

CLAPA's free booklet *Help with Feeding* explains various ways of making feeding easier for you and your baby. You may find it useful to have a look at this together with your cleft nurse specialist, health visitor, or anyone else offering advice on feeding. Please contact CLAPA Head Office if you would like to be sent a copy.

## speech

Some children with cleft palate have difficulties when they begin talking, as air can escape down their noses when they make certain sounds. The palate is a working muscle which goes up and down when we speak, controlling how much air goes through the nose and the mouth (a bit like the dryers in some public washrooms which can be positioned to blow hot air downwards to dry your hands, or upwards to dry your face). Sometimes, even after an operation to repair a cleft palate, it may not work exactly as it should. However, difficulties can be overcome with early attention from a speech and language therapist. Further surgery may occasionally be necessary to ensure that the palate is working properly.

## hearing

Some children born with cleft palate can experience temporary hearing difficulties. This is as a result of 'glue ear', excess fluid in the middle ear, a condition which is also quite common in children born without clefts and which is easily treated. Your baby's hearing will be monitored by your cleft team. Most hearing difficulties will disappear naturally within the first few years.

## teeth

If your baby has a cleft palate, it could be that there is not quite enough space for teeth to grow into as he or she gets a bit older. Again this is something common to many children born without clefts. The orthodontist on the cleft team will keep a close eye on the growth and development of your child's teeth, making sure that they are correctly positioned to bite as they should and to look as good as possible. A paediatric dentist will advise on the health and strength of the teeth, and a local dentist can provide any standard treatment needed (like fillings).

## general appearance

The size and severity of a cleft can vary. Therefore, one baby born with a cleft may look very different from another.

In general, a cleft lip is quite obvious in a new-born baby, and he or she will look different from a baby born without a cleft until the operation to close the cleft. This will probably happen by the time your baby is 6 months old. You may actually find that you are so used to your baby's cleft that it is a bit of a shock to see him or her without it. Your baby's nose may have a slightly irregular shape, which will probably be less noticeable after surgery.

If your baby has a cleft palate, the cleft itself may not be easily visible unless you look inside his or her mouth.





**top:** *Katie at 6 hours.*



**left:** *Katie at 6 weeks, after surgery to repair her cleft lip.*

**bottom:** *Katie at 2 with her baby sister, Rachel.*



## What can I do now?

**Y**ou are the most crucial part of the team dedicated to looking after your child. The members of the cleft team can take care of specific medical treatment, and can give you advice whenever you need it, but the day-to-day care you give your baby is the most important care of all.

## What about when my child gets older?

One way in which you can help ensure your child gets the most out of treatment, is to make sure that his or her teeth are healthy. If orthodontic work is needed when his or her second teeth come through, it is important that these teeth are strong and healthy. You can help this happen by making sure that your child's teeth are properly brushed every day and are not exposed to too much sugar or fizzy drinks. Your dentist will be able to advise you if you have any questions.

You can also help your child feel comfortable about how he or she looks as children can feel quite sensitive about looking even a little bit different from others. They may become particularly aware of this when they begin nursery school and, later, change schools. The more you are able to answer any questions they might have, and respond in a positive way to their concerns as they grow up, the more likely it is that they will be able to stop worrying about it. The psychologist on your cleft team is available to give help and advice on any issues that may be worrying you or your child.

*Changing Faces* is an organisation offering support to those with any form of facial difference. Their contact details are at the back of this booklet.

## How can I cope with all this?

**H**aving a new baby is a lot to cope with in itself, let alone having a baby that looks different in any way. If there are times when you feel overwhelmed by it all, it may help to remember that there are people on hand who are there to help you with any questions you might have, or to be available if you just want to talk about how you feel.

For instance, your cleft team is there to support you and your baby and to help you with any questions that come up. CLAPA is also there to listen, and to provide support and practical advice if this is what you want. If you have not already been given information about your local CLAPA group or our trained Parent Contacts, CLAPA Head Office will be happy to put you in touch with them – our contact details are at the back of this booklet.

# The Treatment of Cleft Lip and/or Palate

This booklet can only give a very general summary of the kind of treatment your baby may receive, and from whom. To find out about the treatment that's best for your baby, you should speak to someone on your cleft team.

## What is a cleft team?

A cleft team is made up of a number of different specialists who work together to ensure that your child gets the best possible treatment. These may include the following:

Surgeon

Specialist nurse

Orthodontist

Paediatrician

Speech and Language Therapist

Counsellor/Psychologist

Geneticist

Some families may have to travel to keep appointments with the cleft team. Even if this takes a bit of organising, it is important that you keep your appointments to ensure that your child receives the best possible care. If you find it difficult to make arrangements to get to your cleft clinic at any time, you could talk to other parents through your local CLAPA group to share information and tips about how organising hospital visits might be made easier.

## The Treatment of Cleft Lip

**A**n operation to repair a cleft lip, whether it is unilateral or bilateral, usually takes place within the first 6 months of your baby's life. Your surgeon will tell you exactly the best time for this operation to take place. It may be necessary for there to be a minor follow-up operation a little later to make any adjustments to the repair before your child starts school.

## The Treatment of Cleft Palate

An operation to repair a cleft palate usually takes place between the ages of 4 months and 12 months, though in some cases a little later. The timing of the operation will depend on your surgeon's assessment of your child's needs. It may be that a second operation is required later on to help your child improve his or her speech.

For each of these operations, you can expect your child to be in hospital for a few days. You can talk to your cleft team about facilities available for you to be able to stay with your baby at these times. Most babies recover from the operations very quickly.

# Contacts

We trust this booklet has answered some of the questions you might have had about cleft lip and/or palate.

For more information, for details of your local CLAPA Group, or of other CLAPA publications, please contact:

**Clapa Head Office:**  
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Other useful addresses:

**Changing Faces:**  
**The Squire Centre**  
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*Killiam, aged 2*



*Marianne at 8 months*



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