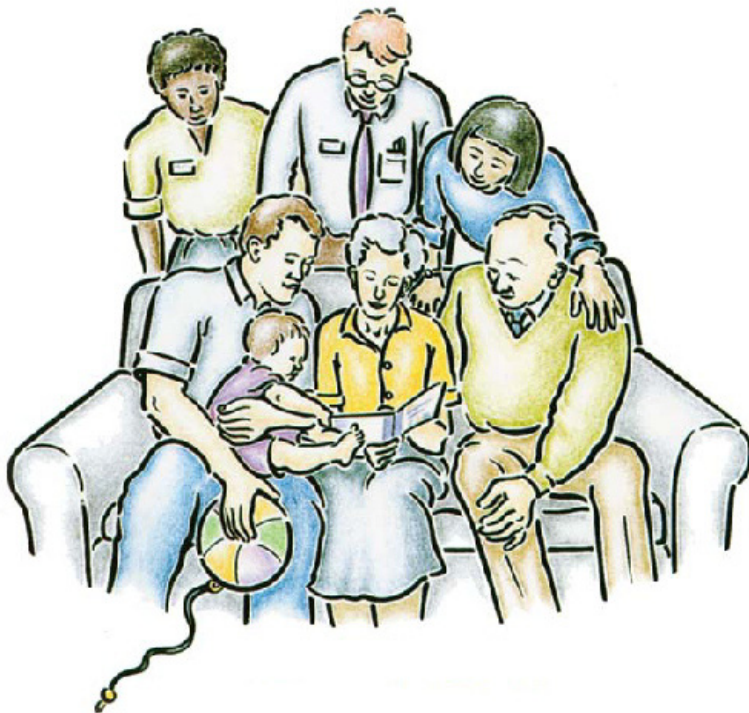


# The treatment of **CLEFT LIP & PALATE**



**A Parent's Guide**



The Royal College of Surgeons of England

In creating this booklet under the auspices of the Royal College of Surgeons of England, the working group has consulted with surgeons, nursing staff, therapists and hospitals. It wishes to acknowledge members of the audit project on the management of cleft lip and palate and the assistance of Dr Doreen Roberts (audiologist) and Dr Jill Clayton-Smith (geneticist) for contributions to parts of the text.

**Copies of this booklet are available from the Cleft Lip and Palate Association (CLAPA):**

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**website: [www.clapa.com](http://www.clapa.com)**



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# The Treatment of Cleft Lip & Palate

## A Parent's Guide

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## INTRODUCTION

# How you can best use this booklet



### **This booklet has three aims:**

- 1.** to help you, the parent, become better informed, more confident, and so more involved in decision-making about your child's care;
- 2.** to explain and guide you through the more common and typical treatments your child may need;
- 3.** to assist you in getting the best for your child by identifying the most important questions your carers should be able to answer.

Cleft lip and/or palate (called clefts here) describes a number of conditions which require the attention of different professionals working as a team (called the cleft team in this booklet) over many years. You as a parent are a member of this team, and must also be consulted on decisions about treatment. This booklet covers those treatments commonly needed between birth and about 10 years. We have drawn upon the latest thinking about the treatment of clefts, and try to describe an ideal arrangement of services, even though not all services in the UK are the same. As every child born with a cleft will have a slightly different condition, the treatments required will be different. Reading about them will show you how much can be done nowadays to help your child reach its full potential. This booklet is written like a route map, identifying the people and the places you will meet along the way.



- *At the back of this booklet there is space for the professionals to write down the treatments your child will have. Ask them to add these details when you visit the clinic. You can use this as a record of when and where these treatments take place, and who is involved.*

## SECTION ONE

# Understanding cleft lip and palate

**Approximately 1000 babies are born with a cleft of the lip and/or the palate per year in the UK. It occurs in all ethnic groups.**

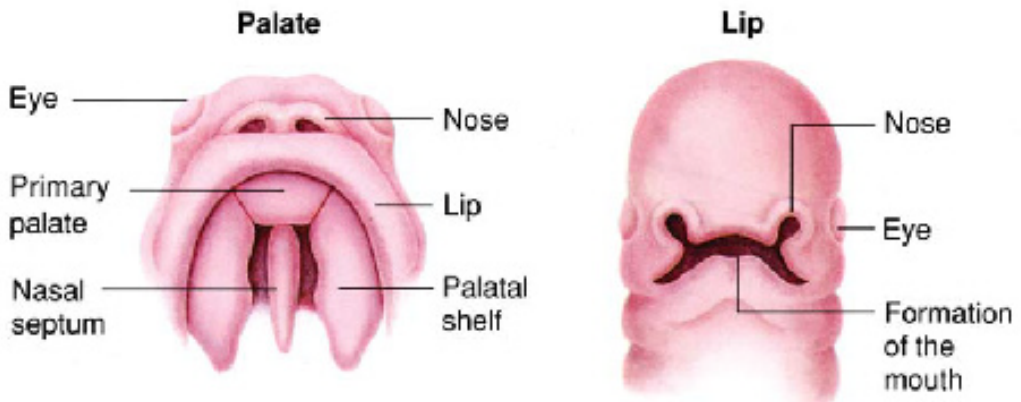
### Why does this condition occur?

As the baby's head develops during the early stage of pregnancy, the face is the last to form. While all faces have clefts (gaps) which must close, some may not close completely. For example, the upper lip develops from 3 separate parts. Though no part is missing, clefts happen when certain parts do not join. It is not understood why the parts of the face have not fused properly.

The formation of the lip and the palate is a very intricate and sensitive process which occurs early in pregnancy. We know that in some cases there is a family history of clefts (see page 35).

In most cases there is no single cause, and the reason is never discovered. Nevertheless, a member of your team may be able to give you some idea of why it happened to you.

### Embryonic development



### How may I (and others) feel about the condition?

The birth of a baby with a cleft has an effect on family and friends. Parents may feel shock and distress, even a sense of loss of the child they had hoped for. It is not uncommon to ask the question, 'what did I do wrong?'. These are normal responses, and explaining your feelings to members of your **cleft team** as well as your family will help.





## SECTION TWO

# Who are the specialists?

### The Cleft Team

A cleft team is made up of specialists who treat different conditions caused by the cleft.

One specialist may deal with several of the conditions.

Treatment for one feature of the cleft may affect another feature so it is important that the different specialists work together as a true team.

One or more of the following health specialists may be involved with your child.



### The Paediatric Dentist

gives advice on preventing dental disease and coordinates routine dental care with your family dentist



### The Orthodontist

is the hospital-based dental surgeon who specialises in positioning teeth and fitting appliances



### The Surgeon/s

repair clefts, and later bone and jaw conditions



### The Paediatrician

is a medical specialist for children





**The Specialist Nurse/ Health Visitor**  
counsels and supports parents at home  
and advises on feeding and other  
problems that may arise



**The Psychologist/  
Specialist Counsellor**

helps the parents and the child deal  
with any difficulties related to the cleft



**The Speech and  
Language Therapist**  
oversees speech and  
language development



**The Otologist**  
treats hearing  
difficulties surgically



**The Clinical Geneticist**  
advises parents and  
children on the chances of  
the cleft being an inherited  
problem that may occur  
again



**The Audiologist**  
tests the child's hearing

### How can I help to get the best for my child?

**Here are some of the issues that you may wish to consider when deciding how well you think your team will treat your child's difficulties.**

**1**

Is there a team member who is responsible for coordinating and keeping you in touch with other members?

**2**

Is it easy for you to use this person to contact any of the team members if you wish to discuss something?

**3**

Do the members of the child's team take the trouble to recognise that your concerns may not be the same as other people's (for example, your partner or other relatives) and make the effort to respond to both sets of needs?





4

Will students be present during my clinic visits?  
If you are unhappy about this you should ask to be seen only by the professionals.

5

If you wish it, are your child's specialists happy for you to see their written reports on your child's treatment to date?

6

Do the members of the team keep you well informed about treatment decisions in such a way that you can understand and take part in decision making?

### 7

How effective and organised is the team and how carefully do they follow-up your child? You might inquire how many babies the team treat yearly, how long the group has been working together, how well the team members work together, and if the team includes the carers identified on the previous page.



Following a report by the Clinical Standards Advisory Group in 1998, a framework document for cleft services was drawn up which stipulates that surgeons should manage at least 40 new patients a year in order to gain the level of expertise necessary in this area. Teams are required to undertake clinical audit of all cleft lip and palate patients. This means that in addition to routine appointments, patients will be asked to visit their teams for a check up at ages 5, 10 and 15.

## 8

What are the arrangements for treatment in your area? Cleft teams have developed independently and are set up differently, depending on the area, specialists and facilities. Only now are comparisons being made to see which arrangements best serve the child. Specialists also have preferences in the type, order or timing of the treatments, and the preferred number and frequency of check-ups. This may be due to different approaches to treatment and/or local service arrangements. If all specialists operate out of the same centre, your child could have several consultations with different specialists in one visit. If no cleft centre exists nearby, you may have to make several visits to specialists in different areas. You may prefer one or other of these options. For example, ask if home visits by some specialists can be arranged to save you travelling. Find out how your team works.

*We now know that the best results come from well-coordinated teams of different specialists working out of the same hospital centre, serving many cleft patients. It is desirable that treatment be planned by a single centre, where your child's records can be kept and the different types of treatment coordinated.*

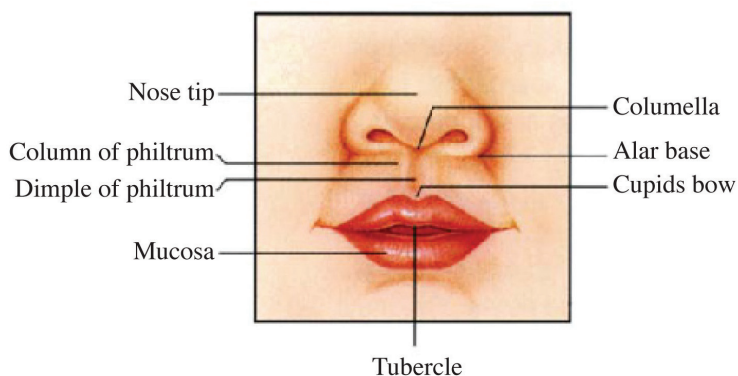
If you are not reassured by the information you are given, you may choose to travel to another area where the team set-up is different. Discuss this with your GP. If you have difficulties take this up with your local health authority.

## SECTION THREE

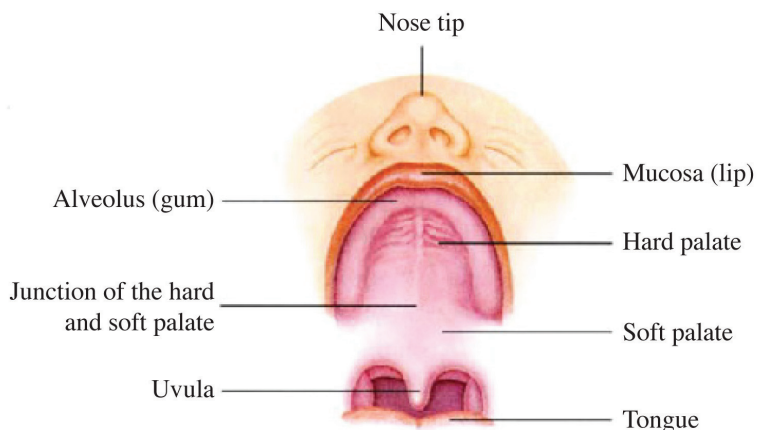
# Treatments of clefts

## What are the major types of clefts?

There are three major types of clefts listed here. Each type will require a number of treatments which together make a 'treatment pathway'. The ten possible treatment points, which children up to 10 years old may require, are described in this section. Each point has a colour code relating to one of the three conditions. You can follow the treatments your baby's condition will need by following the colour code.



**Normal anatomy**





## Cleft lip



**A cleft of the lip** may be complete or incomplete and involves either one side (unilateral) or both sides (bilateral). The upper gum (alveolus) and nose may be affected by this type of cleft.

**Look for the orange code**

## Cleft palate



**A cleft palate** involves some or all of the soft palate and may extend into the hard palate up to the back of the alveolus. Occasionally some children may have a split (bifid) uvula, a condition where the muscles beneath the lining of the mouth and nose (mucosa) are not joined (submucous cleft palate).

**Look for the blue code**

## Cleft lip and palate

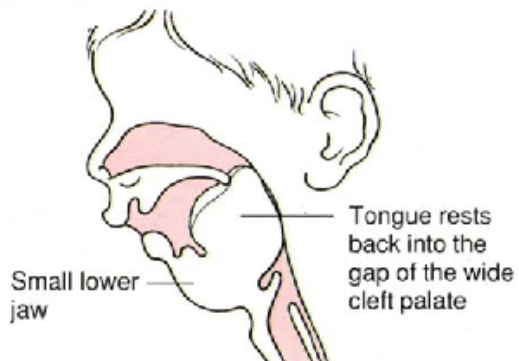


**A cleft lip and palate** involves one (unilateral) or both (bilateral) sides of the lip, base of the nose, gum and palate. Occasionally the lip and palate are clefted but the nose and alveolar ridge are intact.

**Look for the green code**

### Pierre Robin Sequence

*This occurs where the baby has a very small lower jaw (micrognathia) as well as a wide cleft palate. There are feeding and breathing problems due to the position of the tongue. The baby may need hospital care initially.*





**Cleft lip**

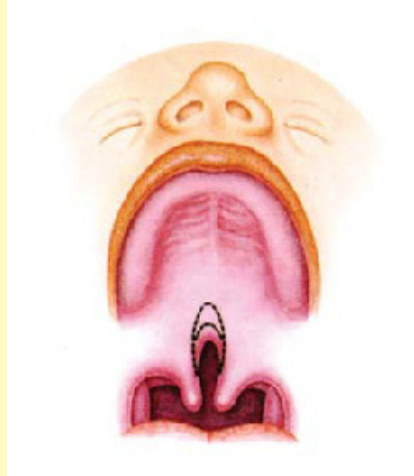


**Incomplete cleft lip**

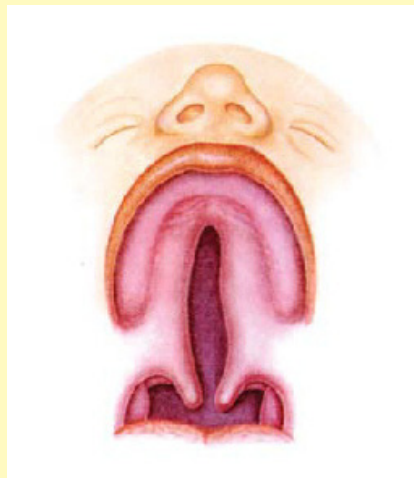


**Complete cleft lip**  
(alveolus (gum) not involved)

**Cleft palate**



**Cleft of the soft palate**

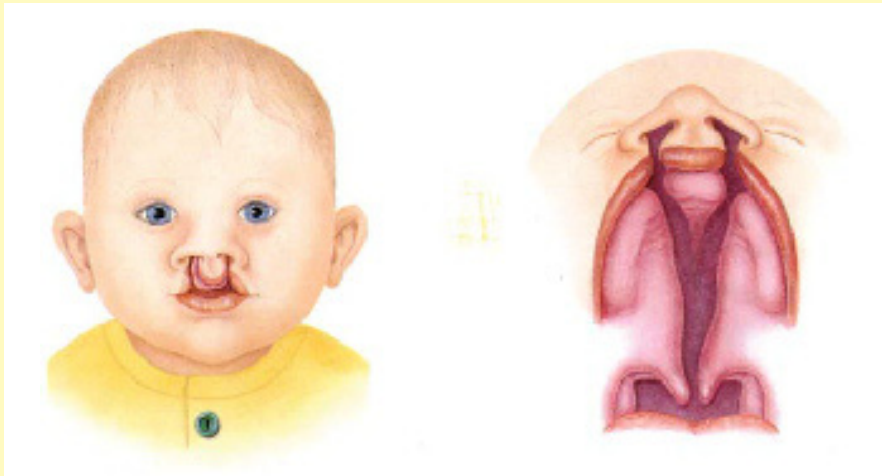


**Cleft of the soft & hard palate**

## Cleft lip and palate



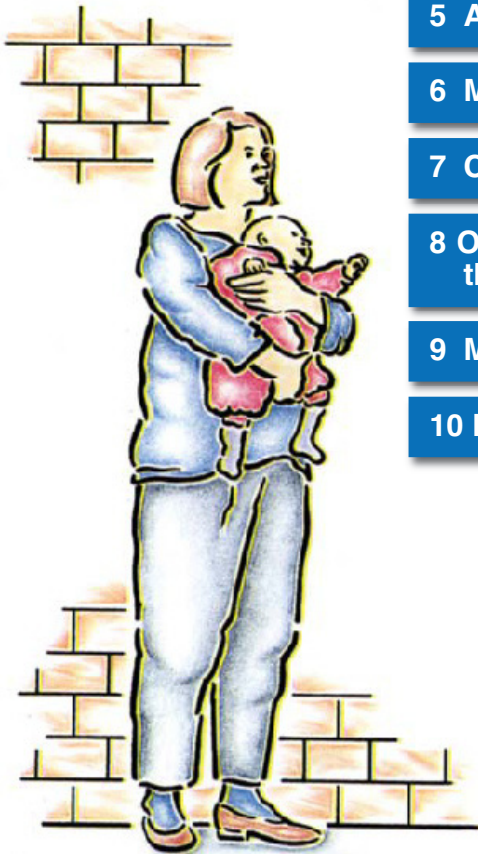
**Unilateral cleft lip and palate**  
(alveolus involved)



**Bilateral cleft lip and palate**  
(alveolus involved)

### **Treatment Points**

- 1 Specialist contact in the hospital**
- 2 Support in feeding the new baby**
- 3 Surgical repair of the lip**
- 4 Surgical repair of the palate**
- 5 Adjustment surgery**
- 6 Monitoring hearing**
- 7 Caring for your child's teeth**
- 8 Orthodontic treatment – correcting the position of the teeth**
- 9 Monitoring speech and language**
- 10 Bone grafting**



## Specialist contact in the hospital

### If cleft diagnosed before birth

#### *What happens?*

You should receive counselling before the birth and have been introduced to the cleft team.

#### *Who is involved?*

You may meet a surgeon, paediatrician, counsellor, nurse specialist or other member of the cleft team.

#### *At what age does it happen?*

Once a second scan has confirmed that your baby has a cleft, your ante-natal team will arrange for specialists to see you.

#### *What should I be aware of?*

You will find it useful to contact the Cleft Lip and Palate Association (CLAPA) for information and support (see inside front cover for contact details for CLAPA). Ask a member of your antenatal team to give you information about the local specialists who will make up your 'cleft team'.



### Treatment point 1

### If the cleft is diagnosed after birth

#### *What happens?*

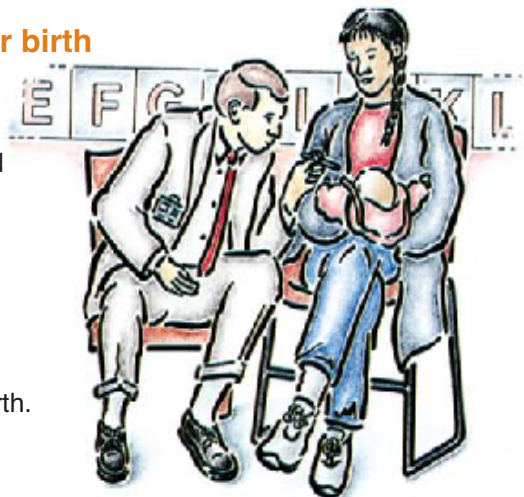
Your child's general health will be assessed and the treatment needed will be explained to you.

#### *Who is involved?*

You may be visited by members of the specialist team in hospital.

#### *At what age does it happen?*

Within the first two days after the birth.



### *What should I be aware of?*

If you have a 24 hour confinement, ask about the arrangements to meet the cleft team and get a contact name and telephone number.

## **Counselling**

### *What happens?*

During the first months after the birth, you and your family should be offered counselling, reassurance and help to cope with your feelings and concerns, particularly after leaving hospital.

### *Who is involved?*

The psychologist, counsellor, or health visitor/nurse.

### *When does it happen?*

Parents may need help immediately after the birth, while others have problems months later. Counselling should be available at any time.

### *What should I be aware of?*

You may wish to ask about:

- your feelings about your baby
- how to handle the feelings of your partner/ relatives/ friends/ other children
- getting help to cope with the stresses of your baby being in hospital for an operation.
- bonding with your baby.

You may be entitled to extra help for special problems; for example, with fares to hospital or child care for other children. You may not want to talk to anyone outside the family, and should never feel that you have to do so. If you feel the counselling is not going well, ask to see someone else. You should be given information about CLAPA (or, see inside front cover for contact details for CLAPA) while in hospital. If you have other children, explain the situation to them in terms they can understand, letting older brothers or sisters know that the baby's face does not hurt and that it will be made better.





### Treatment point 2

#### Support in feeding the new baby

In order to feed, your baby must be able to form a vacuum inside his/her mouth, and position the tongue properly. This is usually done by sealing the lips around the nipple or teat and closing off the back of the mouth with the soft palate. Babies with clefts may not be able to create this vacuum or position the tongue properly. Some have a smaller lower jaw (mandible), making swallowing difficult.

##### *What happens?*

A feeding specialist will decide an appropriate feeding plan with you. A thin feeding tube may be used to help those babies who also have a small jaw.

##### *Who is involved?*

Maternity staff and someone from your team. A specialist nurse (health visitor) should be available to you during the first months back at home.

##### *At what age does it happen?*

Within the first 24 hours following the birth and through the early years.

##### *What should I be aware of?*

Breast feeding is possible for babies with a cleft lip only, but is rarely possible for those with a cleft palate or cleft lip and palate. So a mother should not feel guilty if their baby cannot suck. Supplementary bottles of expressed or formula milk may be necessary if breast feeding is the mother's choice. Many babies will need extra help with feeding using different types of bottles and teats.



The specialist nurse will supply you with these initially. Some babies may not have the energy to suck from a teat, and can benefit from a 'scoop', which requires less effort from the baby. You are able to buy ongoing feeding equipment from CLAPA (see inside front cover for contact details).

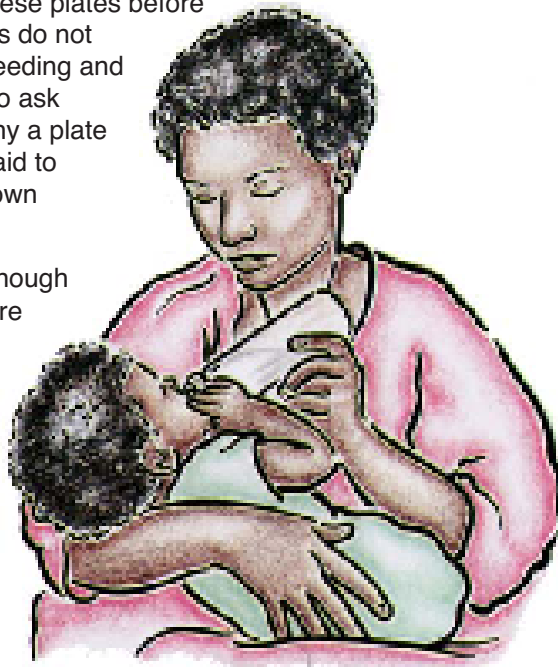
In order to assist with feeding, your orthodontist may be asked to provide a small dental feeding plate. For the majority of babies these are not necessary but there may be other reasons why their use is advised. In some cases, the plate may be used to keep the tongue out of the cleft palate.



A special orthopaedic plate may also be used to begin to apply pressure to close and align the cleft prior to surgery.

The baby will need several of these plates before surgery. Be aware that surgeons do not agree on the benefits of using feeding and orthopaedic plates from birth. So ask members of your team if and why a plate is being used and do not be afraid to give an opinion based on your own experience.

Make sure your baby is given enough time to get used to feeding before trying alternatives. Unless your baby has other problems, you should not need to be separated from your baby. Note the name and telephone number of your specialist nurse.



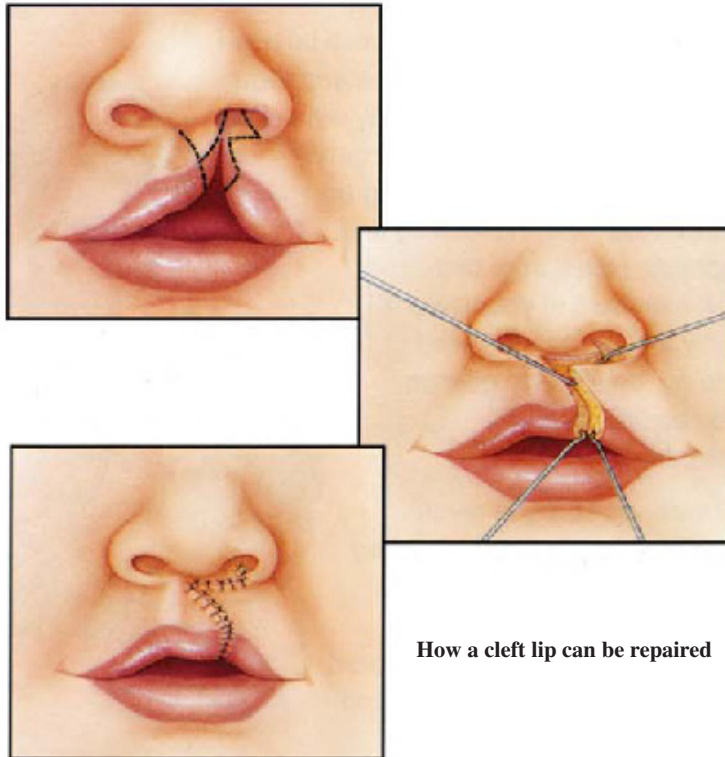


### Treatment point 3

## Surgical repair of the lip

### *What happens?*

Surgery is the only way to repair a cleft lip. Part of the operation involves stitching the skin of the lip together (no skin is taken from anywhere else). The operation may also involve improving the shape of your baby's nose. If the baby also has a cleft palate, some surgeons close the front part of the palate during the same operation. The surgeon will need to know if your baby is fit enough to have the operation. This is decided by taking a blood sample and other tests.



**How a cleft lip can be repaired**

On the day of the operation your baby will be given no food for a few hours beforehand to reduce the chance of being sick. A sedative drug ('pre-med') is given by injection or as a drink. Dental impressions may be taken before or during the operation to give an accurate record of the extent of the cleft to compare with the future development of the mouth. Some bleeding from the mouth afterwards is to be expected. You will see some stitches, swelling and crusting on the lip. A small piece of foam may be used to hold the nose in its new shape. You may find that splints have been placed on your baby's arms to prevent him/her touching the stitches. It is common to find that the baby's scars become red and swollen afterwards, but this will clear up.

#### *Who is involved?*

The cleft surgeon

#### *At what age does it happen?*

Usually in the first few months.

#### *What should I be aware of?*

Surgeons do not agree on the best time to operate or the order of the operations (eg. Some prefer to repair the palate before the lip). You may want to ask the surgeon why he/she carries out lip repair at a particular time.

You may have strong feelings about when your baby should have its operation. The surgeon should take account of your feelings in this decision. Ask how long your baby will have to stay in hospital. You as the parent can expect to stay in the hospital. Ask a member of the cleft team about this. You might also ask to accompany your baby to the operating theatre and recovery room. You should be prepared that your baby may look very different after the operation. Dummies (comforters) should be given to pacify your baby only when really necessary, as some surgeons are concerned about their effect on the healing wound following the operation. Some surgeons prefer babies to feed by spoon after the operation. If so in your case, you may be requested to practise spoon-feeding prior to the operation. Other surgeons are happy for the baby to feed by bottle or breast immediately after surgery.





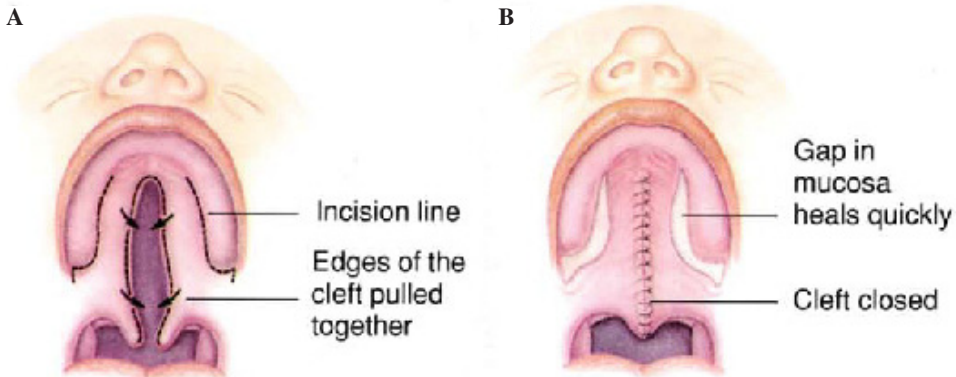
## Treatment point 4

### Surgical repair of the palate

#### *What happens?*

The surgeon aims to repair the palate in layers, with as little surgery to the upper jaw and hard palate as possible. He/she reconstructs the muscle of the soft palate so it can work properly during speech and swallowing. Some surgeons don't attempt to close the gap in the upper gum area completely at this stage. On the day of the operation your baby will be given no food for a few hours beforehand to reduce the chance of being sick. A sedative drug ('pre-med') is given by injection or as a drink. Some bleeding from the mouth afterwards is to be expected. Your child's mouth may also be sore at the corners, where the lip has been stretched a little during the operation. Dental impressions may be taken before or during the operation to give an accurate record of the extent of the cleft to compare with the future development of the mouth. You may find that splints have been placed on your baby's arms to prevent him/her touching the stitches.

#### How a cleft of the palate can be repaired



*Who is involved?*

The cleft surgeon

*At what age does it happen?*

Surgeons still do not agree on the best time to operate or which operation produces the best result. Most surgeons in the UK repair the palate at some time from about 4 months to 12 months. Repairing the palate before the child learns to speak is thought to help normal speech development. Unfortunately, some parts of palate surgery may restrict future growth of the palate and upper jaw. Surgeons are actively working on ways to reduce this. Everyone agrees that, despite these potential problems palate repair in infancy is vital for good speech development.

*What should I be aware of?*

The cleft surgeon will be able to tell you at what age the cleft will be repaired. Do not be surprised if the operation is postponed if your child is not felt to be strong enough for the operation, or if there is another medical problem. Ask how long your baby will have to stay in hospital. You as a parent can expect to stay in the hospital. Ask a member of the cleft team about this. You might also ask to accompany your baby to the operating theatre and recovery room. Dummies (comforters) should be given to pacify your baby only when really necessary, as some surgeons are concerned about their effect on the healing wound following the operation. Some surgeons prefer babies to feed by spoon after the operation. If so in your case you may be requested to practice spoon-feeding prior to the operation. Other surgeons are happy for the baby to feed by bottle or breast immediately after surgery. In some cases, the repair is unable to hold and separates. Most of these holes are small and close completely on their own. Others contract and become very small.





### Treatment point 5

## Adjustment surgery

### *What happens?*

Complete clefts of the lip and palate usually require some adjustment of the original repair. Future surgery may be needed for other reasons. A small hole (fistula) may remain in the palate after the original repair, and may need to be closed if it affects speech or lets food or drink run down the nose. A dental plate may be fitted to cover the hole. Around one in five children with a repaired cleft palate may need further surgery to improve speech (pharyngoplasty). In other cases, the repair may degrade as the child grows. The nose tip may distort and the child may find it difficult to breathe through the nose, particularly on the cleft side. It may be possible to improve the shape of the lip and nose and the look of the scar. It may not have been possible for the surgeon to make as good a repair as desired the first time, because the cleft was severe.

### *Who is involved?*

The cleft surgeon

### *At what age does it happen?*

Timing varies considerably and depends on the assessment of the cleft team.

### *What should I be aware of?*

Not all problems can be corrected by surgery. The side-effects of treatment may outweigh the benefits. The decision about further surgery must include the views of the parents and, of course, the child.

## Monitoring hearing

### *What happens?*

Your child may suffer some hearing loss because of the cleft palate. This is nearly always due to fluid in the middle ear (glue ear) and usually corrects itself as the child grows up.

Very rarely, the inner ear is not fully developed as the baby grows during pregnancy. In this case the loss of hearing may be permanent, and may be more severe if accompanied by 'glue ear'.

Your specialist nurse and health visitor will closely monitor your baby's responses to sound and talk to your cleft surgeon if it is suspected there is a hearing problem, this may be confirmed by the otologist or audiologist. Regular hearing tests will be arranged. Your baby should be referred to an otologist, who may treat him/her with medicine or propose an operation to insert a small tube (grommet) to allow air to enter the middle ear. Alternatively, a hearing aid may also be considered.



## Treatment point 6





### *Who is involved?*

An audiologist, an otologist and a specialist nurse.

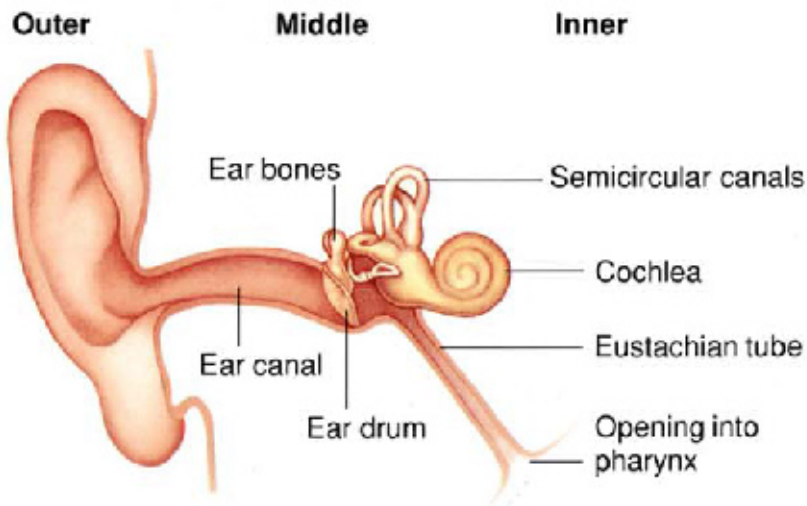
### *At what age does it happen?*

Any hearing loss which is severe enough to affect your baby's language development must be discovered as soon as possible, and steps taken to overcome the loss. Regular hearing tests (performed by playing special games) will be arranged for your baby from age 5-6 months and probably into their teens.

### *What should I be aware of?*

Be sure that you are consulted about the best way to treat your baby's hearing difficulties. If you are concerned about your baby's hearing ask to be referred to an audiologist. Temporary deafness is possible and the grommet operation may not be necessary. However, the otologist may recommend surgery for a reason other than hearing loss. Make sure you are satisfied with the explanation for this. If a grommet operation is necessary, ask if this can be combined with any other operation your baby may need. Your audiologist may wish to contact the local education services so that your child can be monitored in school, and given extra support if necessary.

### **Diagram of the structure of the ear**



## Caring for your child's teeth

### *What happens?*

You must protect your child from tooth decay and gum disease. As your child may have some poorly-formed teeth, the rest must be kept in very good condition as future treatment may be needed to straighten them. You should start to brush the teeth as soon as they appear. Use a small soft toothbrush with a fluoride toothpaste. Depending on your local water supply, you may need an extra fluoride supplement in the form of drops or tablets. Ask your own dentist.

### *Who is involved?*

Your own dentist should be able to do any fillings required. If not, the cleft team will have a dentist who will advise. If teeth need to be removed, ask your dentist to discuss this with the team orthodontist first. The main role of the orthodontist is to correct the position of the teeth, not to provide routine dental care.

### *At what age does it happen?*

From the first signs of teeth appearing. Register your child at birth with your own dentist.

### *What should I be aware of?*

Limit the amount of sugar your child eats. Sweets, sugary drinks and biscuits should be avoided particularly between meals. If your child is on long-term medication ask for a sugar-free variety. Thumb-sucking is a normal comfort habit which is not a problem for children with clefts.



**Treatment point**  
**7**





## Treatment point 8

### Orthodontic treatment

#### Correcting the position of the teeth

The cleft of the lip may result in a gap in the gum and bone of the jaw, beneath the upper lip where the teeth develop. This can lead to some front teeth coming into the mouth twisted and in the wrong position. On either side of the gap in the jaw a tooth may be missing or a small extra one may form.

When there is a repaired cleft palate the upper jaw and arch of teeth may become too narrow. This is especially likely in a complete cleft. As a result, some upper teeth may fit inside the lower ones – called a ‘crossbite’. Over time the upper jaw may not grow forward as well as the lower jaw, and so crossbite of the front teeth becomes more common.

#### *What happens?*

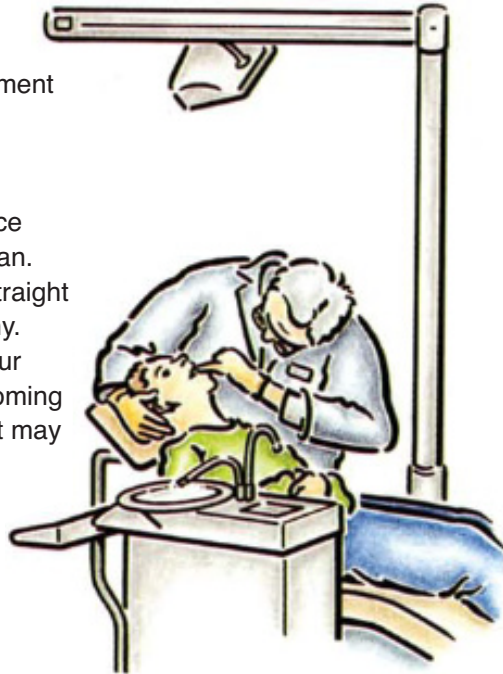
The orthodontist will usually take impressions of the teeth to make plaster models that are used as a record, to plan treatment, and to help construct appliances or braces. X-rays are generally required too as these give information about the jaw bones and the position of teeth that still have to come through. Teeth move into position gradually as gentle pressure is applied by the brace. Small metal brackets are attached to the teeth by means of a special plastic glue or bands cemented to the back teeth. These brackets are joined by wires or elastics that guide the teeth into position. Some can be taken out for cleaning.

### *At what age does it happen?*

Crossbites and other irregular teeth are noticeable as soon as they come through in the baby's mouth. However, orthodontic treatment is not normally recommended for baby teeth. This is because it is difficult for a baby to tolerate and provides no lasting benefit. Treatment is best given for the second set of teeth around 8-9 years old if they interfere with the bite or are difficult to clean. A bone grafting operation may be necessary to provide bone as a base for new teeth to grow if the original cleft has involved the jaw bone beneath the lip cleft, (see page 33). This is usually done when the child is around 8-10 years old, before the permanent canine teeth (eye teeth) come through. If it is necessary, the upper arch of teeth is widened before bone grafting and some straightening of the front teeth can be combined with this, taking 6-12 months. The same appliance is usually left in place for 3 months while the bone graft is healing. The main treatment for children with clefts is provided around age 11-12.

### *What should I be aware of?*

You should decide with your orthodontist how much of this treatment your child should have. Ask to see examples of treatment and typical appliances. The main reasons for offering it are to improve appearance and to make the teeth easier to clean. Teeth do not have to be perfectly straight to look acceptable or remain healthy. If you are unhappy with the way your child's permanent front teeth are coming through an easier start to treatment may be possible. Wearing any form of appliance calls for extra tooth brushing to avoid tooth decay and gum problems. Younger children may need help. In the first few days after the appliance is fitted the teeth may be a little tender.





## Treatment point 9

### Monitoring speech and language

#### *What happens?*

In order to speak correctly there must be a good seal between the mouth and the nasal passage. This is ensured by the movement of the soft palate at the back of the mouth and the movement of the walls of the throat, (See fig. A). Babies born with a cleft palate, with or without a cleft lip, may have speech problems. There is difficulty in making the proper sound of the consonants (such as 'p','b','t','d','s','ch'), and/or a nasal sound to the voice due to air escaping down the nose, (see fig. B). These children should be routinely checked by a speech and language therapist, who will help your child speak as well as possible. This starts with monitoring



**A**

For most of speech the soft palate and walls of the throat move together to act as a seal, closing off the nose from the mouth.

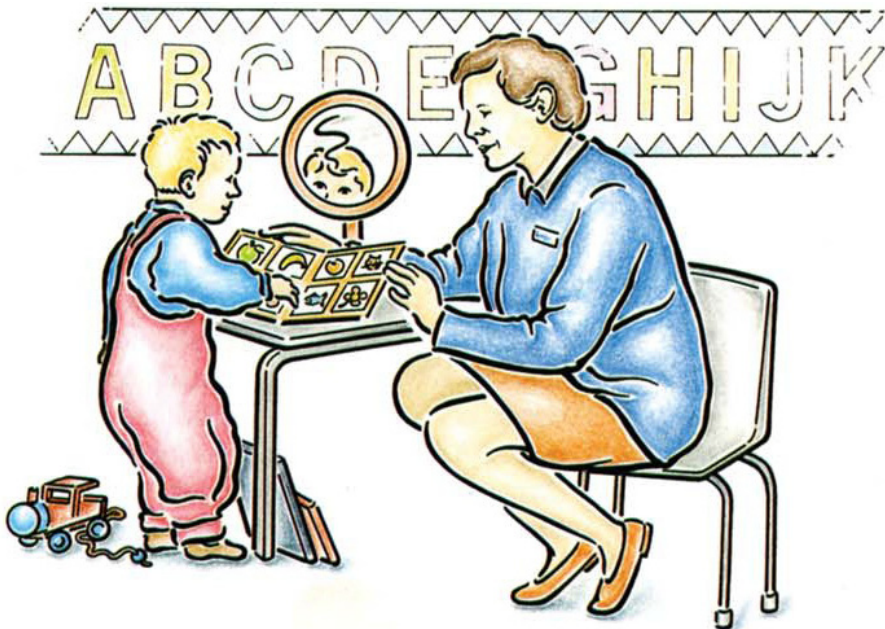


**B**

Sometimes after palate repair the soft palate does not close off the nose from the mouth during speech causing nasal sounding speech.

your baby's first sounds and words and the understanding of what is said. The therapist designs a special programme of activities appropriate to the age and development of the child.

If there is a 'nasal' sound to your child's voice, the therapist may use special computer equipment, or a mirror under the nose to monitor the air passages as your child speaks. Often a tape recorder or video is used. There are methods to examine the way the soft palate and side walls of the throat move during speech. One is a moving X-ray called fluoroscopy. A second method called nasopharyngoscopy involves lightly anaesthetizing one side of the nose. The doctor gently passes a thin fiberoptic telescope to a position above the palate and observes and records the palate and side walls of the throat as they move during speech. You and your child may be able to watch what is happening inside the mouth on the television during these tests. Once the surgeon understands the nature of the problem, he/she may then choose to do an operation (called a pharyngoplasty). This is to remove the nasal sound from



your child's voice and make his/her speech stronger and clearer by stopping too much air escaping down the nose.

### *Who is involved?*

You are seen by the team's therapist at the clinic. When regular speech therapy is required this will be arranged with the local therapist at your health centre.

### *At what ages does this happen?*

You will usually meet the speech and language therapist during your first clinic visit, but definitely by the time your baby's palate has been repaired. Therapy may continue into school age.

### *What should I be aware of?*

If you have not met your therapist by the time of the palate repair, ask to be referred. Know their name and phone number. During clinic sessions, it may appear that the therapist is 'just playing' with your child, but this is a way of monitoring progress. Moreover, you should be involved in the process of helping your child, joining in with the therapist, and carrying out activities given to you to do at home. As services tend to be oversubscribed, tell the cleft team if you feel that your child is receiving insufficient therapy. If a second operation is proposed, be sure this is done after videofluoroscopy and nasopharyngoscopy. Be wary of agreeing to an operation if neither investigation has taken place, and make sure that the possible side-effects are explained. Also be aware that there are causes of speech problems other than the cleft.



## Bone grafting

### *What happens?*

If your baby's cleft affected the jaw bone behind the upper lip, a gap in the bone beneath the gum may remain. This can prevent the second teeth coming through in the correct way and can affect the shape of the nose. Replacing the missing bone will allow the teeth to grow into the gap. Some fragments of bone are taken from the pelvis (commonly called the hip) or the legs. Apart from a small scar, this should not interfere with either appearance or function. After the operation your child will feel more pain from the hip than the mouth wound, though he/she will be up and about one day after the operation.

### *At what ages does this happen?*

At around 7 to 8 years the extent of the bony gap beneath the gum is investigated by a dental Xray. This, and the position of the growing second set of teeth allows the team to plan a timetable for the bone graft. The operation is usually carried out around 9 to 10 years so that the new bone is in place before the canine (eye) teeth grow through.

### *What should I be aware of?*

The graft is done inside the mouth. During the healing process, small chips of bone may loosen and come out painlessly. Normally, a mouth rinse and antibiotics are prescribed. Bone grafting is not always necessary and you should discuss the reasons for this with the surgeon and the orthodontist.



**Treatment point  
10**



## SECTION FOUR

### What the future may hold

The child psychologist or specialist nurse counsellor helps you adjust to the cleft, to the reactions of others and to help cope with treatment. You may find it hard to take your new baby out because of strangers' reactions. As your baby grows up, he/she is likely to ask about the cleft. Be matter-of-fact about giving information to avoid giving the feeling that the condition is something to hide. Explaining the cleft in simple terms can help your child understand and convey this to friends. Early photographs may help with this.

Your child's intelligence is not affected by a cleft. However, speech and hearing difficulties can make it harder for your child to get on with other children and may lead others into thinking he/she is not as bright as other children. It is felt that children with clefts develop best if encouraged to be independent and mix freely with other children. Children may be teased and may need help dealing with this. At the same time it is wise to make good and regular contact with schoolteachers so that the child's condition, treatments and progress are well understood.



### Where can I get further information?

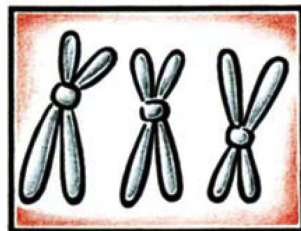
The Cleft Lip and Palate Association (CLAPA) was formed as a partnership between health professionals and parents working with and affected by the cleft lip and palate. It provides guidance and support; for example, CLAPA can arrange for you to meet with parents who also have a baby with a cleft.

**See inside front cover for contact details for CLAPA.**

## Investigating the genetic link

There can be a family link (heredity), but in most cases a child with a cleft will be born without any known previous family history. Sometimes clefting is linked with other conditions. You will be offered the opportunity to talk to a clinical geneticist or counsellor, who can help families understand why they had a child with a cleft. He/she will ask questions about other members of your family, and even ask to examine them to look for minor signs of clefting related characteristics. You will be asked about your pregnancy and your child's health and progress. Your child will be examined and a blood test taken to look at your child's chromosome pattern. Ask if you wish to be involved in researching the genetic link.

The severity of the cleft and sex of the child (more baby boys are born with clefts) will give some indication of the possibility of any family member giving birth to a child with a cleft (or the child's own future family being affected). Cleft lip and palate is also more likely to recur than cleft palate alone. The geneticist will also offer prenatal testing in the case of a future pregnancy. Counselling will be given to help you decide whether you wish to become pregnant again.



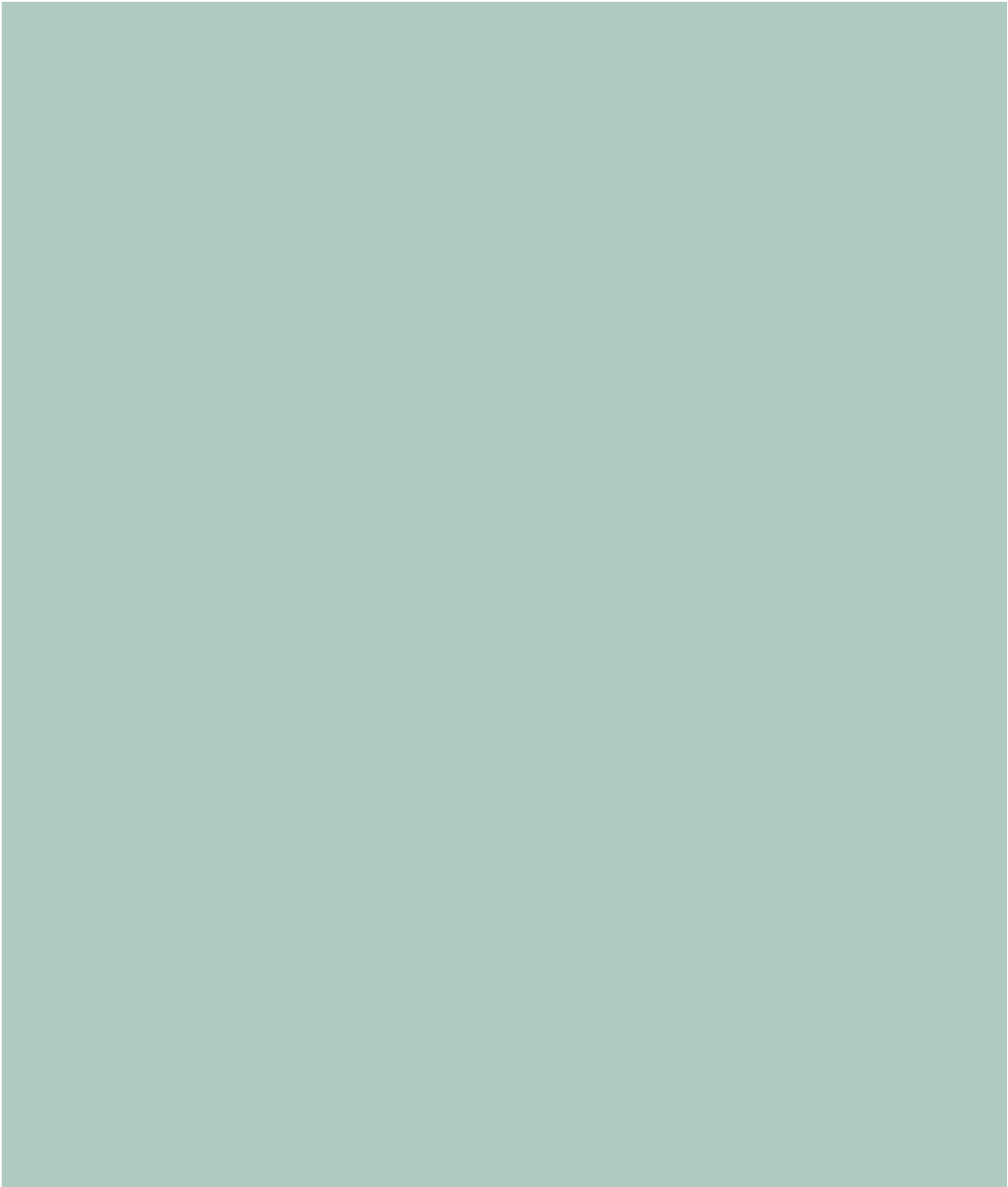
## Your Cleft Team

Title	Telephone
Paediatrician .....	.....
Surgeon(s) .....	.....
.....	.....
Otologist .....	.....
Specialist nurse/ .....	.....
Health visitor	
Speech & .....	.....
language therapist	
Orthodontist .....	.....
Psychologist .....	.....
Specialist counsellor .....	.....
Audiologist .....	.....
Clinical geneticist .....	.....
Paediatric dentist .....	.....

## Your child's treatment pathway

Members of your Cleft Team can use this space to describe your child's treatment and when and where it will take place (continued overleaf).

**Your child’s treatment pathway (continued)**







This title is one of a series which was originally commissioned by the NHS Management Executive Regional General Managers' Patient Empowerment Group and produced by The Royal College of Surgeons of England.

The Royal College of Surgeons of England was established by Royal Charter in 1800 and remains guardian of the highest standards and quality of surgical practice. It has responsibility for the training and continuing education of surgeons, the promotion of surgical advances and the maintenance of standards. As its members, we are committed not only to communicating with the medical and nursing profession, but to all members of the public in need of surgical care. This booklet is a general guide for all those parents who have had a child with a cleft of the lip and/or palate, and who need to understand and manage with carers the surgical and other treatments this child will face.

