Cleft Lip & Palate
The Care of your Child

Information Folder for Parents
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• What do the words used in Cleft Lip and Palate care mean?
• **Introduction**

**Why is this folder useful?**

This information folder will give you information about the treatment and care of your child.

**Who are the people who work in the Cleft Team?**

Your child will be looked after by a number of different people. These people are specialists who work together to make sure your child gets the best possible care.

These are the specialists that may be involved in the care of your child:

**Cleft Nurse Specialists**

We will give advice and support to you and your child throughout the course of their treatment. In the first year we will give you practical feeding advice and help you during your baby’s operations and hospital stay. A nurse specialist is always available in the outpatient clinic and can be contacted by telephone for advice. We will also be there to support and advise you and your child if further treatment is needed.

**Audiologists**

We will test your child’s hearing.

**Speech and Language Therapists**

We will work with you to help develop your child’s speech and language.

**Paediatric Dentists**

We will give you advice on how to keep your child’s teeth clean and healthy. We will also co-ordinate routine dental care with your family dentist.
Orthodontists

We will work with your local Orthodontist to make sure your child’s teeth are positioned correctly and to fit any appliances (e.g. braces).

Consultant Plastic Surgeons

We will repair your child’s cleft lip and/or palate. We may also perform other operations to improve function or appearance as your child grows.

Consultant Ear, Nose & Throat (ENT) Surgeons

We will look after your child’s hearing and treat any problems.

Consultant Oral/ Maxillofacial Surgeon

I will work closely with the Orthodontists and repair any bone and jaw problems.

Geneticist

I can discuss with you the possible reasons for why cleft lip and/or palate might happen and the chances of it being an inherited condition within your family.

Psychologists

We can talk with you or your child about any problems or concerns you may have about living with a cleft lip and palate. If needed we can also help you and your child in making any decision about future treatment.
• **What are the types of cleft and what do they look like?**

The anatomy of the face:
Cleft Lip

A Cleft Lip may happen on one side (unilateral) or both sides (bilateral). It may be incomplete (which does not involve the nose) or complete (involving the nose). In some cases the upper gum (alveolus) and palate (roof of the mouth) are also involved.
Cleft Palate

A cleft of the palate involves some or all of the soft palate and may also go into the hard palate up to the back of the upper gum (alveolus).
Cleft Lip and Palate

A cleft lip and palate may happen on one side (unilateral) or both sides (bilateral). It involves the lip, base of the nose, upper gum (alveolus) and palate. Sometimes the lip and palate are affected, but the nose and upper gum are not affected.

Cleft lip and palate

- Unilateral cleft lip & palate
- Bilateral cleft lip & palate
Pierre Robin Sequence

This happens where the baby has a very small lower jaw, as well as a wide cleft palate. There may be feeding and breathing problems due to the position of the tongue. The baby may need to be monitored in hospital in the early days.

Submucous Cleft Palate

Some children may have a condition where the palate appears to be intact, but there is a gap in the bone and the muscles are not joined under the skin’s surface – this is known as a submucous cleft palate. Sometimes this is suggested by a split uvula (the part of the palate which hangs down at the back). A submucous cleft palate may not be found until a child is speaking.

A submucous cleft palate may happen with a cleft lip, but most happen with no involvement of the lip.
• The First Year

Support and Advice (visits from the Cleft Nurse Specialists):

Meeting you at the Maternity Unit

The Cleft Nurse Specialist will:
• Visit you and your baby at the Maternity Unit within 48 hours of referral.
• Examine your baby and give you information about the type of cleft.
• Find out how you would like to feed your baby and if needed will give you soft squeezy bottles, scoop, or teat.
• Tell you about the future care of your baby and give you written information/leaflets.
• Show you a photograph album of other children if you want to see them.
• Help you deal with any concerns and answer any questions you may have.
• Give you a contact telephone number for the Cleft Nurse Specialists.

Visiting you at home

Following discharge from the Maternity Unit the Cleft Nurse Specialist will:
• Go over the information that you were given after the birth of your baby.
• Discuss any feeding problems.
• Contact your Health Visitor and work with him/her so that you have enough support in the community and in the hospital.

The Cleft Nurse Specialist will keep in touch with you and may offer extra home visits if necessary.

Ways to feed your baby (breast and bottle feeding advice and weaning)

Babies with clefts have the same nutritional needs as any other babies. Where there is a cleft of the lip only, breast-feeding often works better than bottle-feeding. This is because the baby can suck normally when the breast fills the gap in the lip. A bottle teat does
not fill the gap in the lip so well, so the baby tends to suck air as well as milk.

When there is a cleft palate, the baby cannot suck properly, even though jaw movement and swallowing are normal. Therefore breast-feeding a baby with a cleft palate may be difficult, but it is possible for you to express your milk and give it to your baby with a soft bottle. The Cleft Nurse Specialists will help you, offer you advice and support and they may be able to loan you an electric breast pump.

If you wish to bottle-feed your baby this can be done by using a normal latex teat and soft squeezy bottle. The soft bottle is squeezed in time with the baby’s normal sucking pattern. A little practice by both parents and the baby is needed to achieve good feeding.

The Cleft Nurse Specialists will be happy to give you advice together with the midwives in the maternity unit. It is important that feeding should be relaxed and a pleasure for both parents and baby. Feeding provides an ideal time for bonding. Feeding should not take so long that it becomes tiring. If there are any problems, please ask.
Nursing advice

The Cleft Nurse Specialists will be in contact with you until your baby has had their operation/s. They will be in contact with other doctors, health visitors and nurses who are involved in your baby’s care.

Caring for your child in the future

The Cleft Team will keep in touch with you and your child until they are 16 years old. You will need to visit the hospital from time to time to keep a check on things. Some patients are then seen at the adult service at the Queen Elizabeth Hospital in Birmingham. Please see the section on the Adult Cleft Service (page 28).

• Outpatient Clinics

After your baby is born one of the Cleft Nurse Specialists will arrange a date for you to come to the outpatient clinic at Birmingham Children’s Hospital to meet the Cleft Team. Cleft clinics are held every Wednesday in the Main Outpatients Department.

What happens at the first visit to clinic?

When you come to clinic you may be at the hospital for sometime because several members of the Cleft Team will see your baby. At your first visit your baby will be weighed and photographed. The hearing test is now done as a newborn hearing test locally (for further details see page 22).

Please bring your Red Book (Child Health Record) with you.

Who will be there at the first visit?

• Cleft Nurse Specialist
• Surgeon
• Junior Doctors
• Psychologist
• Speech and Language Therapist

A Geneticist is part of the Team, but she may not be available on your first visit. We can arrange an appointment for you if you wish.
How often will we have to go to the hospital?

Throughout your child’s growth and development the Cleft Team will wish to keep in regular contact with you to make sure that all is well. However, we try to keep your visits to a minimum.

• **Coming into hospital for cleft lip/ cleft palate repair**

What happens before coming into hospital?

A Cleft Nurse Specialist will either arrange to visit you at home or see you in a special pre-admission clinic in outpatients. This is to give you all the information about your baby’s stay in hospital and the Nurse will answer any questions.

What do we need to bring with us to the hospital?

For your baby you will need to bring:
- Bottles, teats, spoons and dishes
- Baby gro
- Toiletries
- Nappies
- Red Book (Child Health Record)
- Mitts or socks to cover hands

What happens when we arrive at the hospital?

On arrival a nurse will show you to your baby’s cot and will show you around the ward. After you have settled in you will be seen by one of the doctors and your baby will be weighed, have their temperature taken and have a simple blood test. The nurses on the ward will be able to answer any questions.

Wards

The babies are usually admitted to the Neonatal Surgical Ward, Ward 5 or Ward 9. The nurses on these wards are very experienced in caring for babies with cleft lip and palate. Tea and coffee making facilities are available for parents on all wards. Parent’s meals are available for purchase in the restaurant on the lower ground floor.
Operations

An operation is performed only when your baby is healthy and not suffering from a cold. It is also important that your baby does not have any vaccinations 2 weeks before or 2 weeks after the operation. By 3 months of age, most babies with a cleft lip will be big and strong enough to have it repaired.

The cleft palate is usually repaired between 6 and 10 months of age. The main aim of this operation is to join the muscles so that the palate works properly. This helps with the development of speech.

Your baby will either be admitted to the hospital at 7.30am on the day of the operation, and will stay up to three days after the operation. Or your baby may be pre-admitted, which involves a hospital outpatient visit 2 to 4 weeks before the operation – you will then be asked to arrive early on the day of the operation instead of the day before.

One parent is encouraged to stay with their baby during their hospital stay. You can discuss this with the staff on the ward when your baby is admitted. It helps if your baby has some favourite toys in hospital. Please label them with your child’s name.

If you wish, you may go with your baby to the anaesthetic room where your baby will be prepared for their operation. Once your baby is asleep, the nurse will go with you back to the ward.

What happens after the operation?

If you wish, you may go with the nurse to collect your baby from the recovery room. Your baby may have a drip until feeding is established, which is usually the next day. The nurses will advise you how to feed your baby both on the ward and at discharge.

Your baby will have medicine for pain relief on the ward and you will be given a supply to take home. You will be able to go home once the doctors feel your baby is well enough.
Caring for your baby at home

Following discharge from hospital one of the Cleft Nurse Specialists will be able to give you advice over the phone and arrange to visit you at home.

Risks to your baby during and following an operation

Many things that we do in our lives have a risk, for example, when crossing the road we could be knocked down. As we know that, we look before we cross and cross in the safest place to minimise the risk.

This can apply to having an operation. We know some things that could go wrong and we take action to limit the chance of them happening. Some of the problems that could arise include a small risk of infection, bleeding, and problems with anaesthesia, or intravenous line problems. There is also a possibility that the operation may not work. Your consultant will discuss these risks with you before your baby’s operation. Although it is possible that these problems may arise, the risk is extremely small. The doctors and nurses looking after your baby are very experienced and highly trained. They do everything possible to limit risks.

Alternatives to treatment

There are no alternatives to the cleft lip and palate operations we offer.
• **Speech and Language development**

**Will my child have speech problems?**

Many children with cleft lip and palate or cleft palate develop speech with few or no problems but others need help. They may have difficulty learning how to use their tongue, lips and palate correctly for speech and/or air may escape down their nose when they are speaking.

The Birmingham Children’s Hospital Speech and Language Therapists watch carefully the development of all children who have had clefts of the palate to identify those who may have problems and to make sure that they get the right help when they need it.

Speech problems are rare in children with clefts of the lip only, but we are happy to see them if parents are concerned.
What does your palate do when you speak?

The soft palate is important in speech because it moves upwards and backwards when we talk. This movement combined with the movement of the walls of the throat separates the nose from the mouth. This is necessary to make the most of the sounds of speech, e.g. p, b, t, d, k, g, f, s, sh, ch. However, the soft palate does not have to lift up for the nasal sounds, e.g. m, n, ‘ing’.

![Soft palate raised](image)
Position of palate for most speech sounds.
- e.g. p, b, t, d, k, g, f, s, sh, ch

Air passes through the mouth.

![Soft palate lowered](image)
Position of palate for nasal speech sounds
- e.g. m, n, ‘ing’

Air passes through the nose.

Will I have to bring my child to Birmingham Children’s Hospital for all Speech and Language Therapy appointments?

No. We will ask you to come to specific appointments so that we can check on your child’s progress but most other appointments will be with your local community therapist.

How do local Speech and Language Therapists work with the team at Birmingham Children’s Hospital?

In each district of the West Midlands we have an identified Link Speech & Language Therapist who arranges local care for children with a cleft palate. We work closely together with Link Therapists and provide training for them. They are also an important part of our team.
New babies

When a new baby with a cleft palate or cleft lip and palate has been seen in the outpatient clinic we notify the Link Therapists. They may contact you by phone or letter at this stage.

After the palate operation

At the outpatient appointment following the operation we see all the children to see what progress they are making with babbling and give advice to you. Following this we write to the Link Therapist and ask them to monitor your child’s development and give further support as needed.

When will my child need to see the Speech and Language Therapists at Birmingham Children’s Hospital?

We see all the children who have had cleft palate operations for assessment between the ages of 18 months and 2 years, at 3 years and at 5 years. The 18 month-2 year appointment may be carried out locally or at BCH. The 3 year and 5 year assessments are usually done at BCH.

These assessments are very important and help us to make sure that your child is getting any help they need. They also help us find out the long-term results of the cleft palate operation and to plan future care.

There may be other times when your child needs to see the BCH therapists. These appointments will be discussed with you as necessary. When possible, the local Speech & Language Therapist will also be invited to attend so that therapy aims and activities can be agreed together.
• Hearing

National Hearing Screening Programme (NHSP)

All babies regardless of whether they have a cleft palate have their hearing screened just after birth. This is a national programme and any baby failing to pass the screen will be referred to their local audiology department for diagnostic testing. There are two tests used for both the screen and diagnostic testing. Otoacoustic emission testing uses a probe to present a sound to your baby’s ear, if the inner ear (the Cochlear) is working well we are able to record a response. Auditory brainstem response test involves placing sticky pads on your baby’s head and measuring the response to sound whilst your baby is asleep. This test measures hearing levels at different frequencies in each ear and can pick up any hearing loss. It will tell us whether it is sensorineural (caused by a problem with the hearing nerve or inner ear) or conductive (caused by problems with the middle ear). Conductive problems are more common in babies with cleft palate and often this is due to glue ear (see below).

If a hearing loss is detected your baby will be referred to an ENT consultant to monitor their hearing and decide if any treatment is necessary (see below).

Even if your baby passes their screen any baby with cleft palate will be assessed at around 8 months by their local audiology department. At this age babies are able to turn to sound so this response is used to test their hearing.

Cleft palate babies are then seen at various times in the first 5 years of life at their local hospital to ensure no hearing loss has developed. When your child attends the cleft clinic at Birmingham Children’s Hospital they may also be sent to audiology for a hearing test before they see the ENT consultant.

Will my child have any hearing problems?

Children with a cleft palate are more likely than most children to have ear and hearing problems during the early years of life.

Before palate repair, the surgeons need to know if your child has had an ear infection, discharge or difficulty hearing. Regular hearing tests and examinations are carried out in the cleft clinic. It is important for
speech development that your child can hear clearly.

**What is Glue Ear?**

Glue ear is a common condition in children with a cleft of the palate. Glue ear happens when the *Eustachian tube* (the tube which runs from the middle ear to the back of the throat) becomes blocked. Air is then not able to enter the tube, and the middle ear produces a liquid, which thickens and makes it difficult for children to hear. This produces a temporary hearing loss. It is rather like trying to hear through cotton wool! Children with glue ear may have difficulty hearing quieter sounds, which could affect speech development. Glue ear can be temporary and usually gets better on its own.

**Treating Hearing Loss**

If a hearing loss is due to glue ear the ENT consultant will monitor the hearing loss over time to see if things improve naturally. If not the two options would be a hearing aid to use until hearing improves naturally or grommets.

**Grommets**

Grommets are tiny plastic tubes that are placed in the eardrum. Sometimes this is done at the same time as the palate repair. We find that the grommets usually fall out as the eardrum heals and so the fluid may come back. If this happens, another grommet operation may be needed. The ENT consultant will talk to you about this.

**Hearing aids**

There are different types of hearing aids available. The most appropriate one for your child would be recommended by the audiologist or ENT consultant.

If you think that your child is having hearing difficulties, it is important that you contact the Cleft Team, who will make sure that a specialist doctor, an Ear Nose and Throat [ENT] Consultant, will examine your child’s ears and arrange a hearing test if appropriate.
• Dental Development

Why is it important to look after your child’s teeth?

It is very important that your child’s teeth are kept healthy from the start to stop dental decay. This is because healthy baby teeth keep space in the jaws for adult teeth to grow into.

How do I keep my child’s teeth healthy?

It is important to start tooth brushing as soon as your baby’s teeth appear. Use a baby toothbrush and a children’s minty fluoride toothpaste (500ppm fluoride). It is important that you only use a smear of toothpaste and that your child does not swallow the toothpaste.

At the age of 7 years you can change to use an adult toothpaste (1000ppm fluoride) and a daily fluoride mouthwash. Try and brush your child’s teeth twice a day. Avoid sugary foods and drinks, particularly between meals and at bedtime. Between meals only give drinks that are sugar-free; milk and water are best. Choose snacks with no added sugar.

Who will look after my child’s teeth?

You will need to register your child at your local family dentist or dental clinic by your child’s first birthday. When your child visits the cleft clinic after the palate operation (and for children with cleft lip only, at the age of 2 years) you will see a member of the Paediatric Dental Cleft Team. Advice on dental care is given. An examination of your child’s teeth will be carried out at this visit and at following visits to the cleft clinic.

How will my local dentist work with the Cleft Team?

We would like your child to see their local dentist every six months for check ups and treatment as necessary. Please bring the name and address of your child’s dentist to the clinic so that we may write to them to tell them of any decisions made. We may also ask them to carry out simple treatment for your child.
My child’s teeth are crooked and some are missing

Crooked teeth and missing teeth are common problems in children with cleft lip and palate. An orthodontist is a dentist who is especially involved in moving and straightening teeth. They use braces to do this. Your child will see our Cleft Orthodontist at the age of 8 years. At this stage our Orthodontist may ask an orthodontic unit close to your home to start brace treatment. A further course of orthodontic treatment is often needed in the teenage years.

• The School Years

Orthodontic Treatment:

Cleft Palate only

A cleft of the soft palate, or the hard and soft palate together has little effect on the development of the teeth.

When a wide cleft of the palate is present, the surgery to repair the palate sometimes causes narrowing of the upper jaw. This can produce a bite where the upper teeth bite inside the line of the lower teeth. This is called a crossbite.

If the crossbite is not causing any problems, orthodontic treatment may not be needed. However, crossbites are usually corrected at the same time as other aspects of the bite in the teenage years.

Cleft Lip

When there is a cleft of the lip, it is unusual for the teeth to be affected unless there is a grove or notch in the gum. Should the teeth be affected this may show as missing or small teeth. If there are any problems with the teeth, orthodontic treatment with braces can be carried out in the early teenage years when the adult teeth are all present.

Cleft Lip and Palate

When a cleft affects the gum, the teeth are usually affected. Teeth may be missing or extra teeth may be present near the cleft. Sometimes one or both of the upper front teeth are also missing or oddly shaped. If the jaws are small the teeth tend to be crowded together.
Timing of Orthodontic Treatment

Most orthodontic treatment takes place in two time bands. Firstly, bone grafts to the gum may be preceded by a brace age 8-10 years. Secondly, in common with children without a cleft, braces are usually fitted at about age 14 years to straighten the teeth. However, should there be the need to undertake jaw surgery orthodontic treatment is usually postponed until 16 years or later.

Bone Grafts

After the lip and palate have been repaired, the cleft (or gap) in the gum stays and has to be repaired later. This is done by placing bone into the cleft of the gum at about 8-10 years of age. This operation is called an Alveolar Bone Graft. Once bone is in the cleft, teeth can be guided into normal positions.

Before treatment starts, records need to be taken. These include x-rays, photographs and models of the mouth obtained from impressions (moulds) of the teeth. Sometimes before bone can be grafted into the cleft in the gum, the teeth and the jaw shape need to be improved with a brace. This is placed on the upper teeth for a few months before the grafting operation. Before the operation, it is changed to a simple retainer brace. The retainer brace is also fixed in place but is usually removed at about 6 months after the Bone Graft operation.

It is important to keep teeth and braces very clean by brushing them frequently. This will stop the teeth being damaged by plaque (see the glossary on page 33). If this is done well, the braces do not harm the teeth, and they can improve the position and appearance of the teeth to leave a nice smile at the end of treatment.

Orthodontics after the Bone Graft

If a brace was used prior to the Bone Graft, this is often removed during the six months after the operation. The Orthodontist will review Dental development to ensure the second teeth come in to the mouth properly. Further alignment of the teeth is often needed in the mid-teen years. Where possible, the treatment will be carried out by an orthodontist closer to your home.
The Bone Graft Operation

The operation involves a 2-3 day stay in hospital. The operation lasts about an hour and a half. Children come back from the operation with a drip (fluid line). The operation will cause a slight swelling of the face.

During the operation bone is taken from the hip bone. A small hollow instrument is used to take bone out of the hip bone through a little cut about one inch long. We then fill the gap in the gum with the pieces of bone from the hip and close the lining skin. This should stop any fluid, chocolate or yoghurt leaking into the nose in the future.

After the operation children are able to walk easily and generally go home the next day. It takes about 10 days for the gum to heal up. During this time it is important that the mouth is kept really clean. The lower teeth can be brushed and a mouthwash should be used after eating. It is advisable to keep food really soft until the skin lining has healed.

Usually this operation works well the first time. But in about 1 person out of 10 not enough bone will heal in the gap to allow the braces to work and the bone graft operation may need to be repeated.

**Psychologists**

The Psychologists will meet with you and your child at some of your clinic visits. Their role is to help you and your child cope with the emotional side of growing up with a cleft. We often talk to you about shyness, low confidence, friendship difficulties and coping with teasing. We also assist young people and their families in decisions about surgery, changing schools and relationship difficulties. As well as meeting the psychologists/ counsellor at clinic, you can contact them directly for advice or an appointment. Other members of the Cleft Team may suggest a meeting with us.

**Genetics**

Cleft lip and/or cleft palate usually occur as a ‘one-off’ within a family, and the chances of another baby also having a cleft are usually low. Some families have a hereditary increase to clefting. If you would like to talk more about the possible reasons for cleft lip and/or
palate happening and the chance of it happening again in your family, please ask to see the Geneticist. Adolescents who have had a cleft may also ask to see the Geneticist to talk about their future children’s risk of having a cleft.

• **The Adult Cleft Service at Queen Elizabeth Hospital**

**Moving on to the Adult Cleft Service**

From the age of sixteen, patients with a cleft lip and/ or palate will continue their treatment for any ongoing or new problem relating to their cleft in our adult service. Patients are seen for their final visit at the Children’s Hospital at fifteen. They are then moved on to the adult service. Older patients (16+) can also be referred by their General Practitioner (GP) or another health professional.

The Adult Cleft Service is at the Queen Elizabeth Hospital in Edgbaston, Birmingham. This service is similar to the one at the Children’s Hospital and many members of the Cleft Team at the Children’s Hospital also work at the Queen Elizabeth.

**Surgery**

One of the surgeons at the clinic will ask the patient general questions about previous treatment. You can then talk about any concerns you might have and also talk about any future surgery you might need. Future surgery could be about changing the shape of the lip or nose. The Plastic Surgeon will talk to you about this. Surgery may be offered to improve the shape and size of the upper and lower jaws. The Oral/ Maxillofacial Surgeon will talk to you about this. Before you make up your mind it is often necessary to arrange for photos, X-rays and models of the jaw to be taken. You will then return to talk about what is available and what you might want, at another clinic appointment.

**Restorative Dentistry**

The Restorative Dentist will advise and then treat any dental problems and an Orthodontist will help with the planning of any future jaw operations. (For more information on Restorative Dentistry please see page 36).
Speech and Language Therapy

A cleft palate can affect speech quality. A Speech and Language Therapist will be available at the clinic to advise on any speech problem and what it may mean for any suggested surgery.

Genetic advice

A Geneticist is not routinely available at the adult clinic but patients can ask for an appointment to talk about any possible reasons for why a cleft happened and the chances of this being an inherited condition.

Psychology

The Clinical Psychologist can help talk through some of the feelings and thoughts your child may have had so far about growing up with a cleft and the way it has affected them. As an adult, your child will be able to have a “one-to-one” session with the Psychologist before they see the rest of the Cleft Team in case you prefer to talk about some things more privately. The Psychologist will also be able to discuss some of the treatment options, especially those which involve a change in appearance, so that your child can agree on treatment plans that feel right for them.
• **Support Groups**

**The Cleft Lip and Palate Association (CLAPA)**

The Cleft Lip and Palate Association is a registered charity set up to give information and support to all those affected by cleft lip and/or cleft palate. There are local CLAPA groups based in the West Midlands. If you want to find out more about groups in your area please contact CLAPA head office in London or visit the website.

1st Floor  
Green Man Tower  
332B Goswell Road  
London  
EC1V 7LQ

**Tel:** 020 7833 4883,  
**Email:** info@clapa.com  
**Website:** www.clapa.com

You can also contact them for feeding equipment and for other information.

There are also CLAPA websites for children and young people:

Children’s website: www.clapakidz.com  
Young people’s website: www.clapaedge.com

**How can we contact other families?**

If you wish to speak to other families the CLAPA website also lists details of local parent contacts. The Cleft Team is unable to link families directly.
• **Data Protection**

We collect information about your child relevant to their diagnosis and treatment. We store it in written records and on the computer. We may have to share some of this information with other people and organisations, such as your child’s GP or Health Visitor. If you have any questions and/or do not want us to share that information with others, please talk to the people looking after your child or contact the PALS (Patient Advice and Liaison Service) Officer on 0121 333 8403.

• **Further Information**

We hope this information folder will help you to understand more about Cleft Lip and/or Palate and the treatment offered to your child. You can find out more by looking at our website at www.bch.nhs.uk/cleftlipandpalate.htm

Information and Internet access is available in the Child and Family Information Centre. This is on the Ground Floor of the hospital near the main Reception Desk.

If you would like more information about your child’s cleft lip and/or palate you can contact the Cleft Nurse Specialists on 0121 333 8092.

If you need to speak to someone about your child’s Cleft Clinic appointments, please call: 0121 333 8235.

This booklet was produced by the Cleft Lip and Palate Team.
• This space is for you to write questions that you may want to ask the cleft team:
• What do the words used in Cleft Lip and Palate Care mean?

Alveolar Ridge
The arch of bone under the gums, which houses the teeth in both the upper and lower jaw.

Articulation
The co-ordinated movement of lips, tongue and soft palate to produce speech sounds.

Bifid
Divided, in two parts.

Columella
The central, lower portion of the nose which divides the nostrils.

Crossbite
When the mouth closes together, the top teeth bite inside the bottom teeth.

Dental Arch
This is the shape of the teeth in the gums. It can be well positioned, crowded or spaced depending how tightly the teeth are packed together.

Dental Extraction
Describes the procedure to remove a tooth which could either be diseased, painful, the wrong shape or perhaps in the wrong place.

Dental Restoration
When a tooth is either filled or protected with a material, if it has been broken or affected by decay.

Eardrum (or tympanic membrane)
The eardrum vibrates and transmits sound to the middle ear.

E.N.T.
The abbreviation for ear, nose, and throat.

Eustachian Tube
The air duct which connects the nasopharynx (back of the throat) with the middle ear; usually closed at one end, opens with yawning and swallowing; allows air to pass into the middle ear cavity and so keeps the pressure on two sides of the eardrum equal.
**Fistula**  
An abnormal opening, usually referring to a hole in the palate after repair.

**Genetics**  
The science of heredity (how things pass from one generation to the next).

**Hard Palate**  
The front part of the roof of the mouth containing bone covered by mucosa (pink “skin”).

**Hearing Impairment**  
A loss in hearing which may range from mild loss to complete deafness.

**Hypernasality**  
Speech that sounds overly “nasal,” as if the person is “talking through his/her nose.” Too much air is coming through the nose.

**Hyponasality**  
Speech that sounds as if the person has a blocked nose (as if they have a heavy cold). Not enough air is coming through the nose.

**Malocclusion**  
This is an incorrect positioning of the upper teeth in relation to the lower teeth.

**Mandible**  
The lower jaw.

**Maxilla**  
The upper jaw.

**Middle Ear**  
The portion of the ear behind the eardrum. It contains three small bones which move sound from the eardrum to the inner ear.

**Multidisciplinary Team**  
A group of professionals who work together to help plan and carry out treatment for patients with cleft lip, cleft palate, and related disorders. The group usually includes surgeons, dental specialists, speech and language therapists, and others who meet regularly and talk about the care of their patients.

**Nasal Emission/ Nasal Escape**  
Too much air coming through the nose during speech. May sound like a nasal snort (called Nasal Turbulence).
**Nasal Septum**
The “wall” that divides the nose into right and left halves. It normally joins the roof of the hard palate like an “inverted 7.”

**Nasendoscope**
A small bendy tube (endoscope) attached to a camera is used to look at movement of the palate.

**Occlusion**
Relationship between upper and lower teeth when they are in contact. Refers to the position of teeth as well as relationship of dental arches.

**Oral Hygiene**
Care of the teeth and gums which is performed at home on a daily basis. This is performed first by the child’s parent or carer while the child is small and eventually by the child under continued supervision of the parent or carer.

**Oral and Maxillo Facial**
The specialty of dentistry concerned with management of dental and skeletal abnormalities.

**Orofacial**
Relating to the mouth and face.

**Orthodontics**
The specialty of dentistry concerned with the correction and prevention of irregularities and malocclusion of the teeth and jaws.

**Orthodontic Care**
Dental visits designed to move the teeth into better alignment with one another to improve chewing, oral hygiene, and appearance.

**Otitis Media (Glue Ear)**
Inflammation of the middle ear with build up of thick fluid - ear infection.

**ENT surgeon**
A doctor specialising in diseases of the Ear, Nose and Throat.

**Palate**
The roof of the mouth including the front portion, or hard palate, and the back portion, or the soft palate (also called the velum).
Paediatrician
Medical doctor specialising in treatment of children.

Paediatric Dentistry
The specialty of dentistry concerned with the care of children’s teeth.

Philtral Columns
Normal ridges in the skin of the central upper lip connecting the peaks of the Cupid's bow to the nose.

Pierre Robin Sequence
See page 9.

Plaque
A film of mucus and bacteria on a tooth surface.

Premaxilla
The small bone in the upper jaw which contains the upper four front teeth. Normally connected with the side segments of the upper jaw (maxilla) but separated in some clefts.

Preventative Dental Care
Regular dental visits during which teeth are checked for cavities and cleaned.

Prolabium
The central area of the upper lip underneath the centre of the nose (columella) and between the philtral columns.

Psychologist
A trained person who can help you understand your feelings and reactions associated with a cleft.

Radiography (X-ray)
Photographic film or plate showing pictures of internal body parts. X-ray.

Restorative Dentistry
Restorative dentistry involves the repair of oral and dental tissue. It includes the following dental disciplines: operative dentistry, which involves the filling of teeth; periodontology, which is the prevention and treatment of gum disease; endodontics, which includes root canal treatment; and prosthodontics, which is the replacement of teeth.
Soft Palate
The back part of the roof of the mouth containing muscles and mucosa (pink “skin”). The Latin name for the soft palate is “velum”.

Submucous Clefts
See page 12.

Uvula
The ‘dangly’ bit at the back of the throat.

Velopharyngeal Closure
The closure of the soft palate against the back wall of the throat (pharynx), which separates the mouth and nose during speech.

Velopharyngeal Incompetence/ Insufficiency/ Dysfunction
The palate does not separate the nose from the mouth properly and allows air to escape into the nose when it shouldn’t.

Velum
The Latin name for the soft palate.

Videofluoroscopy
A video recorded x-ray examination of the palate during speech.