Information on the Management of Child with a Cleft Lip and Palate For Parents and Carers

at

Temple Street Children’s University Hospital, Dublin
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This is based on a view from below of a unilateral complete cleft lip and palate on the left side of a child’s face.

This nose tip is top most with a normal nostril on the left of the logo and a stretched flattened nostril on the cleft side.

Below the cleft nostril floor is the cleft lip, the cleft alveolus (gum) and the cleft palate which terminates as a cleft uvula at the apex of the triangle towards the bottom end of the logo.

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Introduction

Congratulations to you and your family on the birth of your new baby. This aim of this booklet is to explain the cleft condition and the stages in treatment required to correct it. We hope that it will provide you and your family with much needed information in the initial stages about feeding and preparing for your child’s first operation.

This booklet will also describe treatment that may be provided for your child during their developing years into adolescence and early adulthood. The management of a child born with a cleft lip and or palate involves a multidisiplinary team which may include the following:

- Plastic Surgeon
- Speech and Language Therapists (SALT)
- Ear, Nose & Throat (ENT) Surgeon
- Audiologists (Hearing)
- Cleft Nurse Specialist
- Paediatric Dentist
- Orthodontist
- Maxillo-Facial Surgeon
- Prostodontist
- Social Worker
- Clinical Photographer
- Department Secretary
- Cleft and Craniofacial Services Manager.

A Geneticist, Psychologists and many others may all have roles to play.

The Cleft Lip & Palate Association (CLAPAI) provides support for parents and children at all stages of this process. They can be contacted at [www.cleft.ie](http://www.cleft.ie).

Cleft lip and palate is a variable condition with a spectrum of severity. It can range from a minor lip deformity or a cleft (gap) of the soft palate only, to a major cleft affecting the lip, nose, palate. Treatment will vary according to the degree of cleft, so some of the information within this booklet may not be appropriate for your child. Treatment may also vary from centre to centre and this booklet reflects the views of the Cleft Lip and Palate Unit based in Temple Street Children’s University Hospital.

Since 2000, the Cleft Units of Temple Street Children’s University Hospital, Mater Misericordiae Hospital, Our Lady’s Children’s Hospital, Crumlin, and St James' Hospital have increased their exchange of information and techniques as well as introducing a Cleft Database.

Together, we refer to these Units as The Dublin Cleft Centre and have as a mission statement the following:

“The Dublin Cleft Centre comprises of a multi-disciplinary group from the Dublin Cleft Teams working to develop and implement standardised best practice guidelines and care in cleft management”.
The Lip, Palate and Nose

The accompanying diagrams show the areas usually involved in cleft management. These terms may seem strange but they will help you understand what is being discussed by specialists at clinics when you attend. The lip has three layers;
- Skin,
- Muscle
- Lining inside the mouth (mucosa).

Palate

The palate consists of a hard palate, which is the solid base for the teeth of the upper jaw, and a soft palate which is muscular and mobile.

It is the soft palate which is so important in both speech and in preventing the escape of air and food from the mouth into the nose. The uvula hangs down from the soft palate and helps the palate form a good seal between the mouth and nose.

Both the soft and hard palates are made up of three layers, with five different groups of muscles all of which are involved in speech.

Face

Nose

The nose is a complex structure consisting of skin and cartilage (gristle) on a bony framework. The ala is often collapsed on the side of a cleft lip and the columella is often pulled to the opposite side of the cleft. The septum (the gristle separating the two nostrils inside the nose) is often displaced into one or other nostril causing difficulty in breathing on that side.
Cleft Lip and Palate

Types of Cleft and Problems Faced

In Ireland, approximately one baby out of 700 babies born alive will have cleft lip and or palate. The following information and diagrams will explain each type of cleft.

Cleft Lip:

The following diagrams show:

A An incomplete cleft lip often affects the shape of the nostril and is sometimes associated with a notch in the gum (alveolus). A baby with this will require repair of the lip and may later need surgery to improve the nose and orthodontics when the adult teeth appear.

B A complete cleft lip and palate will involve the palate and the lip. This baby will require;

- Lip repair
- Palate repair
- Bone graft to the gum (alveolar bone grafting)

Sometimes a child may need surgery again when older to improve their appearance and help to improve their speech.
A bilateral complete cleft lip and palate is a large defect which involves two sides of the lip and a cleft (opening) in the palate. Usually the middle section of the lip, being unattached at both sides, becomes very prominent and the appearance can be upsetting. However, when the lip is repaired this appearance is much improved.
Cleft Palate:

The palate can be cleft alone or associated with a cleft lip. If only the palate is affected it is known as a secondary cleft palate (A). In its most minor form, only the uvula is cleft, but even this leads to an abnormality in the muscles in the palate and, if a child’s speech is affected, a repair will be required. This type is called a submucous cleft palate (B).

A complete cleft lip and palate (C) involves a cleft of the lip on one side, the gum (alveolus) with the outer part of the alveolus tending to collapse inwards and the palate. This is why orthodontic treatment is required later and an alveolar bone graft is used to bridge the gap in the gum.

A complete bilateral cleft lip and palate (D) leaves the central part of the gum unattached, allowing it to grow forwards. This is the premaxilla and carries the upper four central teeth. A double bone graft at the time the permanent teeth are erupting is required for this type of cleft.

The sequence for repair of the lip, palate, gum and nose follows the next section.
The Effects of a Cleft Lip and Palate

The following areas can be affected by a cleft lip and or palate. They are:

- Feeding
- Appearance
- Speech
- Hearing
- Dentition (teeth)
- Facial Growth

**Feeding:**

It is easy to understand why there may be problems with a cleft palate which leaves a large opening between a baby’s mouth and nose. Occasionally, a cleft lip can interfere with your baby’s ability to efficiently suck on either breast or teat of their bottle.

Difficulties with feeding will be discussed later in this booklet on page 11

**Appearance:**

The initial appearance of any cleft, no matter how minor, is a shock to the whole family. This initial shock and upset is normal. At this stage, you may find it helpful to talk to other parents with similar experiences. The Cleft Lip and Palate Association can help you make contact with other parents. The Cleft Team is also available to answer as many questions as possible.

For some, shock is replaced by denial, by anger and often grief. These are normal reactions and parents should concentrate on two main facts; firstly, the joy of a new child and secondly having the reassurance that there are a range of treatment options for your child’s condition.

**Speech:**

Many children develop speech well but approximately 50% will have some speech difficulty. The main problems are;

**Articulation** (making sounds) problems occur when children have difficulties making speech sounds due to poor palate closure and / or have adaptive tongue movement.

A cleft palate may cause air to escape from the mouth into the nose when a child is speaking; this can cause **hypernasality** (a nasal tone to their voice). In addition air can escape down the nose when the child is attempting speech sounds.

Your child will be assessed by a speech and language therapist for any difficulties they may have in their speech. This will be explained later in this booklet on page 16.
Hearing:

Due to the muscles involved in their cleft palate causing poor drainage of their middle ear, some children may have difficulties in hearing.

This is dealt with in detail in a later section on page 24

Dentition (teeth):

A cleft lip by itself does not affect how teeth grow, but if a child’s gum is notched or there is a cleft palate this can cause problems with the growth and development of teeth.

The repair of the palate may unavoidably affect future growth of teeth but as techniques change this has become less likely. It is important that children look after their teeth and visit their own dentist regularly.

Facial Growth:

For children with a large cleft the middle part of their face may fail to grow satisfactorily. This can result in a “dished in” appearance, or a very prominent lower jaw in relation to the upper jaw. Because of this, children may have problems eating, chewing and biting correctly as their teeth do not meet when their mouth is closed.

Children with these difficulties will be monitored by an orthodontist and the maxillo-facial surgeon.

Teamwork

The Core Team (see information sheet) adopts a Team approach towards the management of your child with a cleft lip and or palate. The team approach to working with children is holistic and child centred based, on an accepted care pathway within the Dublin Cleft Centre. The team manages the assessment and diagnosis of referrals and provides intervention from all team members as required to improve your child’s difficulty, to maximise their potential development. Parents and children are considered an integral part of the team. A diagnosis will comprise the core teams’ clinical opinion and a request from peripheral team members for an evaluation of influencing factors in the child’s condition. Intervention will include follow up from each discipline involved in the child’s new plan of care, and will include parental support and links to local services

The Orthodontist acts as a link with Maxillofacial Services and the Maxillofacial Surgeon at St. James’ Hospital. Other specialists are often involved and form the Peripheral Team. This would include psychologists, eye specialists, geneticists etc. Referral to these services is usually carried out by members of the Core Team.

The role of the Cleft Services Manager is to coordinate & manage the team approach to each child’s care. The manager is the first point of contact for new referrals and ensures that each new family receives information, support and reassurance following their child’s diagnosis. Liaison with the cleft team, peripheral team members and community based services is an integral part of the role. The manager works closely with families to ensure their needs are met and continues to provide support during the child’s care.

Should you have any concerns or queries in relation to your child’s care please contact the Cleft Services Manager at 01878 4882 or 01 878 4883
Timing of Surgery for Cleft Lip and Palate

Cleft Lip Repair:

Usually we repair a cleft lip in babies when they are about three months of age and 10 lbs in weight. The emphasis in the repair is to restore the shape of the lip muscles around the mouth and to bring the base of the flattened nostril (ala) inwards. These muscles will then help to mould the alveolus (gum) into the correct position.

After their operation, your baby will be given medication for any pain they may experience and can be breast or bottle fed as normal. You will be able to see stitches in your baby’s lip. These are removed under a general anaesthetic one week after their operation.

After this, the scar will be pink and hard and may sometimes pull the lip upwards. This, however, will settle after a few months and the scar will gradually become softer. We recommend that vitamin E cream is massaged into the scar at this stage. Further operations can be carried out at any stage to improve the appearance of their lip. We encourage parents to tell us about any concerns they or their child may have about their appearance.

Cleft Palate Repair:

This is carried out when a child is 6 - 12 months of age. The smaller clefts of the palate can be operated upon early, but with wide clefts your child’s plastic surgeon may have to wait for the sides of the palate to grow inwards and closer together. The surgeon uses the skin and muscle of the palate itself and closes the cleft in three layers, nasal lining, muscle and oral (mouth) lining.

In our unit, we do not alter a baby’s feeding pattern. Breast and bottle feeds can be continued almost immediately after each operation and they may also use their soother. Your child’s repair operation will not be harmed by sucking or crying. In a complete cleft lip and palate, the gum (alveolus) is not repaired at this stage, so there will be a small hole between the mouth and the nose.

Fistula:

In small number of palate repairs, the centre of the repair does not heal, leaving a hole (fistula) which may cause food or fluids to come down a child’s nose. This type of fistula usually needs to be closed in an operation at a later stage (between 3 and 10 years of age). This type of fistula can occasionally affect speech.

We have studied the rate of fistulae (holes) and their causes in this unit. We have found that babies who suck their fingers (not thumbs and not soothers) have a high risk of damaging the repaired palate. To prevent this we now recommend the use of mittens for all children for 3-4 weeks after their cleft palate repair.

Nose Repair:

For children who have a flattened nose, it is hoped that the first lip repair will help its position greatly, but more operations are often required. We will continue to monitor how your child’s facial features as they grow. Reshaping the nose can be done at an early age if required, however, an operation at this early stage is unlikely to be enough, as their nose will constantly change in shape of throughout teenage years. A final rhinoplasty (“nose job”) when they are 16 to 18 years old maybe needed.
Gum Surgery:

For children with a gap in their gum, this will be permanently bridged during an operation with a bone graft taken from their iliac crest (hip). This is known as alveolar bone grafting and is carried out when their second (permanent) teeth become visible. This operation is usually performed when a child is between 8 and 12 years of age.

The orthodontist makes the decision on the timing of this operation, which is performed by the plastic surgeon or maxillo-facial surgeon. If a child needs a revision of their lip scar, it can sometimes be carried out at the same time.

Surgery for Speech:

Some children with ongoing speech issues may need a second operation on their palate which may help their palatal closure. If needed, this operation is carried out on the advice of the Cleft Team after investigations see the speech and language section on page 16.

Surgery for Hearing:

Some children may have problems with fluid drainage in their middle ear. To drain this fluid grommets (ventilation tubes) can be inserted by an Ear, Nose and Throat (ENT) surgeon after monitoring their hearing using hearing tests.

Late Surgery:

Major bony surgery to move forward the whole of the upper jaw, or to move the mandible (lower jaw) is required in a small number of young adults with a cleft lip and palate. This is carried out by the maxio-facial surgeon in consultation with the young adults themselves, their parents and the wider Cleft Team.

Further surgery to improve the shape of a young adult’s lip and nose is often delayed until they are in their late teens. This surgery will be performed in an adult hospital with the same plastic surgeon.
Following assessment of your child’s needs you will be advised by the Cleft Nurse Specialist and or Speech and Language Therapist on the most appropriate feeding plan for your baby. Many parents decide before the birth of their baby to breast feed and depending on the type of cleft this may be possible. This can be discussed with a member of the cleft team.

**Bottle Feeding:**
Special bottles are available for babies with cleft lip and palate who have difficulties sucking. Examples are MAM bottle or Medela Special Needs Feeder (Haberman). Assisted feeding using one of these bottles will help you to feed your baby. Babies with a small cleft lip or a small cleft of the soft palate may be feed without any significant difficulty. In this case, your baby can be breast fed or bottle fed according to your own preference. Babies with more extensive clefts may have feeding difficulties because they cannot create enough pressure on the nipple or teat to suck. Liquid may also spill into their nose and come back down through the nostrils during feeding. These feeding problems, however, can be overcome by using a special bottle.

**Weaning:**
Your baby should wean in the normal manner. Babies can be introduced to pureed food at around four months and mashed foods can be introduced between 6 and 9 months. Your baby should manage to feed easier using the spoon as the semi-solids, unlike fluids, do not pass up into the nasal cavity to the same extent.

You should finish the feed with a drink of water to help clear any food from the cleft area.

**The Dietitian:**
Our hospital dietitian can help assess if your child is getting enough nourishment and advise on food changes if needed. It is important to be flexible regarding feeding.

Remember that any baby, with or without a cleft, can have difficulty establishing a good feeding pattern.

**Swallowing Difficulties:**
In general, babies with a cleft lip and palate do not have swallowing difficulties. However, if you feel that your child has problems swallowing contact the Cleft Nurse Specialist or the Speech and Language Therapist to arrange for an assessment and guidance.
Speech and Language Development

Many children with a cleft lip or palate learn to speak normally and may not need speech and language therapy. Approximately half of children will have some problems with their speech but many of these problems can be resolved with speech and language therapy.

Children with cleft lip only rarely have any difficulty with their speech. However, all types of cleft palate, particularly cleft of the soft palate, are prone to problems with language development, articulation (speaking) and nasality (a nasal tone to their speech).

During the first few years of life, language development may be delayed in a child with a cleft palate, where a child may not say words at the appropriate age, or using immature phrases or sentences. This problem can be treated with speech and language therapy, and usually by the time the child is going to school, their language development is similar to children of the same age.

Some children may have difficulty with articulation (have difficulty making speech sounds). Articulation problems may be a result of a combination of factors, such as;

- Scarring of the palate
- Poor movement of the soft palate
- Hearing problems

Most children develop normal articulation with ongoing speech therapy. Speech and language therapy can help to eliminate articulation errors, however, some children have persistent hypernasality, nasal emission and or articulation problems which will need further surgery. (see the speaking diagram page 17)

When speaking the soft palate moves backwards and upwards to close against the back wall of the throat preventing sound from escaping into the nasal cavity (see the breathing diagram page 17). The adenoids (adenoidal pad) are important in helping this closure.

If the palate is too short or the movement of the palate is poor, the closing action does not take place and air escapes into the nasal cavity causing nasal emission (an escape of air thorough the nose during speech) and hypernasality. Sometimes further surgery on the soft palate is required.
Breathing

Arrows show the direction of airflow
Babies born with cleft lip and palate will automatically see one of our Speech and Language Therapist at their first visit along with other members of the multidisciplinary Cleft Team. The Speech and Language Therapist will assess how your baby is swallowing and feeding.

After this first visit your child will be referred to a Speech and Language Therapist in your local area who will aim to see your child between nine to twelve months of age for assessment of their communication skills. The Speech Therapist can informally assess the level of your child’s development and provide advice on ways to encourage normal speech and language development.

Early intervention can prevent development of speech and language problems in the future. Your child should be reviewed on a regular basis over next few years with your local Speech and Language Therapist.

At approximately two years of age your child will have a detailed speech assessment by a Cleft Speech and Language Therapist at our hospital. If any problems are discovered, your child can be seen at the Combined Clinic with the Plastic Surgeon and Speech and Language Therapist.

From three years of age, your child will attend a special Combined Cleft Palate Clinic where your child will have a full speech assessment and hearing test. The Plastic Surgeon, Speech and Language Therapist, Ear Nose and Throat (ENT) Consultant and Cleft Manager will attend this clinic.

The team will talk with you about the ongoing treatment plan for your child, which may include surgery and possible ongoing speech and language therapy. Your child’s progress will be monitored on an ongoing basis throughout their childhood into early adulthood until 18 years of age.

If your child has speech or language problems, they should attend regular speech and language therapy within your local area. The Speech and Language Therapist will work closely with you as parents or carers, providing exercises and drills, which should be carried out with your child at home.

**Nasendoscopy and Videofluoroscopy:**

A small percentage of children have a significant speech problems despite ongoing therapy will require specialised assessment of palatal movement during speech. Two special investigations are available:

1. **Videofluoroscopy** involves the use of continuous x-rays during speech, assessing the movement of the palate from the side while a child is speaking or making sounds.

2. **Nasendoscopy** involves inserting a small scope (nasendoscope) into a child’s nose to watch palatal movement from above as they speak.
These assessments complement each other and allow us watch how a child’s palate functions during speech. Information from these specialised assessments can help decide on future management for speech.

If you are concerned or have any questions about your child’s feeding or speech and language development you can phone us at the Speech Therapy Department in Temple Street, Children’s University Hospital, 01 878 4293.
Dental Health

It is important that the primary (baby) teeth and permanent (adult) teeth remain sound and do not decay. Early loss of primary (baby) teeth may complicate and prolong future orthodontic treatment. Loss of permanent (adult) teeth may mean that orthodontic treatment cannot be offered at all, or the outcome of treatment will be compromised. To prevent tooth decay it is important that your child has a healthy diet and that early tooth brushing habits are established from an early stage.

Frequent eating of sugary foods and or drinking sugary drinks causes tooth decay. These foods and drinks should be kept as treats only. Unsweetened fruit juice is a good source of vitamins but it can cause tooth decay if taken too often. It is best kept to mealtimes only. The “no added sugar” variety of fruit drinks can cause tooth erosion and are best kept to a minimum and then only at meal times also.

Snacks and drinks taken between meals should not contain sugar. Milk, water, plain or cheese popcorn*, nuts*, wholemeal or plain scones, fruit yogurt, low sugar breakfast cereals, savoury crackers, cheese triangles or strings, fresh fruit, unsweetened stewed fruit sugar free jelly and toast are some examples of sugar free snack foods.

* Children under five years of age are at risk of choking with these foods.

The purpose in cleaning teeth is to remove the left over food and the layer of bacteria that form on all our teeth regularly. This layer of bacteria is known as dental plaque and if it is removed it can prevent tooth decay and gum disease.

When a child’s first tooth appears in their mouth it can be cleaned by wrapping a piece of cloth around a finger and rubbing the tooth (teeth) and gums gently. Doing this establishes a cleaning routine early and your baby will become used to it. Alternatively you can use a small soft toothbrush.

Children under 2 years of age should not use fluoride toothpaste. Children over 2 years of age should use a pea-sized amount of fluoride toothpaste. An adult should supervise children under 7 years of age so that teeth and gums are cleaned at least twice a day, in the morning and last thing at night, before they go to bed.

After your child’s first visit with us we will send a referral letter to your local HSE dentist for your child to be seen around the time of their first birthday. This treatment is provided free of charge.
Remember

Prevention is the key to healthy teeth and gums.

If you don’t look after your child’s teeth the final result of their cleft treatment is compromised.

Dental decay is totally preventable by a combination of fluoride, diet and oral hygiene.

In Ireland all public water supplies are fluoridated. If fluoride is not in your water supply, please seek advice from your dentist.

Use fluoride toothpaste for children over 2 yrs of age. Only a pea-sized amount is needed.

Teenagers should regularly use dental floss.

If a child has braces on their teeth, your orthodontist will recommend additional oral hygiene aids.

When buying fruit drinks for your child choose no added sugar varieties as these are kinder to their teeth but should only be taken at meal times.

Diet minerals should be taken as a treat only as they can cause erosion of their teeth.

When your child is on medication, ask the doctor to prescribe sugar free brands.
Orthodontic Treatment

Initial Orthodontic Treatment:

Your child will meet the Orthodontist when they are 5-7 years of age. The orthodontist will take records and impressions of the developing teeth, gum and jaw (dental arch). If there are any extra (supernumerary) teeth they can be removed as they can interfere with the proper development of the second or permanent teeth.

Orthodontic Treatment:

For some children, simple orthodontic treatment involving braces to straighten their teeth is all that is required. In children who have either bilateral complete cleft of the lip and palate or unilateral complete cleft of the lip and palate, bone grafting of the alveolus (tooth bearing portion of the upper gum) is required.

Before the bone grafting is carried out, the teeth must be brought into the correct position in relation to each other and this is achieved by the use of orthodontic appliances to expand the upper dental arch and align the anterior teeth where required. The ideal age for this procedure is usually between the age of 8 to 12 years depending on the stage of dental development.

The bone grafting procedure enables the permanent teeth to come down. When all the permanent teeth are through (usually by the age of 13 years), full orthodontic alignment of teeth can start with the use of braces. The aim of orthodontic treatment is where possible to align all the teeth to maximize aesthetics and function.

Alveolar Bone Grafting:

Alveolar bone grafting is necessary in children whose cleft involves the alveolus or gum. It is an operation where bone is taken from another source (hip bone) and placed into the cleft of the gum making a bony socket for the permanent teeth to come down through. It is often carried out between the ages of 8 and 12 years but timing is dependent on the development of the permanent canine tooth. This is determined by the orthodontist. As always, dental hygiene is important before and after surgery as infection may cause the loss of a bone graft.

For children with bilateral clefts involving the alveolus, 2 separate bone graft operations (one for each side) will be necessary. The operations will be at least 3 months apart. Alveolar bone grafting is carried by a Plastic Surgeon or Maxilafacial Surgeon and involves admission to hospital for generally 3 - 4 days but this may vary from child to child. Admission to hospital is usually on the morning of your child’s surgery when routine investigations have been completed previously. Surgery is carried out under general anaesthesia.

If your child needs this surgery, it will be discussed with you and your child in further detail at the Combined Orthodontic Clinic.
Osteotomies

In a number of young adults, the upper and lower jaws may not be aligned correctly and braces alone may not produce the best results. To correct the jaw alignment surgery may be required; this is referred to as Orthognathic Surgery. This is usually carried out by the Maxillofacial Team at St James’ Hospital.

Young adults undergoing this surgery should have a speech assessment before their surgery as there is a small risk that this procedure could result in a deterioration of speech. Speech assessment should be carried out three months before surgery and one year after surgery.

If your child needs this surgery, their treatment plan will be discussed with them in detail at a Combined Orthodontic Clinic.
Hearing Problems and Treatments

Hearing and a Child with Cleft Palate:

The ear is composed of three parts; the outer ear, middle ear and inner ear. Sound waves travel through the air and enter the outer ear canal. Here they strike the eardrum, the eardrum moves inwards and the sound is transmitted across the middle ear by a chain of three tiny bones called ossicles.

The innermost of the three ossicles is called the stirrup bone and it transmits the sound to the inner ear. Here the minute nerve endings pick up the sound and transmit it directly to the brain. The part of the ear which is usually affected in a child with a cleft palate is the middle ear. If sound cannot travel freely across the middle ear to the inner ear, a child has a hearing loss. Normally the inner ear contains the air. It is connected to the back of the nose via the eustachian tube. This tube opens and closes approximately 1,000 times a day and allows air to enter the middle ear from the nose, keeping the air in the middle ear the same as the pressure in the outside world. If, for any reason, the eustachian tube does not function and air does not enter the middle ear regularly, a negative pressure develops in the middle ear. This causes fluid to be secreted into the middle ear by its lining membrane, this fluid interferes with hearing.

Because sound cannot be transmitted efficiently across the middle ear a child can develop hearing loss.
When a child has a cleft lip only, hearing problems usually do not arise. However, when there is a cleft in the palate, hearing problems can arise for the following reason:

The soft palate at the back of the mouth has muscles connected to the eustachian tube. When we yawn, eat or swallow, the palate moves and this pulls the eustachian tube open and allows air to pass into the middle ear as mentioned before. If the eustachian tube does not work properly, air cannot get into the middle ear as it should and its place is taken by fluid.

Your child will have their first hearing test under the national neonate screening programme while in the maternity unit. Children will be listed for targeted follow up at nine months old. Depending on the results of the hearing test your child may require ongoing monitoring and assessment on a regular basis throughout their childhood.

What to look out for

Parents and teachers are usually first to realise that a problem may exist for example;

• Turning up the sound of the television,
• Having to repeat oneself to a child when speaking
• Child unable to hear their parent when called from another room

In a very young child and particularly under the age of 2 years, it is slightly more difficult to detect hearing loss. If the child appears unresponsive and frustrated or withdrawn, this behaviour could be because they may have an ear infection resulting in poor hearing. Their ears may feel congested and uncomfortable and a child may be out of sorts.

If there is any question that your child does have a hearing loss, you should ask your family doctor to assess them and contact the Cleft Team.

Treatment of Hearing Problems

Many children with a cleft palate can have middle ear fluid and some degree of hearing loss. This may require surgical treatment by inserting grommets to drain the fluid and allow air into the middle ear, helping to dry up secretions and bring hearing back to normal. The grommets generally last for 6-9 months after which they usually fall out.

Parents will generally notice an improvement in their child’s hearing within a few days. Unfortunately, grommets may need to be inserted on a number of occasions until the child’s eustachian tubes start to function properly. In many cases, such children be seen regularly by a ENT Surgeon until they are 10 years of age.
Audiology Assessments (hearing test):

A child with a cleft palate is at a higher risk of hearing problems so it is vital that regular hearing tests are performed throughout their childhood by an audiologist.

The type of hearing test that your child receives will depend on their age and level of development. With very young children, generally under the age of 3 years, it is difficult to obtain information for each ear separately. In order to measure hearing levels for each ear, headphones must be worn so that only one ear is listening at a time. Most young children usually do not like wearing headphones. Therefore, with toddlers and children who do not wear headphones, we carry out a test in a sound field environment. This means that the sound comes from a speaker and we teach the child to respond to this sound. The levels at which your child responds gives us an idea as to whether or not they are likely to have enough hearing for normal speech and language development as this is usually possible as long as one ear is functioning at the “pass” level.

If you are worried about your child’s hearing at any time, contact the Audiology Department 01 878 4533 to make an audiology appointment. If the audiologist is concerned about your child’s hearing they will refer your child to an ENT consultant for follow up.

Tonsils / Adenoids:

Like any other child, a child with a cleft palate may suffer from tonsillitis and adenoiditis, causing sore throats or upper respiratory tract infections. Removal of the adenoids at the back of the nose may affect speech.

In cases when a child who has had a cleft palate repair performed and has recurrent tonsillitis (such as 6 genuine attacks per 18 months), requiring antibiotics, surgery may have to be considered despite the risks involved. In such instances, it is suggested if possible that the child be seen at a combined Cleft Clinic and a joint decision regarding surgery be made by the Plastic Surgeon, ENT Surgeon, Speech and Language Therapists and parents.

If surgery is required, there is a risk that the child’s speech may deteriorate post operatively and that even further palatal surgery may have to be considered in due course.

This same risk also applies to the removal of adenoids.
Social and Psychological Aspects

Receiving a diagnosis of Cleft Lip or Palate can represent a crisis for some parents and families. It can challenge your view of your child, yourselves as individuals/parents and family life. It is a significant event in both you, as parents and your child’s life. The timing of and events leading up to the diagnosis can vary between families, so it is important to be mindful of yourselves and each other during this time as your experience will be unique to you and your family.

You and your partner/family may experience:

- Feelings of Shock, disbelief, sadness, guilt and anger,
- Thoughts of “How did this happen?” or “Why me or my child?”,
- Action/Behaviour “What can be done?”, “Can this be fixed?”, “How can I help my child?”

All of these feelings, thoughts, and questions are normal in the circumstances of receiving a diagnosis. The role of the Social Worker on the team is to provide support to help you cope and learn to manage.

If required, parents can meet with the team Social Worker following their child’s diagnosis. After the initial meeting, further appointments can be organised as needed, these can be clinic appointments or home visits. The purpose of these meetings is to provide a space for parents and families to talk about their concerns and feelings. When necessary, it is possible to avail of the services of a broader multidisciplinary team which includes Psychology, Occupational Therapy, and Psychiatry. This multidisciplinary team assessment may be helpful in preparing your child for school, later surgeries, and for dealing with any self esteem issues that may arise.

The social worker is as an integral part of the Cleft team, working primarily to support parents during their child’s treatment plan in our hospital. The social worker can be contacted through the social work department in St. Frances’ Clinic, Temple Street Children University Hospital at 01 878 4293.