The Spires Cleft Centre

Cleft Palate
Information Booklet

www.spirescentre.nhs.uk

Oxford University Hospitals NHS
NHS Foundation Trust

Salisbury NHS
NHS Foundation Trust

The Spires Cleft Centre
Information Booklet

prepared for the parent/guardians of

……………………………………………………

Date of Birth

……………………………………………………

First Hospital Appointment: ________________________________

My Treatment Record

Name: ______________________________

My First appointment date

my cleft nurse is coming to talk about my operation on:

____

I am going to hospital to see my surgeon to talk about my operation on; ____________________

My operation date: ____________________

My cleft nurse is coming to see how I am doing after my operation on: _________________________

I am going to hospital to see my surgeon after my operation on: ________________________________

I will see a speech therapist for early advice on: ________

I will come to hospital when I am 18 months old to see how I am doing on: _____________________

I will see the team again when I am 3 years old to see how I am doing on: ______________

When I am 5 years old, I will have audit records taken at hospital on: _________________

When I am 7 ½ years old the team will talk to me about the next part of my care

Contents

Congratulations on the birth of your baby!

You have been referred to the Spires Cleft Centre because your baby has a cleft lip and palate.
This booklet helps to explain this condition and how it is managed.

Introduction

The Spires Cleft Centre is a twin-site centre, one of nine highly specialised cleft units in the UK.
It provides care for all children with cleft lip and/ or palate born within the Oxford and Salisbury catchment areas.

The Centre is firmly committed to providing a comprehensive, multidisciplinary team approach by drawing upon the expertise of a group of specialists who all work together to provide the highest possible quality of care for your child.

Map of areas covered

Team Contact

The John Radcliffe, Oxford

Clinical Director
Marc Swan 01865 234252

Service Manager:	Steven Berry	01865 234252
Co-ordinator:	Jade McKnight	01865 231450
Cleft Secretaries:	Alison Prescott	01865 234339
	Vicky Ludlow	01865 226965

Clinical Nurse Specialists:

Jane Sibley	07990 528396
Emma Waterworth	07771 812578
Currently vacant	07768 433094
On Call Nurse	07500 127657

www.spirescentre.nhs.uk

The Spires Cleft Team

Oxford Centre

Consultant Primary Cleft Surgeons:
Marc Swan & Guy Thorburn

Clinical Nurse Specialists:
Helen Morland (Lead)
Jane Sibley & Emma Waterworth

Speech and Language Therapists:
Ginette Phippen (Lead)
Carrie Luscombe (Principle),
Lucy McAndrew & Sarah Overton

Consultant ENT Surgeon:
Ricky Pal

Clinical Psychologist:
Dr Jenny Cropper (Lead)
Dr Katie Hamilton

Consultant Orthodontist:
Giles Kidner & Helen Travess

Consultant Restorative Dentist:
Sandip Popat

Consultant Paediatrician:
Dr A Ives

Additional Team Members

Clinical Genetics: Dr Usha Kini

The Spires Cleft Team

Salisbury Centre

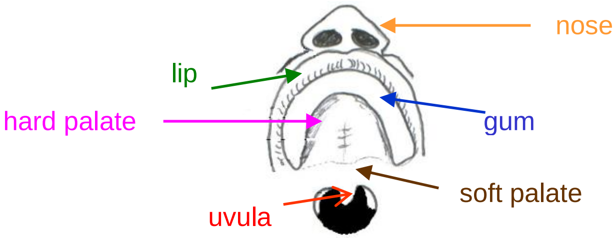
Consultant Primary Cleft Surgeon:	N. Fallico
Clinical Nurse Specialists:	H. Morland (Lead), N. Morgan
Speech & Language Therapists:	G. Phippen (Lead)
	S.Treslove,
	S Lidiard
	Vacant (MDT Assistant)
Consultant ENT Surgeon:	M.Geyer
Clinical Psychologist:	J. Cropper (Lead)
	L. Pick
	A Sanders (assistant)
Consultant Orthodontist:	M. Bussell
Consultant Paediatrician:	J. Baird

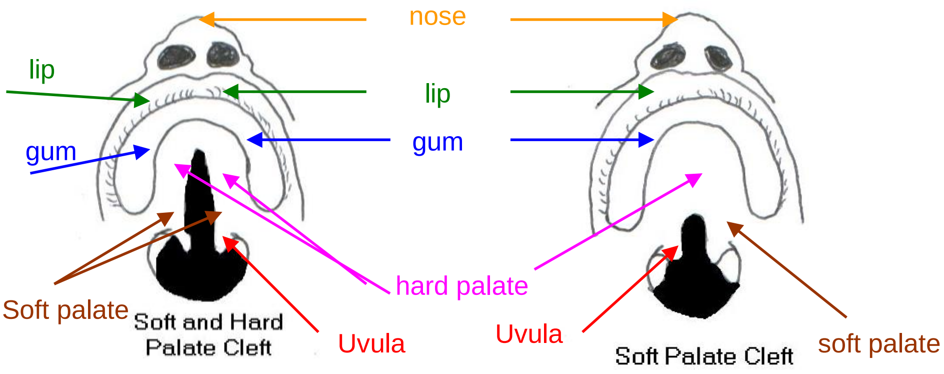
Cleft Palate Explained

What is Cleft Palate?

The palate forms the roof of the mouth. It consists of two parts: the hard palate towards the front, and the soft palate towards the back. The soft palate is made up of muscles, which move and help with speech by controlling the direction of air into the nose or mouth. Some clefts only go part of the way through the palate while others may go all the way through the hard and soft palate.

Non cleft





How common is Cleft Lip and/or Palate?

Cleft lip and/or palate is a relatively common condition, occurring in approximately 1 in 700 babies born within the U.K. At the Spires Cleft Centre, we see 80-100 new referrals per year.

What causes Cleft Palate?

In most children we have no idea why a cleft happens, but we know that it develops at about the seventh to twelfth week of pregnancy. In very rare instances certain drugs taken in early pregnancy may cause it and occasionally it may be passed down in the family.

Clinical Genetics

You may wish to see a Consultant in Clinical Genetics as we know that occasionally cleft lip and palate may be part of a syndrome in which other anomalies are present. You may also wish to discuss the chances of further children having a cleft, particularly if you have a family history of clefts.

We can refer you to the Clinical Genetics Team to discuss these issues.

Advanced Nurse Practitioner/Clinical Nurse Specialist

Jane Sibley

Emma Waterworth

Our role is to support, give advice and information to families regarding feeding and care with the cleft team.

We have 5 Clinical Nurse Specialists in the Spires Team. One main nurse will take responsibility for your baby, but you may meet the other Nurses as we operate an on-call rota for weekends, Bank Holidays and annual leave.

Antenatal Diagnosis

It is unusual at this present time for a baby with a cleft palate to have this diagnosed antenatally. If it is, a CNS will contact, you within 24 hours of you being referred to them. This will enable you to arrange to meet the CNS either at your home, local hospital or regional Cleft Centre. At this meeting you can discuss any questions you have, and the CNS will give you as much or as little information as you feel you need. This may include information about the cleft, treatments available for your baby, feeding issues, the Cleft Team and what they do. It also gives you an opportunity to view photographs of babies before and after the cleft repair should you wish. The CNS will also discuss the care they can offer you once your baby is born. You will have the Nurse Specialist's contact number in case of any further questions.

After this visit the CNS will arrange to meet you again about six weeks before your baby's predicted arrival and discuss feeding in more depth, as well as answering any further questions you may have.

There is opportunity to meet the Cleft Team should you wish. The CNS can arrange this for you.

Post Natal

The CNS aims to visit you and your newborn baby within 24 hours of being informed of the birth. If you have been given an antenatal diagnosis of the cleft then the CNS will continue work with you to enable you to use the feeding method you have chosen and will re-enforce the cleft information that you have already discussed.

If you were unaware of the cleft until after your baby's birth then the CNS will be able to discuss with you your baby's cleft, treatments available for your baby, feeding issues, the Cleft Team and what they do. They will also be able to show you photographs of babies before and after the cleft repair should you wish.

At this post-natal meeting the CNS will carry out a feeding assessment of your baby and give you advice on an appropriate feeding method (see feeding section), working with you in your choice to either breast or formula feed.

The CNS will then arrange to meet with you again, usually after discharge from hospital. This meeting will be at your home. If your baby needs to stay in hospital longer because of any other problems, the next meeting with the CNS may be while you are still in hospital. After this second visit, the CNS will continue to work with you and visit as appropriate.

The CNS will organise for you and your baby to attend the New Baby Clinic with the Cleft Team.

As well as giving information and feeding management, the CNS will also advise you through your baby’s cleft clinic appointments and surgery.

Home visits are arranged as required during the first year of your baby’s life and after this the CNS is a point of contact for you and your child to give advice throughout your care with the Spires Cleft Team.

Feeding Your Baby

Your baby has been born with a cleft palate this means that there will be a gap in the muscles and soft tissue of the roof of the mouth. This will make it difficult for your baby to position and use the nipple or teat as other babies do when sucking and feeding. Although your baby will be able to make sucking/movements with his/her mouth and jaw, he/she will be unable to create and sustain the pressure required to draw the milk from the breast or bottle.

The following sections will give you an overview of different types of feeding for your baby. If you have any problems/concerns/worries regarding feeding, then please contact your CNS.

Breast Feeding

Having a cleft palate makes it very difficult for your baby to latch on to the breast properly and stay latched on. You can still put your baby to the breast, but your baby must be topped up with expressed breast milk or formula after each feed using a cup or bottle. You will need extra advice from your CNS while feeds are being established. Alternatively, you may choose just to express your milk and give it via a recommended bottle. Your CNS will be able to discuss this in depth with you.

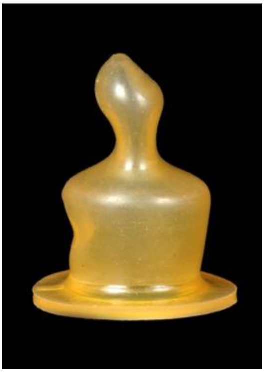
We would recommend the use of an electric pump (e.g. Ameda, Medela). The CNS have a small supply of electric pumps which are available for you to borrow for as long as you wish (these are kindly funded by local cleft charity and Charitable funds). The benefit of an electric pump is that it is usually quicker and more efficient. It is also possible to pump from both breasts at the same time. A few mothers prefer to use a small hand pump as this enables you to move about while you are expressing the milk, but it is usually more time consuming than an electric pump. Again, your CNS, in conjunction with your Midwife and Health Visitor will be able to discuss this with you.

Feeding Your Baby

Bottle Feeding

Your CNS will assess your baby soon after birth and discuss with you which bottle, and teat would be best to use. The bottle we usually recommend is a MAM soft bottle; being soft it allows you to gently squeeze the milk into your baby’s mouth in rhythm with their sucking (assisted feeding). The bottle is used with a latex orthodontic shaped teat size 1 or 2 depending on the weight of your baby. We advise the use of a latex teat because it is softer than silicone making it easier for your baby to suck It also moulds to the shape of the mouth. Your CNS will advise you and work together with your hospital nurse and health visitor to help you through this time.

MAM Soft Bottle



Orthodontic Teat

Your CNS will provide you with a starter pack of bottles and teats. Further bottles and teats are available from CLAPA.

BOTTLES & TEATS

Catalogue and Price List

August 2015

CLAPA Catalogue

Feeding Your Baby

Feeding

If your baby is sick after a feed, you may notice it coming down his/her nose, this is perfectly normal for a baby with a cleft palate.

There is no need to change bottle and teats around the time of surgery.

Any problems which may arise are usually fairly short lived, but occasionally it can take a few weeks before your baby's feeding is well established and has a good weight gain. Your CNS (working together with your Midwife and Health Visitor) will continue to advise you in hospital and at home.

Does it matter if my child sucks a thumb or a 'dummy'?

Thumb sucking is a normal comfort habit and will cause no long-term problem if it stops before the permanent teeth erupt. A 'dummy' has a similar effect on the teeth as the thumb but needs to stop at an earlier stage.

Clinics

The Spires Cleft Centre provides a number of clinics that are tailored to each key stage of your baby's care. These Clinics are held at your regional centre (Oxford or Salisbury) until your baby reaches the age of two. After the age of two it is hoped that we will be able to offer you an appointment at a clinic that is nearest to your home.

Baby Clinic

Your first appointment will be at this clinic which is dedicated to new babies. Your Surgeon and your Clinical Nurse Specialist will be available at this time to provide information about your baby's future care.

Primary Surgery/Pre-assessment Clinic

Following your initial appointment, you will be invited to attend this clinic, where you will meet other key Clinicians who will be involved in preparing you and your baby for their surgery. After your baby's surgery you will be re-invited to a clinic for a post-operative review.

18 Month Clinical Review Clinic

Eighteen months is an important age for your baby and the right time for us to review their progress. Therefore, you will be invited to bring them to this clinic which involves assessment of their progress by the Clinical Nurse Specialists, Psychologist and Speech & Language Therapists.

Combined Cleft Clinic

Combined Cleft Clinics are held monthly across the region. These clinics are dedicated for children over the age of two. Your child will be invited to attend these clinics as appropriate to their needs. All members of the Cleft Team are present at this clinic, providing you with an opportunity to raise any concerns you may have.

Clinical Review Clinic

Clinical review is an important part of your child's care and helps us to ensure that the care your child is receiving is of the highest possible standard. We will ask you to bring your child to these clinics at the age of 5, 10 and 15 years. You may also be asked to attend other clinics with just one member of the team, for instance the Speech Therapist or the Orthodontist.

You are welcome to contact the Cleft Centre at any time should you have any concerns about your child's cleft care, and if appropriate an appointment will be offered to you.

A good tip for any clinic appointment is to write down questions you may want to ask, this prevents you forgetting them on the day.

Psychology

Your Feelings

Most families find the arrival of a new baby marks a huge change in their lives and brings with it a whole new range of feelings and experiences. Whilst a new addition to the family can be a very exciting time, some of the changes it brings can be difficult to come to terms with, particularly with the added difficulties of interrupted sleep and round-the-clock feeding. Having a baby with additional needs such as a cleft lip and palate can put extra pressures on a new family.

Many parents describe feeling an overwhelming sense of shock and distress when they first find out that their baby will be born with a cleft lip. There may be a whole range of different thoughts and feelings about the news; guilt about what caused the cleft, anxiety about how you will cope and worries about the future are also very common. For many parents, these upsetting feelings settle down within a few weeks. Finding out more about the cleft and how it will affect your baby, talking to friends and family and time to make sense of all the information you are being given can help in this process. Expressing worries out loud about how you are feeling or coping can feel difficult and risky; this is very understandable, but it can often be helpful to talk things through with a member of the team.

Bringing Your Baby Home

It is natural for family, friends and even strangers to want to peek at your new baby and comment on their weight, family resemblance and how much they are sleeping! Parents of children with a visible difference such as a cleft lip may feel particularly protective of their babies and parents often worry about other people’s reactions to their baby and how they will manage this. From our experience, most parents are very pleasantly surprised by the reaction of other people to their new baby and don’t get the comments or stares that they were worrying about. However, it is natural to be concerned about what might happen, and you may feel you need to ‘test it out for yourself’ rather than taking our word for it. Going out for the first time with a partner or friend can help you feel more confident. Parents usually find that they quickly build their confidence in taking their baby out and managing any questions that crop up. You might want to think ahead about what information you want to share with other people (which may well be different for a friend, as opposed to a stranger in the supermarket) so that you feel in control of the situation. Practicing a simple response can also help you feel more confident. It is important to remember that while most people do not mean to be rude or unkind, we are all curious about what we see around us. Sometimes people ask questions because they are interested, or don't know what to say. Giving a simple explanation, such as "[Baby's name] was born with a cleft lip" may be helpful. You may then choose to move the conversation on to other familiar baby topics such as their weight, how much sleep you're getting or their favourite activity.

Strategies that some parents have found helpful include:

Reassure and Explain

- "It is just the way (child's name) speech is, its ok to ask them to say it again."
- "You've noticed (child's name) speech – they are having speech therapy to help them practice their sounds."

Changing the Subject

- "It's just the way (child's name) speech is. He/she's settled really well at his/her new school"
- "They are having an operation. Have you ever had an operation?"

Deflecting Questions

If you don't feel able to give an explanation, you could try:

- "Thank you, [child's name] is fine."
- "Sorry we're having a really busy day and can't really talk just now."
- "I'd rather not answer questions at the moment."

If you don't feel able to speak to the person, you could try:

- Shaking your head and walking away
- Walking away, then look back and smile
- Turning your body away

Supporting your child as they grow

Common concerns with any preschool child include behavioural issues around feeding and sleeping, emotional worries, general development and settling into nursery and school. Parents of children with a cleft palate may have particular concerns about issues related to their child's speech or hearing. The most important way to help development is to allow your baby to experience and do exactly the same as all other babies and children. Children are very good at following their parents' lead on what is 'safe' or 'scary', so your child will learn from your attitude and behaviour about coping confidently with the cleft and their treatment. Parenting can feel a daunting experience for everyone at times; the cleft team Psychologists are a resource for you to use throughout your child's treatment with the Spires service and we are always happy to talk through concerns at cleft clinic appointments, by telephone or at separate psychology appointments. Our goal is to support you and your family to minimise the impact of the cleft on your child and ensure that they can achieve their full potential.

If you would like to talk to a psychologists about any of these issues, please contact 01865 234252

Welcome to the Children's Hospital

Entrance to wards

The following information is to give you some idea of the facilities available to you while you are in hospital with your child and ideas as to what you might need to bring with you.

Robins Ward Reception

You will be able to stay with your child. However, there is only accommodation for one parent/carer. It would be helpful if you could bring a pillow and sleeping bag/duvet for your own use at night. There is a small locker and cupboard for your belongings.

Most beds have a Patient line unit which allows you to receive television, internet access and telephone calls at your bedside.

There is no charge for children to watch television. Charges are made for out going calls/internet usage. Mobile phones cannot be used in the ward for safety reasons, but you can use them in non-ward areas throughout the hospital.

Your child may like to bring in a favourite toy/blanket etc. We encourage you to do this but please make sure it is labelled with his/ her name.

We do have some ready-made formula milks (but not all varieties) so please contact us to make sure we have what you need. If not, you will need to bring an unopened tin of your own milk powder. A feed technician will prepare your feeds for you during your stay. Sterilisers are available for your use.

We have a limited choice of baby jar foods so if your baby has any favourites then it is a good idea to bring them in. There is also a daily menu, which your child can order from.
You will need to bring in nappies and toiletries for your baby/child.

Parents' Facilities

The Ronald McDonald House - Oxford is an independent charity at Oxford Children's Hospital providing accommodation for parents and families, who would otherwise have to travel large distances to and from Oxford for treatment/surgery. The House is in a separate building from the main hospital but is just a few minutes' walk from the wards. The House has 62 en-suite rooms, as well as kitchens, laundry rooms, day rooms and a garden.

If you require accommodation whilst your child is in hospital let your child's nurse know as soon as possible so that they can complete an accommodation request form on your behalf and send it to us (please note a request does not guarantee a room). We will let the ward know as soon as a room becomes available and arrange a convenient time for you to be shown to your room and register with us. We will require a fully refundable £20 key deposit for your room The room is for you to use as long as you need it, however due to the high demand for rooms in the House, it is important that each room is utilised. Families must declare if they are keeping a room which they are seldom using.

RMH have issued each ward a Day Pass so that families sleeping next to their child on the ward or waiting for accommodation can make use of the communal washing facilities within the House. If you would like to make use of this pass, please talk to your child's nurse.

Surgery

Aim of the Operation

The cleft of the palate is repaired around 6-12 months. The aim is to repair the muscles of the soft palate to help in feeding and speech development and to repair the cleft in the hard palate.

Coming into Hospital

Your baby will be admitted the day before or the day of the operation and may need to attend a pre-admission clinic. Both admissions enable you to meet the Nurse, Doctor and Anaesthetist who will all explain what will happen during your stay in hospital. Your baby may need to have a routine blood test. Photographs are taken as a baseline for follow-up and audit records (see Medical Photography section). A routine hearing test may be performed prior to your baby's cleft palate repair (see Hearing section).

Arriving at the ward

Baby being weighed

Baby having name tag put on

Speaking with the Anaesthetist

Waiting to go in for operation

Surgery cont.

Day of Operation

Your baby will not be without food or drink for more than 4-6 hours. More detailed instructions will be explained to you at the time.

At least one parent is welcome to accompany their baby into the anaesthetic room. You will be prepared and supported throughout this by your Nurse. Your baby can be away from the ward for up to 3-4 hours. When he/she is ready to return to the ward you can accompany the nurse to the recovery room to collect him/her if you wish.

Mr Swan

Mr Thorburn

After a palate repair your baby may sound different due to the closure of the cleft. You will quickly get used to this, but it will seem strange at first.

Parents and baby in anaesthetic room

View of anaesthetic room & theatre

In recovery room

Surgery cont.

Feeding After the Operation

He/she will return to the ward with a cannula that can be used to give him/her intravenous fluid (drip) until taking adequate drinks. A milk feed using your baby's normal bottle and teat can be offered as soon as required. Also, after cleft palate surgery babies may be reluctant to drink and prefer solids. A soft puree diet will be introduced up to 24 hours following surgery. To help keep the mouth clean you will need to give a small amount of water following feeds and medication. Your ward Nurse and CNS will help you in feeding your baby.

Your baby's feeding routine will be slightly disrupted initially, and you will find that it can take between 2-3 weeks to return to normal.

Will my baby be in pain?

Local anaesthetic and pain killers are given throughout the operation and every effort is made to reduce any pain or discomfort afterwards. Your Nurse and Anaesthetist will discuss and decide upon appropriate pain killers for your baby.

On discharge you will be given advice on how to manage your child's pain. The CNS will be on hand to advise you.

Care of Your Baby's Mouth Following Cleft Palate Repair

It is important to prevent your baby form putting objects, including fingers into his/her mouth. Puree/soft diet needs to be continued for 4 weeks. Continue to give water after feeds for 2 weeks. Dummies may be discouraged, depending on your surgeon's preference, but if your baby has been used to one, they can be reintroduced 2 weeks after surgery.

The stitches in the palate are dissolvable and can take a month or more to disappear.

Follow up

Your CNS will arrange to make a home visit 1-2 weeks after surgery. She will then continue to liaise with you through your child's care. A follow up clinic appointment will be arranged for 4-12 weeks following surgery.

For any questions or concerns please contact your CNS (number at front of booklet).

Will any more operations be required after this?
There is a possibility that further operations may be required on the back of the throat to help speech (usually performed between the ages of 3 and 7 years).

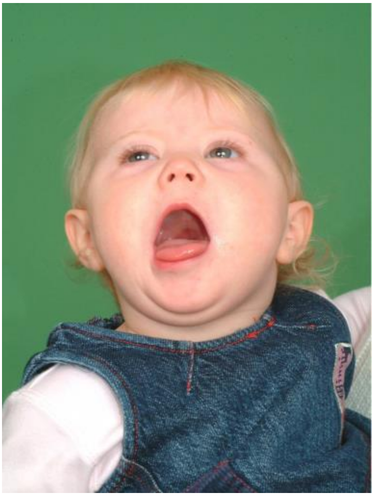
Cleft of Soft and Hard Palate

Pre-Op (aged 9 months)

Post-Op (aged 10 months)

Cleft of Soft Palate Only

Pre-Op (aged 4 months)



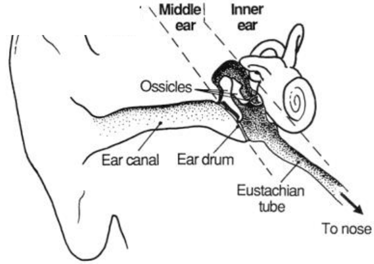
Post-Op (aged 1 year)

Hearing Problems and the ENT Specialist

Hearing Problems and Treatment

Babies with a cleft in the palate are much more likely to develop glue ear. Untreated this may result in difficulties with hearing, which in turn may delay and impair the development of normal speech.

The Ear



The part of the ear that can be affected in a child with a cleft palate is the middle ear. Normally the middle ear contains air. It is connected to the back of the nose via the Eustachian tube. This tube opens and closes and permits air to enter the middle ear from the nose, thus keeping the air in the middle ear at the same pressure as the outside world. If the Eustachian tubes do not function and air does not enter the middle ear regularly, then fluid is secreted into this area and interferes with the movement of the ossicles (three tiny bones in the middle ear). Therefore, sound cannot travel efficiently across the middle ear, producing reduction in hearing. This fluid can clear on its own but if it persists for three months or more then it is referred to as glue ear.

No child is too young for a hearing test. Your baby's hearing will be tested shortly after birth as part of the Universal Neonatal Screening Programme. Testing can be repeated around the age of eight months, prior to any planned palate surgery. Thereafter it will be tested as required.

Why do children with cleft palate get glue ear?

When there is a cleft in the palate, hearing problems can arise due to the muscles in the soft palate not functioning correctly, even after the cleft has been repaired.

These muscles move when we yawn, eat or swallow and they pull open the Eustachian tube to allow passage of air into the middle ear. If this does not happen, then the Eustachian tube's function is impaired and hearing problems can occur. It is not known how many children with a cleft palate this may affect.

The Ear Nose and Throat (ENT) specialist on the cleft team will supervise this and monitor your child's progress, advising on treatment.

How will I know if my child has hearing problems?

Every child with a cleft palate should have extra attention paid to their hearing. Parents and teachers are usually the first to realise that a problem may exist. Turning up the sound of the television, having to repeat oneself to a child when speaking, or noting the inability of a child to hear the parent when called from another room, are indications of a possible hearing loss. In the under two-year old age group, it is more difficult to detect this loss. If you have any concerns about your child, then you can discuss it with the ENT specialist on the Cleft Team.

What is the treatment?

Grommets may be the treatment of choice. These are tiny plastic tubes that are inserted into the eardrum under a general anaesthetic.

Sometimes a hearing aid for your child may be suggested instead of grommets, in particular if glue ear is a recurrent problem.

Speech and Language Development

Carrie Luscombe

Sarah Overton

Lucy McAndrew

At the Spires Cleft Centre, the Speech and Language Therapy (SLT) Team specialise in working with children born with cleft lip and palate. They work in partnership with the SLT service in your local area to help with your child's speech and language development from an early age. Some children with complex feeding difficulties may also benefit from a team approach, with help from a range of professionals including SLT.

Speech and Language Development

Most children born with a cleft lip and palate develop speech like any other child, without needing the help of a SLT. Some children do have difficulty developing clear speech because of the disruption caused by the cleft. It is important that your child's progress is regularly checked so that therapy can be offered if needed. Speech and language difficulties can also occur that are not directly related to the cleft palate, just as they do in other children.

As your child has a palate their speech will be monitored for any effect on the way sounds are made (articulation) and any nasal quality of voice (hypernasality).

Sometimes even after the operation to repair a cleft palate it does not work exactly as it should do. Your child may need another operation to improve the way the palate works, as well as speech therapy in some cases.

Speech and Language Development

Assessment and Monitoring

Early advice about developing speech and language will be offered when your child is 3 – 6 months old and around the time of their palate repair at 9 – 12 months. The first formal assessment of your child's speech and language will be at around 18 months of age. After this, progress will be checked at the Cleft Clinic appointments and separate appointments with a member of the SLT team if needed. You can, of course, contact us at any time with any questions that you have.

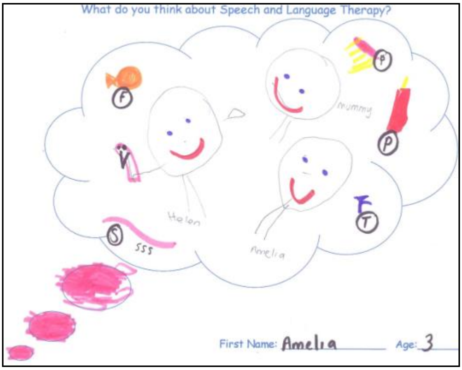
Hearing is very important in the development of speech and language, and this will be monitored by the Ear Nose and Throat (ENT) Service. As with any child it is important to talk with your child from birth and to encourage sound making and sound games. As your child gets older, these will become speech sounds and words.

Therapy

If your child does need regular speech therapy this will be offered with a SLT at the Cleft Centre and/or with a therapist nearer to home/school, depending on what help your child needs. Therapy sessions at the centre can be weekly, or less frequently according to what is best for you and your child. Your local SLT service will tell you what is available locally as this varies in different areas. We can also work with your child's pre-school, nursery or school to help support their speech and language development through play and speech therapy games

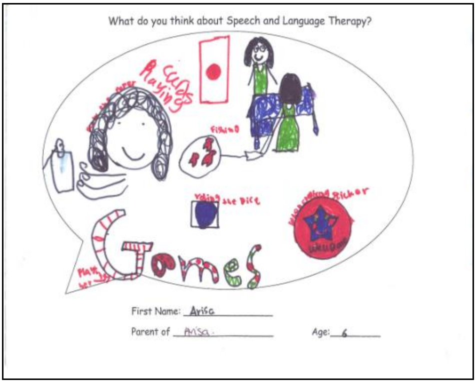
You can contact the Speech and Language Therapy Team
at the Cleft Centre on:

Oxford - 01865 234842/231519



What do you think about Speech and Language Therapy?

First Name: Amelia Age: 3



What do you think about Speech and Language Therapy?

First Name: Arisa

Parent of Arisa. Age: 6

Dental Care and Development

Giles Kidner

Sandip Popat

The teeth can be affected by a cleft particularly where the gum is involved. This section introduces you to some of the dental developmental problems that might present and associated dental health issues of concern. One of our main aims is to ensure all our children have excellent dental health and a pleasing smile in adulthood.

Dental decay and gum disease can affect any children, but the cleft child is particularly vulnerable, and we start a preventative programme soon after birth. You should receive early advice from your Nurse Specialists, and we will encourage you to register your child with a dentist as soon as the first teeth erupt. We have tried to answer some of the most asked questions below and hope they help to explain the dental problems.

What can parents do to help with dental health?

You can help to protect your child from dental decay and gum disease. Register with a dentist at an early stage and start to brush the teeth with a fluoride-based children’s toothpaste as soon as they erupt. Use a small soft toothbrush and try to brush at least once in the morning and once before going to bed. Try to limit the amounts of sugar your child eats. Although sweets, biscuits and fizzy drinks are well known sources of sugar, also look at the labels of other products such as ketchup which contain some surprisingly high levels. If your child is on long-term medication, ask for the low or sugar-free variety.

How does a cleft affect the teeth?

An isolated cleft palate is less likely to involve the teeth, Teeth can be slow to erupt in both baby and adult dentitions.

Will my child have straight teeth?

Misaligned teeth can be corrected with braces in just the same way as any other child. This is typically carried out between the ages of 11 – 14 years,

Who will look after the dental care?

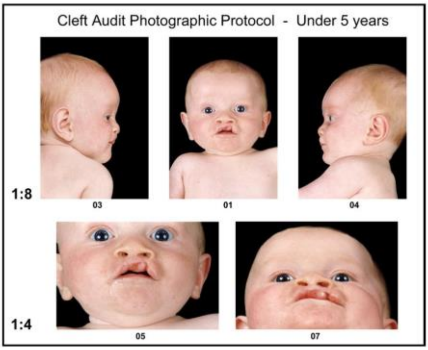
You will need your own family dentist to look after general dental health. If you experience problems finding a dentist, we will do our best to find one in your locality. You will be seen on a regular basis by our dental team including the orthodontist who will monitor dental development as your child grows and initiate treatment with braces when and where it is required.

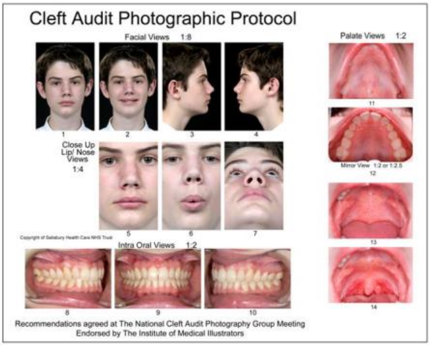
Medical Photography

Your baby or child will have medical photographs taken of his/her cleft lip and/or palate. These photographs are taken on admission to Hospital and at regular clinics. Photographs are taken to provide an accurate record of your child's development.

Your baby will have five views taken of his/her face and palate if appropriate. For children aged 5 years and over, a complete set of medical photographs may be taken at a Review Clinic or Combined Cleft Clinic. Additional sets of photographs may be requested by the Secondary Cleft Surgeon and the Orthodontist at other times.

The photographs are placed in your child's hospital notes.





Other Referrals

Dietician

Occasionally a Dietician may be consulted.

Paediatrician

Your child will be under the care of a Consultant Paediatrician who is part of the Cleft Team. He will be consulted when appropriate.

Striving to Provide Quality of Care

In the Spires Cleft Centre, we are constantly striving to provide the highest possible standard of care for all of our patients. We hold regular Review Clinics, to which your child will be invited when they are 5, 10 and 15 years old. At these special clinics you will be seen by the Speech and Language Therapists, Audiologists, Orthodontists and Psychologist. The records they take will help us check your child’s progress so far and plan their pathway of care. These assessments also enable us to compare our results with those from cleft services throughout the world. All our data is recorded into an electronic patient record.

We also have an active program of research and present regularly both at national and international meetings. From time to time, we may invite families and young people to take part in a research project to help us develop our understanding and pioneer the best possible care. We will always give you plenty of information to help you decide if you would like to take part; we do understand that some people may not wish to be involved, and this would not affect your care in any way.

Our aim is also to foster links with the cleft services in the UK and in Europe in order that we can be at the forefront of cleft care.

Website: www.spirescentre.nhs.uk

Glossary

You will hear and read many unfamiliar words. This glossary helps to explain some of them.

Alveolar Bone Grafting
An operation needed by some children with a cleft affecting their gum, to help the development of normal teeth alignment. It is performed at between 8 – 10 years of age with bone graft being taken, usually from the hip, and introduced into the gum.

Alveolar Ridge
The bony ridge of the upper jaw (maxilla) and lower jaw (mandible), which holds the teeth.

Articulation
The process of forming speech sounds using the lips, tongue, teeth and palate.

Articulation Test
A test which provides information about how accurately speech sounds are formed.

Audiogram
A standard graph used to record hearing levels or sensitivity.

Audiologist
A person with a degree, licence and certification in audiology (science of hearing) who measures hearing, identifies hearing loss and participates in rehabilitation of hearing impairment.

Cannula
A small plastic tube that sits in a vein just underneath the skin

Clinical Nurse Specialist
We are a team of registered nurses, led by a senior Nurse, who specialise in caring for children and families affected by cleft lip and palate. The team combines the skills of, paediatric and adult nursing, health visiting and counselling. We work closely with health professionals from your local community, specialist hospitals and other members of the Cleft Team

Combined Cleft Clinic
A clinic in which all members of the Cleft Team are present.

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

Comprehension
The ability to understand spoken or written language.

Congenital
A disease, deformity or deficiency existing at time of birth.

Crossbite
A dental condition where the upper teeth are behind the lower teeth rather than in front of them. It can also apply to the back teeth, laterally (from side to side)

Dental Arch
The curved structure formed by the teeth in their normal position.

Eardrum (Tympanic Membrane)
This vibrates and transmits sound to the middle ear.

ENT
The abbreviation for ear, nose and throat.

ENT Surgeon
A surgeon specialising in the diagnosis and treatment of the ear, nose and larynx (throat) and in treatment of problems diagnosed.

Eustachian Tube
The air duct, which connects the back of the throat (the nasopharynx) with the middle ear. This tube is usually closed at one end becoming opened during yawning and swallowing. It allows ventilation of the middle ear and permits the equalisation of pressure on two sides of the ear drum.

Fistula
An opening between two spaces, which in the case of cleft lip and palate is a hole in the hard palate causing an abnormal opening between the mouth and the nose cavities.

Genetics
The science of heredity.

Glue Ear
An excess of fluid in the middle ear resulting from impaired drainage via the Eustachian Tube which results in hearing impairment.

Grommets
Tiny plastic tubes inserted into the eardrums to allow ventilation of the middle ears and prevent the abnormal accumulation of fluid (glue ear)

Hearing Impairment
A loss in hearing which may range from mild loss to complete loss, and which may be temporary or permanent.

Heredity
The total of the physical characteristics, abilities and potentialities genetically derived from one's ancestors.

Hypernasality
A nasal tone of voice caused by too much air in the nose during speech. Sometimes referred to as 'nasal speech' or 'nasality'. The opposite is 'hyponasality' where there is too little air passing into the nose so that the speaker sounds as if they have a cold.

Speech and Language Disorder
The inability to communicate normally and effectively due to problems with comprehension or expression of language.

Malocclusion
A deviation from normal occlusion (bite) or incorrect positioning of the upper teeth in relation to the lower teeth.

Mandible.
The lower jaw.

Maxilla
The upper jaw.

Maxillofacial Surgery
Maxillofacial surgery is the surgical speciality concerned with the diagnosis and treatment of disease affecting the mouth, jaws, face and neck.

Medical Photographer
Clinically trained specialist photographer, generally working in the Hospital environment.

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

Myringotomy
A surgical procedure in which a small slit is made in the eardrum to allow fluid to drain from the middle ear.

Nasal Emission
An excessive flow of air through the nose during speech. Usually indicative of an incomplete seal between the oral and the nasal cavities.

Nasendoscopy
A procedure in which a small telescope is passed through the nostril to assess the movements of the soft palate during speech.

Occlusion
Relationship between the upper and the lower teeth when they are in contact. It refers to the alignment of the teeth as well as the relationship of the dental arches.

Oral Cavity
The roof of the mouth from the teeth in the front to the soft palate at the back.

Orofacial
Relating to the mouth and face.

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

Ossicles
3 tiny bones in the middle ear

Osteotomy
Surgical cut made in bone. Occasionally required on the maxilla (the upper jaw) in patients with cleft lip and palate at the age of about sixteen, when seeking to improve the alignment of the teeth and to improve the facial profile.

Otitis Media
Inflammation of the middle ear with accumulation of thick, mucous fluid.

Palatal Insufficiency
A lack or shortness or palate tissue preventing the soft palate from sealing against the back of the throat (pharynx) during speech.

Palate
The roof of the mouth including the front portion (hard palate), and the back (soft palate or velum).

Paediatric Dentistry
The speciality of dentistry concerned with the care of children's teeth.

Paediatrician
A doctor specialising in the treatment of children.

Pharyngeal Flap or Pharyngoplasty
A surgical procedure in which a flap of the lining of the throat is used to close most of the opening between the soft palate and the back of the throat (nasopharynx). This is used to treat nasal speech.

Philtral Column or Ridge
The ridge in the upper lip running from the nostril down to the lip margin.

Pierre Robin Sequence
Pierre Robin Sequence or Complex (pronounced "Roban") is the name given to a birth condition that involves the lower jaw being either small (micrognathia) or set back from the upper jaw (retrognathia). As a result, the tongue tends to be displaced back towards the throat, where it can fall back and obstruct the airway (glossoptosis). Most infants, but not all, will also have a cleft palate, but none will have a cleft lip.

Plastic Surgery
The surgical speciality dealing with the restoration and repair of various external defects.

Premaxilla
The small bone in the upper jaw which contains the upper four teeth. It connects with the lateral segments of the upper jaw or maxilla.

Pre-Surgical Orthopaedics
Term used to describe a variety of orthodontic plates and tapes which can be used prior to the surgical repair of the cleft to improve the alignment of the segments of the cleft (either lip or palate)

Prosthesis
An artificial substitute for a missing body part.

Prosthetic Speech Aid
A removable acrylic appliance worn in the mouth which provides a structural means of achieving velopharyngeal closure, thereby aiding speech.

Prosthodontist
A dentist who specialises in providing prosthetic appliances for the mouth.
Psychologist (Clinical Psychologist)
A highly trained psychologist who is chartered (that is, regulated by law). Psychologists have expertise in how people develop, think, feel and behave and how they relate to one another. In the Cleft Service, they work across the lifespan, with children, parents and adult patients.

Resonance
Voice quality associated with the vibration of air in the oral (mouth) and nasal (nose) cavities.

Soft Palate
The mobile soft tissue attached to the back of the hard part of the palate. It contains muscles whose function results in the closure of the mouth from the nose during speech and swallowing.

Speech & Language Therapist
An individual with the necessary academic training and experience to be certified or licensed to diagnose and treat disorders of speech, language and communication.

Tympanic Membrane (Eardrum)
This vibrates and transmits sound to the middle ear.

Uvula
The small cone shaped process hanging from the back of the soft palate “the dangly bit”.

Velopharyngeal Closure
The closing of the nasal cavity (nose) from the oral cavity (mouth), which directs air used in speech through the mouth rather than the nose. It requires interaction of the muscles in the palate and back of the throat.

Velopharyngeal Dysfunction
A structural or functional disorder affecting the soft palate resulting in the inability to achieve adequate separation of the nasal and oral cavities.

Velum
The soft palate.

Videofluoroscopy
An investigation using X-Rays to assess the movements of the soft palate during speech.

CLAPA

The Cleft Lip and Palate Association

CLAPA was set up in 1979 by parents of children born with clefts and health professionals involved in providing the children's care. It offers information and support to anyone affected by Cleft Lip and/ or Cleft Palate by providing written material and mutual telephone and face to face support via its network of branches across the UK. It also works to raise funds for equipment and research.

The address of the central office of CLAPA is:
244-254 Cambridge Heath Rd, London E2 9DA
Tel: 020 7833 4883 Fax: 020 7833 5999
E-mail: info@clapa.com Website: www.clapa.com

Congratulations on the birth of your new baby!

Spires Smiles is an independent, voluntary, non-profit charity set up to support The Spires Cleft Centres in Salisbury and Oxford, and the patients and their families who are treated there.

Just register your details with Spires Smiles and in return we will send you a £5 Amazon voucher

(One voucher per family on new registration with Spires Smiles)

We will add you to our mailing list to keep you updated on the latest events and news

YOUR DETAILS	
Contact name	
Email address *	
Address	
Telephone number	
Child’s name	
Child’s date of birth	
How do you think Spires Smiles could help you and/or The Spires Cleft Centre?	

This form is for Spires Smiles use only, not the Spires Cleft Centre.
The Spires Cleft Team have kindly offered to include this form with their literature

* We shall email you to confirm your details are correct; to qualify you must reply, we shall then send your Amazon voucher. If we have not contacted you within 30 days, please email us at info@spiressmiles.co.uk

Post back to: Spires Smiles, Oakbank, Crawley Hill, West Wellow, Romsey, SO51 6APFind us on Facebook or email: info@spiressmiles.co.uk
Website: www.spiressmiles.co.uk
Telephone: Ann 07910 382584 Denise: 07897 981707 John: 07850 776238
Registered charity number: 1161277 HMRC charity reference: EW33567

Find us on Facebook

Useful References

Cleft Information

Changing Faces – a charity giving support to people with facial difference: www.changingfaces.org.uk

CLAPA – Cleft Lip and Palate Association, 1st Floor Green Man Tower,
332 Goswell Road, London, EC1V 7LQ www.clapa.com
E mail info@clapa.com

Salisbury – discharge from hospital (after cleft related surgery) information can be found on the Salisbury District Hospital web site under patient information: www.salisbury.nhs.uk

Spires Cleft Centre Website – www.spirescentre.nhs.uk

Breast Feeding Help

Breast Pump Web Sites – www.expressyourselfmums.co.uk, www.breastpumps.co.uk (you may find others)

La Leche League –www.laleche.org.uk

Medela US Easy Expression Bustier (to hold breast pump in place) - www.expressyourselfmums.co.uk (you may find other web sites)

National Childbirth Trust – www.nct.org.uk

Speech and Language

Association of Speech and Language Therapists in Independent Practice (ASLTIP) – www.helpwithtalking.com

ICAN – a charity working for children with speech and language difficulties www.ican.org.uk

Psychology

British Association of Behavioural and Cognitive Psychotherapists – offers information about cognitive-behaviour therapy and a searchable register of accredited therapists in the UK – www.babcp.com

Cry-sis – support families with excessively crying, sleepless and demanding babies. Tel: 0845 122 8669 (7 days a week, 9am – 10pm), web: www.cry-sis.org.uk.

Samaritans – A confidential listening service for any person who is despairing or in crisis. Tel: 0845 790 9090, web: www.samaritans.org.uk.

The Association for Postnatal Illness – provides support to mothers with postnatal depression. Address: 145 Dawes Road, London, SW6 7EB, tel: 02073 860868, fax: 02073 868885, email: info@apni.org, web: www.apni.org.

The National Information Centre on Fatherhood – news, training information, policy updates, research summaries and guides for supporting fathers and their families. Web: www.fatherhoodinstitute.org.

Dental

British Dental Association – web: www.bda.org

British Orthodontic Society - web: www.bos.org.uk

Max Appeal (22q11 deletion syndrome, VCFS) – address: Lansdowne House, 15 Meriden Avenue, Stourbridge, DY8 4QN, tel: 0800 389 1049 (free phone helpline) or 01384 821227, email: info@maxappeal.org.uk, web: www.maxappeal.org.uk.

Pierre Robin Information (useful web sites) – www.cafamily.org.uk & www.clapa.com

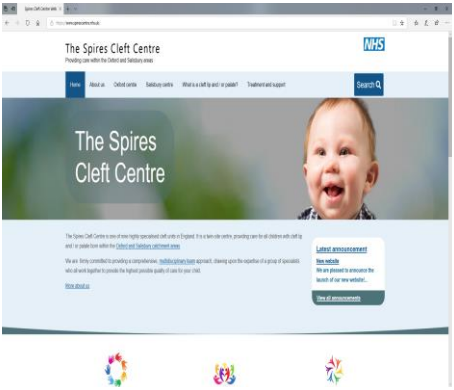
General Hospital Information

Hospital maps and general information about getting to the hospitals can be accessed on the hospital websites:

Salisbury: www.salisbury.nhs.uk, tel: 01722 336262

Oxford: www.oxfordradcliffe.nhs.uk, tel: 01865 741166*Both web sites contain details about the PALS (Patient Advice and Liaison Service) that you can access for advice and support regarding any concerns you may have.*

Patient Information leaflets



Did you know that the Spires Cleft Centre has a website: www.spirescentre.nhs.uk.

Would you like to share any of your experiences with others?

Or perhaps you would like to draw us a picture that we can share with others?

It is very easy…

You can complete the box below and hand it to anyone in the Cleft Team, or you can post it back to us. There is also space on the next page. You can even submit your story through the website.

Name:____

Are you a (please circle): Patient/Parent(s)

Return address by post
Steven Berry
Network Service Manager
The Spires Cleft Lip and Palate Centre
Level 2 Children's Hospital
John Radcliffe Hospital
OXFORD
OX3 9DU

Notes

Notes

Acknowledgments

Many thanks to all the parents and children that have given their permission to appear in this information booklet. Without their help this publication would not have been possible.

If you need this information in another language or medium (audio, large print etc.) please contact PALS on:
0800 374 208
Email: palservice@salisbury.nhs.uk or your CNS

You are entitled to a copy of any letter that we write about you. Please ask if you would like one when you come to the hospital.

We ask for information about you so that you can receive proper care and treatment. This information remains confidential and is stored securely by the Trust in accordance with the provisions of the Data Protection Act 1998.

Author: The Spires Cleft Team
Version June 2016
To be reviewed June 2022
Updated as and when required

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www.salisbury.nhs.uk


Minnie
1928