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Welsh Centre for Cleft Lip and Palate

Information booklet for parents of babies born with Cleft Lip



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http://www.wales.nhs.uk/cleft-team

Welcome to the South Wales Cleft Team

The Welsh Centre for Cleft Lip and Palate is based in Morriston Hospital in Swansea. The team looks after all children born with a cleft lip and/or cleft palate in South Wales and parts of Mid Wales. We are part of the South Wales South West Managed Clinical Network for cleft lip and/or palate.

The Welsh Centre for Cleft Lip and Palate consists of a number of different professionals including Specialist Cleft Nurses, Cleft Surgeons, Clinical Psychologists, Paediatricians, Speech and Language Therapists, Paediatric Dentist, Ear, Nose and Throat (ENT) Surgeon, Orthodontists, Geneticist and Restorative Dentists. We also have a Coordinator for the team. This booklet gives you some information about babies born with a Cleft Lip and what you and your baby can expect from the team. We hope you find it helpful. You can also find further information from our website www.wales.nhs.uk/cleft-team.

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Adjusting to the birth of your baby

Congratulations on the birth of your baby!

The birth of your baby is a wonderful event – an event you have probably waited for with a mixture of excitement and happiness. You may have known that your baby had a cleft before they were born or this may be something you learned at the time your baby was born. You may find you experience all sorts of emotional reactions, from shock to worry to feelings of protectiveness. It is not unusual to switch from one emotion to another or to feel several emotions at once. It is also very common to have thoughts such as ‘why us?’ or ‘why my baby?’ As parents, you are adjusting to learning that your child was born with a cleft lip. Some people adjust quite quickly while for others this can be a more gradual process that takes slightly longer. These are all very normal reactions and are understood by all those people involved with your care and the care of your baby.

You may have lots of questions from the start, or these may take a while to become clear to you. You may find that the information given to you at and around the time of the birth of your baby is confusing and just too much. Don’t worry. We understand that this can be the case and will always be happy to discuss any of your questions when you feel ready. Please feel free to ask anything at any time if you have any questions or concerns. No questions are too small or unimportant. If you are not sure who to contact, you can call our Cleft Team Coordinator, on 01792 703810.

For many parents, the next most difficult stage can be explaining to other people that their baby was born with a cleft, particularly if they feel confused and uncertain themselves. Take it slowly. We are happy to help you find the right words and to help explain to your relatives and friends should you wish us to. As soon as you and your relatives and friends understand about the cleft, and that your baby can be effectively treated, you will probably find that you feel happier and can start to relax and enjoy this special time.

If you would like to speak to someone about your feelings, or how to deal with other people's reactions, you can telephone the Cleft Team Psychologist. Details about their service are included in this booklet and you can contact them on 01792 703810.

This pack contains a lot of information for you. You may not feel you want to read it all now. There is no rush. You can keep this booklet and refer back to it at the right time for you.

As you learn more about cleft lip and the services we provide, we understand there can be lots of new words to learn. We have included a glossary at the back of this booklet so you can check any medical terms that are unfamiliar to you. There is also a list of members of the South Wales Cleft Team and contact details. Again, please feel free to ring us with any queries on 01792 703810. We are here to support you.

Background Information - Cleft Lip

What is Cleft Lip ?

A cleft lip happens very early on in pregnancy where the two sides of the baby's lip do not join together properly. A cleft of the lip can be on one side (unilateral) or both sides (bilateral). It can be as small as a notch, or may extend up into the nose. Generally, a cleft lip does not cause any speech or hearing problems.

Babies can also be born with a cleft palate, where there is a cleft or gap in the roof of the mouth. Babies can have a cleft palate with or without a cleft lip. **The information in this leaflet is about babies who are born with a cleft lip only**.



How common are clefts?

In the UK, around 1 in 700 children are born with a cleft lip and/or cleft palate. Of these, about 25% (25 out of every hundred born with a cleft) have a cleft lip only; 40% have a cleft palate only and the remaining 35% have a Cleft lip and cleft palate.

What is the chance of another baby being affected?

For most children born with a Cleft Lip and/or Palate it is an isolated problem. Isolated means that the cleft is the only problem they have. In this situation, although we are usually unable to say why the cleft has occurred, the risks of another child being affected are likely to be low.

In a small number of families there is a higher chance of having more children affected by a cleft. Families with a higher chance of having another child with a cleft are those where one or more of the following apply:

- there is a family history of cleft lip and /or palate
- the cleft is not isolated and the baby has other problems e.g. a heart problem
- the baby has a central cleft lip and/or palate
- there is a known genetic cause for the cleft which has a high chance of occurring again*.

*In some families there may be a genetic cause for the cleft. This means either that the cleft is part of a recognised pattern of problems for which there is a genetic diagnosis, or the cleft is associated with a change in a chromosome or a gene.

Genes are tiny packets of inherited information that are passed from parents to children. Chromosomes are the structures that carry the genes in our bodies. Identifying a genetic cause for a cleft does not mean it is someone's fault. Some genetic causes of cleft have a high chance of happening again, but others do not.

If you have concerns about the risk of another baby being born with a cleft lip and/or palate in your family you can be referred to the All Wales Medical Genetics service for information and advice. Please let us know if you would like to be referred. You can contact the Cleft Team Coordinator on 01792 703810.

The journey ahead

We have produced a separate chart that tries to show in simple terms the journey we will be sharing with you and your child over the years ahead. If you would like a copy of this it is available on the downloads section of our website at www.wales.nhs.uk/cleft-team or you can ask any member of the team for a paper version.

It is very important to recognise that every child is an individual and will follow their own unique journey. Any dates can only be approximate. At any stage, please feel free to ask one of the Cleft Team "where have we got to?" or "what happens next?".

Following any clinic appointments, we routinely send a letter to your child's GP summarising the consultation. When the clinic appointment has been with a number of different professionals, known as a multi-disciplinary team (MDT) clinic, we will also send a summary letter to you.

Please tell us at any time if more than one person has what the law calls ‘parental responsibility’, with the result that separate copies need to be sent to different addresses. Sometimes, these can be difficult situations, so we need to insist that such requests are made in writing.

Growing up

Feeling loved and valued as they are growing up, is an important part of any child’s happiness and wellbeing. Families are probably the most important factor in providing these feelings of security and happiness.

If you are worried at any point about the way your child feels about themselves and you don’t feel that your support alone is enough, please ask us to help. We have Clinical Psychologists as part of the cleft team who can offer psychosocial advice and support to you as a family, as parents and to your child when he or she is older.

Further information about the psychology service is included at the end of this booklet.



Feeding babies born with a cleft lip

An essential role of the Cleft Service is to work with the network of people involved in your baby's care to support you in establishing a good feeding regime that gives baby what he or she needs and is acceptable to the family.

All babies spend most of their early weeks feeding and sleeping. As well as satisfying hunger and thirst, feeding is a time of social interaction when a baby is most alert and parents and babies begin to get to know each other.

Normal breast or bottle-feeding takes place by a sucking action where the lips surround the nipple or teat. The milk is pumped out by the thrusting action of the tongue and a negative pressure built up in the baby's mouth by the closing off of the back of the nose with the soft palate. Babies with a cleft lip only do not usually have a problem with feeding, but some may find making a seal around the nipple or teat difficult. The specialist team will provide you with advice and any equipment you need to help you feed your baby.

However you choose to feed your baby, spending time having skin to skin contact can be beneficial to you both. This will keep your baby warm and help to calm them, giving you time to bond together. If your baby is unable to breastfeed and you would still like to use breast milk, we still encourage you to put baby to the breast to encourage lactation. Massaging the breast or using a breast pump will also help the flow of milk. Your Midwife and the Cleft Team will be able to give you more advice about this.

Pre-natal diagnosis

If your baby's cleft has been diagnosed before birth, one of the Cleft Team's Specialist Nurses will be in contact before your baby arrives to talk through the feeding problems that may occur and other issues which you may wish to discuss. They will be available to help and co-ordinate any feeding support your baby needs and will visit you soon after your baby is born.

At birth

When your baby is born, your maternity unit will contact us and you should receive a visit within 24 - 48 hours from one of the Cleft Team's Specialist Nurses. They will talk through any issues or concerns you may have in relation to your baby's cleft. They will also assess your baby's feeding and offer support to you and the maternity staff to establish a feeding regime suitable for, and individual to, you and your baby. The Specialist Cleft Nurses will also follow you up at home and you can contact them directly for advice when you need to.

Equipment

There are many bottles and teats available to help with your baby's feeding. In South Wales we recommend the MAM soft bottle. You will be shown how to use these bottles.

One or two babies each year may need other ways of feeding and if this is necessary we will discuss these with you.

You will be given 2 bottles and a pack of teats by the Specialist Cleft Nurses. Further supplies can be obtained from CLAPA - you will find their contact details in the CLAPA section of this leaflet. The Welsh Centre for Cleft Lip and Palate also have breast pumps that are available for you to use if you wish to express breast milk for your baby.

Coming to the New Baby Clinic

When your baby is between about 6 and 12 weeks, you will be given an appointment to come to the New Baby Clinic. This clinic is held once a month and it is a chance for you to come and meet the Team. The team members you will meet at the clinic are as follows:

Specialist Cleft Nurses – Specialist Cleft Nurses will welcome you to the clinic and make sure you have everything you need. They will check your baby's weight and length and talk to you about how your baby is feeding.
Consultant Cleft Surgeon – The Consultant Cleft Surgeon will examine your baby's cleft and will talk to you about the surgical treatment your baby will need. He will be happy to try to answer any questions you have.
Paediatricians - You will meet the Consultant Paediatricians. They will ask some routine questions, examine your baby and carry out an echocardiogram (heart ultrasound scan) if this has not already been done.
Psychologist - The Psychologist will introduce themselves and the service (see Psychological Support section) and you will have the opportunity to talk about any worries or concerns you may have.
Anaesthetist - You will meet the Consultant Paediatric Anaesthetist who will be able to answer any questions you have in relation to anaesthetic for surgery.



Surgery for your baby's cleft lip

We understand that the beginning of the treatment for your baby's cleft lip and thinking about surgery can be quite an anxious time. We hope that this booklet, with information about what to expect, will help to reassure you. You and your baby will be coming into Morriston Hospital for an operation to repair the cleft lip. One of our Specialist Cleft Nurses will contact you before you come into hospital so that you can ask any questions, but you can also ring her at any time.

Coming into Hospital at Morriston

The children's ward at Morriston Hospital is called Ward M. It is a 24-bedded ward specialising in paediatric (children's) surgery, including cleft surgery. The unit admits children between the ages of birth and 16 years old. There is a playroom with plenty of toys and play equipment.

You are encouraged to stay with your baby while they are in hospital. The staff would like you, as parents, to spend as much time as possible participating in your baby's care. There will be a bed beside your baby's cot for one parent to stay. There are parent facilities that you can use including a small kitchen/lounge area, showers and bathrooms.



We understand that when your child or baby is coming to hospital you may be feeling a little anxious. The ward staff have cared for many children with similar problems and can answer many of your questions and help you to resolve difficulties as they arise. Please feel free to contact the ward on 01792 618891 or a member of the cleft team at any time.

Preparing for surgery

The operation to repair the lip and the nose, is designed depending upon the extent of the cleft. It is performed when your baby is around 3 months old. On the day of admission, your baby will be examined by the medical team including a Paediatric Anaesthetist and the Cleft Surgeon. Blood samples and photographs will be taken.

Before the operation

Your baby has to be given their last feed a certain number of hours before the operation to ensure their stomach is empty. Your baby may be given formula milk up to 6 hours before the operation, breast-fed up to 4 hours before and given water up to 1 hour before. The Paediatric Anaesthetist will decide this and together with the ward nurses will advise you of the times.

Your baby will be away from the ward for about 3 hours, returning to the ward when fully awake. Don't worry if they seem to have been gone for a long time, the preparation and recovery stages add to the time your baby will be away. Do ask the ward staff if you are worried.

What the operation involves

In the operation, the lip will be joined together in a line running from the nostril to the edge of the lip. We will ensure that the lip and nose are as anatomically correct as possible at this stage.

If there is a cleft in the alveolus (a gap in the bone in the area of the cleft) this will be repaired in a further operation when your child's permanent teeth begin to develop, usually around the age of 8 years old.

After the operation

Your baby may look very different after the operation. Don't worry if this takes a little time to adjust to.

There will be dissolvable stitches at the very top and bottom of the lip. They look like fine white hairs.

Local anaesthetic is given during the operation to reduce any pain or discomfort your baby may have. To supplement this, painkillers will be given after surgery.

The nursing staff on the ward will help you to feed your baby after the operation, using your baby's usual teat if your baby is bottle-fed. It will take 2 to 3 days for your baby to return to their normal feeding patterns.



Caring for your baby's scar

You will notice that your baby's scar becomes red, firm and raised over the weeks after the operation. This is part of the normal healing process. The scar will shrink and will relax over subsequent weeks and months. The time scale varies from child to child. In the majority this process is complete in 3 to 6 months and should leave a fine, pale, soft scar. Some babies form scars that remain firm and red for much longer. Why the healing process varies is not known at present.

It helps the scars to settle if you massage them with Dermatix ointment. This will be given to you at your baby's post- operation follow up appointment with the Surgeon and you will be shown how to use it. The scars should also be protected from the sun using a sun block for the first year because the scars do not tan but burn and may change colour permanently. Infection of the lip repair is very rare but if it does occur it will be treated with antibiotics. Occasionally the scar may stretch slightly if this occurs.



Information on your child's ears and hearing

Children born with a cleft lip may have hearing problems, just like any other child, but it should reassure you to know that your child's chances of having a hearing problem are the same as they would be if your child did not have a cleft lip.

As any child can have a hearing problem it is important that your child's hearing is tested. **The first hearing test** your child will have will be the newborn hearing screen, which will be done soon after your baby is born. The screener will explain the result and tell you whether more tests are needed.

If your baby has a **clear response** on the screen, then no formal arrangements will be made for further hearing tests at this time. If you are concerned about your child's hearing at any time, please speak to your GP or Health Visitor.

If your baby **does not have clear responses** on the screen and is referred for more tests, the audiologist (hearing specialist) will explain the results of these tests.

As your child grows up, your child will have a hearing test shortly after he/she starts school. However, if you are concerned about your child's hearing at any time between appointments, please speak to your GP or Health Visitor.



Looking after your child’s teeth

When your child was born the deciduous (baby) teeth and permanent (adult) teeth were already beginning to form under the gum. The first teeth will start to appear from about six months. It will take a further two years for all of the deciduous teeth to come through. The first permanent teeth usually appear at about six years. Over the next five years each of the primary teeth will be replaced in turn, by permanent teeth.

There is much variation in the times at which teeth appear, and there is no need to worry if your child’s teeth take a little longer than normal to come through.

Giving your child’s teeth a healthy start in life is important. To prevent tooth decay and gum disease there are several things you can do from an early age.

Take care with diet

Feeding bottles should only contain water or milk to ensure the best healthy start for your child's teeth. The best advice is to keep the amount of sugar in the diet as low as possible. Try to limit the number of times that your child has sugar-containing food or drinks. A good guide is to give any sugar-containing foods or drinks at meal times only.

Encourage your baby to drink from a free-flow feeding cup rather than a bottle as soon as possible, a night time bottle should be stopped when your baby is 12 months old as this can cause tooth decay (even if filled with milk).

Clean the teeth regularly

Once your child's teeth erupt (come through the gums) brush twice a day with a toothpaste containing fluoride. Because little children tend to swallow toothpaste, use only a pea sized amount of paste.



Take your child to visit the dentist

It is a good idea if you take your baby with you to your own check-up visits initially, to get them used to visiting a dentist. You will be sent an appointment once your child is 12 months old to meet the Cleft Team's Paediatric Dentist. We will be able to give you more advice about tooth eruption, brushing and diet in relation to the cleft. You should also register your baby with your family dentist to provide general dental care.

If you have any questions or concerns about your baby's teeth, please contact the Cleft Dental Team for advice.



Dental care for a child born with a cleft lip

How does a cleft lip affect the teeth?

A cleft of the lip alone has little impact on potential dental problems. Occasionally, there may also be a cleft in the alveolus (a gap in the bone in the cleft area) which may produce dental problems. If this is the case, the team will advise you. The development of the teeth will be monitored by the Paediatric Dentist and Orthodontist within the cleft team to check whether the alveolus is affected.

How does this affect dental care?

Keeping your child's teeth and gums healthy is important from a very early age and will continue to be so. This reduces potential problems at a later stage.

Orthodontic care

An Orthodontist will monitor your child’s dental development from an early age. Photographs and other records will be taken at different stages to monitor progress.

Where surgery has been limited to the lip only, the development of the teeth may be entirely normal. However, the adult tooth closest to the surgery, may be smaller than normal or, occasionally, absent.

The Orthodontist may arrange to treat any irregularities of your child’s teeth. Where teeth are small or have failed to develop, it may be necessary to work with paediatric and restorative dentists to improve the appearance of the teeth.

Restorative dental care

In future, treatment may be necessary to improve the appearance of any unusually shaped teeth. If teeth are missing and the resulting space cannot be closed using braces, a bridge or denture or implant can often be used to fill the space.

Speech and Language Development In Children Born With A Cleft Lip

A cleft lip without a cleft palate does not normally impact on the development of speech and language. Any speech or language difficulties your child may have are unlikely to be a result of their cleft lip. Your child will benefit from all the things you would normally do such as singing songs and nursery rhymes. If you have any concerns about the clarity of your child's speech please do not hesitate to contact a member of the cleft team.



Psychological Support

Many children with a cleft lip and/or palate have no problems or concerns psychologically, but we know that parents often worry about how their child will develop and about difficulties they may face in the future. Parents may want information about how to support their child through the treatment. Some parents are unsure what to tell other people or how to talk to their child about their cleft. Others are concerned about the possibility of teasing when their child starts school. Occasionally, children born with a cleft can have some additional learning needs and the psychology team will be available to discuss any concerns with you. Parents may also find it helpful to talk about ways to help their child to grow up with good self-esteem, confidence and to be able to deal with life's 'ups and downs'.



Support from the cleft psychology team

There is support available to you, your child and other family members from the cleft psychology team at any stage. We are happy to talk with you on the phone to discuss how we can help and we can arrange appointments to meet up face to face. It doesn't have to be a big problem or concern before you contact us.

When will I see a Psychologist?

We are part of the team who you will meet routinely when you attend cleft clinics, such as the New Baby Clinic. We are happy to talk about any concerns, worries or questions you may have at these times.

Meeting you and your child at these clinics also gives us a chance just to check how you all are and to talk about how you can support your child through normal events such as starting school. We can also talk about ways to prevent potential difficulties and to promote positive self-esteem, confidence and coping.



When else can the psychology team help?

We can provide counselling, therapy, advice and support for various difficulties, including:

- Coming to terms with a diagnosis
- Preparing for surgery or other treatment or procedures
- Dealing with the attitudes and behaviour of other people, including comments, questions and staring
- How to talk to your child about their cleft and what to say to brothers, sisters, family and friends

- Support when there is a diagnosis of a genetic condition
- Communication difficulties
- Preparing for change, e.g. change of school, house move, post-surgery adjustment, relationship changes
- Worries about how you will cope
- Developmental assessment
- Depression or anxiety
- Family or relationship tensions
- Appearance concerns

What else does the psychology team offer?

We also have a number of leaflets which you may find helpful on topics such as dealing with comments and questions about your child's cleft, talking to your child about having been born with a cleft and settling your baby to sleep. These are all available on our website at www.wales.nhs.uk/cleft-team or you can ask any member of the team for a paper copy.



CLAPA: The Cleft Lip and Palate Association

CLAPA is the representative organisation for all people with and affected by a cleft lip and/or palate in the UK.

CLAPA's key functions are to:

- Organise local parent-to-parent support through its nationwide network.
- Run a specialist service for parents and health professionals seeking help feeding babies with clefts.
- Develop support for children and adolescents affected by clefts at school and in social settings through such activities as confidence-building camps.
- Encourage and support research into causes and treatment of cleft lip and palate.
- Represent the interests of patients and parents, influencing policy on future treatment of cleft lip and palate.
- Conduct educational seminars for health professionals and the general public.
- Raise funds in the community for equipment, literature and services.
- Publish and distribute a range of information leaflets, increasing public awareness of the condition.
- Support projects in countries where cleft treatment is limited or unavailable.

CLAPA work closely with the specialist cleft teams and generic health professionals to ensure that people receive the best possible care.

CLAPA offers free membership for anyone affected by or interested in cleft lip and palate.

Contact details (Head Office)

CLAPA
The Green House
244-254 Cambridge Heath Road
LONDON
E2 9DA

Tel: 020 7833 4883 Fax: 020 7833 5999

e-mail: info@clapa.com Web site: www.clapa.com

Glossary

Acute Otitis Media	An infection, associated with a build up of pus, in the middle ear space (see below).
Alveolar Bone Graft (ABG)	An operation in which bone taken from the hip (pelvis) is inserted under the upper gum of the mouth in the gap where the cleft is and where bone is missing. This is only carried out when there is bone missing and takes place at the age of 8-11 years; it depends to some extent on the stage of development of the teeth. Quite often at this operation, remaining holes in the gum of the mouth are also repaired and if necessary teeth extracted.
Alveolar ridge / alveolus	The bony part of the upper jaw (maxilla) and lower jaw (mandible) which hold the teeth.
Anatomically	Related to the shape or physical aspects of something.
Articulation	Lip, tongue and mouth movements used to create speech sounds.
Articulation test	Assessment of whether speech sounds are formed and used accurately.
Audiogram	A standard graph used to record how well your child responds to sounds.
Audiologist	Person with a degree, license, and certification in audiology (science of hearing) who measures hearing, and records the results on an audiogram (see above). With this information, an audiologist identifies if a hearing loss is present. If your child needs a hearing aid, it is the audiologist who will organise this.
Assistant Psychologist	Person with a university degree in psychology, usually working with supervision from a Clinical Psychologist
Bilateral	On both sides. If your child has a bilateral cleft, this means it is on both sides of the mouth.

Clinical Psychologist	Person professionally qualified to support individuals of all ages who are experiencing difficulties such as depression, bullying or teasing, anxiety, worries about treatment and coping with loss. Psychologists also work to promote positive wellbeing and mental health.
Columella	The central, lower portion inside of the nose which divides the nostrils.
Communication disorder	Difficulty with one or more aspects of communication which may involve understanding or use of language.
Comprehension	Ability to understand language (spoken, written or nonverbal).
Congenital	A disease, deformity, or deficiency existing at the time of birth.
Dental arch	The curve on which the teeth in the upper or lower jaw are aligned.
Eardrum	Also called the tympanic membrane. It vibrates and transmits sound to the middle ear and hearing bones.
Effusion	The build up of pressure from accumulation of fluid in the middle ear.
E.N.T.	Abbreviation for ear, nose and throat.
E.N.T. surgeon	Surgeon specialising in the diagnosis and treatment of the ear, nose and throat (larynx). Often now called Otolaryngologists.
Eustachian tube	The tube which connects the back of the nose (nasopharynx) with the middle ear; it opens with yawning and swallowing, filing the middle ear cavity with air, and helps keep the pressure on two sides of the eardrum equal. This tube does not work very well in children, especially those who have had a cleft palate, and this leaves some children prone to getting glue ear
Expressive language	Communication through speech, writing or non-verbal means.
Fistula	A hole which may occur between the mouth and nose, usually very small and at the site of the cleft repair.

Genetics	The science of heredity. The branch of biology that deals with heredity and genetic variations.
Glue ear	A condition in which fluid collects behind the ear drum, common in young children and more common in children with cleft palate. It can be associated with a hearing loss and make everything sound muffled.
Hearing impairment	A loss in hearing which may range from mild loss to complete loss. There are many causes for a hearing loss and the ENT Surgeon or Audiologist will explain the results of your child's hearing test to you.
Heredity	The total of the physical characteristics, abilities and potential genetically derived from one's ancestors.
Hypernasality	Too much air escaping into the nose, resulting in nasal sounding speech.
Hyponasality	Opposite of hypernasality, resulting in speech that sounds as though you have a cold/blocked nose.
Language disorder or impairment	Inability to communicate normally and effectively due to problems with comprehension or expression of language.
Malocclusion	Imperfect alignment (straightness) of the teeth in each arch and/or imperfect relationship of the teeth between each dental arch (bite)
Mandible	Lower jaw.
Maxilla	Upper jaw.
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.
Middle ear effusion	Fluid in the middle ear. The middle ear is the space in behind the ear drum, and fluid can build up in the space. This fluid is also called glue ear (see above).
Myringotomy	A small cut which is made in the ear drum, to allow insertion of a grommet.

Nasal emission or nasal escape	An abnormal flow of air through the nose during speech. Usually indicative of an incomplete seal between oral and nasal cavities (mouth and nose).
Nasopharynx	Tube which runs between the nose and throat and allows air to pass through during speech and breathing.
Nasoendoscope	A soft, flexible telescope with a light on the end used for examining the passages in the back of the throat. Useful in assessing soft palate function.
Occlusion	How the teeth in each arch are aligned and how the teeth in upper and lower arches teeth meet together
Orthodontics	Specialty of dentistry concerned with the correction of irregularities of the teeth and jaws.
Orthodontist	Specialist dentist who prevents or corrects irregularities of the teeth and jaws.
Otitis media with effusion	Also called OME, or Glue ear (see above).
Otolaryngologist	Modern term for an ENT Surgeon (See above).
Palatal insufficiency	A lack of, or shortness of, tissue preventing the soft palate from contacting the back of the throat (pharynx).
Palate	The roof of the mouth including the front portion or hard palate and the back portion or soft palate (the soft palate is also called the velum).
Paediatric dentistry	Dentistry concerned with the care of children's teeth.
Paediatrician	Doctor specialising in treatment of children.
Pharyngeal flap	Surgical procedure in which a flap of the lining of the throat is used to close most of the opening between the velum (soft palate) and the nasopharynx (back of the throat).
Prosthetic speech aid	A removable acrylic appliance which provides a structural means of closing the gap between the nose and mouth, thereby aiding speech.

Soft palate	(The velum) Mobile soft tissue at the back of the roof of the mouth attached to the hard palate. The soft palate is crucial to swallowing and speech. Moves to open and close the gap between the nose and the mouth.
Speech & language therapist	Professional who works with children or adults who have difficulty with communication.
Uvula	Small, cone-shaped muscular process hanging at the back of the soft palate. (The dangly bit that hangs down at the back of the throat).
Velopharyngeal closure	The closing of the nasal cavity from the oral cavity 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 (VPD)	Inability to achieve adequate velopharyngeal closure.
Velum	The soft palate.

Notes

Welsh Centre for Cleft Lip and Palate Contact Details

Clinical Director

Mrs Helen Extence	Clinical Director and Lead Speech and Language therapist

Cleft Team Coordinator

Mrs Andrea Thomas	Cleft Coordinator

Clinical Leads

Mr Karl Bishop	Lead Consultant Restorative Dentist (West)
Dr Mechelle Collard	Lead Consultant Paediatric Dentist
Miss Sinéad Davies	Lead Consultant ENT Surgeon
Mr Tomas O'Neill	Consultant Cleft Surgeon
Mrs Helen Extence	Lead Speech and Language Therapist
Dr Vanessa Hammond	Lead Consultant Clinical Psychologist
Dr Charlotte Eckhardt	Lead Consultant Orthodontist

Dr Maha Mansour	Lead Consultant Neonatologist
Mr William McLaughlin	Lead Consultant Restorative Dentist (East)
Dr Annie Proctor	Lead Consultant Geneticist
Mrs Michaela Rowe	Lead Specialist Cleft Nurse
Dr Ingo Scholler	Lead Consultant Paediatrician

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