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If you have any questions, queries, or require more information, please contact the department:

Telephone: (01792) 618816

Monday to Friday (excluding bank holidays)

8.30 am to 4.30 pm

An out-of-hours answering machine is available

Email: ABM.CleftEnquiries@wales.nhs.uk

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Author: Cleft Psychologists
The Welsh Centre for Cleft Lip and Palate

What Do We Know About Cleft Lip And Palate?

The Welsh Centre for Cleft Lip and Palate

Cleft Psychology Service

Morrison Hospital

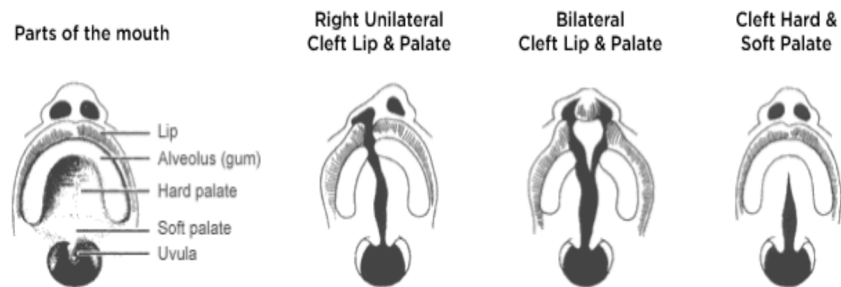
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www.wales.nhs.uk/cleft-team

What is a cleft?

Cleft means gap. During the 6th to 10th week of pregnancy, the bones and tissues of a baby's upper jaw, nose and mouth normally join together to form the roof of the mouth and upper lip. If the tissues in the developing mouth and palate don't join properly, a baby could be born with a condition called a Cleft Lip, Cleft Palate or Cleft Lip & Palate. The type and severity of a cleft can vary. A unilateral cleft is on one side, whereas a bilateral cleft is on both sides. Nothing is missing when a baby has a cleft lip or cleft palate. All parts of the lip and palate are there, they just haven't joined up.

Below is a diagram looking up into the roof of the mouth



Cleft Lip

A cleft lip is a condition that creates an opening in the upper lip between the mouth and nose. It looks as though there is a split in the lip. It can range from a slight groove or notch in the lip to complete separation in one or both sides of the lip extending up and into the nose.

A cleft in the boney part of the gum may occur in association with a cleft lip. This may range from a small notch in the gum to a complete division of the gum into separate parts.

Cleft Palate

A cleft palate occurs when the roof of the mouth has not joined completely. The back of the palate (towards the throat) is called the soft palate and the front (towards the mouth) is known as the hard palate. If you feel the inside of your mouth with your tongue, you will be able to notice the difference between the soft and the hard palate.

In babies with cleft palate, there is an opening between the roof of the mouth and the nose. A cleft palate can range from just a small opening at the back of the soft palate to a nearly complete separation of the roof of the mouth (soft and hard palate).

Sometimes a baby with a cleft palate may have a small lower jaw and a few babies with this combination may have difficulties with breathing easily. This condition is called Pierre Robin Sequence.

Why do some babies have a cleft?

- Although we know *how* a cleft forms, we don't know *why* it happens.
- It can happen to anybody, although sometimes it seems to run in families.
- 1 baby in every 700 babies is born with a cleft—it is the most common congenital craniofacial anomaly. Congenital means something you are born with, craniofacial means to do with the skull and face, and anomaly means different from the norm.
- Every year about 45 babies are born in South, Mid and West Wales with a cleft.
- Slightly more boys are born with a cleft than girls.



CLAPA is the cleft lip and palate association. They have a really good website with lots of information about cleft, parent support, and more. They provide support for new parents, and for people with the condition and their families, from infancy through to adulthood.

www.clapa.com

Cleft Team Contacts

Adrian Sugar Cleft Clinical Director
Andrea Thomas Cleft Coordinator

If you would like to contact the Cleft Team please telephone 01792 703810.

Psychological wellbeing

Many people who are born with a cleft do not find this impacts on their lives and go through life with the same ups and downs as anyone else. Some people though have some concerns and difficulties, for example wondering what to say to other people, concerns about feeling different or teasing and bullying.

There are psychologists in the cleft service who are happy to meet up or talk on the telephone and can offer support. We also try to meet with all young people to check how they are getting on and talk about ways to increase wellbeing or self-esteem and talk about ways to cope with life's ups and downs.



What can be done to repair a cleft?

- Babies have an operation at 3-4 months old to repair the cleft lip.
- Babies with a cleft palate have an operation at 6-12 months to repair the cleft palate.
- If the cleft goes through the boney part of the gum, children usually have a bone graft operation to repair this around the age of 8-10 years.

What other difficulties might occur for someone born with a cleft?

- Babies born with a cleft lip and palate can have difficulty feeding. Some babies with a cleft lip can breast feed but others have difficulty in sucking properly.
- Babies with a cleft palate will not be able to breastfeed as they will have difficulty sucking. There are special teats and bottles available which help the baby to get milk to the back of the throat to swallow more easily.
- If a baby is having difficulty feeding, weight gain may be slower than normal at first but usually develops normally by about the age of six months.

- The development of the teeth and growth of the jaw may sometimes be affected by a cleft lip. Some first or permanent teeth may be missing, unusually shaped or crooked. These problems are usually easily corrected by the dentist and orthodontist. Make sure you don't eat too many sugary treats or fizzy drinks so that you look after your teeth.



- Cleft palate can sometimes cause problems with speech, and this may be the case even if the cleft is a small one. After the palate is repaired most children will go on to achieve normal speech. However some children may require further surgery or speech and language therapy.

- As the muscles of the palate affect the ear there may be an increased likelihood of 'glue ear', which can cause hearing loss. This occurs when a sticky fluid builds up behind the eardrum often as a result of an infection in the middle ear. Some people will need a hearing aid or a minor operation to insert a tiny plastic tube or grommet through the eardrum, preventing the fluid from coming back.



- Sometimes being born with a cleft lip can affect the appearance of the nose. Some people, but not all, opt to have an operation to improve the appearance of their nose.
- The growth of the upper jaw may sometimes be affected by a cleft palate. Some people opt for jaw surgery in their late teens/early adulthood to correct this.