

Managing your pregnancy if we suspect your baby has a cleft lip or palate

Information for patients



This leaflet is aimed at pregnant women in whom a cleft lip is suspected in their baby on ultrasound examination.

The leaflet should only be supplied in supplement to a consultation with a senior obstetrician and/or fetal medicine specialist.

What is a cleft lip?

Cleft lip is a term used to describe a gap in the top lip. The cleft may be on one side of the upper (unilateral) or both sides (bilateral) of the upper lip or in the middle (midline).

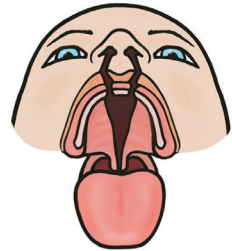
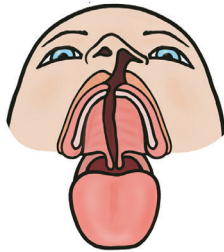
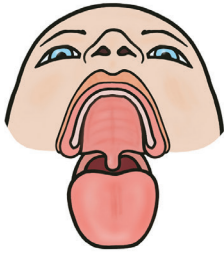
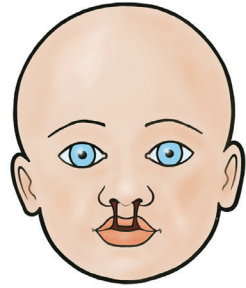
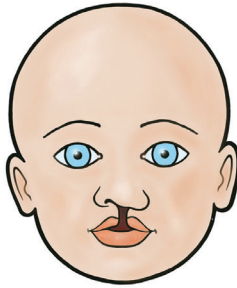
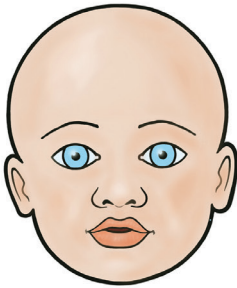
What is a cleft palate?

The gap found in the upper lip can, in some cases, also involve the roof of the mouth. This is called a cleft palate.

As with a cleft lip, a cleft palate can occur on one side (unilateral cleft palate) or on both sides (bilateral cleft palate). In most cases where there is a cleft palate found before birth, there will be a cleft lip as well.

Cleft lip and palate (CLAP) are quite common problems and a cleft lip and/or palate occurs in approximately 1 in 700 babies every year in the UK.

Diagram of types of CLAP



Normal Palate

Unilateral Cleft
Lip and Palate

Bilateral Cleft
Lip and Palate

What causes it?

The lip and the roof of the mouth develop in the very early stages of pregnancy. To start with they are in two parts (left and right) and, as the tiny baby grows, the two sides join together. In some babies the joining process fails leaving a gap in the lip and/or palate

Cleft lip and palate usually occurs as an isolated problem however, in about 5% of cases there will be an underlying chromosomal or genetic problem which is responsible for the cleft.

The actual risk for your baby will depend on the type of cleft that has been found. A chromosomal or genetic problem is much less likely if the baby only has a cleft lip but more likely if there is a cleft in the palate as well or if the cleft is in an unusual place.

This is unlikely to have been caused by anything you have done during your pregnancy and there is nothing you could have done to prevent it. In a small group of women, the use of certain medicines early in pregnancy, particularly those needed to control the symptoms of epilepsy, can be associated with the development of CLAP in the baby.

How is it diagnosed?

This problem can be diagnosed in pregnancy during an ultrasound scan.

If CLAP is suspected on a scan you will be referred to a Fetal Medicine specialist in Leeds who will carry out a full assessment of your baby to look for other problems which might be associated with CLAP

The Fetal Medicine doctor will carry out a detailed ultrasound scan, including the use of 3D/4D ultrasound to examine the baby's face and mouth in detail.

What does it mean for my baby?

All babies with a cleft lip and/or palate will require at least one operation to close the gap. These operations are not needed immediately after birth but, because of the cleft, you will require support from the specialist cleft nurse whilst your baby learns to feed.

What treatments/operations are needed?

Your baby will need an operation:

1. To close the cleft lip at around 3-4 months of age
2. The hard palate (the part at the very back of the roof of the mouth) around 6-12 months of age
3. Surgery may be needed before your child starts school to help with speech to help the teeth come through the gum correctly
4. Your child will be assessed between the ages of 7-9 years to see if a bone graft is required to help the teeth come through the gums properly
5. Further surgery may be required between the ages of 13-20 years for cosmetic reasons or to help with speech

Your baby will be cared for by a team of specialists to help with:

- ◆ The operations
- ◆ Speech and language development
- ◆ Hearing
- ◆ Teeth

If you have not already been referred to the Cleft team you will be very soon.

Is it likely to happen again?

The chances of having another baby with CLAP will depend on your individual family circumstances. If there is no history of clefts in the family and this is your first affected child, then the chances of it happening again are relatively low at around 2 - 8 in 100. The chances can be as high as 1 in 2 in some families.

You may be offered scans with a Fetal Medicine specialist in future pregnancies, depending on your family circumstances or even genetic testing if the cause is found to have been genetic.

Where can I get more information and support?

Be sure to ask questions to the doctor supplying you with this leaflet and make a note of any questions you would like to ask at your Fetal Medicine Unit appointment. Your local hospital will also have a specialist midwife who you will be able to contact for further discussion.

There is a list of helpful websites and organisations that provide useful and reliable information below.

Antenatal Results and Choices

- www.arc-uk.org

Cleft lip and palate association

- www.clapa.com

Northern cleft service

- www.leedsth.nhs.uk/a-z-of-services/cleft-lip-and-palate-service/
- Telephone: 0113 392 5115



What did you think of your care?

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