

Cleft lip

Information for parents



Information to help you understand more about cleft lip.

1. What is cleft lip?

'Cleft' means split or divided in two. During the first few weeks of pregnancy, separate areas of the face develop and then join together. If some parts do not join together completely, the result is a cleft. The type and severity of clefts can vary.

A cleft lip can range from a slight split in the lip to a complete split, in one or both sides of the lip, which extends up into the nose. A cleft on one side is called a unilateral cleft. If there is a cleft on both sides of the lip it is called a bilateral cleft.

A cleft palate is where the parts which form the roof of the mouth (the palate) have not joined completely. The back of the palate is called the soft palate and the front is known as the hard palate.

A cleft palate can range from an opening at the back of the soft palate to a complete separation of the roof of the mouth (soft and hard palate). A child can have just a cleft lip or a cleft palate, or both.

Most scans only pick up a cleft lip. A scan cannot reliably identify a cleft palate, even if a cleft lip is noticed.

The cause of cleft lip is not known. It is most likely caused by a combination of environmental and genetic factors.

Although cleft lip can run in some families, most babies with this condition are born into families with no previous history of the condition. Also, the majority of babies born to parents with a cleft lip will not have a cleft.

2. How common is it?

Cleft lip with or without cleft palate occurs in about 10 of every 10,000 births.

3. How is it diagnosed and confirmed?

A cleft lip is usually noticed at the Fetal Anomaly ultrasound scan carried out between 18 weeks and 21 weeks of pregnancy.

4. Is there any treatment?

Babies born with a cleft lip will need an operation to repair the cleft. This operation usually takes place within the first six months of your baby's life. The exact timing and type of treatment will be discussed with you and will depend on how serious the cleft lip is and whether it is associated with any other conditions.

Some babies may need further surgery as they grow up.

The Specialist Cleft Lip and Palate Team will discuss a long-term care plan for your baby with you because some babies will need continuous help throughout their childhood.

5. What is the outlook for the baby?

A cleft lip without a cleft palate is often easy to correct with surgery. The procedure usually leaves only a small scar. Most children born with a cleft have no other medical conditions, so your child should grow and develop normally. The cleft may sometimes cause difficulties with feeding, and the position of teeth. However, with treatment and support from the Specialist Cleft Lip and Palate Team, most children will have good outcomes.

6. What happens next?

You will be given the chance to talk to specialists and the Specialist Cleft Lip and Palate Team about what having a baby with a cleft lip might mean to you and your family.

They will offer you another scan to check whether the baby has other disorders and discuss tests such as CVS (chorionic villus sampling) or amniocentesis to check for genetic disorders. There is more information on CVS and amniocentesis in leaflets called *Chorionic villus sampling (CVS) – information for parents* and *Amniocentesis test – information for parents*. These are available on our website at www.fetalanomaly.screening.nhs.uk/publicationsandleaflets.

Your doctor may talk to you about the option of having a termination to end your pregnancy. You will have the opportunity to discuss the possible implications of continuing or ending your pregnancy.

If you choose to continue your pregnancy, your healthcare team will help you plan how your care, including delivery, is managed.

Arrangements will be made for you to meet some of the paediatric team, including one of the paediatric surgeons, who will care for you and your baby during pregnancy and after birth.

If you choose to have a termination, your health professional will talk to you about the procedure and support you through the process.

Whatever you decide, your decision will be respected and you will be supported by your midwife and doctor.

7. How likely is it to happen in a future pregnancy?

You are more likely to have a normal, healthy baby in your next pregnancy than to have another baby with a cleft lip. In most cases we have no idea why a cleft lip happens. Anyone can have a baby with a cleft lip. It is unlikely that your baby's cleft resulted from anything that you did or did not do during pregnancy.

You are more likely to have a baby with a cleft lip if you smoke, drink large amounts of alcohol during pregnancy or are obese. Smoking and drinking alcohol are not advised during pregnancy.

8. Where can I get more information and support?

You may feel you only want to talk to your family and friends, a particular doctor or midwife, or the Specialist Cleft Lip and Palate Team. However, there are other people and organisations that can provide information, help you make your decisions and support you in your pregnancy and afterwards. You may also want to talk things through with the hospital chaplain or your own minister or faith leader.

9. Further information, charities and support organisations

The following organisations can offer you support. There are details of other support organisations on our website at www.fetalanomaly.screening.nhs.uk. If you have any questions about the information in this leaflet or where the information came from, email us at enquiries@ansnsc.co.uk.

Antenatal Results and Choices (ARC)

Email: info@arc-uk.org

Helpline: 0845 077 2290

Website: www.arc-uk.org

Antenatal Results and Choices (ARC) provides information and support to parents before, during and after antenatal screening and diagnostic tests, especially those parents making difficult decisions about testing, or about continuing or ending a pregnancy after a diagnosis. ARC offers ongoing support whatever decisions are made.

CLAPA – Cleft Lip and Palate Association

Phone: 0207 833 4883

Fax: 0207 833 5999

Email : info@clapa.com

Website: www.clapa.com

CLAPA is the only UK-wide voluntary organisation specifically helping those with, and affected by, cleft lip and palate. Branches are run by people who have benefited from the organisation, often working in partnership with local health professionals. CLAPA has a team of trained Parent Contacts who have personal experience of having a child with a cleft lip and are available to talk to parents after diagnosis.

This information has been produced on behalf of the NHS Fetal Anomaly Screening Programme for the NHS in England. In other countries, check with a health professional to find out whether there are any differences in approaches to screening.

This leaflet has been developed through consultation with the NHS Fetal Anomaly Screening Programme expert groups and is based on a leaflet issued by CLAPA. That leaflet is on the CLAPA website at www.clapa.com.

All of our publications can be found online at www.fetalanomaly.screening.nhs.uk.

NHS staff can reproduce any information in this booklet. Please make sure you have permission to reuse images. You must discuss any amendments with the original author.

© NHS Fetal Anomaly Screening Programme 2012

If you have any comments or feedback, email them to us at enquiries@ansnsc.co.uk.