

Cleft lip

Information for health professionals



Cleft lip

Information for health professionals

The aim of this information sheet is to support staff involved in counselling pregnant women and their partners when a suspected or confirmed diagnosis of a cleft lip has been made, following an ultrasound scan.

All diagnoses of the conditions must be recorded and audited to ensure the effectiveness of the screening programme.

1. Definition

A cleft lip is a congenital malformation characterised by partial or complete clefting of the upper lip, with or without clefting of the alveolar ridge or the hard palate.

The upper lip and palate form separately and over different gestational ages. Although clefts in the lip and palate often occur together they arise from different embryological processes.

The upper lip develops from the growing together and fusing of the tissue that forms the nose and the centre of the face. Formation of the upper lip takes place between the 7th and 9th week of gestation.

The palate develops from the growing together and fusing of the tissue that forms the centre of the upper lip and gum and the sides of the inner mouth. Formation of the palate takes place between the 7th and the 14th week of gestation.

Approximately 25% of affected babies will be born with a cleft lip, 50% with a cleft lip and a cleft palate and 25% with a cleft palate (Sommerlad, 1994). An isolated cleft palate is unlikely to be seen prenatally.

The condition appears to be caused by a combination of genetic factors and environmental influences. The specific genes and environmental factors are not completely understood.

2. Prevalence

The overall prevalence of cleft lip with or without palate is approximately 10 in every 10,000 births (Boyd et al. 2011).

3. Screening and diagnosis

Many cases of cleft lip are now diagnosed at the 18⁺⁰–20⁺⁶ weeks Fetal Anomaly ultrasound scan. A scan cannot reliably identify a cleft palate, either when associated with a cleft lip or on its own.

A second scan may be needed to confirm the diagnosis and to rule out any other abnormalities.

4. Treatment

An isolated cleft lip is often easy to correct with surgery. The operation usually takes place within the first six months of the baby's life and is often carried out in the first three months of life.

During this surgery, the cleft lip is pulled down and rotated to produce a more normal looking appearance, before being stitched into place. The operation usually leaves a slight scar, but attempts are made to line up the scar with the natural lines of the lip in order to make the cleft less noticeable.

This type of surgery is carried out by specialist Cleft Lip and Palate Teams. If there is no Specialist Cleft Lip and Palate Team in your hospital, women should be referred to a hospital that has one. In some cases, infants may also need additional surgery to improve the appearance and function of the lip and mouth in the future.

5. Prognosis

For most children born with a cleft, there are no other associated abnormalities, so infants should grow and develop normally. The cleft lip may sometimes cause difficulties with feeding, appearance or the position of teeth. However, with treatment and support from the Specialist Cleft Lip and Palate Team, the majority of children have very good outcomes. A cleft lip is sometimes associated with genetic syndromes. Overall approximately 16% of babies diagnosed with a cleft lip have other structural abnormalities and approximately 7% occur as part of a recognised syndrome (IPDTC Working Group 2011).

6. Recurrence

Clefts can run in families, although the majority of babies who are born to parents with clefts do not develop clefts themselves. Research indicates that the genes a child inherits from their parents can make them more susceptible to developing a cleft.

A number of environmental risk factors have been identified that can increase the risk of cleft lip and palate, such as maternal smoking (Hackshaw et al., 2011), alcohol consumption and obesity. Women are therefore advised to avoid smoking during pregnancy.

7. Prevention

There is no known way to prevent a cleft lip from happening.

8. Referral pathway

Following diagnosis of a cleft lip, referral should be made to a specialist in fetal medicine for a second opinion and further information. Parents should be offered referral to the Specialist Cleft Lip and Palate Team. These teams provide life-long support to children and parents.

The second scans will involve careful assessment of the fetus to identify any additional abnormalities. Where appropriate, the offer of karyotyping (by chorionic villus sampling (CVS) or amniocentesis) to exclude a chromosomal abnormality should be discussed.¹

A termination of pregnancy should be offered following appropriate counselling. Women should be offered the opportunity to discuss the possible implications of continuing or ending their pregnancy.

Some women choose to continue the pregnancy and these parents will need ongoing care and support.

9. Further information, charities and support organisations

This information booklet has been produced by the NHS FASP and is based on a leaflet developed by CLAPA. CLAPA is the representative organisation for people with and affected by cleft lip and/or palate in the UK. The complete leaflet can be found on the CLAPA website www.clapa.com or by contacting them directly.

A more extensive list of support organisations is available on the website www.fetalanomaly.screening.nhs.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.

¹More information on CVS and amniocentesis can be found in the following leaflets: *Chorionic villus sampling (CVS) – information for parents*, *Amniocentesis test – information for parents*, *Chorionic Villus Sampling (CVS) and Amniocentesis – for health professionals*. These are available here: www.fetalanomaly.screening.nhs.uk/publicationsandleaflets.

References

Sommerlad, B. The management of cleft lip and palate. *Current Paediatrics*: 1994; 4: 189-195.

Boyd PA, Tonks AM, Rankin J, Rounding C, Wellesley D, Draper ES. Monitoring the prenatal detection of structural fetal congenital anomalies in England and Wales: register-based study. *Journal of Medical Screening* 2011; 18(1): 2.

Hackshaw A, Rodeck C, Boniface S. Maternal smoking in pregnancy and birth defects: a systematic review based on 173 687 malformed cases and 11.7 million controls. *Human Reproduction Update* 2011, First published online: July 11.

IPDTC Working Group Prevalence at Birth of Cleft Lip With or Without Cleft Palate: Data From the International Perinatal Database of Typical Oral Clefts (IPDTC). *The Cleft Palate-Craniofacial Journal* January 2011; 48(1): 66-81.

This information has been produced on behalf of the NHS Fetal Anomaly Screening Programme for the NHS in England. There may be differences in clinical practice in other UK countries. The leaflets have been developed through consultation with the NHS Fetal Anomaly Screening Programme expert groups.

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

NHS staff can reproduce any information in this booklet. Please ensure you have permission to reuse images. Amendments must be discussed with the original author.

© NHS Fetal Anomaly Screening Programme 2012

Please email any comments or feedback to: enquiries@ansnsc.co.uk.