Antenatal Information for Parents and Carers

You have recently been seen at the antenatal scan department and have been told that your baby may be born with a cleft lip, and possibly also with a cleft palate. For most parents this diagnosis comes as a shock and you may be worried about how this will affect your plans for parenthood. As your local cleft team, we are here to support you following diagnosis, to help you to look forward to the arrival of your baby and to support you throughout the cleft treatment pathway.

This leaflet provides information about the cleft lip and palate service which we hope you will find useful.

What is a cleft lip and/or palate?

The parts that form your baby’s upper lip grow and join together to form the mouth by around week 7 of pregnancy. If this joining does not happen then the result is a gap in the upper lip, on one side, or occasionally on both sides. This gap in the lip is called a cleft lip. Following on from this, the two sides of the palate (the roof of the mouth) grow towards each other and join together by around week 11 of pregnancy. If this does not happen, your baby will have a cleft palate. A baby can have a cleft lip, a cleft lip and palate or an isolated cleft palate. A cleft lip and palate can happen on one side (unilateral) or both sides (bilateral). Isolated cleft palate is not routinely picked up on antenatal scan at the time of writing this leaflet.

Why might this happen?

The cause of cleft lip remains generally unknown, although in some cases there may be a family history. In the UK, 1 in 700 babies are born with a cleft, making it a common condition. In the light of current knowledge, there is nothing that you have done to cause the cleft, nor is there anything you could have done to prevent it happening. There is however research being carried out, in an attempt to identify the causes of cleft.

How might my child be affected?

For most babies born with a cleft lip, the cleft is an isolated condition which will not affect your child’s general development. A cleft lip and palate may affect feeding, hearing, speech, appearance and position of teeth as they come through. With your support and the specialist support and treatment of the cleft team and local teams, few children have long-term issues.
**What treatment is available?**
The Cleft.NET.East team is made up of specialists from a variety of different health professions. Clinical nurse specialists, cleft surgeons, speech and language therapists, audiologists, clinical psychologists and dental specialists may be involved in helping you and your child. One of the aims of the cleft team is to help your child to develop into a happy and confident individual.

A cleft lip is usually closed surgically at around 3-6 months of age and a cleft palate is usually repaired between 8-12 months of age. We hold clinics at Addenbrooke’s Hospital and at some other centres across the Eastern region. All cleft operations take place at Addenbrooke’s Hospital.

**What support is available?**
A clinical nurse specialist from the cleft team will contact you within 24 hours of referral, on the telephone number provided by your referring hospital; we will then arrange to meet you and explain what to expect of treatment. If you are referred for further scans at the Fetal Medicine department, a clinical nurse specialist will try to meet you there. Alternatively, if you are not coming to the Rosie Maternity Hospital at Addenbrooke’s Hospital for your follow up scans, we may meet you at home. We will also arrange to meet you at home before your baby arrives, to answer any questions about feeding.

You may want to look up cleft on the internet but be aware that there is a lot of information available and it can be difficult to decide what is relevant to you. You may wish to look at the NHS Choices pages (www.nhs.uk) or the Cleft Lip and Palate Association (CLAPA) website (www.clapa.com) which is a parent support website. CLAPA also have a team of trained Parent Support Contacts.

**How do I access support?**
Your scan department will make a referral to us here at Cleft.NET.East, you may want to check with them that this has happened. You should expect to hear from us within 24 hours of the referral. However, you can also contact us yourself by calling the cleft team office on 01223 596272 between 08:00 and 16:00, Monday to Friday. The clinical nurse specialist team use an on call system over weekends and bank holidays. During these times, the telephone number of the clinical nurse specialist on call will be provided on the office answer machine.

**Confidentiality**
All information that you share with us is treated confidentially unless there are concerns that someone’s safety is at risk.
Letters are exchanged between members of the team so that we can provide you with the best quality care. Copies of letters are also sent to you, your child’s GP (family doctor), Health Visitor, local Paediatrician and other members of the cleft team. If there is information that you do not want to be shared with the rest of the team you can talk to your clinical nurse specialist about this.
Suggestions/comments

The staff are here to help and it is important for them to know if you have any comments or suggestions about the services you have received. If you wish to speak to a member of the Cleft Team please telephone us on:
01223 596272 Monday to Friday 9:00 am to 5:00 pm

Alternatively you can contact the Patient Advice and Liaison Service (PALS) on:
Tel: 01223 216756
Email: pals@addenbrookes.nhs.uk

External contacts and information

Cleft Lip and Palate Association (CLAPA)
First Floor, Green Man Tower, 332b Goswell Road, London, EC1V 7LQ
Tel: 0207 833 4883
Fax: 0207 833 5999
Email: info@clapa.com
Web: www.clapa.com

Changing Faces
The Squire Centre, 33-37 University Street, London, WC1E 6JN
Tel: 0845 4500 275
Fax: 0845 4500 276
Email: info@changingfaces.org.uk
Web: www.changingfaces.org.uk

Cleft.NET.East
Box 46, Addenbrooke’s Hospital, Hills Road, Cambridge, CB2 0QQ
Tel: 01223 596272
Fax: 01223 274244
Web: www.cuh.org.uk/cleft
We are now a smoke-free site: smoking will not be allowed anywhere on the hospital site.
For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0 169.

Other formats:

If you would like this information in another language, large print or audio, please ask the department where you are being treated, to contact the patient information team: patient.information@addenbrookes.nhs.uk.

Please note: We do not currently hold many leaflets in other languages; written translation requests are funded and agreed by the department who has authored the leaflet.

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