



CLAPA

Registered Charity
no.1108160

CLEFT LIP AND PALATE ASSOCIATION



Antenatal Diagnosis of Cleft Lip & Palate

Name

Telephone

Obstetrician:

Midwife:

Cleft Team Contact:

Hospital Address:

Date of next scan: . . . / . . . / . . . Time: am/pm
(if applicable)

Date of appointments: . . . / . . . / . . . Time: am/pm

General notes:

If you have recently had a scan indicating that your baby has a cleft lip and/or palate, you may have some questions about the condition, and/or you may feel distressed. This leaflet hopes to address some of these issues and to give you some information about the condition. It will also explain some of the technical terms that you may hear used by health professionals. All the issues raised in this leaflet are covered in more depth in other literature from CLAPA, The Cleft Lip and Palate Association, a registered charity.

What is a cleft lip/palate?

‘Cleft’ means a split or separation of parts. 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 which can vary.

A cleft lip can range from a slight notch in the coloured portion of the lip to a complete separation 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 a cleft occurs on both sides it is called a bilateral cleft.

A cleft palate occurs when the parts which form the roof of the mouth 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 just an opening at the back of the soft palate to a complete separation of the roof of the mouth (soft and hard palate). Cleft lip and palate can occur separately or together.

Most scans only ever pick up the presence of a cleft lip and sometimes a cleft gum. A scan cannot reliably identify a cleft palate, either when associated with a cleft lip or on its own.

Why does it happen?

Although cleft lip and/or palate can run in some families, most cleft babies are born into families with no previous history of the condition. One in every 700 babies in the UK is born with a cleft lip and/or palate but the causes are not well understood. Much research is being conducted to understand more about why clefts occur. However, it is very unlikely that your baby's cleft resulted from anything that you did or did not do during pregnancy.

Will my baby need treatment?

Your baby will need an operation to repair the cleft.

A cleft lip is usually repaired within the first 6 months of a baby's life. A cleft palate is usually repaired a little later, probably by the time the baby is a year old. If there is a gap in your baby's gums, this will be repaired as his or her second teeth are coming through. The specific timing of treatment will be discussed with you by the cleft team. Most babies recover very quickly and will not experience much pain after these operations.

Medication is given for any discomfort. When your baby comes to hospital for his or her operation, he or she will usually need to stay in hospital for 3 to 5 days. It may be necessary for your child to receive follow-up treatment later in his or her development.

Aspects of treatment may vary and this will depend on the type and severity of each individual's cleft.

What will happen now?

The most important step once the diagnosis has been confirmed is to be put in touch with a Specialist Cleft Lip and Palate Team, at a hospital designated for cleft treatment.

Once a referral has been made by your obstetrician or midwife, someone from the team should make contact with you and arrange to see you. Nearer the time that your baby is due, you may also be invited to meet other members of the team at the hospital.

Never be afraid to ask questions. Sometimes it helps to write questions down before meeting with the cleft team. You may find it useful to contact CLAPA and ask for some further information. CLAPA may also be able to help your obstetrician or GP by providing contact details for your nearest cleft centre if they are not readily available.

Many parents of babies born with the condition find it helpful and comforting to talk to someone who has experience of a child with a cleft. CLAPA can help, and will try to put you in touch with another family.

One mother's experiences of having a child diagnosed with cleft lip and palate:

"When, during my twenty week scan I was told that the baby I was expecting had a cleft lip and possible cleft palate, my reaction was disbelief. My first baby had been perfect, I was very healthy, and had done everything the leaflets advised. Things like this didn't happen to me.

The sonographer was very understanding and assured me that with the help of current surgical techniques, if there had to be a problem, then this was a good problem to have.



We decided to be as open as possible with everyone and that we weren't going to hide away. If everyone got used to the idea before he was born, his birth would be as happy an event as his brother's.

On September 2nd, Ben was born - a huge bouncy baby boy. No matter how much we had prepared for it, seeing him for the first time was still a huge shock. But within minutes we got used to his face and focused on the huge eyes staring back at us.

He had his lip repaired when he was fourteen weeks old. By this time we had grown to love his cute face and in

Ben, the day before the operation

particular his enchanting smile. The first couple of hours after the operation my husband and I were speechless. It was almost as if someone had taken our baby away and replaced him with a stranger. Ben looked so different - the clever hands of a surgeon had done the work nature had failed to do.

We are not at the end of the road yet. We know that there will be more treatment to come, but at the moment we're enjoying our very lovely little boy."



Ben, aged 4 months

CLAPA Contacts

CLAPA Head Office: Green Man Tower, 332B Goswell Road,
London EC1V 7LQ

Tel: 020 7833 4883

Fax: 020 7833 5999

Email: info@clapa.com

Web site: www.clapa.com

*Contact Head Office for details of local
CLAPA Contacts*

Acknowledgements:

Booklet compiled by CLAPA with help from Trish Chudleigh
and Katy Cook, Fetal Medicine Unit,
St George's Hospital, London

Produced with support from the Department of Health

*Design & layout by Stephen Read
020 8516 1906, e-mail: sefread@hotmail.com*