



Cleft Lip and/or Palate: Information for families and friends

Introduction

This leaflet has been produced for family members, or friends, of someone who has given birth to, or is due to give birth to, a child with a cleft lip and/or palate.

Although about 1 in 700 babies are born with a cleft in the UK (about 1,000 per year), the cause is not fully understood. Whilst we know **what** happens, we don't know **why** it happens. Sometimes clefts run in families and sometimes a baby is born with a cleft without anyone else in the family having one.

About 70% of cleft babies are diagnosed pre birth and parents can suddenly feel overwhelmed with worries and unanswered questions: Is it their fault? What is a cleft lip? What is a cleft palate? What can be done for their new baby?

We hope that this leaflet will provide you with practical information to help support your family or friend.

When you first find out that someone has been diagnosed or given birth to a baby with cleft lip and/or palate it can give rise to many different feelings.

These feelings may include:

- Shock: Why has this happened?
- Worry: For the parents and for the child.
- Helplessness: What can I do?
- The need to be supportive and strong for your family.
- You may want to know why this has happened and need more information.

What practical support can I give? When will my support be needed?

After an antenatal diagnosis family and friends can help by:

- **Be reassuring:** Help them to find the information they may need. Use the CLAPA website to get up to date, accurate information about cleft lip and/or palate.
- **Be a good listener:** Talking things through will help them to adjust. Often people need to go through things again and again to make it clear in their own minds. Let them lead the pace as everyone reacts differently
- **Be positive:** They may have some negative feelings such as blame, denial or guilt. Encourage them to talk about their feelings and if necessary refer them to CLAPA or their specialist cleft team.
- **Using the correct terms:-Cleft lip, cleft palate, or cleft lip and palate:** Don't use old fashioned names such as 'Hare Lip' that can cause offence.
- **Provide practical support:** Take some of the day to day pressures off of them by offering to look after older siblings whilst they adjust to the unexpected situation.

After the birth you might need to help by:

- Not letting the cleft take over. Talk about ordinary baby things too.
- Give practical assistance by offering to do the shopping, collect siblings from school, or offer to help with feeding the baby. Feeding issues can cause a lot of strain and tiredness on the new family so any help would be much appreciated at this time. Parents quickly become experts about cleft lip and palate. Give them credit for this and offer advice only if it is asked for.
- Parents may feel anxious about the baby meeting people for the first time so don't pretend that the cleft isn't there. Help them to rehearse what to say or do when people are curious about the cleft or ask questions.
- If you are unsure about something contact CLAPA rather than give the wrong information.

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