NHS
SCOTLAND

The National Cleft Surgical
Service for Scotland

Having a baby with a cleft:

Common worries and ways to cope

Cleft Clinical Psychology Service

Congratulations on the birth of your baby!

Whilst the first few months of a baby's life can be very challenging (whether they have a cleft or not), the cleft team are here to support with any questions or worries you may have about cleft.

Cleft Clinical Psychology

This booklet has been written by the Cleft Clinical Psychologists and Cleft Specialist Nurses on the cleft team. The psychologist's role is to support families (and later children and adults themselves) with any concerns or worries related to cleft, in addition to the practical support from other cleft team members.

Importantly, we are not here because we are expecting children with a cleft will have psychological difficulties. In fact, what we see, expect and aim for is that most children (and adults) with a cleft will cope well with this.

Common worries in the first year

We have written this booklet about the most common worries families have mentioned in the first year. These are:

1. **Difficult or mixed feelings about their baby/their baby's cleft**
2. **Talking to others about their baby's cleft**
3. **Others' reactions to their baby's cleft**
4. **Worries about surgery**
5. **Worries about their child's future**

Of course, everyone is different, so you may not share each (or even any of these. However, if you do, we hope this will offer guidance, and reassure that you are not alone in feeling this way.

The back page of this leaflet has information on helpful resources, and how to find extra support if you feel you need it.

Common worry 1: Difficult or mixed feelings

When a baby's cleft is first discovered, what it means to a family depends partly on what they already know about clefts.

- Having difficult feelings about an unexpected event, like your baby having a cleft, is **entirely normal and understandable**. You are absolutely not the only person to have felt this way.
- Adjusting to your baby having a cleft **is a process, and takes time**.
- **These feelings do not make you a 'bad' parent**. Many worry they should feel positive about their baby 100% of the time. This is not true. The 'perfect' ever positive parent does not exist (despite what you see on TV/social media!).
- **Take regular time to take care of yourself, doing things you enjoy** e.g. time with friends, reading, taking baths, and/or exercise.
- Some find **speaking to others in the same situation** helpful. CLAPA (see back page) are a charity who can connect families with cleft.

CLAPA
Cleft Lip & Palate Association

- It is common for one parent to feel another is 'coping' better. This can lead to tension and frustration. It can help to realise **what we feel differs, and what helps one person may not help another**.
- If you are struggling with feelings and think it might be helpful to talk to us, **we are here to support without judgment** (see back page).

Common worry 2: Talking to others about cleft

As clefts are rare (we see around 80 new babies in Scotland every year), most people don't know much about them unless they have any personal experience.

Many families worry about explaining their child's cleft to others. They can worry others' reactions will be negative. They may be worried about the topic coming up, or tempted to avoid it. However, there are times when talking about cleft can be helpful.

- **You only need to say as much as you feel comfortable to**. This may vary with different people, situations, days - this is totally normal.
- **You may prefer to explain about cleft unprompted, or only when asked** - it is entirely up to you what you feel okay with at the time. However, a few general options you have in any situation are:
    1. **Short explanation:** It can help to prepare a quick explanation you feel happy with e.g. "*It's called a cleft lip*" or "*He has a gap in the roof of his mouth*". You may want to follow up with a reassurance, like "*it doesn't hurt him*" or "*it doesn't stop him smiling!*"
    2. **Longer discussion:** You may feel comfortable going into more detail than the above, or answering more questions - it is up to you!
    3. **Ignore/change the subject:** If someone asks and you don't want to talk about it at that time, you can try this as a way to divert the conversation.
    4. **Assert if don't want to talk about it at that moment:** Alternatively, you have every right to say so directly e.g. "*I don't want to talk about it*".

We have particular advice on discussing cleft with the following people:

Health professionals: Don't assume those outside the cleft team will know about cleft. Taking letters or information to appointments may help.

Siblings: Avoiding talking about cleft can suggest it is a 'bad' thing. Explain it as you would any other topic, in simple words (e.g. 'gap in lip/mouth'). Reassure them that it isn't a big deal, and that it doesn't hurt.

Common worry 3: Others' reactions to cleft

Some families worry that people will respond negatively to their baby's cleft. They may be anxious, upset or annoyed about other's reactions.

Noticing visible difference

Some babies will have a cleft lip, medical equipment (e.g. tubes for feeding/breathing), and/or a small chin if they have Pierre Robin Sequence (your nurse will tell you if this applies). These differences are visible, and other people can notice them. Things we don't see often catch our attention even if we don't mean them to.

Importantly, **someone noticing your baby's difference is not the same as them judging it negatively**.

Many people say they don't mind young children looking, commenting or asking about the baby's cleft because they don't mean it in a 'bad' way. Not all adults mean it in a bad way, either. However, as it can be uncomfortable, our suggestions for dealing with looking/staring are:

1. Make eye contact: Often, realising they have been seen will make people notice they are looking, and stop. If you feel like it, you can also smile, to show that you and baby are perfectly friendly.

2. Talk to them: You can ask or explain what they are looking at.

3. Ignore them: You can carry on as if you haven't noticed.

4. Ask them to stop: It is absolutely acceptable to do this if you like.

Again, what you feel you can or want to do will depend on the situation. Don't worry if you find yourself responding in a way that you don't think is 'ideal'- there is no right way to respond.

Dealing with negative comments or reactions

Whilst most people will not respond to a cleft in a negative way, unfortunately some families do experience this. If this happens, it is totally acceptable to **tell the person clearly that this is not an okay thing to say/do**.

If you experience reactions that you find difficult to deal with, and/or are anxious to go out in case of them, we can offer support (see back page).

Common worry 4: Worries about surgery

Once families have had time to adjust to the fact their child has a cleft, the thought of upcoming surgery can become a worry.

Anxiety about surgery: This is very common, and very understandable. Most people have limited experience of hospitals or surgery, and the unfamiliarity can make it seem scary. Others may have had (or heard of others') negative experiences. Commonly mentioned worries are:

Anaesthetic: Specifically the worry that as babies are small, they might not wake up. In reality, paediatric anaesthetists only treat babies and children and are experts in this. Your anaesthetist and cleft nurse will talk to you about the more common side effects of anaesthesia in babies e.g. grouchiness, disrupted sleep and feeling or being sick.

Pain / Trauma: Some families worry babies won't know what is happening, will be in pain, and/or be traumatised. Whilst babies won't know what is going on, your comforting can reassure them. They will be given pain relief to keep them comfortable (though their new mouth probably will feel unusual to them).

There is no evidence that babies are traumatised by surgery, though they may be unhappy with the unfamiliar environment and having to fast before surgery. Whilst anaesthetic and disruption to routine can unsettle them for short while after surgery, babies otherwise cope with surgery better than adults in many respects.

Worried about a new smile: If your baby has a cleft lip, it can be hard to see the face you love change. Take lots of photos and videos of their smile before surgery - many children love to see these later!

Some families feel repairing a cleft in the lip or palate is only needed 'for others', which makes them angry. However, the Cleft Team does not offer surgery unless they expect it to provide clear benefit for a child in the future.

Siblings: Families sometimes have other children who they worry will be upset by their sibling's surgery. Children can sometimes think that hospitals mean people are not well. It can help to explain that their sibling is not sick, the doctors are just going to help close the hole in their mouth.

If you have worries around surgery, we can offer support (see back page).

Common worry 5: Worries about the future

Will having a cleft affect my child's confidence?

We know from research and from meeting lots of children and adults with a cleft that some are very confident, some are very shy, and some are in between - just like any group of people. Research has shown that having a more obvious cleft does not mean a child will be less confident. We know that the type of experiences and messages we have growing up play a big part in things like confidence and self-esteem.

What can I do to help my child feel confident?

“Different isn’t bad- it is just different.

As each child experiences things differently, we can’t know for sure how a child will feel about their cleft as they grow older.

A cleft is only a small part of a person (or family) – there are lots of other things that make the person who they are! A cleft is best framed as something that makes the individual unique, and not something that will hold them back or disadvantage them.

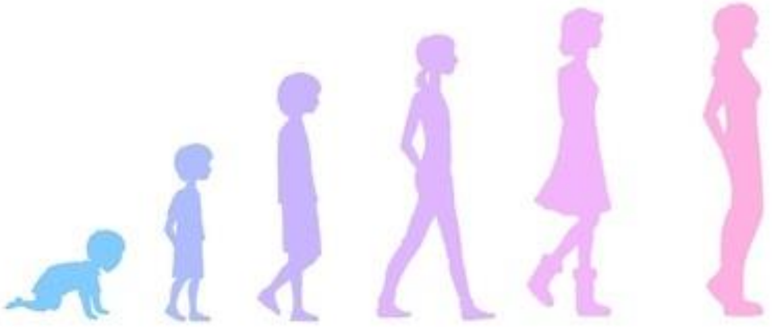
Talking to your child about cleft

We know that a child benefits from knowing what a cleft is, and how to explain it to other people. We encourage parents to talk to their child about their cleft – help them to have a ‘story’. We often find using baby pictures and talking about operations is a helpful way to encourage the child to ask questions and have open conversations about cleft in the future.

Anticipating teasing/bullying

Teasing/bullying in the school environment occurs for a whole range of reasons, and it is very important to notify the school early on if this occurs. However, it is also important to remember that just because someone is born with a cleft, it **does not mean** they will be bullied.

We encourage both children and parents to have ‘ready–prepared’ answers to curious questions about their cleft – to empower themselves while educating others. Talk to your child’s teachers if necessary, or support your child to talk to their school about their cleft.



Further support and information

Cleft Clinical Psychology

Should support around cleft related issues ever be helpful, we are here. In addition to the issues in this booklet, our Cleft Clinical Psychology leaflet lists the kind of issues we support. If you would like support, you can contact us on the details below, or ask your cleft nurse to let us know.
0141 451 6524 / ggc.cleftpsychologyscotland@nhs.scot

Cleft Team

If you need to reach the cleft team for any other reason, our coordinator or secretaries can direct you to the right person or information. Please contact:
0141 451 6524 / ggc.cleftteamscotland@nhs.scot

Paediatric Clinical Psychology

If your child has any additional medical issues (e.g. a genetic disorder) you may be able to access psychological support from a local Paediatric Clinical Psychology service. **Please tell your specialty team, GP or cleft nurse if you would like to access this.**

CLAPA: Information, support groups, shared experiences of cleft care from patients and families, parent/peer contacts, residential weekends and events for people with cleft and their families. **clapa.com / info@clapa.com** 020 7833 4883

Health Talk: Shared experiences of cleft/care from patients and families
healthtalk.org/cleft-lip-and-palate

Royal Hospital for Children: Information on hospital facilities, travel etc
nhsggc.org.uk/locations/hospitals/royal-hospital-for-children-glasgow

Royal College of Anaesthetists: Information about child anaesthesia
rcoa.ac.uk/childrensinfo

Teddy Hospital: Uses play to prepare children and/or siblings for surgery
0141 452 4009 (Royal Hospital for Children, Glasgow)

Pyjama Fairies: Charity providing free colourful hospital gowns for babies
pyjamafairies.org

What? Why? Children in Hospital: Site providing resources for children and families who will be admitted to hospital for treatment**Whatwhychildreninhospital.org.uk**

Review October 2025