

PARENT GROUP TRAINING



Module One

Parents supporting new parents positively



Background to training parents to provide best support

- CLAPA UK experiences 25 + years ago
- Recognition that some key skills must be learned for parents of children with clefts in order for them to actively provide support for new parents
- Health professionals endorsed this approach as it demonstrated that we were providing a safe and supportive service for parents

Parents of children with clefts providing support to new parents?

(5 minutes own time)

Potential POSITIVES?

Potential NEGATIVES?

Why was training offered?

- Boundaries - going beyond what we are qualified to say/do
- Wrong information being given out
- Imparting own difficult experiences
- Emotional burden of talking to people who may be distressed

Development of course for parents who want to support new parents

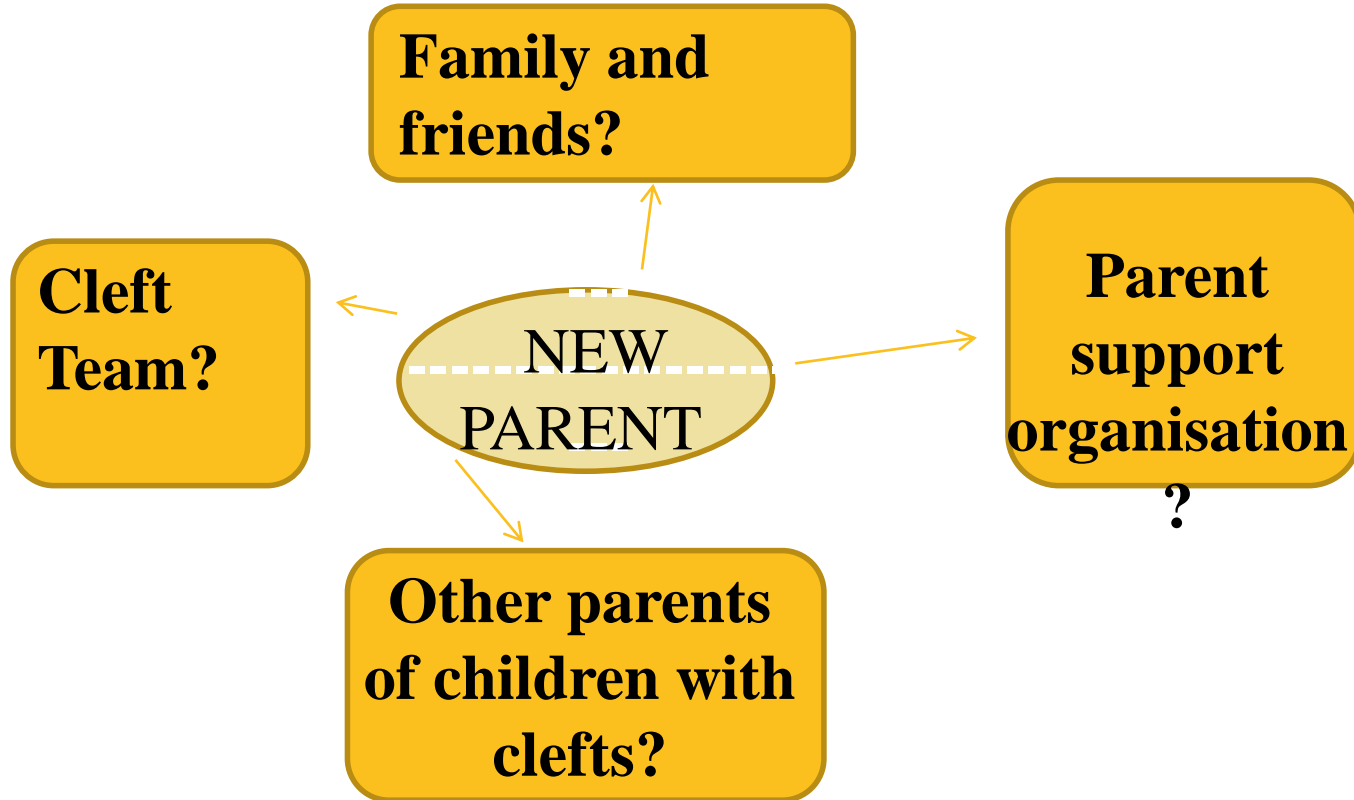
- **Always organised with the support the cleft team**
- **Selection criteria**
 - have a child of more than one year old
 - references sought from cleft team
- **3 full days training – must be completed in full**
- **Provision of supervision for active parent contact**

Today's session is not meant to replicate that course – we will just look at some important areas that can be put into practice by anyone who is meeting with, or talking to, a new parent of a child with a cleft – or indeed an older child, adult or family member

Key topics covered in this module

1. Sources & types of support
2. The wide range of potential challenges faced by parents
3. Key skills in offering support
4. Boundaries & limits
5. Its not all about clefts!!

What types of support are needed & where might the support come from?



Brainstorm types of support – 5 minutes, own time (return to previous slide)

It is helpful to think about support in two key ways

- **Emotional or moral support**
- **Practical support**

Friends & Family

- **Emotional/moral support**
 - Understanding
- **Practical support**
 - Day to day general help
- **There be may also some negative feelings such as blame, denial or guilt**

The cleft team

- **Practical support**
 - Ongoing medical care
 - Information and guidance
 - Help with specific problems e.g. feeding
- **Emotional support**
 - Future expectations – prognosis
 - Some team members can provide emotional support.
- **Previous feedback from parents it that the team may give too much information too soon.....**

Trained parent contacts

- **Emotional support**
 - Personal experience
 - Empathy
 - A regular point of contact
 - Normalizing emotions – letting people know its ok to feel what they feel, including negative emotions
 - Someone to be honest with – can say anything
 - Seeing the baby as a person rather than as a cleft
- **Practical support**
 - Providing bottles
 - Shared travel to appointments

Parent support group

- **Practical support**

- Equipment - bottles and teats.
- Information in terms can understand
- Referrals to the Cleft Team
- Confidence to ask the right questions of the health professionals – suggestion of checklist
- Information leaflets

- **Emotional support**

- Shared experiences; knowing 'you are not the only one'
- Support for older children
- Children's parties

Common Challenges: Developmental Stages & Treatment Protocols

- **Diagnosis**
 - Prenatal
 - At birth
- **Infancy**
- **Early Childhood**
- **School age**
- **Adolescence & Teenage Years**
- **Adulthood**

A typical patient journey for an individual born with a cleft



1. First Symptoms

Cleft of the lip (unilateral or bilateral) and/or cleft of the palate (hard palate and/or soft palate)

Needs: Information on condition and rapid referral to expert team. Initial difficulties are likely to be around feeding and these need assessing urgently by a specialist dietitian or equivalent

Ideally: Feeding established and normal bonding begins. Family positively adjusts to birth of a baby with a condition they did not expect and moves on to a place of certainty

2. Diagnosis

Diagnosis of a cleft lip can be made antenatally at around 20 weeks but it is rarely possible to accurately diagnose a cleft palate antenatally. Diagnosis at birth will involve an examination of the roof of the mouth with a torch.

Needs: It is imperative that at diagnosis checks are made for any other associated abnormalities so these can be addressed.

3. Impact on child

There can be problems with feeding as a baby. Subsequently there can be speech difficulties, dental misalignment and missing teeth, hearing problems (glue ear) and appearance issues. Children and young adults with clefts may have low self esteem as a result of looking or sounding different, and may perform less well at school.

Needs: Treatment pathway needs to be coordinated clearly by the cleft team with appropriate follow-up, checks and interventions at the right ages. Psychosocial adjustment and educational attainment should be monitored. Clear precise information and involvement of family in decisions around aspects of treatment is important.

Ideally: Child and family feel informed and involved in the care being given. They can explain clearly all aspects of treatment to the child's school and teachers. Absences from school will be inevitable for clinic visits and surgical interventions.

4. Treatment ++

A cleft is repaired by surgery usually between 3 months to a year but can vary. Early speech assessment takes place around 18 months. Secondary surgery to repair the cleft in the gum (alveolus) takes place at around 9-11 years, and sometimes earlier. Speech therapy may be needed during the school years together with extensive orthodontic treatment. Further surgery may be required to improve speech and appearance in the teenage years. Psychological support should be available where needed.

Needs: Patient and family needs change with age of the child. All clinical interventions should be properly explained and should be decided by a joint multidisciplinary team. Psychosocial support is important for the whole family and especially at life change points such as changing schools. The teenage child should be involved in decisions about their care.

5. Follow Up

While the majority of physical issues around clefts are 'sorted out' by adulthood, there needs to be an open door for someone to return to treatment if they need to. Often this is problematic because most cleft units are in pediatric hospitals

Needs: There may be some continuing physical needs (dentition, speech, fistulae – small holes in the palate). However it may be more on a psychosocial level that support is needed relating to looking or sounding different. This can potentially affect development of intimate relationships. There can also be issues around self esteem and in particular confidence at job interviews, etc. **Ideally:** At the end of treatment some young adults with clefts may feel they are alone facing the world with no further support. There need to be opportunities for the young adult to reconnect with the team or other relevant support networks so they feel supported in areas where they may continue to have needs.

Burden of treatment

Treatment for a cleft may involve a considerable burden of care and this may be associated with time away from school, disruption to normal family routines and the expense of attending appointments



Potential Emotional Responses to Cleft Lip/Palate (own time - 5 minutes)

What might be the emotional responses of:

- **New parents of children born with cleft lip and/or cleft palate?**
- **Other family members of children born with clefts?**

Possible emotional responses of new parents

- Shock
- Guilt
- Worry
- Bonding issues
- Coping with physical appearance of the baby
- Concerns over how to tell people
- Isolation.
- Relief not something worse
- Feeding and breast feeding issues
- Surgery including the whole treatment pathway
- Issues common to all new parents, with nothing to do Pre/Post Operation worries?

Possible concerns of wider family members

- They feel they have to be strong for everyone
- They want to be included
- Need information
- Feel they are being kept in the dark; not enough information
- They want to treat the child the same as the siblings
- Possible negative feelings (blame)

Potential Emotional Responses to Cleft Lip/Palate

(own time - 5 minutes)

What might be the emotional responses of:

- **Children with clefts themselves (8yrs +)?**
- **Siblings of children with clefts?**

Emotional responses of those born with clefts

- Why me?
- Anxiety
- Feeling different
- Frustration due to speech differences/hearing problems
- Potential lack of confidence
- Appearance issues
- Forming relationships
- Resentment towards parents
- Falling behind at school

Possible issues for siblings

- Jealousy
- Resentment
- Want to intervene to stop bullying by other children
- Over-protectiveness
- Why don't I get attention/time off school?
- Concerns about genetic link

Key skills in offering support.....

- The art of LISTENING
- The art of ASKING

Good Listening

Own time – 5 minutes - reflection

- **What is good listening?**
- **What happens when you are not listened to well?**
- **What happens when you *are* listened to well?**

Listening

You are NOT listening to me when...

- You say you understand before you know me well enough.
- You have an answer for my problem before I have finished telling you what my problem is.
- You want to jump right in before I invite your response.
- You are trying to sort out all the details and are not aware of the feelings behind the words.
- You tell me about your experience, which makes mine seem unimportant.
- You are communicating with someone else in the room.
- You cut me off before I have finished speaking.

You ARE listening to me when...

- You really try to understand me when I do not make much sense.
- You hold back your desire to give me good advice.
- You give me enough room to discover for myself why I feel upset, and enough time to think for myself what is best.
- You allow me the dignity of making my own decisions even though you feel I am wrong.
- You allow me to make my experience one that really matters.
- You grasp my point of view even when it goes against your sincere convictions.
- You accept me as I am
- You spend a short valuable time with me and make me feel it is forever.

“Listen”

When I ask you to listen to me and you start giving me advice you have not done what I asked.

When I ask you to listen to me and you begin to tell me why I shouldn't feel that way you are trampling on my feelings.

When I ask you to listen to me and I feel you have to do something to solve my problems you have failed me, strange as it may seem.

When you do something for me that I can and need to do for myself you contribute to my weakness.

So please listen and just hear me and if you want to talk, wait your turn and I will listen to you.

What happens if you are not listened to well

You feel:

- **angry**
- **uncomfortable**
- **disappointed**
- **not respected**
- **confused**
- **drop in confidence**

What happens if you are listened to well

You feel:

- **positive**
- **that you have shared a burden**
- **that your self-esteem has risen**
- **happier**
- **empowered**



The Art of Asking

Different kinds of questions lead to different kinds of responses:

- **Closed questions** receive a ‘yes’ or ‘no’ response.
e.g. ‘Are you happy?’
- **Leading Questions** reveal the opinion of the questioner and suggest that a particular sort of response is required.
E.g. ‘Shouldn’t you be doing that differently?’
- **Questions that change the subject or avoid something important that has been said** suggest that the other person has not been heard.

The Art of Asking

- **Open questions** keep the attention on the other person and invite them to develop their thinking as they talk.
e.g. 'How are you feeling?'
- **Prompting questions** indicate that the listener is listening and encourage the other person to carry on talking.
e.g. 'What else?' or 'Can you say a bit more?'
- **Questions that begin with a summary what the other person has just said** can be helpful in encouraging them to continue and also indicate that they have been heard.
e.g. 'So what your friend said upset you; what was that like?'
- **Questions that check out what someone has said** can avoid misunderstandings, especially when someone is describing something quite complex, and show that you really want to hear and understand them.
e.g. 'Let me just check that I've understood properly – your son had his lip repaired while you were abroad, and his palate repaired here?'

The Art of Asking

- **Questions that begin with a summary what the other person has just said** can be helpful in encouraging them to continue and also indicate that they have been heard.
e.g. ‘So what your friend said upset you; what was that like?’
- **Questions that check out what someone has said** can avoid misunderstandings, especially when someone is describing something quite complex, and show that you really want to hear and understand them.
e.g. ‘Let me just check that I’ve understood properly – your son had his lip repaired in another hospital, and his palate repaired here?’

Closed and open questions

- *'Are you feeling better now?'*
change to
- *'How are you feeling about things now?'*

How many children do you have?
change to

'Tell me about your family...'

Words and Phrases to Watch out for

Words and phrases that can *disempower* people include:

Should

Must

Ought to

Got to

Have to

Words and phrases that can *empower* people include:

Could

Want to

Would like to

Need to

Limits

Questions or worries about specific medical issues should *always* be directed to the family's cleft team.

“The most valuable thing you can do is provide a listening ear, talk about ‘coming through the other side’ of what might seem like an endless process, and offer to put parents in touch with the relevant health professionals if there are specific concerns”

A few comments on social media

Pros

- Can reduce feelings of isolation; improve connectivity by offering a forum for shared experiences ("I am not alone")
- Can be a great platform to steer members of the group to authoritative sources of additional information and advice (and away from potential unhelpful content)
- Social media works best (in terms of wellbeing) when the user actively curates their own feeds - so effective support offered this way can be a good example of a feed that makes us feel better

Cons

- Participants may feel that others are doing better than them
- It's difficult to judge how members of the group are doing with an on-line only presence. (This is much easier to do face-to-face when you can pick up info from their non-verbal communication - or there is the opportunity for a 'private' chat).
- Some people may feel they are 'engaging' by joining a social media group, but then use this as a reason to avoid face-to-face contact with others
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Issues

- Social media groups/streams need to be actively managed by someone - conversations need to be checked regularly for authenticity and factual accuracy;
- Consideration needs to be given on a very regular basis to how the posts by members are making others feel. Dominant members may not be representative of others
- 'Lurkers' (people who are in the group but don't join in) may be feeling worse rather than better - need to be checked outside of the group.
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Summary approach to online support

- A mixed approach of a moderated social media group/stream backed up by phone calls to individual members probably best
- *Look out for each other in the 'real world' as well as online!*

It's not all about the cleft.....

- I surprised an audience at one of the first parent meetings I attended when I said “*stop talking about clefts all the time*”
- These are babies and children – not to be defined by having a cleft
- Children – especially in adolescent years – often have their own specific concerns, maybe totally unrelated to having a cleft;
- Like their peers, they may have appearance concerns that are not related to the cleft
- Talk about ordinary life events, everyday achievements and the ‘world out there’

A Parent Contact is a named point of contact for a new parent wishing to talk to someone outside of the medical environment. It is a unique position from which empathy and support can be offered to others.

Parent Contact Experience

How can your own experiences help you in offering support to new parents and others affected by cleft lip and palate?

Thank you!

