

Children Born with Cleft Lip & Palate



The School Years

Information for Teachers,
Parents and Carers



CLAPA

produced by

Cleft Lip and Palate Association
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CLAPA

The Cleft Lip and Palate Association (CLAPA) is a registered charity set up to give information and support to anyone affected by cleft lip and/or palate, directly or indirectly. The support we offer complements the care provided by specialist health professionals. Most of us involved with CLAPA are parents of children born with clefts and are not medically trained.



Sam age 9 1/2



Donald, age 7

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Introduction

This booklet is for anyone involved in the care of a school-age child born with a cleft - especially teachers.

One child in every 700 in the UK is born with a cleft. Statistically this means that there is a likelihood of there being 2 children born with cleft lip/palate in every large secondary school in the country. This booklet offers teachers and other carers the opportunity to learn about the condition and to become aware of potential issues to watch out for and address.



Alex, age 5

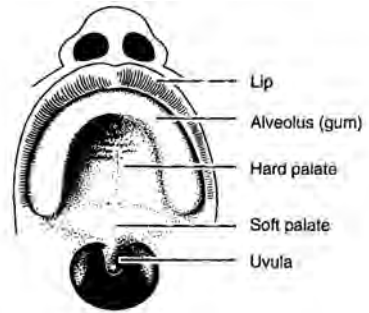
Cleft Lip and Palate: the facts.

What is a cleft?

Cleft means 'split' or 'separation'. During early pregnancy, separate areas of the face develop and then join together. If some parts do not join properly the result is a cleft, the type and severity of which can vary. Cleft lip and palate can occur separately or together.

A **cleft lip** can range from a slight notch in the coloured part of the upper lip to complete separation in one (unilateral) or both (bilateral) sides of the lip, extending up and into the nose.

A **cleft palate** occurs when the roof of the mouth has not joined completely. The back of the palate (towards the throat) is called the soft palate and the front (towards the lips) is called the hard palate. If you feel the inside of your mouth with your tongue, you will be able to notice the difference between the soft and the hard palate. A cleft can affect the soft palate, or both the soft and the hard palate.



Cleft Palate



Right Unilateral Cleft Lip & Palate



Bilateral Cleft Lip & Palate

How common is it?

About 1 in 700 babies in the UK is born with a cleft.

What causes it?

Though cleft lip and palate can run in some families, most cleft babies are born into families with no previous history of the condition. Though it is the most common anomaly of the head and neck region, the causes are not well understood.

How is it treated?

Cleft lip and palate is a complex condition and affected children will have a long relationship with a hospital Cleft Lip and Palate Team, from birth until early adulthood. The number of specialists making up a cleft team reflect the complexity of the condition. They include: Surgeons, Orthodontists, Speech and Language Therapists, Paediatricians, Clinical Psychologists, and Specialist Cleft Nurses.

Myths

Some people have an idea that a child born with a cleft lip/palate will have learning difficulties. This is not the case. Although there are a number of congenital syndromes of which cleft palate is a feature - and some of these may be associated with learning difficulties - most children born with cleft lip/palate are not affected by any other condition.

Some people may regard a child born with cleft lip and palate as having a disability, perhaps because of associated speech or hearing difficulties. Others prefer to think of cleft lip and palate as an inconvenience, sometimes a major inconvenience and sometimes a distressing one. There are no hard and fast rules about children born with clefts and disability. Each child must be seen as an individual and this issue must be considered sensitively.

It is often assumed that levels of distress are directly linked to the degree of disfigurement for any individual. It is actually the case that children with relatively minor disfigurements (like cleft lip and/or palate) might experience greater feelings of anxiety, due to the unpredictability of other peoples' reactions.



Ryan, age 6 together with his sister, Amy

Physical Issues

The following are potential areas of concern for children born with the condition:

Appearance

Surgery to repair a cleft lip and/or palate is usually carried out within the first 18 months of a child's life. Further surgery may be carried out before a child starts school, and more surgery is often carried out when a child is about 9 years old, during teenage years, and sometimes also later. Children born with a cleft lip will have a visible scar, and some will have a slightly irregular nose. Children born with a cleft palate may also have very irregular teeth, and may therefore wear braces before any of their peers.

- ***Some children born with clefts might feel self-conscious about looking different to their peers, and this might have a significant effect on general confidence levels, class participation, and sensitivity to comments from other children.***
- ***Society can sometimes have lower expectations of people who look different. It is important for teachers to be aware that children born with a cleft might reflect this by having low expectations of themselves. This might be addressed by encouraging them to think well of themselves and of their abilities.***

Hearing

Children born with cleft palate are more likely than other children to suffer from glue ear. This is usually temporary and can be treated with grommets. However, hearing problems might continue for some time.

- ***Any hearing loss, temporary or otherwise, can make it very difficult for a child, both in hearing what the teacher says and in coping in noisy break times. A child who does not seem to be paying attention, or whose comprehension levels seem low, may be having hearing problems.***

- ***Very young children with hearing difficulties may attract attention in their efforts to be involved. They may make physical contact in order to see people's faces and lip-read.***
- ***Hearing difficulty can affect language acquisition which may, in turn, affect communication abilities. Care should be taken to notice whether hearing is an issue for a child who appears to be struggling with language acquisition and help given where necessary.***
- ***Special consideration might need to be made in examinations that involve listening to tape recordings, perhaps in large rooms or halls.***
- ***Hearing may fluctuate, since hearing loss is often intermittent.***

Speech

Children born with a cleft sometimes have difficulties in making certain sounds, and may sound slightly nasal. Volume control may also be difficult for those children with temporary hearing problems.

- ***Sounding 'different' can make a child feel very self-conscious about speaking. This could affect class participation, and how a child behaves with other children.***
- ***Children who find it difficult to make themselves understood might become tactile in their efforts to communicate and to be included in peer groups. It is important to avoid misunderstanding a child's desire to communicate in this way.***
- ***Children born with cleft lip/palate might need to take time off school to attend speech and language therapy sessions.***
- ***Language teachers particularly should be aware that a child born with a cleft might physically not be able to make some of the sounds required in the process of learning a new language.***
- ***Special consideration might need to be made for oral examinations (or applied for where relevant).***

Psychosocial issues

A child born with a cleft lip and/or a cleft palate will differ from other children physically only in very minor ways. However, he or she may be sensitive to any small differences in appearance, speech and hearing. He or she may therefore be in need of a little extra attention and support in the following areas in order to be able to flourish.

Helping children respond well to other children

It can sometimes be hard for a child to differentiate between genuine curiosity, friendly teasing and deliberate cruelty. Though it is not helpful to minimize a child's hurt feelings, it can be helpful to encourage them to think about whether hurt feelings always reflect the situation. If, for example, a child is very self-conscious of and sensitive to how they look, the child is much more likely to be upset by any reference to looking or sounding "different" and to feel like a bullying victim. If, on the other hand, he or she is comfortable with who they are and how they look and sound, they will find it a lot easier to assess a situation and respond to comments appropriately.

Encouraging a child to understand that the way in which other people act towards them has more to do with how they act than how they look or sound can be very helpful. Some children might find practicing positive self-talk a good way of coping with other people's interest in their cleft (*'All they can see is my cleft; my friend Jo could tell them a lot of other things about me!'*).

It is quite normal for children to be curious and to stare or do some extra looking when they first meet someone whose face or speech is affected by any difference, like a cleft lip and/or palate. Encouraging a child born with a cleft to understand that they cannot do anything to stop this from

happening, and to learn ways of coping with this extra attention can be helpful. Having something to say upon meeting someone new and introducing an interesting topic of conversation is a good example of this (*'I was born with a cleft, it's no big deal. Are you new, like me? Do you know your way around yet?'*).

Not every child born with a cleft will feel self-conscious, but some might find *Changing Faces'* literature helpful in feeling more comfortable in uncomfortable situations (*see p.15 for contact details*).

Self Esteem

Children who look and/or sound 'different' may have low expectations of themselves and believe that others do too. This could affect class participation, social behaviour, and academic performance. If a child has low self-esteem, hearing and communication difficulties, they may find it hard to make friends and to cope in noisy environments.

Children who tease or bully often choose to pick on something particular about other children to focus on. A child born with a cleft might look and sound different to his/her peers, and this might be noticed and pointed out by other children. To be picked on for any reason can be upsetting and if it develops into long-term bullying, psychologically damaging. A child who has been bullied may suffer from low self-esteem, and might benefit from some of these ideas:

- ***Poor academic and social achievement could be linked more closely to low-self-esteem than to ability.***
- ***Children with low self-esteem can benefit from help in recognising their abilities and encouragement in developing these. Children often become aware of an ability for the first time by having it named and being able to talk about it.***
- ***Teachers could help children recognise how they use the abilities they have helped to name, and how they may be used to achieve their goals. (See page 12 for an example of how this could be done.)***

Example of helping a child with low Self Esteem

Timmy's teacher noticed that he had become noticeably withdrawn, and had stopped participating in class and playing with other children during breaks. She managed to spend some time with him, and gently asked him about his hopes and dreams for the future. Timmy told her that he wanted to be a pilot. They thought together about which of his skills and abilities would help him achieve that goal. One of the abilities they identified was his enthusiasm.

Timmy's teacher then spent some time in helping Timmy to think about when his enthusiasm might show, and who might notice it. She also wondered with him how his enthusiasm might help him achieve more immediate goals, like managing his shyness in speaking up in class because he spoke a little differently to other children.

Timmy found that wanting to show his enthusiasm to other people helped him to speak up in class and to join in more with other children.

(Children invariably have any number of abilities, in sport, working with their hands, academic achievement, storytelling, as well as in less tangible areas like 'enthusiasm'.)

Teasing and bullying

Some children who look and sound different to their peers are more sensitive to teasing than other children, and perhaps more susceptible to bullying.

How to recognise bullying

Though many schools have procedures for addressing bullying, it is not always easy for teachers to recognise that a child is being bullied. Children who are being bullied are often too scared to tell anyone about it, especially if they have been threatened. A child may be being bullied if you notice any of the following signs:

- ***They are frightened of walking to or from school***
- ***They are often absent from school***
- ***They change their route to school***
- ***They begin doing poorly in their schoolwork***
- ***Their books are regularly destroyed***
- ***They are not able to buy lunch (because their dinner money is taken from them)***
- ***They become withdrawn, distressed, stop eating or start stammering***
- ***They attempt suicide***
- ***They have unexplained bruises, scratches or cuts***
- ***They have their possessions go 'missing', or continually 'lose' their money***
- ***They ask for money or begin stealing money (to give to the bully)***
- ***They refuse to say what's wrong***
- ***They give improbable excuses to explain any of the above.***

If a child behaves in any of these ways, it may show that they are being bullied, though it could be that they are seriously distressed by something else. By asking gently, remembering that they may be very frightened to speak about what's going on, you could find out what is distressing them.

Based on information in the Kidscape booklet: **Stop Bullying**

How to Address Bullying

There are 3 parts to addressing Bullying:

1. Helping the child to cope

- ***There are a number of practical techniques to help children cope with bullying. These range from trying to stick with friends and avoid being alone, to learning and practising responses to bullies.***
- ***Increased confidence is one of the most important ways for a child to address bullying. The more confident a child feels in general, the more able they are to deal with bullies.***
- ***Some children find it hard to make friends. Learning and practising ways of making friends can make a big difference.***

Though most of this can be talked through and practised together with teachers, friends and families, there are times when some extra help can make a big difference. A child could benefit from speaking to a counsellor about what is going on, or directly contacting one or more of the organisations listed at the end of this booklet.

2. Encouraging the child's family to become aware of the problem and to help change the situation

- ***Children who are bullied at school often do not speak to their parents about what is happening. Teachers can gently encourage children to make their families aware of what is going on, and offer to work together with parents to address the situation.***

3. Encouraging the School to act appropriately

- ***Schools are responsible for ensuring that children are taught in a safe environment; they have a duty to do something about bullying. If a child is being bullied, teachers could help by encouraging other school staff members to be aware of the problem and work to prevent it happening again in the future.***

See Kidscape literature for more information and/or for practical ideas for children, parents and schools. Contact details on p.15.

We hope you have found this booklet useful. If you would like to find out more about cleft lip and palate and/or about The Cleft Lip & Palate Association (CLAPA), please contact us at:

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

Tel - 020 7833 4883

Fax - 020 7833 5999

Web - www.clapa.com

Email - info@clapa.com

Other useful contacts:

Changing Faces
The Squire Centre, 33-37 University Street
London WC1E 6JN

Tel - 0845 4500 275

Fax - 0845 4500 276

Email - info@changingfaces.co.uk

Web - www.changingfaces.co.uk

Offer support to anyone with visible difference. They also produce some excellent literature for children with visible difference and for teachers

CHIPS - Childline in Partnership

Tel - 020 7650 3234

Web - www.nspcc.org.uk/chips

The CHIPS Programme raises awareness about children's work and and the issues young people face.

Kidscape

2 Grosvenor Gardens, London SW1W 0DH

Tel - 020 7730 3300

Helpline - 08451 205024

Web - www.kidscape.org.uk

Produce a series of booklets on dealing with bullying for use by teachers, children and parents.

References

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Visibly Different: Coping with Disfigurement.

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Nash, P. (1995) ***Living with Disfigurement***, Avebury, Aldershot.

Range of bullying literature from Kidscape

Range of literature from Changing Faces



children celebrating CLAPA's 18th birthday at the Royal Victoria Hospital in Belfast.