

# Teacher Guide

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## Supporting Young People Born with a Cleft at Primary School



# About Cleft Lip and Palate

1 in 700 babies are born with a cleft. That's around 100 every month in the UK.

In early pregnancy, different parts of a baby's face develop separately and then join together just above the top lip. If they don't join properly, the baby is born with a gap or 'cleft.' This gap can be on one or both sides of their lip (cleft lip), in the roof of their mouth (cleft palate), or both. There's no single cause of cleft. It can happen in any pregnancy, and it's no one's fault.

NHS Cleft Services provide comprehensive treatment into adulthood.

This can include:

- One or more surgeries to close the cleft between 3-12 months old
- Additional surgeries to help with speech, dental concerns, breathing, and appearance.
- Speech therapy
- Help with hearing
- Orthodontic work
- Psychological support

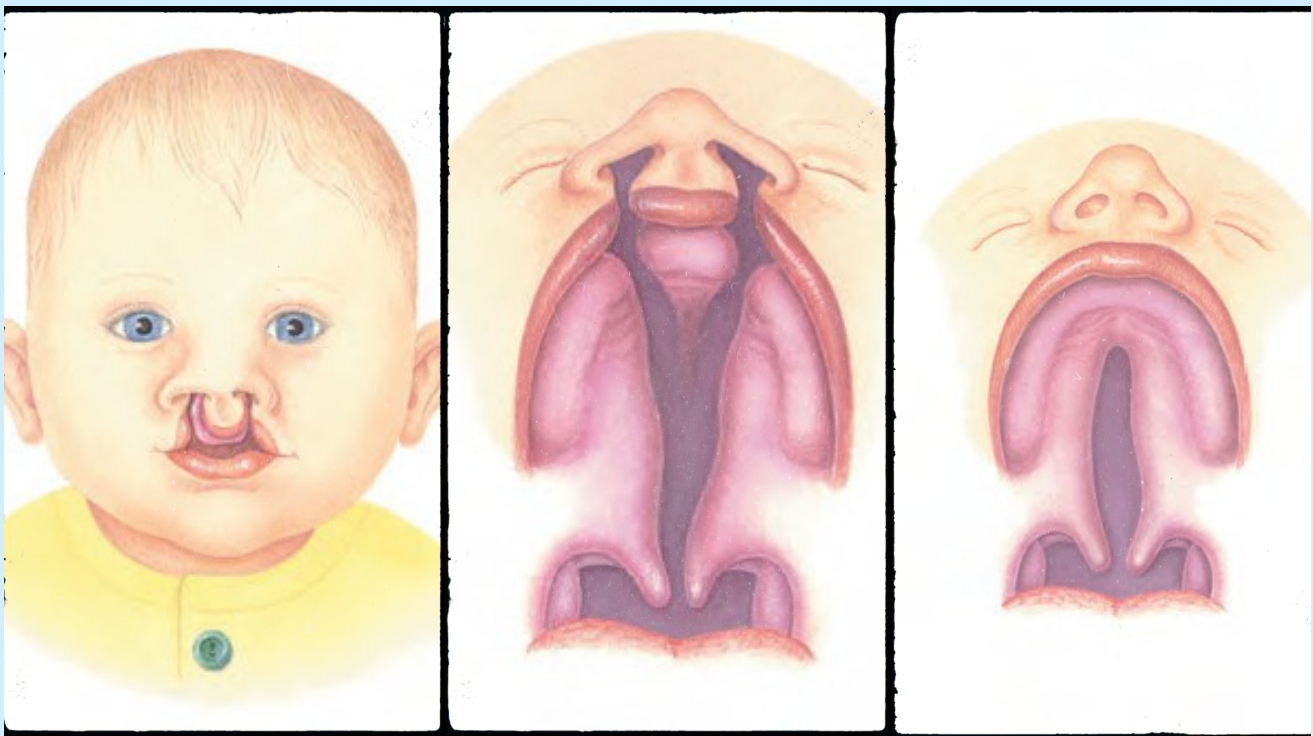
This guide is intended to help teachers understand some of the issues that a child born with a cleft might face and what they can do to help. Please keep in mind that many children will not want to draw attention to themselves or their cleft, and any interventions which involve the rest of the class should be carefully discussed with the child and their parents first.

**Q: Is cleft a disability?**

**A: A cleft by itself is not considered a disability. Sometimes, issues caused by a cleft can be severe enough that someone needs extra support. Cleft is also linked to a number of other conditions and syndromes which may require extra support.**

**Q: How do children cope with looking or sounding different?**

**A: Every child and young person will feel differently about their cleft. Do not make assumptions about how someone will feel about their cleft based on how noticeable it may be to you.**



# Things To Look Out For



## Time Off School

Children and young people born with a cleft will need time off school to attend the cleft clinic and hospital appointments and, when necessary, for surgical procedures. If they need regular treatment such as Speech and Language Therapy, they may need to come out of class more frequently.

It is rarely possible for these appointments to be scheduled outside of school hours, which can lead to children missing out on attendance awards or even receiving warning letters about 'persistent absences,' even when these have been authorised.

## How Schools Can Help

- Understand that unlike routine dental or other appointments, these are not easily rescheduled and may involve a great deal of planning and travelling on the family's part. They may also be a source of stress for young people who have an appointment coming up.
- Adapt their attendance reward policy so it doesn't exclude pupils absent for medical reasons.
- Work with parents to make sure children are given a chance to catch up on any work they've missed and aren't blamed for their absence.

# Appearance Concerns

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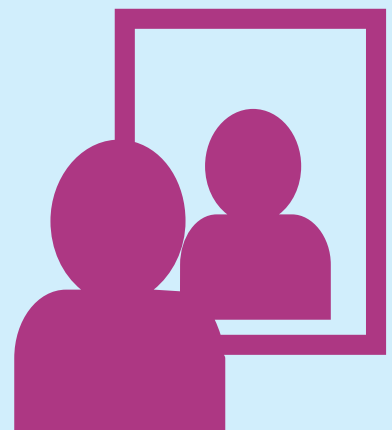
Children with a cleft lip may have a visible scar. They may have missing or crooked teeth, and often have to wear braces before their peers. From around 6-7 years old, children may start to feel self-conscious about their appearance, and this can have a negative impact on their confidence levels and class participation [CE1].

They may also experience bullying or uncomfortable comments about their appearance from other young people.

[CE1] And they may be experiencing bullying

## How Schools Can Help

- If a child is particularly conscious about their appearance, teachers should take extra care to look out for teasing or comments around this, and should support children who wish to explain to the rest of the class why they may look different. They should also sensitively approach any lessons which may bring up issues to do with a child's cleft or appearance, e.g. self-portraits.



# Speech

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Around 40% of children with a cleft palate being treated for speech issues will still not have 'normal' speech by the time they start school, and may sound nasal or be hard to understand. [CE1] Sounding different can make a child feel self-conscious about their voice, and they may avoid talking as a result.

This can affect class participation and social interaction with other children.

A child who finds it difficult to be understood by their peers may become physical in their attempts to communicate, or may be easily frustrated by the need to repeat themselves.

[CE1] Sounds negative, needs re wording

## How Schools Can Help

- Certain lessons may cause concerns for children with speech difficulties, such as music (especially with wind or brass instruments), languages (children may not be able to physically pronounce certain sounds), and reading out loud.
- Teachers who find it hard to understand children should avoid interrupting or 'correcting' their speech as this can cause feelings of anxiety around talking. If they have to ask the child to repeat themselves, they should do this only once, and if they are still having trouble they should then repeat back clearly what they think the child is trying to communicate until an understanding is reached.

- Teachers should be patient, encourage children to use their voices, and praise their successes and milestones. If possible, teachers should work in partnership with parents/carers and a child's Speech and Language Therapist to support their therapy targets.

## Hearing

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- 'Glue ear' is a common childhood condition which can cause hearing to be 'muffled', almost like someone is underwater. Children born with a cleft palate are more likely to develop glue ear, and this is more likely to be recurring.

Because it can develop gradually, they may not realise anything is wrong. Teachers may notice that children and young people:

- Don't respond when their name is called
- Appear to ignore or misunderstand instructions
- Watch what others do before doing it themselves
- Watch people's faces and lips while they're talking
- Talk too loudly or softly
- Get easily tired and frustrated
- Become more physical in their attempts to communicate



## How Schools Can Help

- Teachers should look out for problems like this and alert parents if they suspect anything. It can help to sit the child somewhere in the room where they can clearly see the teacher's face.
- During group work it may be especially challenging for children to maintain concentration if they're having to lip-read and actively listen. Encourage pupils to signal when they're going to talk and to talk one at a time. It can also help to reduce background noise. Using pictures and other visual aids can help a child follow along with the discussion.
- Special allowances may also need to be made for examinations that involve listening to tape recorders in large rooms or learning in environments where there may be a lot of background noise.

NDCS tips for supporting Deaf children in the classroom:

<https://www.ndcs.org.uk/information-and-support/being-deaf-friendly/information-for-professionals/primary-education/>

## Low Self-esteem

Children who look and/or sound different may have low expectations of themselves and believe that others do too. This can affect how they participate or behave in class and at break times, as well as how they do academically. They may behave in ways that can be seen as disruptive, such as refusing to do tasks or becoming aggressive, or they may become more insular.



## How Schools Can Help

Making teachers aware of these issues is the first step towards managing them. There are a number of strategies that might help. For example, teachers could ensure that groups for activities are chosen by some other means than popularity or friendship groups.

Recognising a child's abilities and encouraging them in focusing on and developing these can be a big help. Children often become aware of these abilities for the first time by having it named and being able to talk about it, even if these abilities are simple things like being compassionate or enthusiastic.

## Questions from Others

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Children born with a cleft may get questions and comments from classmates about issues to do with their cleft. Even when these are well-meaning, they may be upsetting for children who don't know how to answer, or who are particularly sensitive to others noticing their difference.

## How Schools Can Help

Make sure Teachers having a basic understanding of cleft lip and palate and. Treat it like any other trait a child might be born with, such as eye colour, to avoid them feeling embarrassed. You may want to mention their bravery at dealing with surgery and hospital appointments. If you think it would help, encourage children to come up with a simple way to explain their difference to others who ask, e.g. 'I was born with a hole in my lip but doctors sewed it up when I was a baby.'

# Discussion Points around Cleft

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Having a child born with a cleft in the class is a good chance to talk to pupils about diversity, acceptance, and empathy.

If you are interested in doing a lesson about cleft, and have a child in your class who is comfortable talking about cleft and their journey, then it is a good idea to invite them up to talk to their class about their cleft and what this means for them. If the child isn't comfortable with this, the teacher can talk about it instead. For this CLAPAs suggest using the below discussion points to help to cover how we are all different in our own way.

**Q. Everyone is made differently. Ask pupils to name one thing that is different about them.**

**Q. Ask the class to think about what the world would be like if we were all the same, and then about the benefits of us all being different.**

**Q: Ask pupils to think about someone else in the class – what differences and similarities do they have with one another, and how does this change their relationship?**

**Q: Ask the class to think about why people might have medical treatment or surgery (e.g. injuries, health reasons, appearance, etc.). How would they feel if they needed an operation? What would they bring with them to the hospital? Who would they like to visit them?**

# Discussion Points around Cleft

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**Q: Ask the class to describe the person next to them in three words that have nothing to do with their appearance (e.g. funny, kind, loves dancing)**

**Q: Ask the class to think about the most important qualities in a friend. Pick out when they focus on things that are to do with someone's personality, not how they look or sound.**

- Share quotes from young people
- Make the whole document less medical model
- Focus on how teachers can help to feel less conscious
- If there's a problem – don't automatically assume it's related to their cleft