



[www.clapa.com](http://www.clapa.com)



[info@clapa.com](mailto:info@clapa.com)



# Teachers' Guide

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Supporting Young People  
Born with a Cleft  
at Primary School



# About Cleft Lip and Palate

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

In early pregnancy, different parts of a baby's face develop separately and join together just above the top lip. If they don't join all the way, 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.



## Treatment

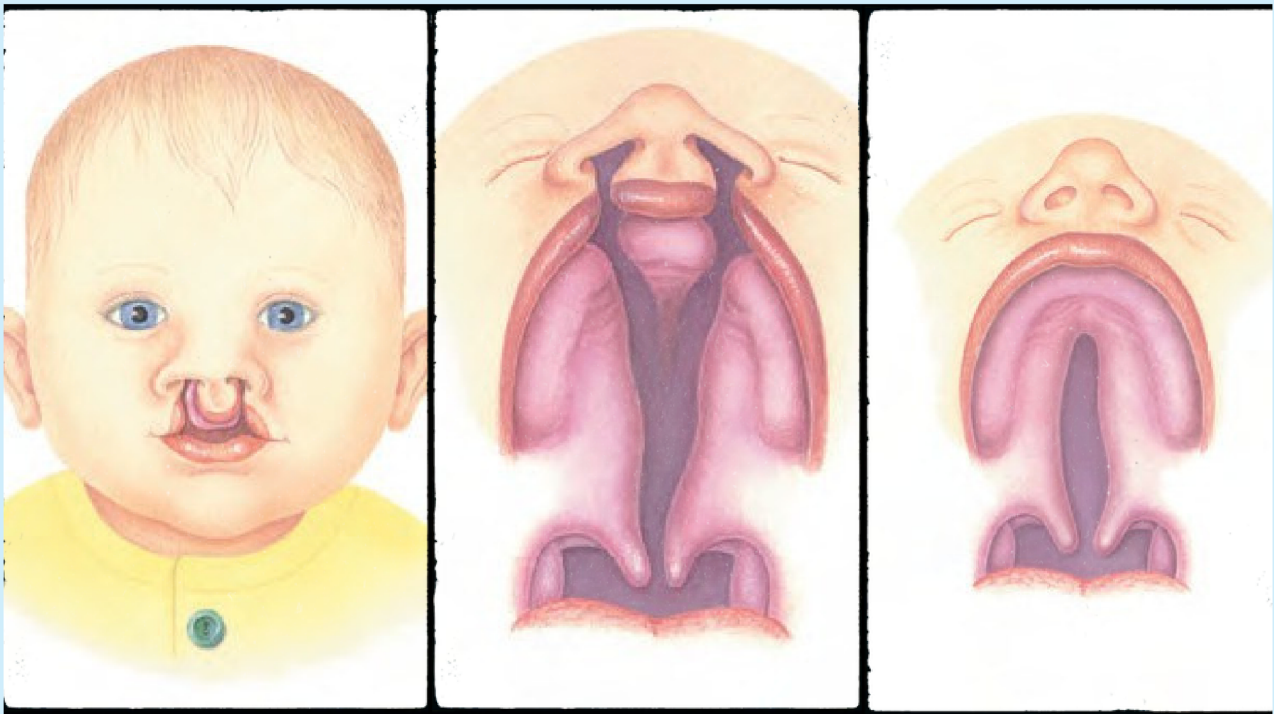
**NHS Cleft Services provide comprehensive treatment into adulthood.**

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** problems
- **Orthodontic** work
- **Psychological** support

This guide is intended to help teachers understand some of the issues a child born with a cleft might face and what they can do to help.

Please remember that **many children might not want to draw attention to themselves or their cleft**, and any interventions involving the rest of the class should be carefully discussed with the child and their parents first.



**A bilateral cleft lip**

**A bilateral cleft lip  
and palate**

**A cleft of the hard  
and soft palate**

A cleft lip is often incorrectly called a 'cleft palate'. The palate is the roof of the mouth; a cleft palate often isn't visible from the outside. A child can be born with a cleft lip, a cleft palate, or both.

A cleft can be on one side (unilateral), both sides (bilateral) or both. A cleft lip can range from a small notch to a gap that extends into the nostril.

### **Is cleft a disability?**

A cleft by itself is not considered a disability. Sometimes, an issue caused by a cleft can mean that someone needs extra support, and this issue might be significant and long-term enough to be considered a disability, such as some speech issues. Cleft is also linked to several other conditions and syndromes, some of which are disabilities.

### **How do children cope with looking or sounding different?**

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.

# Time Off School

Children and young people born with a cleft will need time off school to attend hospitals and local clinics for appointments and treatments, which may include surgery.

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, meaning that children can miss out on attendance awards or even receive warning letters about 'persistent absences'. This can happen even when absences have been arranged and authorised in advance.

Unlike routine dental or other appointments, these are not easily rearranged for a time that better suits the school. Families may be given a surgery date at the last minute, and this may be cancelled or rearranged without warning. Some appointments will involve a lot of planning and travelling on the family's part.



## How Schools Can Help

Adapt your attendance reward policy so it doesn't exclude pupils absent for medical reasons.

Understand that upcoming appointments, especially surgeries, can be a source of stress for young people.

Work with parents to ensure children are given a chance to catch up on any work they've missed and aren't blamed for their absence.

# Appearance Concerns

Children with a cleft lip may have a visible scar. They may have missing or crooked teeth and will often wear braces or start other orthodontic treatments 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.

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

## How Schools Can Help

If a child is particularly conscious about their appearance, take extra care to look out for teasing or comments around this and support children who wish to explain to the rest of the class why they may look different.

Be aware of lessons or topics that may bring up issues concerning a child's cleft or appearance (e.g. self-portraits), and make sure to approach these sensitively.



# Speech

Half of all children born with a cleft palate (a gap in the roof of the mouth) will have ongoing speech therapy. By the time they start school, around 40% of these children will still have speech which is 'noticeably different' to their peers. They may sound nasal, struggle to make certain sounds, or otherwise be hard to understand.

This might make a child self-conscious about their voice, and they may avoid talking. This could affect how they join the class and interact with their peers.

A child who finds it difficult to be understood by their peers may be easily frustrated by the need to repeat themselves and need support from their teacher to communicate using pictures.

## How Schools Can Help

Certain lessons may cause concerns for children with these difficulties, so these must be approached sensitively, with exceptions or alternatives offered where possible. This could include **music lessons** (children born with a cleft palate may struggle to play wind or brass instruments), **languages** (they may not be able to physically make certain sounds), and **reading out loud**.

**Avoid interrupting or 'correcting' their speech**, as this can cause feelings of anxiety around talking. If you have to ask the child to repeat themselves, do this discreetly, try to do this only once, and repeat back clearly what you think the child is trying to communicate to make sure you understand them.

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

# Hearing

'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, which is more likely to be recurring.

Because it can develop gradually, they may not realise anything is wrong. You may notice that a student:

- Doesn't respond when their name is called
- Appears to ignore or misunderstand instructions
- Watches what others do before doing it themselves
- Watches people's faces and lips while they're talking
- Talks too loudly or softly
- Gets easily tired and frustrated
- Becomes more physical in their attempts to communicate



## How Schools Can Help

Teachers should look 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.

It may be especially challenging for children to maintain concentration during group work if they have to lip-read and actively listen. Encourage pupils to signal when they will talk and 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.

The National Deaf Children's Society has more tips for supporting children in the classroom at [www.NDCS.org.uk](http://www.NDCS.org.uk)

# Low Self-Esteem

Children who look and/or sound different may have low expectations of themselves and believe others do too. This can affect how they participate or behave in class and at break times and 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.

Do not assume that cleft is why a child may be showing different behavior; other reasons may need monitoring.

## How Schools Can Help

Being aware of these issues is the first step toward managing them.

Several strategies 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 to focus on and develop these can be a big help. Children often become aware of these abilities for the first time by having them named and being able to talk about them, even if these abilities are simple things like being compassionate or enthusiastic.





# Questions from Others

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

Have a basic understanding of cleft lip and palate. Treat it like any other trait a child might be born with, such as eye colour, to avoid them feeling embarrassed. You could mention their bravery in 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.'



# Talking About Cleft in Class

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 to talk to their class about their cleft and what this means for them.

If the child isn't comfortable with talking about it themselves, they may be happy to have you talk about it instead. You can use the discussion points on the next page to help cover how we are all different in our own way.

## Discussion Points



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



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.



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?



Ask the class to consider 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?



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).



Ask the class to think about the most important qualities of a friend. Pick out when they focus on things that concern someone's personality, not how they look or sound.

