

## ABOUT CLAPA

The Cleft Lip and Palate Association (CLAPA) is the only national charity supporting people affected by cleft lip and palate in the United Kingdom.

CLAPA is there from the moment of diagnosis with reassurance, information, and a welcoming community for families, children and adults born with a cleft. Our purpose is to make sure no one affected by cleft in the UK goes through their journey alone.

## **OUR WORK:**

- **Online support groups and events** help people to connect with others who share their experiences
- Trained volunteers give **one-to-one support** to help people cope with the most difficult parts of their journeys
- Babies born with a cleft often need **special bottles and teats** to feed, and CLAPA produces and provides these to hundreds of new families every year
- Services for **under-18s** help them to build confidence and feel in control of their care.
- Adult Services connect **adults born with a cleft** to others with shared experiences and ensure they can access the care and support they need
- Working closely with the **nine specialist NHS Cleft Teams** in the UK to improve care
- Supporting people affected by cleft to get involved with **research projects**

CLAPA receives no NHS or government funding and relies on donations from the public to continue our vital work. Find out more about our services: [www.clapa.com/about-us/what-we-do/](http://www.clapa.com/about-us/what-we-do/)

## ABOUT CLEFT LIP AND PALATE

In early pregnancy, the different parts of the face form separately and then come together. For one in every 700 babies, this doesn't happen all the way, and the result is a gap or 'cleft' in the upper lip or the roof of the mouth.

Every day in the UK, three babies are born with a cleft. It can have an ongoing impact on feeding, speech, hearing, teeth placement and more. The treatment pathway is 20+ years, and many babies have their first surgery at just three months old.

A '**cleft lip**' is one or two notches or gaps in the upper lip which can range from a small notch in the coloured part of the lip to wide gaps that extend up into the nostrils. A '**cleft palate**' is a gap in the roof of the mouth. Babies can be born with a cleft lip, a cleft palate, or both together.

### How does it happen?

For some, it runs in the family. For most, it's a complete surprise; the result of many different genetic and environmental factors coming together in a way that can't be predicted or prevented. **It can happen in any pregnancy.**

It is very unlikely that a child's cleft developed because of something the parents did or didn't do. In some cases, a cleft is caused by a **syndrome** such as Pierre Robin Sequence or Stickler Syndrome, and these will have their own causes and outcomes.

Because there are so many complex factors that can lead to a cleft, it's unlikely there will ever be a 'cure' that will stop it from happening. This is why CLAPA focuses on improving the lives of people born with a cleft and supporting their families.

## What is the impact of being born with a cleft?

- **Surgeries:** Starting at just three months old, people born with a cleft will need one or more surgeries to close the gap(s) and help with any ongoing issues. Some will have more than 20 surgeries by the time they reach adulthood.
- **Feeding:** Babies born with a cleft often can't form a vacuum with their mouths; it's like trying to suck through a straw with a hole poked in it. This means they can't feed from a breast or regular bottle.
  - CLAPA is the only UK supplier of specialist bottles and teats for babies born with a cleft. These bottles and teats are used and recommended by NHS Cleft Nurse Specialists.
- **Hearing:** Children with a cleft palate are more likely to develop glue ear and associated ongoing hearing difficulties#
- **Speech:** Half of children with a cleft palate need ongoing speech therapy, and by the time they start school, around 40% still have noticeably different-sounding speech to their peers.
- **Teeth:** A cleft can cause issues with teeth placement and growth that can require surgery and dental work stretching well into adulthood.
- **Self-esteem:** A cleft often means a child will grow up looking or sounding different to their peers and having multiple hospital appointments which may include surgeries. Coping with staring, comments and bullying and discrimination can impact on self-esteem and educational achievement.

## How is it treated?

Cleft has a 20 year treatment pathway which is handled from the point of diagnosis by one of the multidisciplinary NHS Cleft Teams around the UK. Every child's cleft is unique, as are their treatment and support needs.

One or more surgeries is needed to close the gap in the lip and/or palate. These start at just three months old. Further surgeries may aim to address issues with speech, hearing, teeth placement, and change the appearance of the face and profile. Some of these are major surgical procedures requiring years of preparation and a lengthy recovery time. Hearing aids or grommets are commonly used to help with hearing in children with a cleft palate, and around half will also undergo speech therapy.

CLAPA provides non-medical support beyond the hospital walls. Our work aims to bring people affected by cleft together to support each other, build knowledge and confidence to help them take an active role in their cleft care, and feel more positive about the future.

## LANGUAGE & TERMINOLOGY

### Writing about cleft

The term **'harelip'** (or **'hairlip'**) is outdated and offensive; it should not be used.

We use the term 'cleft' (or 'cleft lip and/or palate') to indicate everyone who has any kind of cleft. **'Cleft palate' is often incorrectly used** to mean 'cleft lip' or 'cleft lip and palate'. Please see these diagrams for more information: [www.clapa.com/what-is-cleft-lip-palate/](http://www.clapa.com/what-is-cleft-lip-palate/)

We refer to cleft and types of cleft as **singular**, so 'people born with a cleft palate' rather than 'cleft palates'.

**'Disfigurement'** has a legally protected meaning, but we prefer not to use it. The same goes for 'birth defect' and 'deformity'. We prefer more neutral words like **'condition'**, 'visible difference' (meaning a mark, scar or other difference which is noticeable by others), or a description of what a cleft is.

We avoid words like **'improve'**, **'fix'**, **'problems'**, or **'normal/abnormal'**, as these are value judgements which make assumptions about how people may think of their cleft. We prefer more neutral terms like 'affects', 'change' or 'difference', e.g. 'A cleft can affect teeth', 'surgery to change the shape of the nose', or 'Jane's cleft palate means her speech sounds different to other children'.

### Writing about people affected by cleft

CLAPA uses **'People First Language'** when talking about anyone with a cleft. This means we mention the individual before we mention the condition, e.g. 'baby with a cleft' instead of 'cleft baby'.

Avoid **sensationalising** or **evoking pity** for the subject, and never suggest that the audience's inaction will cause direct harm e.g. "Without your help, Jane's CLAPA support group will be shut down".

Avoid phrases that suggest someone's personality or another quality is more important than their appearance (e.g. "It's what on the inside that counts"), as this can be patronising and assumptive of someone's values and their view of their cleft.

Readers should never be asked to **express an opinion** on someone's appearance, e.g. "Click 'Like' if you think Jane is beautiful regardless of her cleft." Similarly, particular person born with a cleft should never be used to **'prove a point'**, e.g. "The media doesn't think people with scars are beautiful, but look at Jane!"

## CONTACT DETAILS

For general media enquiries, please contact Anna Martindale on 020 7833 4883, or at [anna.martindale@clapa.com](mailto:anna.martindale@clapa.com)

We would be happy to act as a sensitivity reader to ensure the correct terms are used.