

[ABOUT CLAPA](#)

The Cleft Lip and Palate Association (CLAPA) is a small charity working to improve the lives of people born with a cleft and their families in the UK.

Three babies are born with a cleft every day in the UK. CLAPA is a community of families, patients and health professionals, all dedicated to raising awareness and working together to overcome any barriers caused by cleft lip and palate.

Our **vision** is of a society where everyone affected by cleft feels supported, connected and empowered to take control wherever they are on their cleft journey.

OUR WORK:

- Online and local **support groups** to help people affected by cleft to feel positive, connected, and in control.
- Local and national **events** to bring people together so no one has to go through their journey alone.
- Providing **specialist feeding equipment** for babies born with a cleft in the UK, including supplying over 700 new families with free 'Welcome Packs' each year.
- Training parent and patient volunteers to provide **one-on-one support** to those in need of reassurance, information and a listening ear.
- An accredited **information service** that is comprehensive, accessible and community-led.
- Training volunteers who help to **educate schools, local communities and healthcare professionals** about cleft lip and palate here in the UK.
- **Collaboration with researchers** to make their work accessible to our community. We are well-respected as the voice of people affected by cleft in the UK, and our staff and volunteers sit on a number of boards and committees looking to improve and inform cleft care.

[ABOUT CLEFT LIP AND PALATE](#)

Cleft means 'split' or 'separation'. During early pregnancy separate areas of the face develop and then join together (fuse) in the middle. If some parts do not join properly the result is a gap or 'cleft'. Repair surgery involves taking the tissues that did not join up during pregnancy and putting them back together.

A '**cleft lip**' is a notch or gap in the upper lip which can range from a small notch in the coloured part of the lip to a wide gap that extends up into the nostrils. A '**cleft palate**' is a gap in the roof of the mouth.

1 in 700 babies are born with a cleft across the world. That's 1,200 each year in the UK.

[How does it happen?](#)

The causes are complicated; for some it runs in the family, but for many 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 knowingly prevented. It is very unlikely that a child's cleft developed because of something the parents did or didn't do. In a minority of 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 of how complex cleft is, it's unlikely there will ever be 'a cure', but there is a great deal of research focused on improving our understanding of the many factors that can contribute to a cleft. In the meantime, CLAPA is focusing its efforts on supporting people with and affected by the condition.

[What does it mean for a child?](#)

A cleft can have an impact on **feeding** (a cleft palate often means a vacuum cannot be formed with the mouth which prevents suckling from a breast or bottle), **hearing** (such as glue ear), **speech** (around 50% of children with a cleft palate need ongoing speech therapy to be understood by their peers), **facial growth**, **teeth placement** (most children with a cleft affecting their gum will need some orthodontic work which may include surgery), and other dental issues (children with a cleft are more susceptible to tooth decay).

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 even 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.

A cleft lip is surgically repaired when a child is 3-6 months old. A cleft palate is repaired between 6-12 months. Every child's cleft is unique, as are their treatment needs, which will be handled by one of the multidisciplinary NHS Cleft Teams around the UK.

Treatment may include further surgeries to improve 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 improve hearing in children with a cleft palate, and around half will also undergo speech therapy.

TERMINOLOGY

Writing about cleft

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

We use the term 'cleft lip and/or palate' (or just 'cleft') 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/

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

'**Disfigurement**' has a legally protected meaning, but we prefer not to use it. The same goes for 'birth defect' and 'deformity'. We prefer 'condition', 'visible difference', 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 harm e.g. "Without your help, Jane's local CLAPA 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 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." A 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 (Communications & Information Manager) on 020 7833 4883, or at anna.martindale@clapa.com

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

Registered Charity England & Wales (1108160) and Scotland (SC041034)