

Language Guide



This guide walks through the words and phrases CLAPA uses when talking about cleft and the wider community, and the guiding principles behind our communications.

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Purpose

Cleft is a condition that can affect anyone. People affected by cleft in the UK will have varied experiences and feelings associated with the condition. CLAPA aims to support people of all ages, cultures and backgrounds, and wishes to create a community which is inclusive and open

to all. It is therefore crucial that the language CLAPA uses is inclusive and does not make assumptions about someone's background, circumstances or feelings about cleft.

This guide is intended to help staff, volunteers, and others working on our behalf write and talk about CLAPA and our work in a consistent way which aligns with our values, respects our diverse community, and is inclusive to all.

About Cleft Lip and Palate

Communications about cleft should keep in mind the wide range of ways in which people are affected and how they may feel about this, and avoid making assumptions or generalisations.

We refer to cleft as a '**condition**', as this is a neutral way to refer to a way in which someone's health is affected without making assumptions about the impact this may have on them. Cleft itself is not an illness, sickness or disease.

Disability is a label which has a wide range of connotations and applications, both legal and otherwise. **A cleft by itself is not typically considered a disability**, though it may affect someone in a way that means they need extra support, e.g. hearing aids or speech therapy. In some cases, the extra support needed is substantial and long-term enough for it to be considered a disability. It can also be helpful to look at cleft as being 'under the umbrella' of disability when considering what extra support should be made available to those in need.

Cleft/Clefts

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

When referring to multiple individuals we will still use cleft as singular, e.g. '[Name] and [Name] were both born with a cleft lip' rather than 'with cleft lips'.

Types of Cleft

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.

'**Cleft palate**' is often mistakenly used to refer to a cleft lip.

When referring to the condition itself, we use '**cleft lip and/or palate**' or just '**cleft**' to talk about all types and combinations of cleft of the lip and palate.

If we wished to single out one type of cleft, we would say, for example, ‘**cleft palate**’ to refer to everyone with a cleft palate (including those who *also* have a cleft lip), or ‘**isolated cleft palate**’ (or ‘cleft palate on its own’, etc.) to talk about people with cleft palate but not a cleft lip.

Avoid using terms such as ‘**only has a cleft palate**’ outside of a medical or other formal context, as this can minimise the impact of a particular kind of cleft on a person.

We use ‘**people affected by cleft**’ as shorthand for everyone whose lives have been personally affected by cleft in some way, including people born with a cleft, their families, close friends, and anyone else who may need support in relation to someone being born with a cleft. The word ‘affected’ is intended to be neutral and has neither positive nor negative implications, as people have very different experiences of cleft in their lives.

People First Language

CLAPA uses ‘[People First Language](#)’ when talking about anyone with a cleft. This means we mention the individual before we mention their condition. This is not preferred for every condition or difference, but when communicating about cleft, please use the below examples as a guide.

Instead of “cleft child/baby” **use** “child/baby born with a cleft” or “[Name] was born with a cleft”

Instead of “Cleft mum” **use** “Mum of a child born with a cleft”

We use ‘born with a cleft’ rather than ‘has a cleft’ as people who are no longer in treatment may not consider a cleft to be something they ‘have’, just something they were born with.

When in doubt, the best name to call someone is the name they use to introduce themselves. Use names where possible, and, when discussing people born with a cleft, always put the person first.

Controversial or Offensive Terms

‘Clefty’

Some people affected by cleft may use this term to refer to themselves or their children.

CLAPA does not use this term as it is felt by many that it reduced a person to a condition they were born with, and it can be seen as belittling or patronising.

‘Harelip’ (or variants like ‘hairlip’)

This is a term for cleft lip that has fallen out of use and is now widely considered to be offensive.

This is due to the comparison to rabbits/hares, and the connection to superstitious beliefs about how a cleft is caused. It should never be used unless the word itself is what is being discussed, or it is part of a quote (see below).

‘Disfigurement’ or ‘Deformity’

These have negative connotations for many people. Use **‘visible difference’** (see below) instead.

Some organisations (such as Changing Faces) use ‘disfigurement’ because of its legally protected meaning. This term may be used in this context, but the reason must be made clear.

‘Birth defect’

This term has negative connotations and should not be used.

In general, we will refer to cleft as a **‘condition’**, **‘facial difference’** or **‘condition a baby is born with’** rather than using either of these terms, as this is both neutral and widely understood. E.G. ‘Cleft lip and palate is the most common facial difference a baby can be born with’.

In a more medical context, the term **‘congenital abnormality’** (a difference that someone has inherited or was born with) may be used as it is more neutral. When using ‘congenital abnormality’, the term should be defined immediately after its first use as it is in this paragraph.

Exceptions

We believe it is up to the person with a condition to decide what terms they prefer. If someone uses the term ‘harelip’ to refer to themselves, or says they were a ‘clefty’ or ‘cleft baby’, etc., we will not ‘correct’ them or change this when quoting them. If you’re concerned this may cause offence, you may find it helpful to include a note explaining this policy and providing context to the use of the word.

For example: “The word ‘harelip’ is used in this story, and while this is not a term CLAPA uses, many adults born with a cleft will have grown up using it as standard. CLAPA believes it is up to

individuals to decide how to describe themselves and their experiences, and so we have published [name]'s story here as it was written."

Describing Differences

When describing people born with a cleft, use neutral language which acknowledges a difference without placing a value judgement on this difference, assuming the impact it has on the individual, or implying it's the fault of the individual or their family.

Instead of "Children born with a cleft have problems with their speech and appearance," **use**, "Children born with a cleft may look or sound different to their peers," or "A cleft can affect speech and appearance."

Instead of "A child born with a cleft may have speech problems," **use** "may find it difficult to make certain sounds", "may speak in a way which other people struggle to understand."

We use the term '**visible difference**' to describe an appearance that is altered as a result of a congenital or acquired condition, accident or surgery, such as a scar from a cleft lip repair surgery.

Unless it is used in a medical/research context, we **don't** use value-laden terms such as **normal/abnormal**. When these must be used, we use inverted commas as a distancing device to indicate we don't entirely agree with its usage and understand it may not be helpful for people who find themselves outside of this 'normal' bracket. The term 'norm' is preferred as this describes an average, and doesn't imply something is or isn't acceptable.

Where possible, we describe specifically the ways in which something isn't 'normal' in order to avoid this term.

Instead of "By the time they start school, 2/5 children born with a cleft palate still don't have normal speech", **use**, "...still have speech which sounds noticeably different to their peers."

Describing Surgery

The preferred way to describe any kind of surgery is by describing what it intends to do in a neutral way, making sure to include any functional concerns (e.g. breathing, eating) when applicable. Where appropriate, the medical name of the surgery should be included in brackets afterwards to help familiarise readers with the medical terms they may need to use in the future.

For example, 'Surgery to fill the gap in the gum so adult teeth can come through (Alveolar Bone Graft)' or 'Surgery to realign the jaws and change the facial profile (osteotomy or orthognathic surgery)'.

Avoid using terms with a value judgement such as 'improve' or 'fix'.

Instead of 'Surgery to fix the shape of her nose', **use** 'surgery to change the shape of her nose,' or 'surgery to change the shape of her nose and help with breathing (rhinoplasty)'

Instead of 'Surgery to improve the appearance of a scar," **use** "Surgery to make a scar less visible."

We use the general term '**Repair Surgery**' when describing surgery to close a cleft palate and/or cleft lip performed on a baby or very young child. This is useful shorthand, but describing the purpose of the surgery as above is still preferred where possible.

Writing with Respect

When writing about people affected by cleft, and particularly about people born with a cleft, care should be taken not to sensationalise cleft or the ways in which it may affect someone's life, and to humanise the subjects of any case studies used. It's important to highlight the needs of this community, but there are ways to do this effectively without patronising or infantilising people affected by cleft.

Avoid evoking pity for the subject, and never suggest that the audience's inaction will cause harm to a particular individual (e.g. "Without your help [name] will have no one to talk to.")

Avoid overly patronising phrases about how someone's personality or another quality is more important than their appearance (e.g. "It's what on the inside that counts"), as this is typically uncalled for and assumptive of an individual's values and views of cleft.

Readers should never be asked to express an opinion on someone's appearance (e.g. "Like this post if you think [name] is beautiful regardless of their cleft"), and a particular person born with a cleft should never be used to 'prove a point' (e.g. "The media doesn't believe people with scars are beautiful, but look at [name]").

About CLAPA

In writing, CLAPA should be introduced as 'the Cleft Lip and Palate Association (CLAPA)', and later on referred to as 'CLAPA'. The word 'and' should be used rather than the ampersand (&), although the ampersand is used in our logo.

'CLAPA' is always capitalised, it should not be written as 'C.L.A.P.A.' and never as 'Clapa'.

The Charity's Work

Refer to the Branding Guidelines for specific guidance and examples to help with writing about CLAPA's work, including guidance on tone. External writers may use the information on CLAPA's website and ['About Us'](#) page.

Contacts

Contact info@clapa.com to talk to someone at CLAPA about writing sensitively about cleft lip and palate.

We would be happy to offer 'sensitivity readings' or consult with our community of people affected by cleft to get feedback about a piece of writing or other media.

Please note that some projects will be subject to a [consultancy fee](#). This helps us to keep our other services free and accessible to all who need them. This consultancy service has been designed for researchers and health professionals, but we would be happy to discuss your project any project where this sort of feedback may be useful.