

# Talking About CLAPA



## What is cleft lip and palate?

Parts of the face develop separately and then come together in the womb. If they don't come together all the way, the result is a gap (a 'cleft') in the upper lip, the roof of the mouth (palate), or both. There's no single cause; it can happen in any pregnancy.

One in 700 babies is born with a cleft. That's around three every day in the UK. It's more common than Down's Syndrome. People born with a cleft can face a number of challenges, including:

- Difficulty feeding from the breast or regular bottles (The gap in their mouth makes it hard to form a vacuum)
- Surgeries starting at just 3 months old (Some will have 20+ surgeries)
- Issues with hearing and speech (Half of children with cleft palate need ongoing speech therapy; 40% will have significantly different speech to peers by the time they start school)
- Ongoing concerns with appearance, self-esteem, dental issues, and more.

## What is CLAPA

The Cleft Lip and Palate Association (CLAPA) is a small charity supporting people and families in the UK affected by cleft. The charity:

- Manufactures and supplies special bottles and teats for babies with a cleft, used by families as well as NHS Cleft Nurses
- Hosts online support groups and regular events so people can share their experiences
- Trains volunteers to give one-to-one support to people in need, especially new families
- Creates information resources led by the needs and experiences of patients and families
- Runs adventure weekends for young people so they can make friends and grow in confidence
- Does much more, including working with researchers and the NHS, advocacy, and promoting patient voices

## Your Connection

If you have a personal connection to cleft, share this by explaining how you were affected, and how CLAPA helped.

E.G. "My daughter Jane was born with a cleft. It was a big shock, and we were so worried; we didn't know how we were going to feed her. CLAPA gave us some special bottles so we could feed her at home, and since then, they've connected us with so many other families and have been a real source of support."

## About the Appeal

CLAPA is a small charity with a shoestring budget. They have no government or NHS funding and rely on fundraising from the community to fund their services. This fundraising was severely impacted by the pandemic and has not bounced back. They urgently need help to avoid cutting back on services.

You can find resources and make a donation at [www.clapa.com/saveclapa](http://www.clapa.com/saveclapa)

## How you can help

- CLAPA needs 250 new regular donors by Christmas. Make a donation at [clapa.com/saveclapa](http://clapa.com/saveclapa).
- Fundraise at work. This can be anything from a dress-down day to a full Corporate Social Responsibility initiative. CLAPA can't compete with bigger charities to win support like this on our own, but your personal story can make all the difference.
- Talk about CLAPA to local fundraising groups such as Rotary Clubs, Freemasons, sports clubs, or even grant-makers like Trusts. What we need most is general, unrestricted funding, but there are also a number of projects and initiatives that groups like this could contribute towards.
- Share your story with your network on social media (including LinkedIn) and ask for support. As a small charity, every donation can make a big difference. See the next page for top tips, or visit [clapa.com/yourstory](http://clapa.com/yourstory) for resources.



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## Why Share Your Story?

Facts and figures are useful, but for many people, giving an example is the best way to help them understand something new.

By sharing your story, you're putting a human face on an issue many people will be unfamiliar with. With just a few sentences, you can explain the reality of cleft lip and palate, the need for CLAPA, and the impact our services can have.

It can be intimidating if you're not sure where to start. This short guide will explain how to structure your story in a way that makes it easy for people to understand why CLAPA matters to you and why they should support this appeal.

**TOP TIP: Other people might not be able to relate to your experiences, but they'll be able to relate to your emotions. Talk about how you felt throughout your story to give it a bigger impact.**

## Getting Started

For this appeal to reach a wider audience, we need to convince people that cleft is something they should care about and that CLAPA is a good charity to support. Get started by answering these questions:

- Problem: What were you struggling with before you used this service? How did it make you feel?
- Solution: What CLAPA service did you use? How did you feel when you used it?
- Outcome: What are things like now? What was the long-term impact of using this service?
- Call to Action: What should people do now? Add some facts about CLAPA from the previous page, and ask for support!

For social media, keep your story to just a few paragraphs. If you'd like to write something longer, visit [clapa.com/yourstory](https://clapa.com/yourstory).

**TOP TIP: If you're not used to writing, imagine you're talking aloud to a close friend and write what you'd say. You can always tidy it up afterwards, but it's much easier once you've started!**

## Example

This story follows the basic structure outlined above.

"My son was born with a cleft palate. It was a big shock, and I didn't know how I'd cope. I was so worried about the surgeries and other treatments he might have in the future.

"I contacted CLAPA and was put in touch with another parent, a trained volunteer who helped me talk through all my worries and drew from their own experiences to answer all my questions. They were a huge source of comfort and support and helped me feel much more prepared for what was to come.

"My son has come through his surgeries well and is now a happy, healthy five-year-old, but I know he may face more challenges in the future. It's so reassuring to know that CLAPA is there whenever we need them and will support him as he grows older.

"Three babies are born with a cleft every day in the UK. CLAPA do so much for these families, but now this charity needs our help. Please donate what you can to help them support families like mine in the future."

**TOP TIP: Make sure you share a link to [clapa.com/saveclapa](https://clapa.com/saveclapa), or share one of CLAPA's posts along with your story. This ensures people have somewhere to go to learn more after reading your story.**

