

Questions for People With α Cleft

How to use these questions

These questions are designed as prompts to get you thinking about things you may want to include in your case study. You don't have to answer all (or any!) of them if you don't want to – what's important is that your story includes what matters to you.

Think about WHY you want to share your story – is it so you can raise awareness? Share some lessons learnt with others? Reassure people in a similar position that they aren't alone? Whatever the reason, make sure this is a message that comes across strongly in your story.

How CLAPA will use your story

CLAPA will likely publish your story (in whole or in part) on our website, www.clapa.com, and may also include it in CLAPA News, our annual magazine. This may be shared on social media along with photos you submit. CLAPA may also use parts of your story in funding applications, information leaflets, and any other relevant publicity materials. You can ask us to publish your story anonymously or under a different name if you wish, and you can also ask us to remove your story from our website at any time.

Please send any stories or photos through to anna.martindale@clapa.com, or submit them through our website here: https://www.clapa.com/support/your-stories/

Ouestions

When did you first become aware of the fact that you had a cleft? Was it something your family talked about? How was it treated in your family?

How did a cleft affect you growing up? How did you cope with any surgeries or treatments? Were there any problems you did not expect, or that other people might not expect? What would have helped?

Have you had any treatment as an adult? What made you want to do this? How did it make you feel?

Do people ever ask you about your cleft? How do you react? Do you ever bring it up?

When did you join the CLAPA Community and why? How has it affected you? Do you think it is important to have a community for people with and affected by cleft?

What would you say to young people with a cleft who may be struggling in some way? What is the one piece of advice you would give?

Examples: https://www.clapa.com/sitetag/adult-stories/