

Questions for Parents and Carers

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/>

Questions

What was your **experience of diagnosis** like? Was it particularly positive or negative? How did this affect how you felt about your pregnancy/baby?

How did your **family and other people** react to the diagnosis?

What were your experiences with **surgery and treatment** like? Were there any **challenges** related to your child's cleft that **you didn't expect** or that you weren't prepared for?

Do you talk to your child about their cleft? Why/why not? How do you think your child feels about their cleft?

What is one **piece of advice** you wish you had received when your child was diagnosed, or one thing you wish you'd known?

When did you join the CLAPA Community? How has this helped? What can you get from CLAPA that you can't get from the Cleft Team? Do you think it's important for parents to have support from an organisation like CLAPA?

Examples: <https://www.clapa.com/sitetag/parent-stories/>