



# *Cleft Lip and Palate:*



## *My Story*

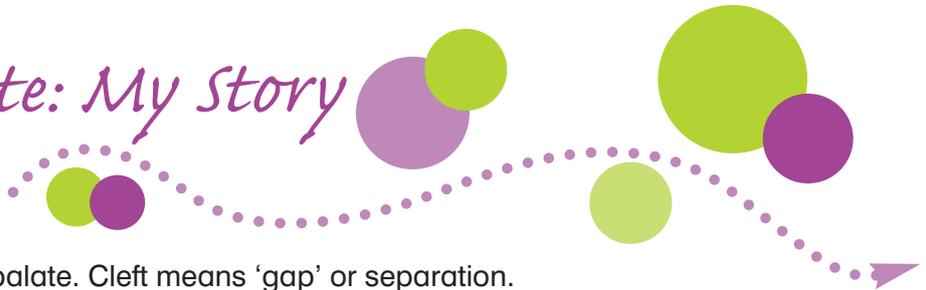


*Young people talk*



# Cleft Lip and Palate: My story

## Young people talk



Some babies are born with a cleft lip or palate. Cleft means ‘gap’ or separation.

A cleft happens because different areas of the face don’t join together while a baby is developing in the mother’s womb. Surgeons can repair both a cleft lip and palate so that babies can grow up to live active and fulfilling lives.

Children with a cleft lip or palate need surgery as babies, and may need further operations as they grow.

They may still look or sound a bit different from other people. At the Cleft Team, we see that children or their parents sometimes feel low about having a cleft lip or palate. But we also see that most of the time, they forget about having a cleft. Despite the stresses of treatment, these children and their families, like other families, are funny, beautiful, talented and caring.

Every child and family has a different experience. This booklet gives some insight into their journeys, their fears, their thoughts and their positive achievements. I hope parents who have recently heard that their child has a cleft lip and/or palate will draw strength from these stories. I hope other young people with a cleft lip and/or palate will be reminded that they are not alone. I hope people who know very little about cleft lip and palate will read it and come away with more understanding. I know that I will continue to be inspired by the young people I help to look after.

Rona Slator, Consultant Plastic Surgeon

*Clinical Lead, West Midlands Cleft Lip and Palate Service, on behalf of the West Midlands Cleft Team*

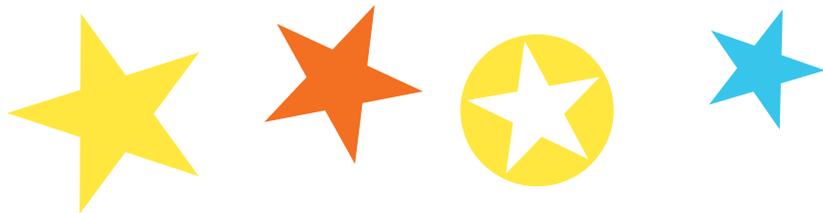
# Jacob

Jacob is 9. He is a sporty boy. He likes breakdancing, skateboarding and football – especially scoring goals!

Jacob was born with a deep cleft in his lip and palate. When he was a baby, his parents used a soft, squeezezy bottle to feed him. He had his first operation at three months, another at seven months, and a third when he was two, to join up muscles that were too far apart before.

‘But I don’t remember any of it!’ says Jacob. If anyone asks about his mouth, Jacob explains, ‘When I was younger, I had a cleft lip, when you don’t have a top lip. I’ve had a lot of operations to fix it.’

**You can still look good and be cool**



Jacob's parents felt protective when he started school, but they were keen not to wrap him in cotton wool. At first, Jacob struggled with his spelling, because his speech and hearing was affected. But intensive speech therapy helped, and suddenly last year everything seemed to click into place. Now his reading and spelling have zoomed ahead. Jacob's teacher says he's a confident lad, with loads of friends.

Jacob's mum mentions that Staffordshire bull terrier pups can be born with a cleft lip too. 'Can we have one, Mum?' begs Jacob. 'I'd love it!'



## *Parents' story*

'It was devastating to discover Jacob's cleft lip and palate at the birth,' says Jacob's mum, Kelly. 'If we'd known at the scan, we would have had longer to get used to the idea.'

The cleft team nurse came just a few hours after Jacob was born. She said his first operation would be in about three months' time. At the time, Kelly protested, 'He needs it done before we leave the hospital!'

But looking back now, Kelly says, 'We can't fault the service Jacob's had from the Cleft Team. We couldn't have wanted anything more'.

Jacob as a new baby



# Junaid and Ben



Junaid (left) is 10 and Ben (right) is 11. Both boys are keen footballers – and both were born with cleft lip and palate.

Junaid had his bone graft operation recently. This operation takes a small amount of bone from the hip and uses it to build up the gums, ready to straighten the teeth. Ben had his done when he was eight. Junaid admits he felt a bit scared beforehand. 'I stayed in hospital for one night,' he says, 'and my dad slept on a little bed beside me.'

'You don't need to be scared about your operation,' says Ben. 'It feels as if it's done in five seconds! They give you medicine to stop it hurting.'

'And everyone's friendly at the hospital,' says Junaid. Both boys remember eating soft food after their operations.

'Nice things like pasta, yoghurt and ice cream,' they agree.

'I was back at school after about a week or 10 days, part time at first,' Ben remembers. Now he has just a little neat scar on his hip.

Ben has had a bit of bullying at school. The cleft team psychologist helped him to deal with it – by changing the subject, or by saying, "I don't want to talk about that."

Now both boys have better things to worry about. Like whether their team's going to win the cup (Chelsea for Junaid, Man U for Ben).

Ben with Lamby, a soft toy showing a cleft lip repair



You don't need to be scared about your operation



Ben as a baby after his repair surgery

## *Parents' story*

Ben's parents felt daunted when he was born with a cleft lip and palate. 'But you grow up with your baby, and your understanding grows,' says mum Nichola. 'And then you can help other people.'

'Everyone wants a perfect baby – although there's no such thing as a perfect baby. And of course you fall in love with your baby. Everybody's baby is perfect to them!'

Nichola was upset when the photographer at the hospital turned Ben on his side. Nichola took lots of full-face pictures of him. 'Put up those baby photos!' she says. 'It's important not to hide the cleft. Children need to know, and

have it spoken about. A cleft lip or palate is just a small thing that is simple to fix. We are so lucky in this country, with all these services provided.'

A little girl once asked Nichola, "Why hasn't your baby got a proper mouth and nose?" Nichola says she prefers people to ask directly like that, rather than turning away or staring, or not asking.

Nichola is involved now with the CLAPA network online. 'It's a great support network,' she adds, 'a helpful and friendly community. It's good too to feel you can help others.'



# Lara



Lara is 11. 'My cleft does make me feel a bit special,' she says. 'But I'm more proud of playing the tenor horn!'



Lara plays her tenor horn in a beginner band, and they played recently in Birmingham's famous Symphony Hall. Lara is a busy person. She likes swimming and dancing too. Mum Kate says it's good to get absorbed in things that have nothing to do with her cleft lip and palate.

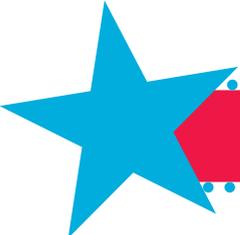
Lara couldn't play the tenor horn for a few weeks after her bone graft operation – so she took up the piano as well!



Lara's dad Martyn is the joker of the family. 'When I woke up from the op, I couldn't talk at first,' she says. 'Dad kept making me laugh, but it hurt! I had to write in my little notebook, *Dad, stop making me laugh!*'

Lara (front) with her mum and sister





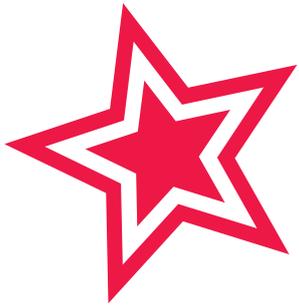
## Wearing braces will be worth it in the end

In the past Lara has worn braces on her teeth, and soon she will need to again. 'It's not much fun,' she admits, 'but I put up with it, because I know it will be worth it in the end.'

Lara knows that many children around the world can't get medical treatment, and she wants to do something to help. 'Next summer, I'm hoping to do a sponsored bike ride to raise money for CLAPA or for Smile Train,' she says.

Lara (left) with her sister Jess





Baby Lara before her first repair operation



## *Parents' story*

Lara was Kate's third baby. She planned a home birth, unaware of Lara's cleft. After a smooth birth, Kate felt sad to have to go into hospital over Christmas until she got Lara's feeding established.

Kate says, 'Of course they have to warn you at the beginning of all the potential problems – feeding, hearing, grommets (tubes to drain fluid) for glue ear, speech difficulties – and that can feel frightening. In fact Lara hasn't really had any of those difficulties, although speech therapy has boosted her confidence.'

Kate found it helpful to meet other families with children with cleft lip or palate. Now CLAPA is training members to support new parents. 'It's reassuring to see another child with a cleft playing with other children and developing normally,' says Kate.

Once or twice, when Lara was in her pram, people stopped Kate to say, "Thirty years ago I had a baby with a cleft, and look, here's a photo of him now. Everything will be all right."

'It was nice to get positive encouragement from strangers who knew just how it felt,' smiles Kate.



# Maya

Maya is 10. She likes creative writing and has already started writing her autobiography – including the operations she had when she was a baby.

‘The cleft team encouraged us to take baby photographs of Maya,’ says her mum, Akbal. ‘They said she needs to know her history, and pictures to match the story.’

‘But it’s a bit shocking to look at the photos,’ admits Maya.

Maya lacked confidence when she started at kindergarten. For her first few years at school, she chose not to speak at all. But the speech therapist worked with Maya to build her confidence, and by Year 2, Maya was ready to speak out.

‘We don’t know if it was related to her cleft palate,’ says Akbal. ‘At the time it was very worrying. But looking back, we can see that Maya has overcome a great deal.’



Maya as a baby and as a little girl



It annoys me that I can't whistle

## But no-one's perfect



'A cleft lip or palate isn't much to worry about,' says Maya. 'Not many people notice that I had it. And in any case, no-one's perfect.'

Akbal agrees. 'Maya's cleft doesn't affect her quality of life at all,' she says.

'Though it annoys me that I can't whistle,' frowns Maya, 'or blow up a balloon.'



### *Parents' story*

'It was hard to deal with at first,' says Akbal. 'All those new mums with their perfect babies... I did have moments of jealousy. I felt nervous taking Maya out in her pram. But everyone around me was supportive. And now we know that it isn't such a big deal after all.'

Akbal continues, 'We see the adverts for cleft charities helping children in other countries. They make you realise that that it's no big deal here because we have access to excellent medical care. Without that, a cleft can have a heavy impact on children's lives.'



# Shawn and Ben

Shawn, 14, and Ben, 6, are brothers. Both boys were born with a cleft in their soft palates. Both Shawn and Ben have had grommets for glue ear, which affects their hearing too. Shawn is about to try hearing aids for the first time.

Every so often Shawn and Ben go to the hospital to have their ears 'hoovered', as Shawn describes it, to clear out gunk and relieve the pressure. 'It doesn't hurt,' he says, 'but it makes my eyes water.'

Their mum, Becky, says, 'When we go to the hospital, we make a day of it. We take the DS and games in case we have to wait. And then afterwards, we go for a pizza.'

**You can ask the doctors anything  
you need to know**





Shawn has just joined the army cadets. 'I wanted to be a submariner in the Navy, like my grandad. But I know my ears wouldn't cope with the pressure underwater.' Instead, Shawn hopes to join up as a trainee engineer or mechanic.

Ben wants to be an Olympic swimmer when he grows up – or else a fireman. Mum Becky grins. 'We don't let our boys use their clefts as an excuse. We say to them, "You've got two arms, two legs, two eyes and a brain!" If they find something difficult, we say, "Well, try harder!"'

Shawn and Ben's cousin has a palate weakness too. Both families have been referred for genetic counselling. 'By the time they're ready to have children, maybe science will have a solution,' says Becky.

Shawn's advice? 'The doctors are friendly. They explain things so you can understand.'

Ben adds, 'Don't be scared. The doctors are funny!'



# Isabelle

16-year-old Isabelle and her friends spend hours together, talking and listening to music. 'I like reggae and ska,' says Isabelle. 'And I like drawing. And shopping!'

Isabelle has had seven operations in total, plus orthodontic treatment. 'I do get scared in the run-up to an operation,' she admits. 'It plays on my mind, and I bottle up my feelings. But my family are really supportive and caring.'

When she was younger, Isabelle went on residential holidays run by CLAPA. 'They were fun!' she says. But at about 14, Isabelle grew self-conscious, and lost some of her confidence. She feels that the media puts young women under pressure about their appearance. 'I would ask, why isn't my face symmetrical? I was so focused on my cleft that I thought everyone else was staring at it.'

No one was staring at me. I felt much more comfortable when I realised that



Isabelle today and (below) as a little girl



Isabelle met the cleft team psychologist a few times. 'We went for a walk together around the hospital,' says Isabelle, 'and she was right – no one was staring at me. After a few sessions, I felt much more comfortable with myself.'

Isabelle thinks that boys aren't so good at talking about things with their friends. 'I think in some ways that makes it harder for them,' she says.

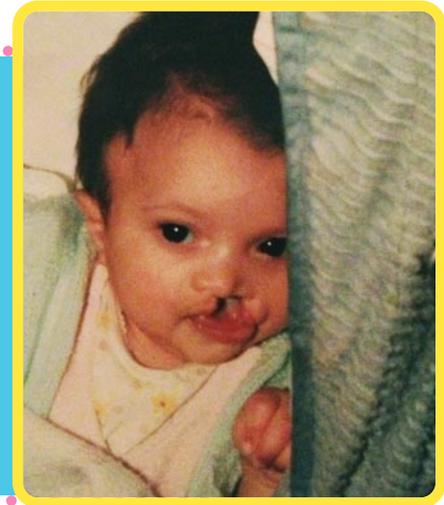
Isabelle would like to train to become a nurse – and then perhaps one day she can work for a cleft team herself.



## *Parents' story*

Jasmine, Isabelle's mum, says, 'At first, it's the parents who are affected. The baby doesn't know any different.' Isabelle's cleft was spotted at the 20 week scan. Jasmine spent the second half of her pregnancy worrying about feeding the baby, and apprehensive about how she would look. 'But she was beautiful, despite her cleft,' she says. And Isabelle could feed from a normal bottle with a slightly bigger hole in the teat.

'I worried more than I needed to,' said Jasmine. 'In some ways I think it might be better not to know in advance.'



# Attia – an adult's perspective



Attia as a baby after surgery

Attia is a pharmacist. She is tall, beautiful and assured. Attia got married recently. She met her husband-to-be at university.

'I'm very happy with how I look now,' says Attia. 'As a child, I knew that I looked different. I was shy, and lacked confidence. But as a teenager, you're finding out who you are.'

Attia continues, 'Asian families can find it hard to talk about feelings, but I

had lots of love from my family.' Attia feels she didn't get enough support at school and college, but her cousins at university encouraged her. 'Now I know you have to stick up for what you want,' she says.

When she was 16, the cleft team first asked Attia what she would like to change about her appearance. 'I found that difficult and emotional,' Attia admits. But she decided to have surgery to shape her nose and her upper lip. 'And it has really helped my confidence,' she says.



'If anything, my speech has been harder for me. If I could change anything, it would be that. I have to talk slowly, and I get self-conscious if I have to repeat myself.'

Attia is Muslim. 'In our faith, we believe that what will be, will be. I see it as a test from Allah.' Attia believes that her struggle with her cleft lip and palate has taught her insight. 'I would never put anyone down. It makes you sensitive – perhaps too sensitive. You realise that material things are not the most important thing. I am glad I have learnt that lesson.'

## *Other resources*

**[www.clapa.com](http://www.clapa.com)** The Cleft Lip and Palate Association (CLAPA) offers information and support for people affected by cleft. CLAPA has a Children and Young People's Council (CYPC) and a Facebook page for under 18s with a cleft: **[www.facebook.com/groups/430338053652813/](https://www.facebook.com/groups/430338053652813/)**

**[www.childline.org.uk](http://www.childline.org.uk)** You can contact Childline online or phone 0800 1111 for advice and support

**[www.cuddlycleftlamb.co.uk](http://www.cuddlycleftlamb.co.uk)** Soft toys with cleft lip or palate repair as shown by Ben on p7

**[www.changingfaces.org.uk](http://www.changingfaces.org.uk)** Support for people and families affected by facial or other disfigurement

**Dealing with Questions and Staring:** Online patient information leaflets for parents and children from Spire Cleft Centre, Oxford Radcliffe Hospitals. Search online for 'questions staring cleft'

**Wonder by R J Palacio** Further reading: a novel dealing with looking different, aimed at 9-13 year olds

# *Cleft Lip and Palate: My story*

*Young people talk*



Children born with a cleft lip or palate - and their parents - may worry about how they look and speak, and the treatment they will need. It is good to know that someone else shares your experience and understands. This booklet is a collection of true stories and photos of real children and young people with a cleft lip or palate, so you can read about how they coped with it.

Introduction by Rona Slator, Consultant Plastic Surgeon,  
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If you would like a copy of this booklet, please e-mail [cleft.services@bch.nhs.uk](mailto:cleft.services@bch.nhs.uk) or write to Cleft Services, Birmingham Children's Hospital, Steelhouse Lane, Birmingham B4 6NH with your name and address details, asking for a copy of 'Cleft Lip and Palate: My Story'

Professionals can obtain copies (minimum 25) from [bch.charities@bch.nhs.uk](mailto:bch.charities@bch.nhs.uk)

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