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My Story:

Young people born with a
cleft and their parents

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Y Ganolfan Gymraeg i

Wefus a Thafod Holtt

The Welsh Centre for

Cleft Lip & Palate

This booklet has been written by the Welsh Centre for Cleft Lip and Palate Psychology Service. We would like to thank all the young people and their parents who generously shared their stories with us.

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Other Resources

Welsh Centre for Cleft Lip & Palate Morriston Hospital,
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Our Psychology Leaflets We have other leaflets available, including “Dealing with Comments and Questions,” “Teasing and Bullying” and “What do we know about Cleft Lip & Palate”. Please contact us to request a copy.

www.clapa.com The Cleft Lip and Palate Association (CLAPA) offers information and support for people affected by cleft. The CLAPA website has areas for people born with a cleft, parents and professionals.

www.changingfaces.org.uk Support for people and families affected by facial or other disfigurement.

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<https://sbuhb.nhs.wales/hospitals/a-z-hospital-services/cleft-team/>

We hope you will enjoy reading this booklet. The booklet contains the stories of 9 very different children and young people who were born with a cleft lip and/or a cleft palate. For some people we have also included their parents' story.

Every child born with a cleft and their family has a different experience. This booklet gives some insight into their journeys, the things they have found difficult, their thoughts and their positive achievements. Some people have talked about how being born with a cleft has made a positive difference to their lives. Some people have passed on their advice to other young people.

We hope that this booklet may be helpful to lots of people for lots of reasons. We hope that young people reading the booklet will find it helpful to read about other young people in South Wales and their ups and downs. We hope that parents of children of all ages will be reassured to learn about these young people who, in spite of having some difficulties along the way, are getting on with their lives, as well as reading about other parents' experiences.

We hope that this booklet highlights the obvious, that having been born with a cleft lip and/or cleft palate is just one part of these young people's stories. We are sure that you, like us in the Cleft Team, will enjoy and be inspired by these stories.

Vanessa Hammond

Ellie's Story

Ellie is 10 years old and lives with her mum, dad and little brother. She's in primary school and enjoys maths and history. She has a big group of friends and likes playing netball with them and having a laugh. Ellie has been playing the violin for a year and thinks that when she's older she'd like to either be a violinist or a netball player.



Every single person is different and unique in their own way

Ellie was born with a cleft palate and had an operation to fix it when she was a baby. She doesn't remember it but "I've seen a picture of me in a hospital bed." Ellie also remembers going to speech therapy and reading from cards. She thought the therapists were lovely, but because she has always been tall the chairs were a bit small! "I'm the tallest in the school!"

"I've never been bullied. I try to be friends with everyone, and try to be nice to everyone." Only close friends know about her cleft. "I don't really think about having a cleft though.. and I don't have any problems talking now - I talk a lot!"



I don't really think about having a cleft though and I don't have any problems talking now - I talk a lot!



Jackson feels that having been born with a cleft is a double edged sword.

"People will always look twice if there is something different about a person - it's just human nature. I find that I get a lot of stares, although that could just be my fantastic leg muscles!"

But he also thinks it gives him a memorable feature, uniqueness, and ice breaker all rolled into one!

At times things have been tough for Jackson. The bullying he faced at high school affected him and made him shy.

"Thanks to family and friends I made in school, college, and university, I learned that being different teaches you courage, empathy, and a good moral compass."

Jackson knows that his mum has always supported him, and he can't think of anyone he looks up to more than her.

"She went out of her way to improve my quality of life and instil values that helped me immensely in times of need".

He also saw a psychologist in the Cleft Service for support.

"She really allowed me to find myself again and look past some of the negatives."

Jackson's attitude is very inspiring.

"Whether you're tall, skinny, round, freckly, hairy, smooth or rough there's something different about you - something that every single person is different and unique in their own way.

My cleft lip is no different to my brown eyes or my 'sticky-out' ears. It's just another tiny piece of what makes me 'me'. So I've learned that it's okay to be different, great even! Be strong, be different and be whatever you want to be!"



Mum's Story

Ellie's mum didn't find out Ellie had a cleft palate until a few months after she was born.

"My friend picked up on the cleft - she noticed the hole in Ellie's palate. I thought something wasn't quite right because feeding seemed hard, so we took her to the doctor and they confirmed it." Ellie had the operation when she was 9 months old. Mum found it scary because Ellie was so tiny, but when she came out of theatre she was fine.

"She woke up, smiled, and went back to sleep!" Mum said that Ellie had a lot of speech therapy when she was younger because she struggled pronouncing some of her sounds.

"She went once a week for about 6 months, and someone still comes into school now and again... but they haven't been for a while because her speech is fine. She's eating and drinking fine now."

Ellie has also had some dental work because of the cleft. She recently had some teeth removed to make some space for the others. Mum thinks it's really good Ellie gets extra dental care from the service.

"Not only does she see our own dentist but we get help at Morriston Hospital too."

Mum feels positive about Ellie's future.

"There's nothing I can say I'm worried about. She's beautiful and I just hope she's happy and does whatever she wants to do."

Lauren's Story

Lauren is a very creative and helpful 14 year old girl. In school she enjoys art, music and likes swimming and going to a choir after school. Having a good group of friends inside and outside school is also important to her.



Lauren was born with a cleft lip and she had her operation to repair it when she was a baby so she doesn't remember it.

"I don't feel it's made much of a difference having a cleft. Some people ask, but not in a mean way," says Lauren. She finds that people accept what she says, and because she feels confident, no one seems to think anything of it.

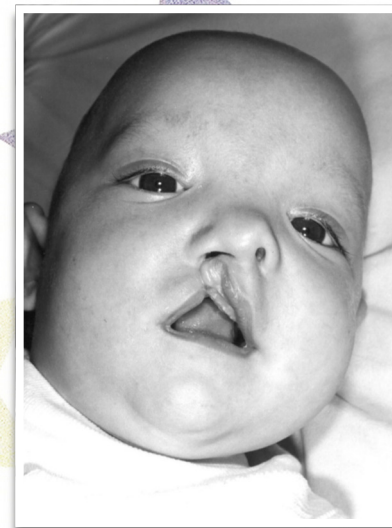
Lauren liked going to the Cleft Service at Morriston Hospital because they helped her with ideas about what to say to people about her cleft. She thinks that having the knowledge about what a cleft is has given her the confidence to talk about it.

"I used to be quite shy, but now I've made lots of good friends."

Now, Lauren loves raising money and awareness for people born with clefts. She has hosted lots of events including a coffee morning and has raised over £2.5K so far.

Lauren is going to be doing a concert in her choir to continue to raise money for the Cleft Lip and Palate Association (CLAPA). One day she hopes to work in medicine or helping other children born with clefts.

to drastically improve my fear of hospitals. So much so I now volunteer in them!"



“Having a cleft gives you a unique memorable feature and an ice breaker rolled into one!”

Jackson's Story

Jackson is a creative 24 year old with a brilliant sense of humour. He enjoys writing music and short stories, film-making, and hanging out with friends. He jokes that he often feels lazy and plays videogames, but when he's not so lazy, he'll work out.



"I'd say I'm good at making my friends laugh at inopportune moments. I don't take myself too seriously. I can also play various instruments, and I cook a mean chilli con carne!"

After finishing school, Jackson studied for a degree in creative sound and music. He uses his degree a lot by playing in bands and making music videos in his spare time. He also has a caring side to him and is currently thinking about a future in Occupational Therapy or Teaching.

"Regardless of where I end up or what I may be doing, I know I want music to be a big part of my life. I also wouldn't mind winning the lottery and growing a big beard!"

Jackson was born with a unilateral cleft lip and palate. He was a baby when he had his first cleft operation, and has had many other surgeries since then.

"I started to dread hospital visits - even for check-ups. Before surgery I would get very anxious and restless." But Jackson said that staff helped him get through it.

"They were always exceptionally helpful and kind, helping me

Mum's Story

"We only found out that Lauren had a cleft when she was born. We had IVF to have her and so it was surprising to find out considering the number of scans she had. It was initially a bit of a shock because they took her away with a sense of urgency and that made us worry that there were further complications," says Lauren's mum Sian.



Lauren's parents found the operation extremely hard, and mum Sian admitted that when she had to leave Lauren she ran off and burst into tears.

"We were desperate to have her, and would have been happy if she had stayed the way she was, to us she was perfect."

Today, Sian is really pleased with how Lauren is growing up. Sian says Lauren is confident and happy and 'that's all I care about'.

"She's doing well in life. It doesn't make any difference having the cleft. She cares more about her hair!"

“ If I didn't have a cleft I wouldn't be so confident

Ben's Story

Ben is 10 years old and lives with his mum, dad and younger sister, Izabel. He is in primary school at the moment and enjoys most subjects. However, he modestly admits to being quite good at maths, science, literacy and art. Outside of studying, Ben and his friends Josh and Dan also help out at their school by handing out toys to younger children during their lunch breaks. In his spare time, Ben likes playing Xbox, building Lego models and watching TV.



“I was kind of nervous when I first came into hospital, but I’m used to it now

Ben was born with a cleft lip and palate. When asked what it's like to grow up with a cleft, Ben is very positive.

“Having a cleft makes me feel special. I get to meet new people and I get to see family members more often.”

He doesn't remember any of the operations he had when he was a baby but he does remember the alveolar bone graft (ABG) operation that he had when he was 7. This involved taking some bone from Ben's hip and putting it into his gum.

“I was kind of nervous when I first came into hospital, but I'm used to it now. And I got to go home early for walking so well!”

Something that Ben didn't enjoy was the videofluoroscopy x-ray (the x-ray that you stand up next to and looks at your head and palate as you speak). He was very afraid of it at first and wasn't sure what to expect. His parents had the idea of taking him to see the same machine in another

Emily is very chatty, but she said she wasn't always this way.

“I used to worry about what other people thought. When I got to year 10 and did drama I felt more confident. I was with a smaller group of people who were my friends.”

It was then that Emily started to explain to people why she was going to hospital more, and it was fine.

“There's no shame in talking about it.”

Seeing one of the psychologists in the cleft service has also helped Emily.

“It was like I finally started talking to someone who understood how I see things, and was willing to listen to how I was feeling.”

The whole cleft service has been helpful, and Emily felt as though any questions she had were never a problem.

“After spending years holding back I feel as though I'm on a roll now. I've signed up for a 10k race, and I've booked my holiday for next year. I want to do everything that I want to do now. I'm going to buy a pair of Christian Louboutin shoes, a Mulberry handbag and go to New York!”



Emily's Story

Emily is 21, and loves shopping and going on holidays! Since finishing school she's worked in insurance as well as a care home. She says she enjoys her jobs because she's really sociable and loves talking to people. Looking after older people makes her feel like she's giving something back.



"That could be your nan or granddad one day. Some of them just need someone to talk to - which I'm good at!"

Emily says she is very focussed, likes to get tasks done - except Maths!

"As long as you know your good qualities, it doesn't matter about the bad ones!"

Emily had a cleft palate and has had lots of operations - ones on her palate, her jaws and her nose.

"I had braces when I was 11, had them taken off at 16, and then put them back on for preparation for jaw surgery. My braces didn't come off until I was 20. It felt like a lifetime, and I had a lot of hospital appointments but when you see the outcome you think it's worth it."

Emily thinks they prepare you for the worst when you go into surgery, which was good because when she came out of theatre she thought it wasn't too bad.



There's no shame in talking about your cleft

hospital.

"It worked a treat," his parents remember. "On the second visit, Ben felt comfortable enough to have the X-ray. It was no longer a traumatic procedure. No crying, no tantrums or bribery!"

Ben and his family recently returned from Qatar, where they lived for three years. Ben and his family all enjoyed the opportunity to experience different cultures and meet lots of new friends from different countries. One of Ben's favourite places was a chocolate cafe! It was much hotter than Wales there and Ben used to love having water fights with his friends.

Ben has recently had braces fitted, which he loves. In particular he likes the fact that he can have new colours fitted every time he goes for a check up. In the long term, Ben said that he might like to work with his dad as an engineer when he grows up. Whatever he does, Ben's parents 'just want him to deal with any situation that arises and not to feel any different to anybody else.'

Ben's parents found out that Ben would be born with a cleft while Ben's mum was still pregnant with him.

"We were really shocked and upset at first. But once Ben was born everything started to fall into place with operations and everything. It's been fine. No problem at all. I think the shock was more worry for Ben than anything else."

In terms of speaking to Ben about his cleft, his parents have supported Ben to discuss this when he wants. "We've left it as natural as it comes really. We've let it naturally come up and spoken to Ben about it when he asks."

Ben's Parents' Story

To Ben's parents it has always been very important that Ben doesn't feel any different to other children. "To us, he's as normal as our second child. We just want him to be happy and to do all of things he wants to do in life."

Evan's Story

Evan is 13. He enjoys karate, going to his local youth club with friends and playing dodgeball. At school Evan likes maths and science, and when he gets older he really wants to become a surgeon.



Evan was born with a cleft lip and palate. He doesn't remember the first few operations he had on his mouth, but he can remember the ones he's had more recently. He says he likes the nurses on the children's ward, and especially the presents his stepdad gives him when he's in hospital! It helps to take his mind off what's going on.

Evan said that having problems with speech has been hard. "Sometimes children ask questions but if anyone seems rude, I know I can ignore them or tell a teacher."

Evan thinks there are lots of good things about having been born with a cleft.

"I have no school sometimes, my grandparents come over from France, and I love the presents I get!"

Her family are really important to her, and have helped her through the hard times, so having her own family is important to her too.

"Hopefully I will have the confidence to get a job," and one day she wants to volunteer with CLAPA so she can help younger children who are going through similar experiences.

Mum's Story

It was a big surprise for Nikita's mum, Mrs Henry, when Nikita was born with a cleft lip and palate.

"I had no knowledge of it and didn't know what it was."

Talking to the midwife was helpful but Mrs Henry remembers feeling in a daze for the first three months after Nikita was born.

Taking Nikita down to have surgery for her first operation was the worst bit.

"When she came back I felt a lot better." Nikita's mum feels it has been really hard getting the right support for Nikita with her confidence, and that other people who haven't had a cleft might not understand how hard it has been on her self-esteem. Now that Nikita is getting extra support in the cleft team mum says she feels as though there has been a load off her.

"I want her to be a happy 21 year old girl, getting out and meeting people."



Nikita's Story

Nikita is 21 and enjoys playing the guitar, and being an active swimmer. She was born with a bilateral cleft lip and palate.



Nikita doesn't remember the first few cleft operations she had but can think of the more recent ones on her lip and nose. The operations were okay.

"Everyone is nice on the children's ward and they let mum stay." Nikita can really notice the changes the operations have had on her face, and she has really liked the members of the Cleft team who helped her through the surgeries.

Nikita has had problems with confidence in the past and still finds certain situations difficult. However, since leaving school and having recent operations to her nose and lip she finds she is much less concerned about her appearance. Nikita felt that she did not get much support with her confidence as a teenager but now she's seeing a psychologist in the Cleft Service things are starting to improve slowly.

Although things haven't been easy for Nikita, she has a lot going for her and recently passed her driving theory test.

"I feel more hopeful about the future now... I don't think it's going to be easy, but I have extra support to help with confidence."

Mum's Story

Evan's mum found out Evan had a cleft at the 20 week antenatal scan. Shortly after the scan, she had her first contact with the cleft team. Michaela, the nurse, saw her and gave her information about clefts, CLAPA and groups around her. "The support was amazing," she said.

"I wasn't too worried about finding out because Michaela was so good with the support... and I knew that the cleft would be repaired within the first year of him being born."

She did feel apprehensive about his first operation though, and found the waiting the hardest part "...but I have great family support so I felt like I could take it in my stride."

Mum is really pleased with how Evan has grown up.

"He's a confident, happy boy, and has the answers when people ask him questions about his cleft. Nothing seems to faze him. I wholeheartedly believe that Evan would not be the amazing, strong, confident boy he is today without his cleft."



I wholeheartedly believe that Evan would not be the amazing, strong, confident boy he is today without his cleft

James's Story

James is a very sporty and academic thirteen year old boy. He is in secondary school at the moment and enjoys English, geography, maths and science. James particularly loves the outdoors and goes to scouts every Monday evening and also does rock climbing and kayaking whenever he can. He recently went to a survival camp with his fellow scouts.



"We had to make our own tents and campfires," he remembers. "It was good, but quite cold!" He has a group of supportive and understanding friends, who he says are very important to him. They spend their time either studying in the library or socialising in the school yard at break times.

James was born with a unilateral cleft lip and palate. He doesn't really remember any of the operations that he's had. Having a cleft doesn't make James feel any different to other people.

"There's no difference between a normal life and having a cleft. Obviously you've got the appointments, but I just think of them like going to the dentist. Other than that it's normal."

James and his mum had some sessions with one of the cleft psychologists before James started secondary school. They both found this helpful, saying:

"James was well prepared to answer questions about having a cleft, just in case. That's made a big difference."

When he grows up, James would like to be a primary school teacher as he enjoys working with children. He has already chosen his GCSE subjects with this in mind.

"We saw them regularly and they all coordinated together and knew what was going on for Natasha. They also worked around Mum has noticed that it's been useful for other families to meet Natasha and other children born with clefts.

"We would have liked that when Natasha was born... sometimes it's hard to visualise how your child's appearance will change after a cleft operation, so if you see another child who has been through it you can see that things will be ok." Mum describes Natasha as a very strong person.

"If she does have any doubts or worries then she will come and talk to us. She doesn't just accept what we say, she'll go away and think and come back."

Mum thinks that having a good circle of friends has also been really important for giving Natasha the support she's needed...

"...and supportive parents!" chimes in Natasha!



“There's no difference between a normal life and having a cleft

Natasha's Parents' Story

Natasha's parents didn't know anything about cleft lip and palate when Natasha's cleft was detected before she was born.

At the antenatal scan the sonographer noticed the cleft, and they were really surprised that you see it.

"Like all parents we were worried because we didn't know what it entailed. We were given a long list of what could happen in the worst case scenario, but none of that seemed to happen to Natasha."

They feel happy that she's grown up so well.

"We're relieved that it wasn't anything more serious - a cleft can be corrected, whereas other problems can be harder to treat".

"The first operation was hard for me, because she was just a baby. It's hard seeing your baby unconscious." Although it was hard having her baby in hospital, mum tried to remember that it would only be for a short time. She also adds that the team were very good regarding school and exams when planning operations.

James's Parents' Story

James' parents found out that he would be born with a cleft at his twenty weeks scan.

"I'm glad we had that time to prepare practically and mentally. It would have been a shock otherwise."

James' mum found the news difficult at first, but this didn't last.

"I did all my worrying before he was born. From the minute he was born, we didn't have any worries. After he had his cleft repaired, I missed James with the gap in his lip because he looked so cute! But the outcome of the surgery was really good and that made things easier."

James' mum was also born with a cleft. She sees this as something that she and James share.

"We're lucky because we've got each other to talk to. I think that's been quite beneficial. We've got a bit more of an emotional attachment, which is good."

Like her parents did for her, James' mum took a very proactive approach to helping James with things like speech therapy.

"Whatever you put in beforehand, in the early years, it's worth it. You reap the benefits then."

James' mum believes that being born with a cleft has changed James for the better.

"James is a sensitive soul. I don't think he would have been so sensitive had he not been born with a cleft. It's made him a little deeper. He thinks a lot and is more perceptive of others and their feelings."

She does worry that James won't always be so accepting of his cleft. However, she recognises that it's important to remain optimistic.

"I think you've got to be positive and not dwell on it too much."

When asked about her hopes for James' future, his mum had this to say:

"I have high hopes for James, very high hopes. He has turned out to be a really popular, loving young boy. And clever as well, which is a bonus. I'm ever so proud of how he's coped with it all."

Natasha's Story

Natasha is 18. She's just finished her A Levels in Biology, Chemistry and Maths and has been offered a place at Cardiff University to study Medicine. Family and friends are very important to Natasha, and she enjoys reading books, playing the violin, and doing sports like jogging and badminton.



Natasha had a cleft lip and palate when she was born. She doesn't remember her first cleft operations, but can remember having an alveolar bone graft (ABG) operation when she was 8, and orthognathic (jaw) surgery 6 months ago. She was very determined to walk after her ABG surgery. She remembers that the nurses and her family were surprised at how brave she was being getting up and walking around after the surgery. After orthognathic surgery her face was very swollen, but it wasn't too much of a hindrance

"...except I love my food! And it was Christmas so I had to miss out on Christmas dinner! There obviously was some pain, but I was ok with it." Natasha thinks that the Cleft Team have all been friendly. The only down side can be waiting in the waiting room for appointments, so she usually brings a book or chats to her parents.

Having a cleft can affect you in different ways. "I didn't feel this as much, but you might feel different to others and that people might judge you based on your appearance."

She says it can be helpful to remember that you're born this way and it's not your fault, so it's good to try not to worry about having a cleft. She also thinks that having a cleft has taught her to appreciate things more because of all the operations and therapy she's been through.

Having supportive parents and friends has really helped Natasha.

"I have a sister who doesn't have a cleft and my parents always made me feel as though there was no difference between us. I was also lucky that in my school there wasn't much bullying, and if there were any mean comments I had loads of support around me. If you have a problem, don't keep it inside".



If you have a problem, don't keep it inside