HAMPSHIRE
SEND
Youth Forum

PHOEBE'S STORY

My name is Phoebe and
I would like to tell you
about my life with a cleft palate
and being hard of hearing

Lets go back to the beggining

1

When I was first born nobody knew what was wrong they didnt know why I couldnt cry or make a sound.

2

I was taken off into specialist care so they could find out what was wrong.

3

Within the first few hours of me being born they discovered I had a birth defect I had no soft palate at the roof of my mouth.. The doctors told my parents I could have an operation but I had to be a specific weight.

4

I had my first surgery when I was 11 months old they took muscle from my hip and used it to build up my soft palate. They also used this opportunity to place grommets in my ears.

5

Having no soft palate meant I struggled to learn to talk I didnt learn until I was in primary school through a speech and language therapist at school and also at Salisbury district hospital.

What is a cleft I hear you say?

- In early pregnancy different parts of the face form and then join together in the middle. Most people have a little dip above their top lip where this happens.
- For 1 in 700 babies, the different parts don't join together all the way.
- The result is a gap or cleft. This cleft can be in the top lip (cleft lip), the roof of the mouth (cleft palate), or both. The causes are complicated. Usually, it's a mix of many genetic and environmental factors that can’t be predicted or prevented.
- This isn't anyone's fault- a cleft can happen in any pregnancy even if there isn't any family history.

How else having a birth defect has impacted me?

Having a birth defect has also meant I was born with glue ear meaning I have had trouble all my life with my ears.

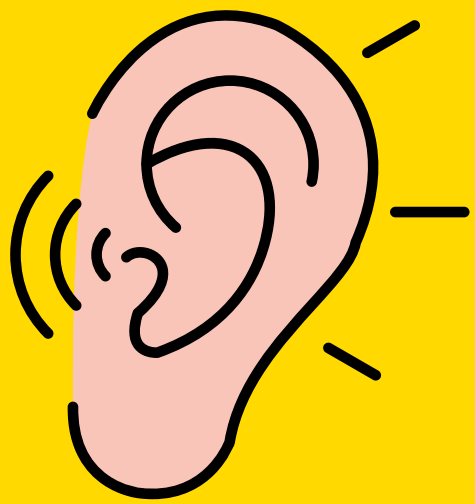
What is glue ear?

Glue ear is where the middle part of the ear fills up with fluid it can causes temporary and maybe even permanent hearing loss.

Since a young age I have always enjoyed going swimming but by the age of 15 or 16 I had to stop due to recurring ear infections the doctors would give me antibiotics but I became immune to them.

The doctors even tried from a young age putting grommets in and taking them out again several times.

The grommets stopped doing their job and the doctors had no other solution.



How was this all resolved?

Back in 2017 my Ear, Nose and Throat Consultant decided to do a CT scan to find out why I was getting so many ear infections.

This is when they discovered I had no mastoid cells (air cells) in my ears and my hearing was constantly getting worse everytime they did a hearing test.

At that point they had to make a decision so they decided a hearing device would be the best option for me. I was given the option of normal hearing devices but due to a constant battle with ear infections they decided to go with the BAHA hearing device - because this sits outside the ear.

At first they did a trial to see how I would get on with the BAHA on a band and it allowed me to hear again so we decided to go along with the surgery.

How it changed my life?

After having the metal pole put into my head which attaches to my hearing bone I had to wait a couple of months for them to officially give me my BAHA as soon as it was put on the pole and turned on I was the happiest person on earth because I was able to hear again.
I still go back for check ups and hearing tests. I have also had many daily struggles of not being able to hear people with accents and face masks but I am generally able to hear properly again. It isnt waterproof so I cant go swimming with it on.

How can you support someone who is deaf/ hard of hearing?

- Some people who are deaf/ hard of hearing can also lip read so when you are talking to them make sure you are facing them.
- Be patient they may not hear you the first time so you may have to repeat yourself several times in order for them to understand. This may be harder if you have an accent or if you are wearing a face mask.
- Please speak loud and clear if you are mumbling we can't understand you or what you are saying.
- Please also remember if we have a hearing device we might be having a bad day with it or it may be a new one and we are trying to get used to it and how it works.