

Cochlear Implant

My Story



Young people talk

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Being born deaf or losing hearing can be devastating for children and their families. I have often seen this in my work with deaf and hearing-impaired children, as a consultant ENT surgeon with a special interest in otology and cochlear implantation.

There are many medical conditions that doctors can't do anything about. But hearing loss is an exception, thanks to the cochlear implant, a clever electronic hearing aid that can restore a child's hearing via an operation and appropriate rehabilitation.

In this booklet, children and young people and their families tell their stories about living with a cochlear implant. For most this is an exciting journey – though there can still be anxiety about deafness or about looking different. The best attitude is to feel lucky that the cochlear implant helps you to hear.

The biggest challenge in my job is explaining to parents that babies who are born profoundly deaf can

only benefit from a cochlear implant if it's done very early in life. Parents sometimes feel that they are not ready to make such a decision for their baby. They may want to leave this for later.

But the earlier a child has a cochlear implant, the greater the benefit. With plenty of help and support, a very young child with a cochlear implant can learn to hear and speak well. Unfortunately a cochlear implant is not usually helpful for older children born with a profound hearing loss.

I hope reading these real stories will help parents understand, so they can give their child the gift of hearing and the joy of sound.

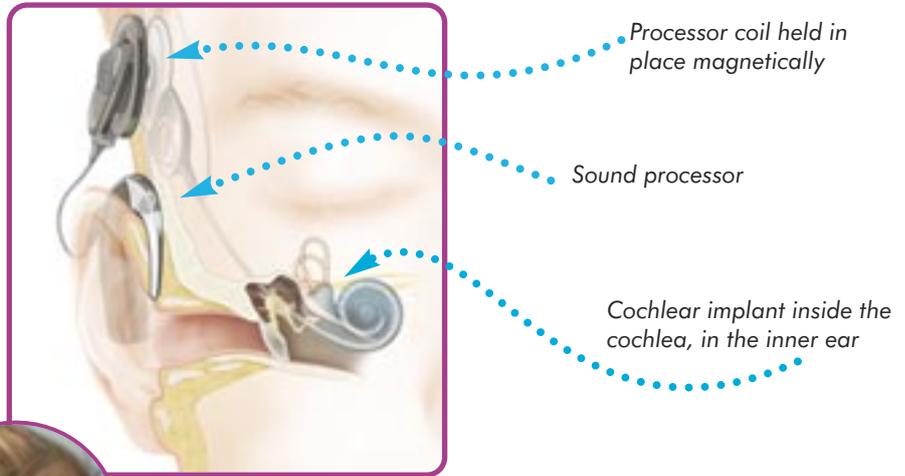
It is a privilege for me and the team at the cochlear implant centre to help deaf children to hear and achieve their potential in life.

Mrs Konstance Tzifa MPhil, FRCS (ORL-HNS), DLO
*Consultant ENT Surgeon with special interest in Cochlear Implantation,
Birmingham Children's Hospital*

How does a cochlear implant work?

A cochlear implant has two parts. The outside part is called a sound processor and the inside part is called a cochlear implant. Both parts need to be working for a person with a cochlear implant to hear.

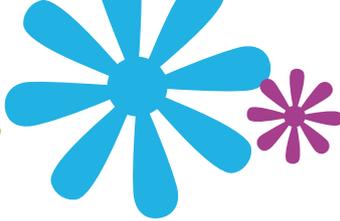
The sound processor picks up sound and turns it into a digital code. The code is transmitted through the coil to the implant just under the skin. The implant turns the digital code into electrical signals and sends these to the part that sits inside the cochlea in the inner ear. The cochlea's hearing nerve is stimulated by the electrical signals and sends this information to the brain, to be interpreted as sound.



A baby or young child who is born deaf needs to learn how to interpret the signals, so he or she can learn to listen and talk. The child's family need to actively support this process, and we offer regular appointments to help you.

Diagram courtesy of Cochlear Ltd.

Tayahana



Seven-year-old Tayahana explains, 'When I was born, I couldn't hear. When I was one year old, I had an operation to use this hearing aid, to make me hear. Some people need glasses; I need this. It's called a cochlear implant.'

Tayahana enjoys gymnastics, Thai boxing and swimming. She's keen on all types of dancing too, jazz, modern and ballet. She recently changed dance classes to find a more deaf-aware teacher.

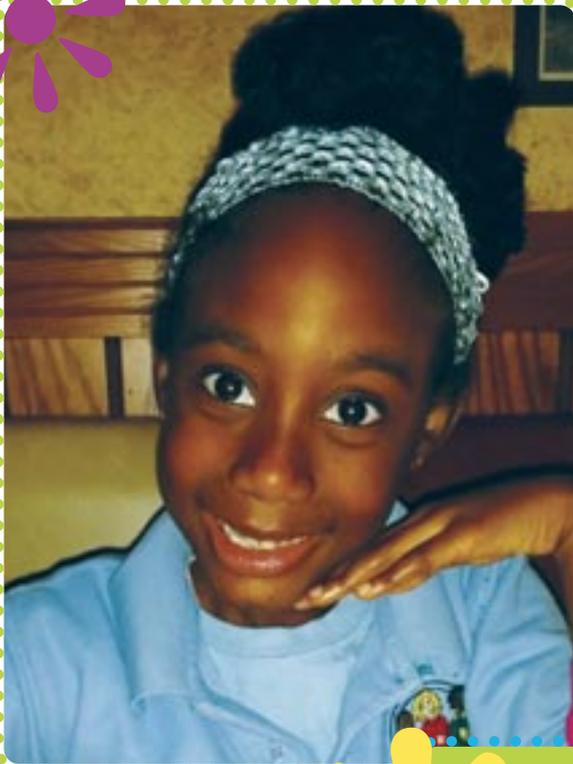
At three days old, Tayahana failed her newborn hearing test, and then her six-week test. But her mum, Maureen, didn't want to believe the news. Tayahana was offered a cochlear implant, but her family felt they could not make a decision straight away.



Some people need glasses;
I need a cochlear implant

Tayahana proudly showing her dance trophy





Tayahana

A few months later, they went to visit relatives in Jamaica. Baby Tayahana loved splashing in the sea, but Maureen realised that her daughter couldn't hear the waves or the birds. And that was when they decided to go ahead and have a cochlear implant.

So Tayahana had the operation soon after her first birthday. 'We celebrate my "hearing birthday" every February, as well as my real birthday in January,' she smiles.

'It will give her independence,' says Maureen. 'In time, with a cochlear implant, Tayahana will be able to use the phone, travel, be active. She will have more opportunities for success.'

Now Tayahana goes to mainstream school. She has an Education, Health and Care Plan (previously SEN or Statement), a powerful tool to make sure she gets the support she needs. Her school has been very supportive.

We celebrate my "hearing birthday" every February



Each year, her teacher chooses a classroom with carpets, lower ceilings and fewer windows to reduce noise levels. Tayahana sits where she can see the teacher best. A teaching assistant supports her every day, and a teacher of the deaf visits fortnightly. A home-school diary keeps everyone informed.

Tayahana wears the processor clipped to her hair, rather than behind her ear, to give her more central hearing. She has learned to treat it as a valuable piece of equipment. 'We call it "my ear", and I have to look after it,' she says.

When Tayahana is 16, she will decide for herself whether to have a second implant.



Tayahana talking on the phone

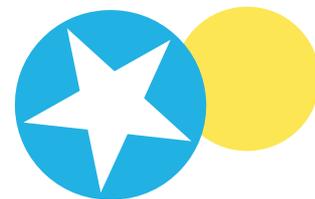
Tayahana's mum, Maureen says:

The process of rehabilitation after the operation was a big commitment. Every fortnight for two years we went for an appointment to help Tayahana learn to understand and respond to sound, and to speak and listen. For instance, they would switch the implant on, then turn on the vacuum cleaner. Tayahana would look round and work out where the sound was coming from. The next step was for her to turn the sound on for herself. She needed to link sound and meaning.

As a parent, you have to understand that you get out what you put in. The more you sing and play and talk with your child, the better they will learn to speak and listen. As a civil servant, I could take a five-year career break. Financially it was a struggle, but we wanted to do our best for her.



Matthew



Matthew, 16, had his first cochlear implant when he was two years old. He had a second at 10, when NHS guidelines changed to allow it.

'I was scared, but it didn't hurt. I think I had a stiff neck afterwards,' remembers Matthew. 'I stayed in hospital for one night. You have an anaesthetic to make you sleep, so you don't feel anything. They cut behind your ear and drill into the bone. They put electrodes into the pea-sized cochlea, which sends messages into your brain. And they drill a shallow well at the side of your skull to position a magnet, which holds the processor (or amplifier) on the outside.'



I wear a rugby helmet when I'm playing football



Matthew on the football field



Having two cochlear implants made it easier for Matthew to hear. 'Before that I always had to sit at the front of the class, but now I can sit wherever I want. I can tell where sound is coming from. Plus, if one cochlear implant isn't working, I can rely on the other one.'

You can always find a way round. Do what you want to do

At primary school, Matthew's teacher wore a radio aid microphone to help him hear. He had a teacher of the deaf at home, saw the speech therapist weekly, and had a support teacher at school. But at secondary school, he didn't want to feel different from everyone else. He was glad not to need extra support.

Now Matthew plays the guitar in a rock band, and enjoys high-adrenaline sports including bike trials and boating. He swims, plays football, and has tried rugby. 'Mum didn't find out about that till later,' he grins. 'I wear just one processor when I'm playing football, and I wear a rugby helmet to protect it. And of course I take them both off for swimming.' Nowadays in fact some cochlear implant processors are designed to be waterproof.



Matthew practising his guitar





Matthew removes the processors when he goes to sleep, and uses a vibrating buzzer under his pillow to wake him in the morning. His advice? 'You can use the phone on speaker, and texting is fab. You can always find a way round. Do what you want to do.'

Matthew on his scooter



Matthew's mum, Jennie says:

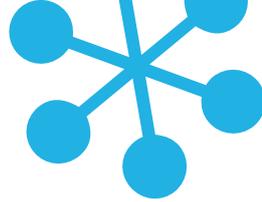
At first we had no idea Matthew was deaf. As a baby, he looked up when I came in. I didn't want to believe the diagnosis. But once, when an ambulance stopped right beside us with its siren screaming, I saw that Matthew didn't even look round. That's when I knew.

He had his first cochlear implant at two years and four months. As soon as it was switched on, he looked up and round, as if to ask what's going on? It was very emotional. We felt that this was the beginning.

So then we started on a two-year mission to help Matthew catch up with all he'd missed. It took some time for his brain to listen and recognise sounds. We had to remove all natural gesture, so he would learn to listen. For instance when the doorbell went, what did that mean?

Matthew's older brother Sam was talking nonstop at that point about cars and animals. He was my secret weapon. The boys are still close.

Briar



Briar is seven. Briar had a cochlear implant when she was three years old. 'I love my magic ear,' she says. Briar has a teddy with a toy cochlear implant attached by velcro. Now she and her younger brother, Flint, often play games pretending their toys are deaf.

Briar is interested in working out who is hearing and who isn't. Grandad uses two hearing aids. Poor 'T-for' Tortoise doesn't hear well, but has no hearing aid. 'Are fish hearing?' Briar asks. At school she has recently been learning how to look after pets.

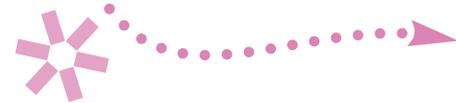
Briar attends a school for deaf children, where she is learning both British Sign Language and speech and reading. She loves computers, and she's good with techie things. 'I like PE and cricket, but I don't like football,' she says. But best of all Briar loves dancing, especially singing along with her dad to The Jam, his favourite band.

By coincidence, Briar's mum Leanne worked with deaf people before Briar was born, and she had already learned sign language. But Dad Gareth is not very good at sign language. 'So we can talk secrets that he doesn't understand!' says Briar, with a mischievous grin.



Briar

 I love my magic ear 





Briar taking her Brownie promise

Mom r u ok? – Yes I'm ok r u ok?



– I love u. See u later



It's hard for Briar to hear on the phone, so sometimes she texts her mum from the school bus: *Mom r u ok? – Yes I'm ok r u ok? – I love u. See u later*

Briar, a part-time wheelchair user, is a keen Brownie. She has learned to make the Brownie Promise in sign language, and now she is teaching it to her Brownie friends. 'She goes to a mainstream Brownie group. That way, she meets local friends – as well as through our church,' says Leanne.



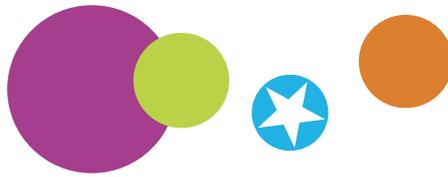
First thing every day at 6am, before breakfast, Briar changes the batteries for her cochlear implant. She wears the cochlear implant when she goes to sleep at night now too. Briar used to cry when the cochlear implant was taken off at night. She finds it comforting to hear the sounds of the house during the night.

Briar's mum, Leanne says:

At three years old, Briar was late having her cochlear implant, because of her other health issues. By then she was already learning to sign, in order to communicate. We chose a school for deaf children so that she could learn both British Sign Language and speech, and now she is growing up bilingual. Some people worry that signing can delay or impair spoken language, but we haven't found that to be a problem. For Briar it seems like the best of both worlds!



Vasili



Vasili is 19 months old. He is seriously disabled, and needs round-the-clock care.

As a baby, Vasili was nervous and jumpy, and he needed lots of holding to reassure him. 'Sometimes he jumped with surprise when we touched him,' says mum Elena. Vasili can detect light and colours, but he doesn't see very well.



Vasili loves rough and tumble with his sister



Vasili is profoundly deaf. 'Our hearts were sinking as they tested his hearing,' says dad Mike. Without hearing, he had very little awareness of the world around him. The multi-sensory team showed Elena how to put Vasili's hand to her throat so he could feel the vibrations when she spoke. Then they advised that a cochlear implant might help him.



Vasili with his big sister, Ellie



Vasili's parents weren't sure whether the cochlear implant would work, but they decided to give it a go. The prospect of a five-hour operation was scary, but Vasili recovered within a week. 'It was a hard week, though,' admits Elena.

When the cochlear implant was switched on, Vasili showed an immediate response. He looked round as if in shock. 'It was very emotional,' says Mike.

At first they found it tricky to help him keep the cochlear implant in place.

Now that Vasili wears glasses too, the apparatus can be strapped in place. He turns his head to hear better on the side where he has cochlear implant, and he becomes upset if it gets knocked off, which is all too easy for him to do. He will have his second cochlear implant about a year after the first one.

Vasili turns his head to hear better with the cochlear implant

Ellie and baby Maria. Five-year-old Ellie jumps on the bed to make him bounce, plays choo-choo train with him, spins him round on his feeding chair and pinches his cheeks. 'He loves the rough and tumble,' smiles Elena. 'I call him my little Spartan,' says dad Mike.



Videeing the moment when Vasili's cochlear implant was switched on

Now Vasili knows his name, and he recognises family members, perhaps by their voices. 'He loves music, and we sing to him,' says Elena. His grandmother speaks Greek to him, and takes his hand to make the sign of the cross over his chest.

Vasili has a particular connection with his sisters,

Abdur Rahman

Abdur Rahman was one year old when he had his first cochlear implant, and two years old for his second. 'And that was just the beginning!' says his mum, Uzma. 'After that, we had an appointment every week, and later every fortnight, so they could help me teach Abdur Rahman how to talk. We'd set up a game, talking all the time. Or we'd draw a map of an island, put people on it, and make up their stories.'

I want to be a scientist
when I grow up

Abdur Rahman went to a toddler group for hearing-impaired toddlers, with specialist support. 'It was beneficial to meet other children and families,' says Uzma.





Abdur Rahman with his younger sister and brothers

Abdur Rahman is eight now, and the eldest of four children. He is a sporty, chatty boy. He loves football and swimming, and he enjoys climbing trees and cycling in the park. He is so active that he keeps the battery pack clipped to his top. For trampolining, Abdur Rahman switches to a stronger magnet to keep the coil in place. Indoor sports can be difficult if the sound is too echoey, but there are plenty of outdoor alternatives to enjoy.

He takes them off last thing before he sleeps. Overnight they are charging on his dad's desk, ready to put on first thing in the morning.

Abdur Rahman wears both his cochlear implants all day.

Well, not quite first thing. He stays in bed reading for a bit of quiet time without the

People ask questions because they are curious. Be confident to explain

cochlear implants, before he gets ready for school. Then he runs away and hides, while his mum chases him, signing, 'Let's get ready! Mustn't be late for school!'

'I want to be a scientist when I grow up,' says Abdur Rahman. It's important that his teacher is aware of his needs. She uses a radio aid to help him hear clearly. 'Sometimes she forgets to switch it off,' grins Abdur Rahman, 'and then I can overhear her talking and find out what she's planning next.'

Abdur Rahman is learning to speak Arabic now. 'We were encouraged to use whichever language I was more comfortable with,' says Uzma.

'My implant just looks like a Bluetooth,' says Abdur Rahman. And his advice for other cochlear implant users? 'People ask questions because they are curious. Be confident to explain about the cochlear implant. They do appreciate it!'



Abdur Rahman with his grandfather



Abdur Rahman's mum, Uzma says:

We see Abdur Rahman's deafness positively, as a test chosen for our family by Allah. The consultant said to us, this is the best time to be deaf. But the technology is God-given too, so we thank Allah for the cochlear implants, which help him to reach his potential. So despite the initial risks, we just dived in.

Teaching Abdur Rahman to speak felt a demanding responsibility. But the support was great, and it helped us to be better parents and teachers to our other children. Abdur Rahman's grandparents are interested in how he is getting on. There is some stigma and uncertainty in our community about how to approach a deaf person. So it was important that they knew how to communicate with him and support his games and language learning. His deafness has brought him closer to them.

When Abdur Rahman was four, we went to Morocco. We weren't sure if we should go abroad. What if the cochlear implants stopped working? But you can't let it stop you. It's good for children to see the world!



Emma – a young adult's perspective

Emma is 19. She loves her job as a dog groomer. 'You have to be quick,' she says. 'If a dog plays up, it takes longer. And some pet owners are a bit fussy...!' Emma always wanted to work with animals. She studied at agricultural college to get her qualifications.

Emma was fitted with a cochlear implant when she was 3 – a little later than usual, as her family had to fight for the funding then. She had a second implant at 17. Her hearing and her confidence are still growing. Face to face, she lip-reads to help in noisy places, and sometimes she asks people to speak more slowly. 'I can use the phone, once I'm familiar with someone's voice,' she says. 'And I text a lot!'

She attended mainstream primary school, and chose a secondary school with a special unit for hearing-impaired students. 'I attended lessons in the main classes, and had some extra support in the unit. I had friends in both.'

Emma loves going out with friends for a meal or to socialise. She watches films and television with subtitles to help her. She passed her driving test first

Grab every opportunity!

time, and has just bought her dream car, a silver Mini. Now she loves driving to work! Emma's advice if you're considering a cochlear implant? 'Don't wait. Get it done now! The younger you have an implant, the more you can hear, and the more confident you'll be. Grab every opportunity before it's too late.'



More information and support

www.cicsgroup.org.uk Cochlear Implanted Children's Support Group offers support for parents of deaf children who want information about cochlear implants

www.ndcs.org.uk National Deaf Children's Society is a charity working to support deaf children and young people in the UK

www.earfoundation.org.uk The Ear Foundation aims to bridge the gap between clinical services, technologies and home, school and work where they are used in daily life

www.bcig.org.uk British Cochlear Implant Group provides information to patients and their families, carers and educators

www.actiononhearingloss.org.uk Action on Hearing Loss (formerly RNID) offers information, support and equipment

Companies making cochlear implants, who also offer advice and information:

www.cochlear.com • **www.advancedbionics.com** • **www.medel.com**

Donations to Birmingham Children's Hospital Charities are greatly appreciated.

You can donate on 0121 333 8506 or at www.bch.org.uk/donate

To donate specifically to our Cochlear Implant Charity Fund, please type in Sound Bank Fund (33-4-107). For Children's Hearing Services, type in Teddy Trust Fund (33-1-052).

Cochlear Implant: My Story

Young people talk

Cochlear implants can provide a young child with hearing, so that he or she can learn to listen and speak. But going through the operation and rehabilitation can be a big decision – and a big commitment for the child’s family. In this booklet, children, young people and their families tell their stories about living with cochlear implants.

Introduction by Mrs Konstance Tzifa MPhil, FRCS (ORL-HNS), DLO
Consultant ENT Surgeon with special interest in Cochlear Implantation

Written by Mandy Ross Designed by Heather Blackham

Original series conceived by Celia Moss and Mandy Ross, developed by Birmingham Children’s Hospital Charities, and designed by Anne Matthews



Professionals can obtain copies (minimum 25)
from bch.charities@bch.nhs.uk