

*Discovering their eleven-year old son was deaf came as a shock to parents Dave and Emma West and presented them with some difficult challenges. First there was Sam's refusal to wear hearing aids, followed by his initial refusal to consider cochlear implants, and when he finally came round to that possibility consideration had to be given to the impact on Sam's passion for taking part in rugby. Investigation of this led to Sam being part of a trial for a new head guard being developed in Australia. Mum, Emma explains ....*



## TACKLING THE CHALLENGES

Our youngest son, Sam, has always been a character who was loud and like a whirlwind. That was just Sam, but then the music and the TV were getting louder, as was he and so we asked for a hearing test. We were referred to the routine school screening, but we were pushing for an earlier test. Then Covid hit and we were lost in a mass of waiting lists.



Finally, in September, 2022 the School Nurses visited Sam at school (reluctantly) and soon realised there was a problem. We were referred straight to Audiology and Sam was diagnosed as profoundly deaf with a bilateral high frequency sensorineural hearing loss. As parents to a total of four children, realizing our eleven-year-old year old who we thought was just a bit loud and annoying, is actually deaf was a blow. How had we missed this? How did we not know?



The Audiology team at Scunthorpe General Hospital were great and quickly fitted Sam with hearing aids. However, right from the start he rejected these and the battle of getting him to wear them commenced and lasted for a year. Sam complained they made it too loud, gave him a headache and were just a bit overwhelming.



In September 2023 Sam and I joined a BSL Level 1 class. I loved it more than Sam but he stuck with it. Our teachers were Gemma and David Webb of Webb BSL. Both are deaf and are fantastic, always making our lessons fun and informative.



Following several audiology appointments, the suggestion of a referral to a specialist team to consider cochlear implants was made. We knew nothing about CI's and took a look at Google. We were overwhelmed; the thought of surgery and whether people would stare at him, were just some of our initial fears. Sam himself was a firm NO! However, in November 2023 we chose to be referred to Bradford and we've not looked back.

Every single person at the Yorkshire Auditory Implant Service (YAIS) was welcoming and took as much time as we needed to explain everything. They undertook more in-depth hearing testing following which it was explained to us that for Sam's type of hearing loss, which is described as a ski slope loss, hearing aids were ineffective; they were only increasing the sounds Sam could hear and not giving him access to sounds he was missing. This was Sam's opportunity to tell us "I told you so" and the hearing aids were never worn again.

However, Sam was also firmly set against even discussing the possibility of cochlear implants. Family and friends rallied round, and all tried to reason with Sam, but reasoning with a then twelve-year-old as many of you will know (!) is impossible as, of course, they know best. Sam could not see the future impact as we could. His timeline for life went from Sunday to Sunday, rugby match to rugby match, with no thought for GCSE's and beyond.



That was the other stumbling block - rugby. Sam loves Rugby and is a loosehead prop in the front row of the scrum. Every professional was telling us that cochlear implants and Rugby are not a good combination, and the advice is not to play. Another reason for Sam to remain a firm with a definite NO.

On a shopping trip to Doncaster to spend Christmas money we went to Sports Direct and Sam nudged me and pointed to a member of staff who was wearing CI's. Much to Sam's annoyance I asked the member of staff if he would mind if we asked him some questions about his CI's. He was a great help! He was 18 and explained that he was 12 when he was implanted and that his brother was also about to be implanted. He took off his processors so that Sam could look at them, and showed him that there was no visible scar from the operation. This was the most important message to Sam - that, and that his friends could stick metal things to the magnets on his head. Sam's attention was caught - he thought this sounded ace and that he would have quite a unique party trick. This chance encounter opened the door for Sam to start considering CI's as an option. I will forever be grateful for the time the young man from Sports Direct gave us that day, it turned out to be life changing.



Sam started talking more about 'what if's' and asking more in depth questions about the process and the operation, but rugby was the blocker. We started doing research and found deaf sports men and women to show Sam that anything is possible.

On New Year's Day 2024 Sam announced that he wanted to get the cochlear implants. We were astounded, thrilled, scared and proud all at once. As soon as we could we contacted the team at Y AIS to share the news and they were equally astounded, thrilled and proud. We were given an appointment to go back and discuss Sam's new decision and the process began.

As part of our ongoing research about CI's and sport, we came across a company in Australia who were developing head gear for Deaf and hard of hearing athletes. Sportswear manufacturer Steeden had partnered with Colgate to create Hear Gear:

<https://www.heargear.com.au/>



We got in touch and were accepted onto the trial which was very exciting for Sam and we waited eagerly for his Hear Gear to arrive.

In May 2024 we arrived at Bradford Royal Infirmary early in the morning for the six hour operation that was to give him cochlear implants. One of the biggest worries for us was the possibility that Sam would lose what hearing he did have following the operation, so it was a huge relief when in the recovery room Sam was answering our questions and we were thrilled to think he could still hear something. However, it was not until the journey home, when we were trying to talk to Sam in the car that we realised he could not hear us, and he had in fact been lip reading in the hospital.

The recovery process began, and Sam took everything in his stride. Two days later we were given the news that the electrode array coil in Sam's right ear had curled back on itself and a repeat surgery was needed. This is one of those exceptionally rare complications and the caring support from the Y AIS team was brilliant throughout. They got Sam back into surgery quickly and repeated the operation in his right ear. Being a bubbly character, the porters and theatre staff had remembered him and his bad jokes from his first operation two weeks earlier.

and this helped to ease any worries Sam had about the further surgery.

Not long after surgery we had our Level 1 BSL assessments - we are pleased to say that we both passed and I am so very proud of Sam for doing this course. I love my Monday evenings with Sam, learning a beautiful new language which we can use when he is not wearing his CI's, or in a crowded noisy place or for me to silently shout at him from the Rugby touch line.



Switch-on day came and Sam got his Cochlear N8. For the first few months Sam was only wearing his 'ears' (as we call them) while he was out of our home. As soon as he walked through the door it was a case of shoes off, ears off. Gradually over time, he began to realise the benefit and is now wearing them from waking to sleeping and the batteries are sometimes running out before he takes them off. This is amazing progress for Sam, and he has said that he is very happy to have them and that it's changed his life.



In September 2024 Sam started playing Rugby again. The Hear Gear head guard had not arrived by then so he was using a normal scrum cap. This was not ideal, but it kept him doing what he loves. As parents on the touchline and seeing him in the scrum or at the bottom of a maul we are watching through our fingers, but the coaches, players and parents have been simply fantastic and all have been very accepting of the need for support and protection of Sam's head during the game.



Just before Christmas the Hear Gear arrived from Steeden in Australia and Sam was understandably keen to start trying it. It turned out to be much more comfortable than what he had been wearing, and he found he could hear much better and more of the game, his team mates and the instructions for game-play given by the captain. It has plenty of room for his processors



*This shows the difference between a normal scrum cap and Sam's*

making it much more pleasant for him to wear as the guard does not rub against the microphone.

However, we have recently found out that these head guards will not be put into production so will not be available for future purchase. We were sad to hear this and have not been able to find out why. I am so glad that I managed to get one for Sam when I did.



Also in September 2024 we joined a BSL Level 2 class, again with Gemma and David. Learning more about BSL, its structure and more about the deaf community continues to fascinate me.

Sam's progress has been fantastic. Six months after switch-on we were amazed at his progress and just couldn't imagine how much even better his hearing will eventually be. He was already hearing sounds he had never heard, the rain on the car roof, the referee's whistle, Small Bells on Christmas ornaments, some birds tweeting. It is a couple of months further on now and we have just been back to Bradford where the excellent results of his audiogram provide concrete evidence of how much he can now hear.



Sam originally had a dream of joining the RAF to train as an Aviation Mechanical Engineer, but this is not possible. Undeterred, he has refocussed and would now like to pursue Agricultural Engineering - Go get it Sam, your future is yours for the making!



Sam has a facebook page if people would like to follow his journey:

<https://www.facebook.com/samssuperpowers?mibextid=wwXIfr>

