



A Father's perspective: Matt Denton

Charlie's Usher's journey has so far been dominated by his deafness. He failed the newborn hearing test and six months later we were told that he was mildly deaf. The Doctor reassured us that it wouldn't really impact on his life but that he may have to sit at the front of the class when he started school.

Both my wife and I are professional musicians and play in the Carducci String Quartet together. Charlie has been surrounded by music all his life and from a very early age, he would jump around enthusiastically whilst we rehearsed and would giggle when we made some unusual sounds on our instruments. It therefore came as a complete shock when we were told two years later that Charlie wouldn't even hear an aeroplane if it took off next to him!

He was an extremely energetic child, not always well behaved, and my mum said it was like looking after a small hurricane! It was hard to have any sense of discipline.



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Charlie had bilateral Cochlear Implants aged 3 1/2 and really flourished. He became calmer and more engaged with the world and he started quickly picking up words without us having to teach them to him. He grew in confidence and, for the first time, started making friendships.

We are fortunate that Charlie likes a challenge. He sets himself goals and has so far met them all. He trains with the GB Deaf Tennis Squad and is on the FA Disability Football Talent Pathway. He loves music and recently played the violin and piano at the Beats of Cochlear Music Festival in Poland. Last year, he gave a speech at the House of Commons #veryproud! It was amazing to see how far he'd come - from a frustrated toddler who couldn't make himself understood, to a confident young man, talking in front of a room full of strangers.



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Emma had talked about Usher Syndrome very early on. Charlie used to cry in bright sunlight and would often try and turn around in his buggy when the sun was out.

Searches on Google brought Usher Syndrome to our attention, but I must admit that I wasn't convinced. Charlie was quick to walk (9 months) and was only mildly deaf at birth. However, Emma seemed to have a sixth sense about it and when we noticed that every now and again he'd fall over for no reason, we pushed to get Charlie tested.

We actually found out the results over the phone, just before going on stage to perform in a concert. Emma came off the phone to the Doctor and seemed in shock. I'll always remember the moment she said "it's positive, Charlie has Ushers 1B." I was in such disbelief that I made her call the Doctor back to double check. We were then called on stage and I played the whole concert without looking over at Emma as I couldn't trust myself not to break down.



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The hardest part was phoning our mums. Charlie was the first grandchild on both sides of the family and our mums have helped look after Charlie backstage and on tour from when he was just a few weeks old. I knew it would break their hearts.

Since then, I can honestly say that Charlie's life has been nothing short of inspirational, and he brings a smile to our faces every day. He has an incredible zest for life and seizes every opportunity given to him.

Last summer, Charlie was diagnosed with the early stages of Retinitis Pigmentosa and that was tough. I'm not sure how I'm going to feel when I see him struggling in the future. What I do know is that we have definitely lived a richer life because of the journey we've been on so far.