



Claire Morley

I was born in 1974. When I was two it was determined that my older sister Catherine was deaf so I was tested too. I was also deaf. I got my first pair of hearing aids then. I don't remember life without them.

We are a catholic family and our local catholic primary school wanted to provide places for us and give us any support we needed. This was before teaching assistants existed. At that point the local education authority wanted to send us to a specialised school for the deaf but our parents resisted. I therefore attended mainstream education and loved it.

I wore a "phonic ear" radio microphone system which in those days was the size of a brick and worn in a harness on the chest. Our grandma sewed us fancy harnesses to match different outfits, I felt very snazzy!

To me that was normal life. The other kids just saw me as Claire, I was no different.

As a kid I never had night sight but again that was normal for us. I do remember being amazed that other people could see in the dark, I was very impressed.



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Fast forward to age 23. I was referred to Manchester Eye Hospital by my optician. He had seen something and wanted it checked out. I didn't give it much thought.

Two days before Christmas I took the morning off work and went to my appointment.

Well I got the shock of my life. The consultant moved his fingers at the side of my face and said "tell me when you see them". And this sick feeling plummeted in my stomach. In that instant I realised I couldn't see them and I should be able to see them. He then asked me about my night vision and my balance. You have something called Usher Syndrome, he said. He then went on to say I would lose my sight but hopefully retain some useful vision, told me there was no cure and sent me on my way. I went back to work and worked the rest of the day in a daze.

It was textbook how NOT to tell someone.

The biggest thing on my mind was that I then had to relay this bombshell to my sister. Finally, an explanation as to why we were born deaf, but here's the next bit - we are losing our sight.

That was hard.



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It sounds daft but neither of us had any idea we were visually impaired. Once I knew, it was obvious. So much started to make sense, the clumsiness, the night blindness, the not recognising people from a distance.

In one way I was glad to have a name, a diagnosis.

My kind and lovely GP wrote to me, apologising for not having heard of Usher Syndrome and therefore not picking up on it. I understood why he hadn't though - nobody had heard of it. This was the 90s, before the internet had really kicked off. I felt like a very rare bird, so few of us were known about.

These days children are being diagnosed much much earlier and of course, for parents it is devastating. As a mother myself I know you don't want your children to suffer in any way.

This is what I say to parents in this situation:

It's ok. It really is. I'm 43 now, married with a beautiful daughter. I got my degree, my post grad, and went on to have a rewarding career in social services. I have just had a cochlear implant this year, last year I got my guide dog Thea. I also use a long cane if Thea is having a day off. I currently still have some useful vision. I use apple products (iPhone, iPad, Apple Watch) as they are the most accessible for me. I plan to learn Braille (when I get a chance!) and I've also learnt the rudiments of deafblind manual sign language.

It's not the end of the world.

Life is different but the value is the same.



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I have life skills that others don't - resilience, adaptability, fast reflexes, problem solving. I can read a situation better than fully sighted/hearing people because I really pay attention. I'm convinced I'm safer out on the street than others because I really focus on my environment. I'm aware of risks, I'm a planner for all eventualities.

The advice I'd give for how to support your kids:

- Give them confidence and belief in themselves that they can do it.
- Help with communication - explain what's going on, when, and why, what's happening next, and if they don't hear a certain word, rephrase it rather than repeat.
- Encourage them to be open about their accessibility requirements - done with a smile, nobody minds being helpful
- In the home use contrasts - so door frames a different colour or other such definitions of space
- Don't leave cupboard doors open



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I could go on and on but every person with Usher is unique and you will find your way. My sister and I had, and continue to have, very different experiences and reactions to Usher Syndrome.

One thing in particular that has been the biggest help to me is finding others with Usher. Other people who get it. It's very liberating and empowering. Social media has been fantastic for that.

For anyone starting out on this journey I give you my best wishes. It will have its ups and downs but ultimately it will be ok.