



Catherine

I am 46 yrs old with Usher syndrome 2a. I am married with two teenage boys 15 and 13. I am Director of EC Energy Ltd, we are a small family run company. I manage the finances of this and 3 other sister companies. There are two of us in our family with Usher syndrome, my sister too who is 3 yrs younger.

I was born with a severe hearing loss, although my parents did not know as it was back in the 70's, my parents started to realise something was amiss and I was taken to the doctors and they were told I was lazy. It was pointed out on a family holiday, by a family next door to us at Pontins who had a deaf son, that maybe I was deaf too, from then on tests started to happen. I was 6yrs old before I got my hearing aids, I had been at the local primary school for a year without them.



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Both my primary and secondary school were fantastic at dealing with our disability. Making sure I was sat at the front, before hearing aids, they used a tape recorder to read stories to me and I would wear headphones. I never felt excluded and the kids were great in my class and one of my best friends there is still very involved and part of my life today.

At secondary school I was given a phonak ear device for me to wear and the teachers to wear, I hated it as it made me look and feel different, so I stopped using it! I left school with 5 O levels and one was a grade A in French!! Since writing this I was telling my best friend who was at school with me and she had a different spin on secondary school, she said when I use to hand the microphone to some of the teachers they would not put it round their necks and just left it on the table, I vaguely remember this.

At 17 I started learning to drive, and after 3 attempts I passed my test before my 18th birthday. I was the first to drive out of all my friends and I loved it. I drove all over the UK , London, Scotland, Ireland, I was a confident driver.



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After my sister went for a routine eye test, she was told she had black spots at the back of her eyes and was seen by Manchester Eye Hospital then diagnosed with RP. It was advised for me to have tests too and I was diagnosed in my mid 20's. At the time it did not have a major impact on me as I was leading a relatively normal life, still am, apart from some major adjustments. It did explain my poor night vision, but I thought everyone was like that, and explained tripping up over kerbs in the dark (nothing to do with alcohol consumed!).

At the age of 37 I had to stop driving, and to be honest that has had the biggest impact on me with this disability. I was stripped of my independence being able to go where I want when I want at a minute's notice, now everything takes longer to get to places and needs more planning.



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The day I was told in January 2009 I was being registered blind was the worst I had experienced with my diagnosis. I was on my own and basically told I was being registered blind. When asked 'why not partially sighted', I was told "it's only going to get worse" which is the truth, and was quite blunt. I left the hospital with no additional support and remember walking down Oxford Rd in a daze, stopping for something to eat and being quite emotional about it. How I got home that day I never know but it was a major impact as now I knew I definitely couldn't drive even though I stopped before that Christmas. It eventually made an impact on where I lived - we had to move to be within walking distance of school, bus stops and shops, although the move was for the better, as we love where we are now.

Last year I had a fall down a small flight of stairs in a restaurant in Manchester and that was the turning point for me to start long cane training. In January this year I passed the training and I love my cane - it now gives me the confidence to walk independently without bumping into people. Last month I was told I am now on the waiting list for a guide dog.



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Advice for families

One of the best advice my mum was given was don't spoil them because of their disability

That gave us good grounding in living a normal life as possible. I felt we were not treated any differently to other people, only just a blip of having to deal with a hearing loss. We are a very positive family and strive to make the best of everything. One plus point I get a decent night's sleep!! With the sight loss that has been a gradual adjustment and as time gone on we have had to adjust with specialist equipment, magnification, canes etc. I don't worry about the future as other things could happen that we can't control.

I enjoy life and living life to the full - being with my family and friends and going out socialising, and my passion is travelling, I love visiting and exploring new places, I won't say it's easy but I enjoy the challenge and won't let Usher syndrome stop me.



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Other advice is practical:

- Never stand in front of a window when speaking as I can't see your face.
- Do not exaggerate your speech by speaking slowly and loudly. (It's condescending and irritating, even though they're trying to help)
- Do not say I'm here or it's over there - we need specific instructions, such as 'I'm sat on the floor' or 'it's next to the kettle'.
- Please do tap me to get my attention in a busy environment such as out at a meal.
- Please do request lighter areas to sit in restaurants, or lighter rooms in hotels, or ask for more lighting. If you don't ask you don't get.
- I'm sure there are many more scenarios and situations and more advice, don't get me started on waiting rooms in hospitals.....