

# My life journey with Usher Syndrome

**Russ Palmer** shares his personal insight to living with Usher syndrome, with points for reflection when working with a young individual with Usher

Growing up with Usher syndrome has been quite a challenge. Nevertheless, there are some aspects children and adults might like to consider in learning to deal with this condition. Probably the most important area is learning to accept the eye condition. I mean, over a period of time, the vision starts to narrow down and this can affect people in different ways. In this article, I hope to highlight some of my own challenges and how I dealt with these, from leaving school, changing careers, and taking early retirement, to learning to take on another career.

I was diagnosed with RP (retinitis pigmentosa), and afterwards with Usher syndrome, in my early 20s. I was in my first job as a computer programmer and at that time drove a car. The journey to and from work took one hour, leaving early morning, coming back late in the evening. At that time I lived in West Sussex, so I used to drive on the busy A27 route. When the doctors said I'd have to give up driving, it was devastating news and very hard to come to terms with because it was taking away my independence. At the time I was living with my parents. I was in the process of thinking of my future in the long term. This involved getting on with my career, studying, getting married and maybe starting a family later. All the usual things people aim for in life.

Strangely enough, it was only last year that I gave up my driving licence, even though I was registered blind in 1992. It felt like giving up something one doesn't want to, but gradually one realises: okay, perhaps now it's time to do this. Also, the driving licence was still a valid ID for many areas of society, but I gradually realised that my passport was just as good to use. I'm now 60+ and coming up to the dreaded retirement age and I could have been asked to retake my driving test, which would've been quite impossible now as I am registered deafblind and using two cochlear implants and a long white cane for mobility and safety.

## What makes up one's identity?

I was born severely deaf but didn't receive my first hearing aid until the age of four. I went to Woodford School for the Deaf, near Leytonstone, and I attended there until the age of seven. We were taught

with the oral method and were not allowed to use sign language, which was fine for me as I grew up with hearing rather than deaf kids in Shenfield, Essex. This was during the 60s. From the age of seven I attended a hearing school where I encountered bullying and teasing because of my body-aid, which looked like a bra. That was part of life and you just had to deal with it. I was the only deaf kid in the school but I still had many hearing friends and did sports, like football and swimming. Later, I focused more on swimming, as hearing aids picked up background noise when playing football, and I completed my personal survival courses up to gold level. In addition, I did the bronze, silver and gold levels of the Duke of Edinburgh Award – it took me 10 years to complete due to moving around the UK, ending up in Aberdeen in Scotland. But in the end I went to Buckingham Palace to



collect my Gold Award from the Duke of Edinburgh himself. That made my mother's day! This was in 1981 when the doors to the palace were not open to the public. The best part of working towards the Award was the expedition up to the mountains of Snowdonia, Dartmoor and the Highlands of Scotland. This was challenging, fun and exciting. It all gave me the confidence to do these things. Moving around the country disrupted my education but also built up my confidence.

In my teens, I noticed I had problems seeing in the dark. Well, I just thought everybody had the same problem. I used to do a paper round, riding my bike and trying to deliver the papers to the right houses and that was difficult. I only did it for a couple of weeks until I realised that wasn't an option. It also assisted me to see there are other people with disabilities more profound than my own. I found I had compassion and understanding for others, and empathy. These qualities to my mind are the most important in today's society. We can all identify our own skills and ways of learning to deal with our own limitations. This is very important to keep in mind, also in a school setting. Confidence-building and acceptance of limitations are the most important factors in learning to deal with Usher. We might have certain goals in life, but they might have to be adjusted, according to one's limitations and reality.

It is important for the children, after diagnosis, to understand the changes in their vision, as sometimes this can lead to anger, guilt and frustration. Some children blame their parents for the changes in their vision. I know my parents felt guilty about my vision changing and tried to support when possible, sometimes the way they did it varied according to the situation.

A very important turning point during my crisis years, including a change of career, was an effective and simple gestalt therapy exercise that my social worker suggested I should do. It involved many newspapers and the chairs in the room – and let me just say, it ended up with shredded newspaper bits and overturned chairs all over the room. Open communication, love, support, believing in yourself and building up your confidence are important in learning to accept what's happening to one's hearing and sight. The changes to the two most important senses can feel frustrating and frightening. A feeling of time running out. But in reality I'm still here.

### Present day

Okay, I cannot read text, books nor see pictures, colours or faces of loved ones, and sometimes it does feel the world is collapsing around me. I started to lose my vision at the age of 55, but I have to say, thank God for technology, the support of family, very good friends, and

people in general. Being open about one's limitations and accepting support, like being guided or using a cane or a guide dog, are important for getting around. I have come to realise that one can access information in new and exciting ways (Russ Palmer, 2020. How to feel the Universe. Spaceflight 62, December 2020, 323-7).

Today, I am a qualified music therapist, I write academic articles (russpalmer.com) with colleagues, I compose and play music and even give performances in various ensembles. This has all been fulfilling and enjoyable to do. Even if you cannot read music, through cooperating you can still do music (see my previous article in BATOD, May 2020). In addition, in the course of 20 years I have been fortunate to give lectures, both in the UK and abroad, and now find myself being involved in EU research projects, which I would not have thought possible when I look back.

Another thing I explored during the lockdown was to rekindle my interest in model-making. I took that up with my friend Andrew, who took up my challenge of making Apollo spacecrafts and airplane models. We do model-making via Zoom or FaceTime, with paints, colours, and glueing bits together. This knowledge is in my memory, having grown up during the Space Race – and being a Fellow of the British Interplanetary Society. There I promote awareness for museums and venues and places of interest, and as a Battlefield Trust member, I've been frustrated by the fact that I cannot access the military history books in audio format – again promoting accessibility for the blind via tactile materials.

I could not have done this without the love and support of my wife, Riitta Lahtinen, and close friends and colleagues. Currently, I also need the support of communicator-guides and personal assistance (PA) services. This allows me to be more independent without having to rely too much on my immediate family. This is all to say not to give up. It is possible to explore new areas and approaches with advances in technological assistive devices. On reflection, Usher syndrome, in some ways, can feel challenging at times, as one has to learn to do things in a new way. But as long as one can be independent, while at the same time not being afraid to ask for assistance, then one's life can be fulfilling. ■



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