

Nick Sturley:

10 ways people positively survive having Usher Syndrome (BSL)

Like with everyone else, they have their up and downs, however, being deaf and having visual impairment, having Usher syndrome can be like a confidence rollercoaster ride.

When they're down, they always bounce back to survive.

So, how do they do it?

1. Be Positive

Easier said than done, yes, but there is no point in being negative or feeling self-pity about not having good vision. People with Usher focus on now rather than what could have happened, and say: "I can do this. I won't let my eyes stop me!"

Helen Keller said: "Self-pity is our worst enemy and if we yield to it, we can never do anything wise in this world".

#dontgiveup

2. Adapting to Changes

When their vision changes, they have to adapt. It's part and parcel of having Usher. They have to give up many things they love to do when their vision no longer allows them to do them.

Examples include: giving up driving a car, retiring from work quite early, or reading – so they need special electronic reading devices to help them.

But as they say: one door closes, another opens. They have to adapt to changes in order to fulfill the best possible quality of life. It does take a certain amount of pride-swallowing, but that's life.

#bitethebullet

3. Usher Social Gatherings

Social gatherings where Usher and deafblind people meet can be enormously beneficial.

It's the same with Deaf people meeting up at social events, but it's even better for Usher people because it helps bring them out of their isolation and to understand that they are not alone in the world as well as to boost their confidence. Interestingly, the most popular ones are organised by Ushers themselves, and many of those, particularly those who use BSL, would gladly come from all over the country to attend them.

#havingfun

4. Facebook

People may have their opinions about Facebook, but for Usher and deafblind people, it's their Holy Grail. It helps them to communicate with their families, friends and Usher/deafblind peers from around the country and the world.

There are many Facebook groups for Ushers and these [recommended Facebook groups](#) can help them to be part of the social network community to share news, knowledge and experience.

#thankfulfortheinternet

5. Sense of Humour

When Ushers are feeling down, their eyes having a bad day, or just had a little accident with a full coffee mug or something, they might feel annoyed or angry at first, but they would gradually laugh it off as being part of having Usher.

There is no point in feeling sorry for themselves, otherwise they would be letting their eyes have the last laugh.

#laughteristhebestmedicine

6. Well Organised

It's so easy for many people to be unorganised with their lives, but for Ushers, being organised is an absolute necessity.

Because of their limited vision, it can be quite easy to lose track of where they had put things around the house. So they tend to make sure that everything is in the same place every time.

Even a TV remote control must always be left in the same place after use, not tucked away between the cushions, on the floor, or wherever, otherwise they would turn the living room upside down looking for it.

So, if you visit an Usher person's house, you'll find the place organised, immaculately clean and tidy!

#housepride

7. Forward Planning

Ushers are keen and experienced forward planners, that's a fact.

If they want to go somewhere for a break or something, they tend to check how long it takes to travel there by train, the number of stations they would pass, the hotel being in an ideal area, the lighting in the rooms, the accessibility of the restaurants and places in the area, and so forth.

The above is just one of many examples of the ways that Ushers always plan ahead.

#astepahead

8. White or Red/White Cane

It's not unusual for some Ushers to be apprehensive about having a white or red/white cane because this kind of confirms that they're fully blind when they still have some sight.

Believe it or not, it's actually one of the most important things in their lives. It's their Moses parting the Red Sea tool.

When people see them with the cane heading their way, they move out of the way (well, for half of the time anyway, as some people can be more blind than them!) and the Usher and deafblind people would feel safer.

More can be said about those stupid cyclists on the pavement though...

#canepower

9. Mobile Phone

It has often been said that Deaf people can't live without their beloved mobiles, or even leave home without it, so that they can text, Facebook and video chat anywhere.

Well, for Ushers, it's an absolute lifeline. If they find themselves in a spot of bother, like being stuck at a rail station on one stormy night and their train is cancelled, they text their partners or friend to come and rescue them.

There are a thousand and one other reasons why they need their mobiles at all times for emergencies, calling up their communicator-guides, and communicating with others if they don't have access to email or internet (as some Usher and deafblind people don't).

And they always ensure that they keep their mobiles fully charged!

#sos

10. Good Friends

Having good friends that live locally are of enormous benefit to Ushers, so that they can be part of their social circuit and not feel isolated.

Of course, the friends can't always be there for Ushers, as they have their own lives to lead too, but when they do

meet up at a pub, or a friend's house, or whatever, this can be great for them and to know they're not unwanted.

#friendship

Nick Sturley is an award-winning author & writer, director and screenwriter who published his new book Innocents of Oppression earlier this year. He has Usher, but he has never let it get in the way of his never-ending challenges in life. His motto is: don't let your eyes rule your life, let your brain do that. Check out his website here or follow him on Twitter as @NickSturley.

The Limping Chicken is the UK's deaf blogs and news website, and is the world's 6th most popular disability blog.

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