

My name is Carol Brill and I come from Dublin, Ireland. I have Usher Syndrome Type 2. I have been invited here to talk to you today about quality of life from a personal view.

Having Usher Syndrome brings many losses, not only visual and hearing loss, but also loss of independence such as driving, playing tennis and basketball, being able to go shopping alone, being able to see in the dark – all these things I once had.

I was a fully sighted person, now I'm partially sighted.

But I've experienced more profound losses in the last 3 years –

I lost my wonderful father to cancer.

I was a wife, now I'm divorced.

I was a mother, but I lost my son when he was 4 days old.

Despite these losses, I would consider my quality of life very rich. Having Usher Syndrome has made me a strong and confident person. It may not have been the case when I first discovered my diagnosis at the age of 21. My parents had known about my condition since I was 11 years old. My 15 year journey (do the maths!!) since discovering that I was facing blindness has been rather interesting. Lots of highs and lows. At first, I turned to alcohol for a short while to deal with the shock of finding out I was going to be blind. Then one morning I woke up and decided that drinking was not going to solve my problems. I remember that day clearly in June 1992 when Ireland lost its chance to play football in the European Championships. So from that day on, my life changed. My horizon consisted of charity involvements, a civil service career, furthering my education, and personal challenges. Having Usher syndrome has provided me with the excuse to grab life with both hands. From parachute jumping, cycling in Australia, trekking in Nepal, to the less physical exertions of being national chairperson of Fighting Blindness Ireland, being appointed by government as a board member of a state agency, and to now, running my own coaching psychology practice, and representing people with Usher Syndrome on the Deafblind International Council.

How come I've experienced these things? For a long time I battled with advice being given to me to learn Braille, learn how to use a white cane, have a career in switchboard telephony, basketweaving or computer programming. I strongly believed I had a lot more to give in life and that life had a lot more to offer me despite my sight and hearing impairments. My inspiration to do this came from my father. He always said "Dare to be different – people will always remember you for that". This advice was given to me for the purpose of job interviews. However, my dear father did not realise the extremes I would take this advice to. I can remember quite clearly when I quoted his advice as justification to do a parachute jump. My father held his hands to his face, in exasperating regret!

So to be different, I decided to pursue a degree in psychology. My motivation to do this was mainly to compliment my work in the public service recruitment sector, where I worked for five years. But as time went on, I realised that it was time to look at new pastures – to work with something I truly enjoy but in an environment that was conducive to my life. I now work from home as a coaching psychologist, so I do not have to worry about travelling with my faulty eyes! I suffer from visual tiredness so I only work the hours that suit me best. Above all, I'm working with people who want to improve their lives – and it is such rewarding work. I have achieved so much in the past through my charity work – with television and radio interviews, giving public talks to many audiences, including British royalty!! I achieved the Presidents Gold Award, a degree in honours psychology and now I'm currently studying for a Masters Degree in Oxford Brookes University. All these achievements make me feel great AND NORMAL.

But all of this has been a challenge of which I had to work quite hard to achieve. In Ireland, very little is known or understood about deafblindness. Deafblindness is like a 'piggy in the middle' situation. There lacks a representative body of deafblind people, providing information and support services, training for vocational or independent living skills and other related services. It is my greatest hope that this will begin to become a reality in Ireland very soon. Because to date, people with acquired blindness and myself have to rely on ourselves to adjust to this significant change in life.

It is too easy to suggest to someone with deafblindness to follow the trend of the established career choices of our previous deafblind generations. There is nothing wrong with those careers. But I firmly believe that deafblind people have so much to teach others. For people with acquired deafblindness, this important transition in life equips us to embrace all the hurdles life brings us. Personally I feel much stronger to cope with loss and to embrace change. My life experiences enable me as a coaching psychologist to help others to enhance their lives. Everyone has the potential to be what they want to be, despite their disabilities or any other limiting factors. My life experiences provide so much benefit for my clients as they work towards enhancing the quality of their own lives. My clients do not see my disability, they see my ability.

We can easily become weighed down by the negativity of our problems rather than lightening our load by seeing the possibility and positivity of solutions. It may not be the solution we desperately want, like a cure or treatment for our failing sight and hearing. But there are other solutions if we allow ourselves to think and act on them. This is what quality of life is about for me. I disable my disability by enabling my ability to achieve my own potential.

Let's do an exercise now. Can I have two volunteers please?

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So as you can see, life is like a battery. For a battery to work, it needs the positive charge and the negative charge. A battery cannot work without the positive and it cannot work without the negative. That's how I have come to view having Usher Syndrome. I have this condition – yes, it upsets me, it gets me down, after all I am human. But my quality of life is so much the better for it. Before I knew about my condition, I was a girl who just went to work and then partied at the weekends. Since I found out, I have had the best life and there is more to come. I will cross my bridges without fear, with optimism and with the willingness to accept that everything serves its purpose, including the mistakes, failures and hurts. By accepting who I am, accepting my disability, my quality of life remains intact. If I deny these things, it would be hard for me to find purpose in my life. For now, I still don't know what my purpose is in life, but I do know that every day serves a purpose – be that helping a

friend in need or doing charity work. For me to have this approach involved a lot of personal work. It involved changing my attitude to everything. I choose to speak and think in positive ways about the negative things. By changing my ways, I work with my visual and hearing limitations, rather than feel limited by them.

What I am trying to say to you today is although Usher syndrome is devastating and life changing, don't let it stop you achieving your dreams. You can be stronger and more confident than other people and capable of achieving much more than anyone else. I do not want to be called 'oh that poor girl who is going blind'. I want to be seen as an achiever and inspire people that life is not made for you, life is what you make of it.

My message to myself and everyone has always been – “when you look at a person with a disability. Don't see the disability – try to see the person. ”

I feel privileged to have Usher Syndrome – I feel lucky. Without Usher syndrome, I would not be here meeting you at this conference.

So thank you ladies and gentlemen. It has been a pleasure to talk to you.