Torch Trust Sight Loss 101.

In conversation with Sheila Armstrong.

Today I’ve got the great pleasure of having Sheila Armstrong with me who's been working for Torch for a long time, I’m sure we'll hear a lot about that, so Sheila thank you so much for being willing to have this conversation with me and I understand that you were blind from birth is that right?

Yes, that's right, a recessive gene unexpectedly popped up which means that my mum and dad unknown to themselves must have been both carrying it, and the result of that was that my retina and optic nerve didn't develop properly before I was born so I was born blind but they didn't realise for some time, I think as parents they look for every little sign of reaction with the baby and they noticed that I wasn't reacting in situations where you would expect a baby to react, so they'd already had my brother and he was fine so they'd had a bit of experience and so they took me to hospital and they told my mum and dad basically that I had got a serious loss of sight, well mum wouldn't believe it, this was when we lived in Inverness.

What sort of age were you when they first took you to get this explored? Probably close to one or one and a half, quite late on they realized that I was just wasn't seeming to react to things as would be expected and when they took me to hospital they were told that I was blind, in Inverness, my mum wouldn't believe it she just couldn't accept it and she made my dad take me on the train all the way down to Glasgow and of course they told him exactly the same thing, so it was confirmed and then they had to accept it so that was very difficult for them because they had no prior experience at all of blindness in the family because it was a recessive gene, it wasn't known about, probably happened several generations ago but it just wasn't known about so it was a shock to them especially my mum, I think she suffered a lot from it really.

That must have been a real shock, and so what was it like for you growing up blind in a household and presumably a community where that was very unusual?

Well, at the age when you're very small you don't really realise that things are not the same for you as they are for other people. I had my older brother, he was two years older than me, and then my sister came along, she's two and a half years younger than me, and I don't remember much about that really but I think the first thing that made me aware was when the headmaster of the blind school in Edinburgh came up to Inverness to visit mum and dad and unfortunately for me he said to them do not treat her any different from anyone else, do not treat her any differently from any of the other two, if she's naughty give her a smack. Of course that's not allowed now but I mean don't let her get away with things just because she can't see, so maybe there was a bit of spoiling going on before this headmaster turned up, but after that things changed. I didn't notice a lot of difference to be fair.

So what did you do for schooling then, what happened?

Well I had to go to a school in Edinburgh which is about 130 miles from Inverness and in those days there were no mobile phones, no social media, no easy way of contacting, so at the age of five they took me down to the blind school and said goodbye and I apparently just started playing with other children, but I think the reason was that I didn't understand what it meant although they tried to tell me. At that age you haven't really the concept of time and I had no idea what a term was so I just didn't worry about being left in the school and I suppose gradually it dawned on me that I wasn't home very often. So from that age to 18 I was at home for two weeks in the summer, sorry, for two weeks at Christmas, two weeks Easter and eight weeks in the summer, and the reason we got eight weeks was because they didn't do half terms or bank holidays so we got an extra couple of weeks on the normal six week school holidays.

Wow, that's very different, and so what level of sight have you? Help me understand what it's like. You've got some light perception, is that right?

Yes, it didn't manage to totally damage everything. I can see light and dark. My husband reckons it's like looking through a piece of opaque paper, so I can't really see anything in front of me but if there's a light source like a window or something I'll probably be able to pick it out and that can be useful when you're walking about inside but it doesn't help me a lot outside. I can't see the cars, the pavement, anything like that, so Guide Dogs came up with a good title for it, they described me as being functionally blind, and I think that that's about the size of it because I don't actually use light to do anything, like I can get dressed in the dark, wash anything, cook.

So I’m not actually using my sight for very much apart from detecting light sources.

Okay, and so I understand from a basket in the corner of the office that you had a guide dog until not too long ago?

I did, I’ve had guide dogs since 1995. I’ve had three of them but the last one unfortunately had cancer and we had to let her go last December, a year past December not this one just gone past, and they haven't managed to fix me up with a new one yet. I think I left the basket there believing that they would fix me up pretty quickly because I’m totally blind, I was working, I sort of tick all the boxes of people that get guide dogs, but that hasn't happened and of course the advent of Covid put a stop to it all together so I’m still waiting.

So presumably you use a stick and have people who guide you? How's that working out in lockdown?

Well I use a long cane, I don't go out all that often and when I come into Torch I use a long cane for that and I go down to the shop with my husband. I go into the town with the long cane myself, it's about a 35 minute walk, I can't do it as quickly as I would if I had the dog but I’m not enjoying the actual need to use a long cane because you have to concentrate a lot. I’m getting better at it, I can walk a bit faster than I did at the beginning but as I said I’ve had guide dogs from 1995 and before that we lived at Hallaton because Torch was based there in a small village, so I didn't use the long cane all that often around the village either, so I hadn't used it in proper housing estates and crossing roads and such like really since I’d left Edinburgh in 1976 so it was a big gap and it's taken me nearly the year really to build up confidence to use it again but I’m hoping to get rid of it as soon as possible.

Let's pray that the new dog comes through really soon. Is there any news on that? Is that something that's planned or possible?

Well I hope it's possible but I haven't had any news.

Help me understand, what are some of the particular frustrations, challenges, that come with your condition, and in sort of everyday life? Help me to understand what that feels like for you.

Well I suppose when you grow up with blindness you don't think about it so much but obviously there are things that are more difficult, for example if I’m cooking a meal, if I’m doing it from scratch which I do as much as I can really, but I don't always, but if I’m doing it from scratch it could take me two or three times longer to prepare the stuff than it would if you could see what you were doing, so I find that frustrating.

So preparing food can be a bit of an aggravation and having to remember a lot of things. If you put something down it helps if you can remember where it is because otherwise you'll be feeling around for it for ages and I think that remembering a lot of things throughout the day does make you tired, it does weigh you down and I find that that can be frustrating and of course when you're out and about people make remarks at you. I think as you get older they maybe float over you a bit more but they tell you obvious things like you're coming to a road, the cars are coming. I find it happens more with the long cane probably because I don't look so confident and maybe they believe the dog can actually see or interpret a lot more than it actually can, but people do leave you in peace quite a lot more when you've got a guide dog than when you've got a long cane, so that can be frustrating. I've been to university and I’ve had an education but people do sometimes speak to you as if you don't know anything about anything and state the obvious. That can feel frustrating but I think the worst thing is in terms of Christian terms. I have been to churches sometimes and people have implied well of course if you had enough faith you'd be sighted now, you'd be able to see and it's like people have already judged my Christian life and my Christian walk with God and that is quite upsetting. It's happened a few times and it's not fair, it really is not fair. I could say to them well maybe it's your faith that's the problem but I’m not that cheeky really, but you sometimes feel like saying things like that but I guess the Lord helps you not to so that can be frustrating and it is deeply unfair because it implies that (a) the Lord can't use you as you are and (b) you're somehow inferior, in an inferior class to people who consider themselves to have no disabilities but I think people have all sorts of different things that hold them back one way or another, maybe they don't always admit to it but it is grossly unfair. Blindness just happens to be a very visible disability, I mean I’m quite aware that you miss out on a lot of things like photographs and like in church maybe if people put up videos, there's a big swathe of life that's cut out for me that I can't enter into but I think if you're a positive blind person which I hope I am you've got to focus on what you can enter into and make the very best of it.

So how do you feel that your faith, your Christian faith, has actually helped you to navigate, to understand how to live with your sight loss?

Well I think I probably didn't feel that I had a problem living with the sight loss so much as how other people reacted to it and I think being a Christian and reading in the Bible how to follow the Lord and getting to know the character of the Lord Jesus and he's left us an example that we should follow. I think that has tempered me, has helped me not to get aggressive when people say things that really can be quite hurtful sometimes. It's just great that you can take a thing like that to the Lord and find peace by praying to him and he knows about it anyway but you can share it with him and I think that's where I’d say my faith helps me to navigate the knocks in life that I might receive as a result of the blindness.

Sheila, last question for you, Torch produces lots of resources to help blind and partially sighted people; have there over the years been anything in particular that stands out as something that's been the greatest help to you?

I think knowing that there's a good library at Torch is something I’ve appreciated and also the resources. When I was a young Christian, I remember getting a book, we don't do it now, but it was a very good book and I think you can still get it on Kindle called Search the Scriptures and it was a study book and for a young Christian that was really good. It was great to have things in braille especially as a new Christian but also I’m reading a Tom Wright book at the moment The Day the Revolution Began and it's all about the cross and what it means to us and the great change that it made when the Lord Jesus died and rose again, and I’m really appreciating reading that book so it's giving opportunities to read things that just weren't available before so I’m really pleased. I read braille, I also listen to audio as well, I can't read large print course or standard print but there's a lot and of course the synthetic voices are getting better and better and if you're able to train your ear to put up with them there are loads of books on Kindle that aren't Christian books as well but there are people who can't do that so it's good to have hard copy books as well and I think you're more relaxed really when you're reading a hard copy book whether it's in print or in braille.

Sheila, thank you, it's been a joy to talk with you, I really appreciate your responses to things and to be learning from you, so thank you for making this opportunity.

Bless you.

Thank you.

Thank you for joining us in Sight Loss 101. For more information on Torch call 01858 438260.