Torch Trust Sight Loss 101

In conversation with Matthew Horspool

Hello and welcome to Sight Loss 101

I have Matthew Horspool with me today and this podcast is all about for me as a sighted person and the Chief Executive of a charity that's for blind and partially sighted people trying to understand what it's like to live in the shoes of those who live every day with sight loss.

So, Matthew, welcome to this, it's wonderful to have you.

Matthew is one of our star members of staff in Torch, it’s wonderful to have folks within the organisation who have different levels of sight loss and, Matthew, I understand that you've been blind since birth is that right? Tell us a little bit of your story, your journey of blindness.

Well, it's a journey that I can only tell second hand really because I can't really remember it. I was born blind and therefore don't know any different at least not intellectually. I know that I’m different, I know that I can't see the way other people can but I don't really have an understanding of what that means in a proper sense but I was born blind. Apparently my mum and dad noticed that things weren't quite right, apparently my eyes weren't opening properly, I mean they still don't do that, they're a bit too small for that. I have bilateral microphthalmia and coloboma which are apparently quite rare conditions but anyway my eyes didn't open properly and apparently they were told ‘oh well it's just babies they don't open their eyes do they?’ and they kept protesting, my mum was an NHS nurse at the time and I think had an instinctive understanding that something was a bit wrong but didn't really want to go any further with that on her own and eventually I got referred to a doctor I think who said ‘yes, actually there is something wrong’ and I ended up in an eye hospital and was registered blind in I think October 1992, I was born in February 1992, and I still have a copy of the BD8 registration form, dated I think the 10th of October 1992, which has my registration information on it.

So growing up obviously you never had sight. How did you sort of become aware of being different and what did that mean for you?

I don't know, that's a really hard question because I’ve always sort of felt normal and for as long as I can remember and I’ve always sort of known that that's actually not quite right and I don't really know what happened but I suppose I went to school for the blind from a very early age, I went to nursery for the blind and carried on all the way through primary and secondary school and even into further education and that school took blind people and partially sighted people and what happened in the early part of primary school when I was about four or five, we used to have to cross the road from one side of the campus to the other, and on school field trips and stuff like that, and the blind students were expected to partner up with partially sighted students, so the partially sighted students would guide the blind students and I’m not convinced this was a really effective way to do things because what it actually did was say ‘well yes the partially sighted people can see and you can't’, it was I suppose just normal because that's what always happened, but I suppose that was probably the first time when I realised that actually some of my friends could be a partner, they could be the more equal partner if you like and they could guide me but I couldn't guide them.

And then, Matthew, obviously you continued through school and on to university, is that right? Did that happen straight away?

Basically I didn't really want to go to university and I actually dropped out of university early, largely because I just didn't really want to go to university but it seemed like the most likely prospect. I went to school, college, studied A levels, went on to Coventry university to study computer science. I say I was interested in computers, I didn't really know what I wanted to do with life I think, probably if I could see well maybe I wouldn't be as interested in computers if I could see because that interest was drawn by the fact that I had this amazing talking computer and I wanted to know more about it but I think probably if I could see I would have ended up on a gap year at that point and probably found some really exotic work and probably stuck at it for two or three years before I came back and settled and it would have turned into more than a gap year and actually I know blind people who have done this but I didn't have the confidence to do it and I didn't at the time know anybody who'd done it and it seemed like it was a thing that blind people didn't do and I wasn't likely to find a job without a degree. I lived in Birmingham but I still wasn't likely to find a job without a degree and so it just seemed like, well I mean I don't really want to go, but I mean you sort of got to really because it's the only way you're going to get anywhere in life.

And so then did you stay the course with the computer science at Coventry, or are you saying you dropped out?

Well I learned braille at school, I was very proud of braille at school, and I find it very useful, it's one of the most useful things I’ve learned is braille along with IT skills but anyway when I was at Coventry I needed some mobility training around the site which basically was somebody coming out and saying how to use a long cane, here are the things that you need to do, here are where the crossings are, here where the landmarks are, here's how to get from this building to this building, that kind of thing and basically just walk me around the campus a few times and show me where everything was and then teach me the safest route to get there. So while all this was going on the person who taught me was part-time at Exhall Grange School which is a school for the blind on the other side of Coventry, the north side of Coventry, and the funding for those mobility lessons ran out and I was made aware at the time that the blind school Exhall Grange had a particularly bright mathematics student, Year 6 at the time, at the top end of primary school, very good at maths and the maths teacher had just left and they didn't have the braille expertise required to teach this very bright student how to do maths. I did have the expertise, not necessarily to teach but I had the braille expertise having been taught them and so an arrangement was worked out where I went into the blind school and volunteered, to lend them my braille expertise in exchange for extra mobility lessons because there was no funding available at the school and there was no funding available at the university, but it sort of just seemed to work out. That reciprocal arrangement was a good idea and that reciprocal arrangement slowly sort of gradually turned into a job where funding did become available because the student went into secondary school and the amount of braille expertise increased and one thing led to another and I had to make a decision about whether I was going to keep the job at the school or carry on and get a degree and by that point I was feeling very disenchanted with the whole university system, I didn't think I was going to go into a computer science career even if I did finish the degree, my level of motivation for the degree was very low and I felt that perhaps even if I did get a degree it wouldn't be a very good one and my level of motivation for work and for the job was very high and so I just decided that given all of that and given the very high level of unemployment in the blind community, it's something like 80% unemployment in the blind community, finding a job was going to be difficult, so I just decided look the best thing to do at this point in my life is to take the job, enjoy it and then if it doesn't work out then go back to university as a mature student, and so far life's worked out enough that I haven't needed to go down the mature student route.

Matthew that's fascinating, how then did you come to Torch? What was your connection with Torch, when did you first hear about Torch, and how did you end up working for Torch?

Well, I first heard about Torch years and years ago. I think it had just moved to Market Harborough, it was the early 2000s and I wanted a copy of Mission Praise in braille and because I was singing in church choirs, and perhaps I’ll come on to that later on, but I wanted a copy of Mission Praise in braille and I specifically needed Mission Praise 1 and Mission Praise 2, the original Mission Praise really slim volumes that were published as part of the Billy Graham movement. When my mum contacted RNIB they said ‘we can do Mission Praise but we can't do that particular edition of Mission Praise, have you tried Torch Trust, they may be able to help?’ And so we tried Torch Trust and Torch Trust could deliver the goods, they had Mission Praise 1 and Mission Praise 2 and they could send it out and it didn't cost an awful lot of money so I got Mission Praise 1 and 2 in braille and that was the last I heard of Torch for a while basically until I was going through my old hymn book collection working out what was worth keeping and what had got so flat that it needed throwing away and I saw in the front of Mission Praise that it was transcribed by Torch Trust, and the job at Exhall was going well but I could also sense that it was perhaps coming to an end, that the student was about to leave, there was not the cohort coming through to maintain my workload so I thought well I’ll have a look at this Torch Trust and see what they're about because clearly they do some good work transcribing Mission Praise and I looked on the website and saw that there was a job opening in the Sight Loss Friendly Church team and I decided it looked perfect, it looked like work from home so I didn't have to leave Coventry and I feel very at home in Coventry so that was kind of a requirement for a new job, it was slightly better paid than what I was getting at Exhall although there were slightly more hours involved, and working for a Christian charity, well I’m a Christian so that seemed to fit, telling people about sight loss in the church which I’ve been doing organically whenever I’ve moved church and it all just seemed like a decent enough fit that it was worth applying and it was worth getting an interview, so I got an interview and then ultimately got the job and since then I’ve been in the Sight Loss Friendly Church team although my role has changed a little bit over time just to keep up with developments in Sight Loss Friendly Church and coronavirus and the economic fallout of that and all of that sort of thing.

Well that's amazing, and so you were a Christian from very young, did you grow up in a Christian family? What was your sort of journey into the Christian world?

My mum was more Christian than my dad but, yes, I grew up in a Christian family. We went to the local Church of England parish church which was walking distance from my house, my childhood home, and very well equipped, it was a very nice old Victorian church and it had a good organ and a good set of bells and a very sort of traditional but very engaged congregation which made it not feel traditional even though it was and I was baptized there I think as a baby I can't really remember that, my brother and sister were both baptized there, and as faith does, it sort of comes and goes doesn't it, or at least mine certainly has, and I think my parents’ certainly did as well, and as my parents’ faith came and went our church going habits came and went, and we would go maybe two or three months without going to church and then one day my mum would wake up and say ‘look we really need to go to church today’ and of course I’d say ‘oh why? I’ve got used to not going thank you very much’ but we went to church and on one of those Sundays when we went to church there was a visiting organist as the regular church organist, unbeknownst to us because we hadn't been going for a while, had actually resigned, he'd moved on to a new post and they were without an organist and they had a visiting organist this Sunday who was a proper organist in that the organist that we'd had before was a pianist who did a very good job but actually wasn't particularly versatile but the new guy who they got in was a trained organist and played in cathedrals and things like that and was making our organ make noises that I’d never heard it make before and I was absolutely fascinated. I was probably about eight or nine at this point and I had a chat with him afterwards and I said ‘can I play the organ?’ and he said ‘go for it’. So I played the organ and he said ‘can you sing?’ and so I sung him some stuff and he said ‘you should join our choir, you'll need to come to church every Sunday and you'll need to come to practice every Friday’ and my parents said ‘I don't think we can commit to that’ and I said ‘yes, but I would like to commit to that’ and the church said ‘well, we'll make sure that he gets there and back’. So I think my parents used to drop me off on a Friday evening and somebody used to give me a lift back and there were similar arrangements like that made on Sundays from time to time and especially for special services, midnight mass and things, and so I was then going to church every Sunday and singing every Sunday and learning a lot about the faith through the music that I was singing and I think ultimately it was that that drew me towards Confirmation and continuing as a Christian in adulthood.

And Matthew, what is your sense of the difference that your faith has made to your life and your work now and the choices you make in life?

I don't really know. I think it's hard to describe my faith because it's not something that I talk about a lot and it's not something that I consciously feel at the moment and perhaps as it develops perhaps I’ll feel it more but I don't wake up in the morning and think I’m a Christian and this is what's going to frame my day. I mean I wake up and pray but I mean like that's sort of par for the course really. I think what I do feel is a very strong sense that I’m not alone, a very strong sense that everything happens for a reason that there is a plan and that I am a part of that plan and that I don't need to worry because whatever the next part of that plan is I’ll fit in somehow and I do have a very strong sense of that and if something doesn't go right I have a very strong sense that it will either go better tomorrow or I’ll learn something very valuable from it and I think that that really underpins everything I do and leaves me generally feeling quite calm and not very stressed. I very rarely wake up and think I’ve got no money in the bank what am I going to do. I quite often wake up with no money in the bank but I don't worry about what I’m going to do about it because I know that it's all going to be sorted out by the next time.

Wow, that's amazing, that's actually really powerful Matthew. I don't know if you realise just how inspiring that is, just the simple trust that actually everything is going to be alright.

Now it sounds like music has been a really key thing for you, and one of the advantages I have is I can see that you have a shirt and tie on which I have to say I’ve not seen you in before, so tell us a little bit about why you're wearing a shirt and tie.

Actually I feel quite comfortable in a shirt and tie but I also feel quite comfortable in jeans and a T-shirt and I feel like a shirt and tie doesn't have impact if you wear it every day so I tend to wear it on special occasions but as an adult I’m now in the lay clerks at Coventry Cathedral so continuing my choral practice if you like, so I sing in the tenor section of the cathedral choir so there's boys and girls that sing soprano and then ladies that sing alto and then the men sing tenor and bass so we're a very progressive cathedral because we have female altos and we have a female top line although I think most cathedrals have a female top line now, but anyway I sing in the lay clerks and this has been really challenging throughout Covid-19, there are real challenges with blind people getting access to music and there are real challenges with everybody actually being allowed to sing at the moment because of the pandemic and certainly during the first lockdown there were virtual choirs and things like that and I just wasn't a part of any of it, I was invited to be a part of it but the repertoire was having to be chosen at such short notice and I just couldn't keep up at all so I went a long period of time without singing but in the second lockdown we're doing things slightly differently and we are championing live music, wherever we can champion live music and that means that the music that we're singing has to be quite simple at the moment because I don't know if it's Government guidance or Church of England guidance or local guidance but some sort of guidance says that we are only allowed to have one singer at a time so effectively one singer per service and there aren't many of us who actually want to do this so those of us who do want to do it go on a rota and periodically get a phone call from the director of music to say ‘would you be able to sing in two or three weeks’ time?’ and this has been really interesting for me. Singing solo in a cathedral has been quite daunting but it's also been a lot of fun, and actually we have a relatively new director of music who's obviously never worked with a blind person before and certainly never worked with me before and sort of she came to the cathedral as assistant director of music but came in as director of music during the pandemic so we haven't really had a great deal of time to actually sit down and go well what can I do, what can't I do, whereas now that I’ve been given the opportunity to sing solo we've really been able to sit down and work out, okay what do you need in order to do this job, and she's been really accommodating at making sure that I do have enough notice and I do have the repertoire and if I can't get the repertoire finding repertoire that I have got and buying in extra music sometimes to accommodate and, as we record this, it's Ash Wednesday today and it's my turn by coincidence on the rota to sing the Ash Wednesday service at the cathedral so I’m actually dressed up, as once we're finished I shall head out to the cathedral and practise for the service and then sing the service as a solo and to a webcam and then the congregation will watch online.

Wow, that's amazing, and what a brilliant thing to do, and I think that your director of music's question was really good, ‘what can we do to make this work for you, how do we make this work?’ That seems to me to be a great question to ask, Matthew.

I’m just intrigued having worked with you a bit over the recent months and seeing just how you navigate life so brilliantly, tell me a little bit about the cane, I think cane is the right word isn't it?

A cane is the right word, I’m not precious that is the word.

I think I called it a ‘stick’ the other day and realised I’d made a mistake, so tell me a little bit about what's it like to use a cane to get around and, I am a very visual person and I do diagrams and maps and my family calls me the family sat nav because I just seem to be able to get around places, do you have a kind of map in your head of the places you go, and how does that work for you?

Yes, so this is a very personal question and you could ask 10 blind people this question and get 10 answers, and actually I personally don't see mobility as one of my greatest strengths, I mean I can do it and I can get around and I can go wherever I want to go and it doesn't hold me back but I know blind people who are much better at this sort of thing than I am but what's it like, I mean I don't really know how to answer the question because again it's normal. I was taught to use a cane almost as soon as I learned to walk! A couple years later I was taught properly how to use a cane, so I’ve been using a cane since I was sort of three or four; a very small cane back in those days, and look I didn't enjoy it because at the same time I was taught to use a cane I was also taught to protect my upper body, protection it was called, so you'd walk with your hand out in front of your face to stop you from bumping into things and to help you stay in a straight line, and particularly at a young age to trail the wall with the back of your hand, and I used to quite enjoy doing that and I used to all the way up to the end of secondary school I used to walk around secondary school just with a hand in front of my face trailing the wall and that was perfectly fine, I didn't see why I should use a cane when that was getting me around and then I tried to walk around outside a bit and realised that trailing the walls of open shop doors and street furniture and one thing or another, that was just not going to happen and also the number of people who were around, the number of people who I’d end up bumping into if I didn't have a cane was just so high that I just thought no this has got to change so I always knew that I could use a cane, I just didn't particularly want to and so I started using the cane a bit more and well it was basically the only way that I was going to be able to navigate unless I got a dog and at the time I was actually scared of dogs so that was a pretty strong disincentive for getting a guide dog. I didn't want one, I mean since I’ve got friends who've grown up and had guide dogs I had to sort of get used to them and actually I quite like dogs now but I was absolutely terrified of them, I did not want a guide dog, I’d do anything not to have one and even now although the idea of a guide dog is quite nice you've got to pick up after them, you've got to free run them, we were in minus temperatures last week and all I really wanted to do was stay in the house and keep warm and if I’d had a dog that wouldn't have been an option, I’d have had to take the dog out for a run and I don't really like that idea so the cane is the way to do it, and I have just been incentivized to keep using it because if I don't use it then I’m not going to get about and there were some pretty strong incentives when I was a student, I was living in university halls and had a friend who actually lived the other side of the city, and as a blind person we get free bus travel, so I could get to my friend's house on the bus for free if I could be bothered to use my cane to walk down to the bus stop but if I couldn't be bothered to use my cane to walk down to the bus stop I was gonna have to pay £10 each way in a taxi and as a student that's a pretty big incentive you could either use your cane or spend 20 quid, well I’m going to use my cane thank you very much!

Thank you. I understand from comments you've made previously that you live on your own. Tell me what are some of the biggest challenges about that, how do you cook, how does it work living on your own as a blind person?

Reluctantly I would love nothing more than to have all the money in the world and pay a chef or something to come and cook for me. But very reluctantly I was taught to cook when I was at college, in particular I went to the Royal National College down at Hereford. It was a boarding college and that gave us plenty of opportunity to be taught formally how to cook and also I was with peers who either enjoyed cooking or were also learning to cook or had learnt to cook previously and so there was this enormous bank of knowledge, and actually I learned more from my peers than I did from formal lessons, so I learned to cook very basic meals like pasta and sauce, spaghetti Bolognese, I think I just about managed cottage pie by the time I left Hereford which isn't actually all that basic now I look back at it but it was cooked in a very basic way and I went through university sort of cooking these very basic meals, jacket potatoes, because they were nice and simple and then I realised that I was starting to put on some weight because actually what I was cooking, although it was nice, it wasn't particularly healthy because spaghetti Bolognese it was basically just mince and pasta sauce and spaghetti, there was not very much veg in it, and so this wasn't happening and so anyway out of necessity more than anything else I started to very reluctantly think well actually look if I can put this in a pan and cook it and I can put this in a pan and cook it what would happen if I put them both in a pan together and cook them at the same time, and there were some absolutely terrible outcomes of food that really didn't taste very nice but there were also some rather nice outcomes of recipes that actually I still cook and I have no idea what to call them because they're not officially recognised recipes but they work and out of that grew an appreciation, if not an enjoyment, I don't particularly enjoy doing it, but I do understand the concept of how to do it. I understand that you can put all this stuff in a pan and it'll work but you don't want to put mushrooms in with it because mushrooms have flavour and the flavour of the mushrooms will get into the rest of the vegetables, so if you want to do mushrooms you really want to fry them up separately and add them afterwards, and so I learned things like that just by doing really although the basic skills of cooking on gas which you would think isn't very safe but actually cooking on gas is brilliant because you can hear when the gas is on and when the gas is off, it cools down very quickly so you don't burn yourself learning to tell if something's cooked by touch or by temperature. I have a talking food thermometer and I can put the probe in something to tell if it's cooked and all those very basic skills I learned while I was at Hereford but actually recipes and things I’ve just devised over the years.

That's fascinating, I have so much respect for you Matthew. Just to finish with I wonder if there are any particular things that you would like to say to me as a sighted person when we interact workwise. What are the things that maybe that I do that kind of frustrate you or have you got any kind of words of wisdom for me in how best to speak about blindness and sight loss? How to make your life as rich and easy as it can be, to kind of not fall into some traps and faux pas that sighted people make, and anything that comes to mind on that front.

I think actually you're doing the right things and nothing really comes to mind other than keep doing what you're doing. I know that there are a lot of chief executives in very high profile positions, what I would call blindness organisations, what the industry would probably call sight loss organisations, who are in the organisation for very well meaning charitable purposes but impose their own opinion of what sight loss means and generally that opinion is that sight loss is so debilitating that we can't do anything and so there's this mentality in the sector of the ‘poor blind person’, we must help them, whereas actually the mentality that I want is we must empower them and there's a difference between the two and there's a a frustration for me that the sector as a whole has this mentality that there's a lot of people that are dependent upon the blindness sector because it's easier for them to stay dependent upon the blind sector than to learn the skills not to depend on it anymore, so that you have societies that do lots of social trips and things like that and, look social trips are helpful, it's very helpful, it's very useful, it's very fulfilling to socialize with other blind people in a secular context and a sacred context to actually talk about these very real issues that only we as blind people have and will really properly understand, so I’m not for a moment saying that we shouldn't have social groups but there are people for whom the social groups are the be-all-and-end-all and actually I don't think that's healthy either. I think we really need to be teaching people to be empowered to be part of the blind world but also to be part of the real world or the sighted world if you like and I don't think that happens enough, I think people are too quick to help and too slow to empower but I think, from what I’ve seen of you through these Sight Loss 101 things and through other things that have been happening at Torch, I don't feel like that's happening at Torch at the moment.

Good, well keep me honest with that one, Matthew! Keep on me about it because one of the things I’ve learned over the last few months is just how gifted and competent so many folk with blindness and with living with sight loss are, and just recognising those gifts and wanting to say how can we help the world benefit from all that you guys have to offer. So, Matthew, thank you for this, thank you for opening up, for telling us about your life in this way, and I hope the singing goes fantastically today. You've sent me the link for it so I’m looking forward to listening, so thank you Matthew, bless you.

Thank you, Tim, it's been a real pleasure being in the conversation.

God bless, bye-bye.

Thank you for joining us in Sight Loss 101.

For more information on Torch call 01858 438260.