Torch Trust

Sight Loss 101

in conversation with Chich Hewitt

Hello and welcome to this episode of Sight Loss 101.

Today I have Chich Hewitt who I’m really looking forward to speaking to. These series of podcasts are for me, a sighted person, now the chief exec of Torch, to understand what it's like living with sight loss and so I’m having conversations with people to understand their perspective, to understand what it's like to walk in their shoes.

So Chich, it's great to have you with us. Thank you for agreeing to do this and I guess to start with, it'd be really helpful for me to understand a little bit about your journey because I hear an accent from you that isn't local to these shores. So a little bit about your journey and then how sight loss has sort of featured in your life.

Thank you, Tim, it's lovely to be with you today. Yes I still carry some of that South African accent. My wife and I were both born in Johannesburg and I schooled there, went to university there and did Maths and Statistics for a first degree, and worked for the South African railways for 10 years in data processing, scientific programming, actually on computers which filled large rooms and couldn't do even the fragment of what this iPad can do on the top of my desk at the moment. And so I had that experience but from my last year of school or last couple of years, I had a calling into the ministry. I had grown up in a Christian family and had attended a South African church school so that was familiar but the calling came and my parents wanted me to qualify something first, hence the degree and I met my wife - she's a medical doctor and when she'd finished her degree I then went to theological training. That was in the late 70s in South Africa and then my first parish was in a place called Vanderbijlpark, a mining or actually an industrial town I should say, large steelworks and coal fields there, and I had 5 years there.

So Chich, what sort of decade was that help us to sort of locate that in our history of South Africa.

Right. In fact in 1976 when the Soweto riots took place my wife was doing her house job at Baragwanath Hospital and the next year, it was quite a time of turmoil in South Africa. The next year 77/78, I went for my theological training. I had already had done some theological studies through university of South Africa, that's the equivalent of the Open University, and so I had a 2 year spell at college, then this time at Vanderbijlpark, 50 miles south of Johannesburg and that was from 1979 to 1984. Then I became chaplain and eventually principal of the theological seminary in Grahamstown southeast between Port Elizabeth and East London, and that was from 84-92.

That's a very pretty part of the world.

Very attractive.

A very beautiful place.

Not quite as attractive perhaps as a Western Cape but still also lovely in its own way. And then after my time at Grahamstown cathedral I was subsequently Dean of the cathedral from 93 it was to 97/98, and I had a sabbatical offered to me. An 8-month one in Nashville Tennessee and we decided after that to do something different and come to the UK for what we thought was a couple of years. We came here in 2000 for the different church experience and never left. We've been in Manchester for that time and our daughters followed. We've got two girls, the younger one came a couple of years after or the same year as we arrived actually and then the older daughter a couple of years later, so I don't think there's any chance of us moving away now. So we're here to stay so I’ve in been in the Manchester diocese; two parishes from 2000 to 2009 and then another one to 2014 when I retired. But the story of eyesight begins in 2008/2009 because up until then I had perfectly normal vision and did everything people do and drove cars and so on, but I had this fading in my left eye and it fooled the doctors. I had eventually a very caring and interested ophthalmologist and she did every test imaginable and nothing showed up, the eye looked normal but I wasn't seeing in the left eye and then just at the time when I was changing parishes, people think I left the first parish because of eyesight but that wasn't true at all. I felt like a change was necessary but at the time of the change I lost eyesight in the second eye and then the ophthalmologist noticed a slight change in the first eye and I was referred to a neurologist who quickly diagnosed this Leber Hereditary Optic Neuropathy it's called. Quite rare and it affects the ovum in women, so women carry it, men tend to get it. I’m an only child, if I’d had a sister she could have been a carrier but I can't pass that on to our children and so what happens is the centre vision goes, the optic nerve, it's like as some people have said, if you've got a computer you've got an external device and it's the cable which is faulty. The mitochondria and the optic nerve are affected, so I’ve got no centre vision but I’ve got peripheral and some side vision. It's bad enough to be registered blind but I can see and enjoy scenery sometimes. Actually looking through binoculars can help a bit but in the in the main things are very vague. I can see your outline, I’d never recognize you if you pass me in the street or anything like that, so I use a white cane. But it was a challenge changing parishes. When they accepted me into the parish with eyesight in one eye and when I eventually arrived I was registered blind.

Gosh and how long was that, was it a very sudden change when you when you lost the second one?

That went very quickly, the second one - the right eye. It went within 3-4 weeks actually, from it becoming a bit hazy to the stage where it is now. I can still see a little bit out of the left eye. If I want to read something, I can blow letters up and magnify and then begin to see things a little bit, but otherwise I had to think on the hop, very quickly; how am I going to take services and especially with the Anglican tradition where you have a said liturgy. How on earth am I going to read that and so I fiddled with equipment and began a system which I’ve used ever since and of course the equipment's got better, and that is to have a recording of the service - my wife kindly put it on or puts it on - she does it better than I do - and I use earphones and as I hear the speech I will say it a couple of words behind, rather like an interpreter would except I don't have to interpret and just say the words that I hear and it works for me. I don't do braille it's a pity out you know listen to Mike Townsend speaking and think, ah, what a wonderful gift that is to have that braille but I don't have that skill but use other technology to help me.

And so as well as the physical impact on your ministry, what was the emotional, spiritual, mental sort of impact of losing your sight in that way?

Funnily enough the emotional thing didn't hit too hard. I think it might have been difficult if I had been at home doing nothing but in the transition from one ministerial post to another, I was so busy thinking about how I was going to cope with the things, that I think that was the all-consuming interest and so I don't think I suffered as much as some have, you know, with the emotional aspect of sight loss. The things I miss - the driving obviously, I can't do that anymore and also I enjoyed playing the piano a bit and reading music and I haven't found any way to do that. I know that Matthew in Torch is quite skilled with braille reading, something I might look at in the future but otherwise modern technology is amazing and it's got so much better between losing my eyesight at the beginning of 2009 and the present that I can cope quite well with the technology that I have.

So what are some of the technologies, Chich, that have been sort of most helpful to you, that you'd recommend to others who are going through a similar sight loss journey?

Some people joke and say that I’m a spokesperson for Apple it's not necessarily true! You know, one device is as good as another; Samsung and Apple devices, you know, they can all do clever things but Apple technology is particularly good sight loss in fact for accessibility, so I can zoom in the screen right now. in and out, which helps me with a little bit of side vision, but also the talking software is brilliant the Siri function and the voice-over function means that it'll read me anything on the screen, emails, books, newspapers, the whole lot, so I can be fairly flexible and versatile and also some of the volunteering work I’m doing now in retirement. There's a local blind organization here called Henshaws and up until the lockdown I was volunteering with a sighted colleague, helping people who are losing eyesight to use some of the technology which I found useful So it's generally the Apple technology but also devices like a clear reader which photograph and you know read stuff to you, a device called a Victor Reader or Victor Streamer which is the one I’ve used so much in church work because that has the recording on it. I can slow it up, speed it up, bookmark so I can move backwards and forwards to different things in the course of a service and so on. That's been a device I couldn't have done without.

Well that's amazing and as I’m a Anglican lay reader and my wife is an Anglican vicar ,so just thinking of having to do that in the way you do, I’m full of admiration for the way that folk are so adaptable, you know when they're losing their sight, to find new things that's lovely to hear. Is there a particular message you would have Chich, so if there was somebody watching this who was in the process of losing their sight, in the early stages of that, is there something that you would say to them?

Yes, there is life out there after eyesight loss and I mean people are in different stages, say with regard to technology, some can cope with it, some can't but you know there are books available on memory sticks through RNIB, there's so much around that you can lead a fairly active life. I had good support from the local authority. I had got white cane training. I haven't got a guide dog but the white cane does fairly well because you know I can't see, I haven't got any depth and can't see steps coming up and things like that, but there are all sorts of devices and there's all sorts of help around; Torch, RNIB as organizations, of course, local blind organizations, other people prepared to help, so there is a life out there after eyesight loss.

That's a great one and how about for me, as a sighted person beginning to understand a little more about the world of folk with sight loss, what would your top tip to me be for my engagement with folk that are blind or partially sighted?

As others say, don't be concerned about language. You know, if you say to me can you see that such and such happens or I shouldn't have used the word "see". I'm not phased by that kind of language at all, just be natural, just talk naturally and so on. The usual thing is to ask what might be helpful rather than assume what I’m needing. I think it's Peter White who runs that programme, you know on the radio every Tuesday evening and he said it a number of times that he's been propelled through a revolving door that he didn't want to go through in the first place by some kind person, and it's not really helpful, so ask what help I might need, is the best way.

I’m particularly also interested to know that you have been doing some volunteering work with Torch's Sight Loss Friendly Church initiative, so if my wife watches this as an Anglican vicar or any other church leader watching this, what would your message be to folk who are leading churches and responsible for church life.

Churches, I’m generalizing a bit, are not great on the whole matter of disability and accessibility and those sort of things until the need arises, so for members of the congregation to engage with the Sight Loss Friendly Church programme would be brilliant. It's an excellent programme and I was involved in running one in the Manchester diocese with colleagues Paul Rhodes and Marcus

and that we did live before lockdown but now that lockdown's come the Sight Loss Friendly Church programme on Zoom, I think is very good and Becky and Matthew do a great job and I volunteer with a

man called James and I would encourage churches to engage with this 90-minute programme and just learn what can be done in a church which people don't think about. The use of steps in churches, marking steps is one issue, and helping people with tea and coffee time, identifying who you are, all those kinds of things come out in the course and I’d encourage people to do that course.

Okay, thank you. Chich, lastly, one of the things that I’ve been doing is, I suppose, looking with fresh eyes at the Bible and how the Bible talks about sight and seeing and blindness and so on. What's your reflection as you've gone from being a sighted vicar to somebody who's lost their sight, on the Bible or some of your insights on what is it that's come afresh to you as you have been on this Sight Loss journey?

Interesting, I remember the disability task group in the diocese and we had a session on the theology of disability with a group of curates in their last year of training and there's a lot of interesting material out there. “The Disabled God” is one of the books and there is some good material that I can let people have, that I can hand on through Torch but John Hull is a very interesting man, who I think many would have heard of him. He lost eyesight totally when he was 40, and he was quite radical in his thinking, believing that Jesus didn't really understand what eyesight loss was about until he, himself, had been blindfolded at the time of his suffering and crucifixion and when people hit him and said “who's hitting you?” and that then he came to realize what it was about. Before then he'd use phrases like, when the blind leap, the blind both fall down into a pit, so he's got quite an interesting aspect on it. The Bible is quite ambiguous in many ways on the aspect of disability and there's a lot that is being done and a lot more can be studied on it.

Thank you. We're actually looking at whether to put together a series of conversations between several people about the theology of sight loss and, you know, the way that the Bible talks about sight and blindness, so Chich, we will have to rope you into some of that, but that's hopefully something that will be coming later this year.

Hopefully you can do that and there's someone very good in our diocese who can supply some material on that.

Well I’ll come back to you for a name and details. Chich, it's been a real pleasure, thank you so much for making time to speak with me and thank you for sharing your story with us and may you know God's blessing on your continued ministry in life. Bless you.

Thanks and God has been absolutely amazing in my journey. You know I think that's one reason why so many things have been less painful than they could have been otherwise, that the Lord's been with me on that journey, and still is.

Bless you.

Thank you for joining us in Sight Loss 101.

For more information on Torch, call 01858 438260